Rare Disease Disability Toolkit

rare voices AUSTRALIA®

Rare Disease Disability Management Plan

Introduction

This guide is part of the Rare Disease Disability Toolkit (the Toolkit). Use it to help develop your own Rare Disease Disability Management Plan (the Plan). This guide was designed with people who live with rare disease disability. It helps you create a Plan that has important disability, medical, daily living, and support information in one place.

The Plan helps make sure your needs, choices, and wishes are understood and respected.

People with rare disease disability may need to manage a lot of information and repeat information many times. The Plan is designed to make this easier. If you choose to, you can share this Plan with the people who support you, so your care is better coordinated and centred around you.

Rare Voices Australia (RVA) led this work. The Australian Government funded the Toolkit through the Peer Support and Capacity Building grant for the National Disability Insurance Scheme (NDIS).

This resource was up to date when it was published in August 2026. The information does not always reflect the views of RVA and does not mean RVA endorses other content. RVA is not responsible for loss, damage, or other problems caused by using or misusing this resource.

What Is a Rare Disease?

A rare disease is a health condition with its own set of signs, symptoms, and clinical features. In Australia, a disease is considered rare if it affects 5 or fewer people out of every 10,000.[1]

Rare Disease Disability

About 2 million Australians live with a rare disease that impacts their daily life over a long time. For many people, these impacts meet the Australian Government's definition of disability.[2,3] Rare disease disability is still not well recognised in policy. There are at least 7,000 known rare diseases, and new diseases are still being found.

A disease is rare if it affects less than

5 in 10,000 people

There are

7,000+

rare diseases

About

2 Million

Australians live with a rare disease

Contents

How to Use This Plan

The Plan has 3 parts:

1 **About Me – One-Page Personal Profile**

2 **General Information, Supports and Adjustments**

3 **Medications and Medical Management**

Guidelines for Use

This Plan has all the important information about you and your rare disease disability in one place. It does not replace every other document. The Plan points to other documents, attachments, or links so you do not have to write the same things again.

You may want to print this guide and the Plan to look at side-by-side when writing your Plan.

You choose what to include and who you share it with.

Different versions: You may have different versions of this Plan for different people or places. For example:

- Keep the **full version** for yourself and people who provide health or disability supports.
- Make **shorter versions** for others (e.g. work or school). For example, your **About Me** may be different for a community group, compared to a hospital.

If you make different versions, label them when saving (e.g. "Work", "Education") and add the date.

Where to Use the Plan

You can use this Plan anywhere you need support. Examples are:

- For family/caregivers/kin and friends.
- During care meetings (e.g. for hospital, NDIS reviews).
- With new support workers, or health/disability service providers.
- Education (e.g. kindergarten, school, TAFE, university).
- In community and social groups.
- At work if you need adjustments or extra help.

Who Can Complete the Plan

- **Part 1 (About Me – One-Page Personal Profile)** and **Part 2 (General Information, Supports and Adjustments)** can be completed by you, or by someone who supports you if you agree. Different people can help with different sections.
- **Part 3 (Medications and Medical Management)** must be completed and signed by a qualified medical professional who cares for you.

How to Complete the Plan

Use simple language to describe what you need, what helps, and what does not help.

If you are not sure what to write, it is okay to leave a section blank or write "not known", "not yet diagnosed", or "unsure".

There is no need to write details that are in another document again. You can:

- Write "attached" and include it as part of the document, or
- Include a link to it, or
- Note where it is stored so others can find it.

Examples of documents you may attach or link to include medical reports, behaviour support plans, or medication lists.

Where to Store the Plan*

This Plan may include private information. To stay in control of your information and protect your privacy, only share it with people who need it.

To keep a digital Plan safe, use passwords. Only give passwords to people you trust and who need to see the Plan.

If you keep paper copies, store them in a locked place. Shred them when you no longer need them.

***Please note:** These are only some ways to protect your information. Ask your care team for help if needed.

Updating the Plan

Write down the date of this Plan, a review date, and who helped put it together. Review the Plan when things change, or at least **every 12 months**.

Other Resources

A health passport or care plan can help in healthcare settings. Examples include:

- **Julian's Key Health Passport (Queensland Health)**
  Shares important health and personal information with healthcare staff.
- **My Health Matters Folder (Council for Intellectual Disability)**
  An Easy Read document to help people with intellectual disability communicate with healthcare providers.
- **Admission2Discharge (A2D) Folder**
  Supports people with cognitive disabilities during hospital stays.

Part 1. About Me – One-Page Personal Profile

Use this section to give a short picture of your needs and preferences.

You may want to make different versions for different places or people.

You can use words, images, photos, symbols, or drawings.

