Rare Disease Disability Management Plan

rare voices AUSTRALIA®

Part 1. About Me – One-Page Personal Profile

Use words, images, photos, symbols, or drawings to give a short picture of your needs and preferences.

My full name	
Date of completion	Suggested review date
Name of person completing this Plan	
Their relationship to me (if applicable)	
Version/Audience	

Rare Disease Disability Management Plan

About Me

A snapshot of my strengths, preferences, and support needs.

A bit about me

What is important to me

How to support me

Top 5 things to know about me

1
2
3
4
5

Rare Disease Disability Management Plan

rare voices AUSTRALIA®

Part 2. General Information, Supports and Adjustments

Section 1: Personal Information

a. Personal Details

Full name

Date of birth

Address

Email

Telephone number

Next of kin contact details

Full name

Email

Telephone number

Emergency contact details

Full name

Email

Telephone number

b. Accessibility and Communication Needs

Gender identity
(preferred pronouns)

Cultural identity
(preferred language/dialect)

Language interpreter required ☐ No ☐ Yes

Type: ☐ Onsite ☐ Phone ☐ Video

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

Communication preferences

My communication methods

☐ Verbal ☐ Written ☐ Easy Read

☐ Visual supports ☐ Key Word Sign

☐ Communication board ☐ AAC device/application

I need a support person/communication partner to assist

☐ No ☐ Yes ☐ Sometimes

My preferred gender of partner (if relevant)

I need an Auslan interpreter ☐ No ☐ Yes

Type: ☐ Onsite ☐ Phone ☐ Video

My preferred gender of interpreter (if relevant)

c. Decision-Making/Consent

I make my decisions

☐ Independently ☐