Part 2. General Information, Supports and Adjustments

Section 1: Personal Information

This section says who the Plan is about and where to find important details.

a. Personal Details

Write your full name, preferred name, and contact details.

b. Accessibility and Communication Needs

Use this section to explain how you communicate and how others can support you to understand information, share preferences, and make decisions.

This may include:

- Plain English
- Easy Read
- Auslan
- Key Word Sign
- Communication boards, or communication devices.

Note if you need an interpreter and language preferences.

Also note if your support team have any communication needs or preferences.

c. Decision-Making/Consent

Explain what helps you to make your own decisions.

Use this section to describe:

- What decision making support looks like for you.
- Who needs to be involved in decision-making.
- How you want to provide your consent.

d. My Support Team

List the main people who support you and what they do. This may include family, carers, kin, friends, communication partners, support coordinators, navigators, advocates, or peer supports.

If any support people also need adjustments, write that here.

Clearly identify emergency contacts.

e. Rare Condition Overview

Sharing diagnosis information can help others understand your needs better. You can use everyday words as well as medical terms.

- If a diagnosis is known, record the name of the rare disease, condition, disorder, or disability.
- If there is no diagnosis, write "**under investigation**" or "**not known**".

Write any other relevant medical conditions.

If you can, explain how each condition affects your daily life.

You may like to include:

- A typical day.
- Symptoms and features of your condition.
- If your condition flares up and how often.
- If your condition is getting worse.
- General daily management – e.g. medication, mobility aids, rest breaks.
- Journal articles.
- Websites.

You can also add trusted information here. For example, published Standards of Care.

f. Other Important Information

Add any other information that could help someone support you safely and respectfully. This may include sensory needs, cultural needs, spiritual needs, religious needs, or gender identity. It can also include words or actions people supporting you should use or avoid.

Section 2: Support and Reasonable Adjustments

Use this section to list what helps you feel safe and confident in different places. Examples are provided below.

Childcare settings may require adjustments such as:

- Access to a low stimulus rest area with trained supervision.
- Medication administration by appropriately trained staff, in line with medical instructions.
- Visual supports or communication tools.

Education settings may include adjustments such as:

- An Individual Education Plan and/or NDIS funded supports.
- Regular rest or sensory breaks.
- Assistive technology to support learning and access.
- Access to a school nurse or health supports.

Employment settings may require adjustments such as:

- Flexible hours, remote work options, or modified workloads.
- Adapted lighting or reduced sensory stimulation.
- Scheduled breaks for health management.
- Assistive equipment.

Disability services may require adjustments such as:

- High intensity personal care supports aligned with NDIS goals.
- Specialised equipment or systems for safe sleeping or positioning.
- Transport arrangements with clear safety protocols.

Health and hospital settings may require adjustments such as:

- Access to a quiet or private room where possible.
- Communication supports, including tools and staff training.
- Behaviour support for distress or pain responses.

Note: Refer to Reasonable Adjustments in Healthcare: What Can I Ask For?

Section 3: Baseline, Early Warnings and Emergency Action Planning

This section helps people understand what is normal for you and when they need to act.

a. Baseline

Baseline means what a “good” day looks like for you. It helps others notice when something has changed.

You may like to include the following:

- How you usually look, feel, and behave.
- What you can usually do without help.
- What support you usually need.
- Your usual ways of communicating.

b. Early Warning Signs and Triggers

Early warning signs are changes that may mean you are becoming unwell or tired. They can be signs that things are getting worse. Triggers are things that may make this more likely. List the signs and triggers that are most important for you.

Examples include:

- Physical: Increased pain, sudden fatigue, increased noises like shouts or groans.
- Cognitive/Emotional: Unwell, confused, easily upset.
- Environmental: Too hot or cold, diet changes, stress, changes in behaviour that signals distress, discomfort, or reduced capacity.

c. Support Required During Escalation or Medical Episodes

This section explains what support you need when things are not going well. Include what helps most when your health or disability is getting worse. Include how people can respect what you want during these times.

You might like to include:

- What usually helps first.
- What does not help or can make things worse.
- When additional support is needed.

d. Emergency Action Plan

This should align with any existing emergency care plan and/or advanced care directive.

Write when emergency services should be called.

Write down what to tell emergency responders, including your preferred hospital or doctors.

Section 4. Disability Impacts

Use this section to explain how your rare disease disability affects daily life and what helps you manage, take part, or stay safe.

This information can help explain your disability support needs to different services, including the NDIS.

The NDIS impairment categories and functional areas are included to help disability service providers and the NDIS understand your support requests.

You do not need to complete every row in the table. Only fill in the rows that apply to you.

Focus on:

- What every day looks like and what is hard to do or not possible without support.
- What support, equipment, or adjustments are needed to make activities possible, safer or easier.
- What may happen if that support is not in place.
- Explain how your support needs change with fatigue, illness, stress, or rare disease symptoms.

The examples can give you some ideas. You can change them or put them in your own words.

NDIS Impairment Category	Functional Area(s)	How This Impacts Everyday Life	Supports, Equipment, Or Adjustments That Help
Physical impairment	▪ Mobility ▪ Self-care	▪ Difficulty moving around the home or community (e.g. walking, stairs, transfers). ▪ Difficulty with daily personal activities (e.g. showering, dressing, toileting, meal preparation).	▪ Assistive technology for mobility and transfers (e.g. walking aids, wheelchair, transfer aids). ▪ Home modifications for access and safety (e.g. ramps). ▪ Assistance with daily personal activities. ▪ Adaptive equipment for meals and daily tasks (e.g. modified cutlery).
Intellectual impairment	▪ Self-care ▪ Self-management ▪ Communication (speech and language) ▪ Social interaction	▪ Difficulty learning new skills and information (e.g. needs new tasks broken down, repeated, or presented visually). ▪ Difficulty with everyday decision-making and routines (e.g. budgeting, planning, sequencing steps). ▪ Support to communicate needs and participate socially.	▪ Support to build or maintain daily living skills (e.g. routines, skill-building). ▪ Support with planning, money skills, and community participation. ▪ Communication supports where needed (e.g. speech pathology, visual supports, Augmentative and Alternative Communication).
Cognitive impairment	▪ Self-management ▪ Learning (cognitive)	▪ Difficulty with memory, attention and concentration (e.g. forgets steps, loses track of tasks). ▪ Difficulty planning, organising and problem-solving (e.g. managing appointments, following health routines).	▪ Strategies and supports for routines (e.g. prompts, checklists, visual schedules). ▪ Assistive technology to support memory/ organisation (e.g. timers). ▪ Capacity building supports (e.g. therapy to build planning skills). ▪ Extra time and simplified instructions for new or complex tasks.
Sensory impairment	▪ Vision ▪ Hearing	▪ Vision impairment affecting reading, navigation, recognising hazards. ▪ Hearing impairment affecting understanding of speech, following instructions, and safety alerts.	▪ Assistive technology for vision (e.g. screen reader, large print, audio formats). ▪ Assistive technology for hearing/communication (e.g. hearing aids, captioning tools). ▪ Communication access supports (e.g. written, visual cues, Auslan).

NDIS Impairment Category	Functional Area(s)	How This Impacts Everyday Life	Supports, Equipment, Or Adjustments That Help
Impairments related to psychosocial disability	▪ Social interaction ▪ Communication ▪ Psychosocial	▪ Difficulty participating in social situations (e.g. difficulty forming or keeping relationships). ▪ Difficulty managing daily life and routines (e.g. motivation, planning, coping with change, managing appointments). ▪ Periods of fluctuating functioning that impact work/study and community participation.	▪ Support to build routines and participate in the community (e.g. coaching, supported attendance). ▪ Psychosocial recovery coaching and capacity building supports. ▪ Therapeutic supports (e.g. psychology/counselling where this is disability-related). ▪ Environmental adjustments (e.g. quiet spaces, smaller groups, clear plans and expectations).
Neurological impairment	▪ Mobility ▪ Communication ▪ Self-management ▪ Learning ▪ Self-care ▪ Social interaction	▪ Difficulty with balance, coordination, or muscle control (e.g. unsteady walking, tremor, muscle weakness or spasticity). ▪ Fatigue that limits daily activities and participation. ▪ Episodes that affect safety or functioning (e.g. seizures). ▪ Difficulty with speech, swallowing, or processing information (varies by person).	▪ Allied health supports (e.g. physiotherapy, occupational therapy). ▪ Assistive technology and equipment (e.g. mobility aids, communication devices, specialised seating). ▪ Home modifications for access and safety. ▪ Support with daily activities and community participation. ▪ Safety planning and strategies for episodic events (e.g. seizure safety strategies). Episodes may require specific safety responses. Refer to Section 3: Baseline, Early Warnings and Emergency Action Planning.

Note: These are general examples only. The NDIS considers how a permanent impairment substantially reduces functional capacity in one or more functional area and what supports are reasonable and necessary for the person's needs and goals

Section 5: Multidisciplinary Team and Key Contacts

This section lists the main people involved in your care and support so that they can be contacted to get the right information.

List contacts that are most urgent/important first. Include people who help you every day and anyone involved in decisions about your care.

Let people know that you have listed them. Update this list whenever care arrangements change.

Part 3. Medications and Medical Management

This part of the Plan covers prescribed medicines, supplements, treatments, and clinical instructions.

It must be completed and signed by a medical professional, such as a doctor or nurse practitioner, who cares for you. You can also refer to an existing signed Medication Authority Form.

Use this section to:

- List all medications and treatments.
- Note where medication plans or administration instructions are stored.
- Identify who can give you medications and what training or authorisation is required.
- Record known allergies, sensitivities, or bad reactions.
- Give instructions about timing, food requirements, positioning, monitoring, or interactions.

Important Safety Information

Medication instructions must be followed exactly as prescribed. Only people who are trained, authorised, and working within their role should give medications or treatments in this section.

a. Medication Review

List who the last medication review was conducted by and the date.

b. Allergies and Adverse Reactions

Use this section to list known allergies and any bad reactions to medicines, substances, or foods. Examples are listed below.

Allergen	Reaction	Severity	Management/Notes
Penicillin, latex, adhesive tape, peanuts	Rash, hives, swelling, vomiting	Mild Moderate Severe Anaphylaxis	Antihistamine Steroids Adrenaline/EpiPen Hospitalisation

c. Prescribed Medications

This table should list all medicines prescribed by a health professional. These may be taken regularly or only when needed.

Refer to any existing signed Medication Authority Forms (where relevant).

Some services and providers ask for Medication Authority Forms to be reviewed every year.

Medication	Dose	Purpose	Special Instructions
[Drug A]	[e.g. 5 mg – daily AM]	Symptom control	Take with food
[Drug B]	[e.g. 5 mg – daily AM]	Symptom control	Take before meals

d. Emergency Medications and Treatments

Read this section together with the Emergency Action Plan, especially if medicines may be needed during escalation or emergencies.

If you are unsure whether emergency medication is required, seek urgent medical advice or contact emergency services on '000'. Only people specifically trained to administer emergency medication(s) can do so.

Medication	Dose	Purpose	Special Instructions
[Drug C]	[e.g. 5 mg – daily AM]	Emergency seizure control	When to administer

e. Regular Supplements (Over-the-Counter Medications)

List any supplements you take regularly, including ones bought from supermarkets, online stores, or pharmacies.

Supplement	Dose	Purpose	Special Instructions
[Supplement A]	[e.g. 500 mg – twice daily]	Nutritional support	Avoid within 1 hour of Drug A

f. Therapy

List therapies needed for health, function, or safety. For example, physiotherapy, psychology, art therapy, music therapy and exercise physiology.

Special instructions: Include anything important about positioning, equipment, fatigue, communication support, or care before or after a session.

Therapy	Schedule	Purpose	Special Instructions
[Therapy A]	Weekly session	Joint mobility	Pre-session stretching
[Therapy B]	Fortnightly session	Speech therapy	Requires a communication partner

g. Medical and Disability Management Plans

This table points to more detailed condition-specific or disability-specific management plans. Write where the full plans are stored if they are not attached.

Management Plan	Prepared By	Date	Review by Date
[Plan A]	General practitioner	[DD/ MM /YYYY]	[DD/MM/YYYY]
[Plan B]	Continence nurse	[DD/ MM/YYYY]	[DD/MM/YYYY]

Examples of related Management Plans may include:

- Advanced Care Plan
- Anaphylaxis Management Plan
- Asthma Management Plan
- Chronic Disease Management Plan
- Comprehensive Health Assessment Plan (Intellectual Disability)
- Diabetes Management Plan
- Medication Management Plan

Examples of Disability-Related Management Plans may include:

- Communication Management Plan
- Complex Bowel Care Management Plan
- Continence Management Plan
- Dysphagia and Mealtime Management Plan
- Emergency Seizure Medication Management Plan
- Epilepsy Management Plan
- Manual Handling Management Plan
- Positive Behaviour Support Plan
- Wound Care/Pressure Sore Management Plan

Medical Professional Declaration

The relevant medical practitioner should complete and sign this section of the Plan. This section must be updated whenever medical management instructions change.

Consent/Authorisation for Medication Administration

This consent confirms who is authorised to provide medication support, in line with medical instructions and organisational policies.

References

1. Commonwealth of Australia. Department of Health, Disability and Ageing. National Strategic Action Plan for Rare Diseases. Canberra; 2020. Accessed on 3 July 2026. Available from: https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-rare-diseases
2. Australian Government. Australian Public Service Commission. Definition of disability. September 2019. Accessed on 3 July 2026. Available from: https://www.apsc.gov.au/working-aps/diversity-and-inclusion/disability/definition-disability
3. Australian Bureau of Statistics. Disability, ageing and carers, Australia: Summary of findings. July 2024. Accessed on 3 July 2026. Available from: https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#disability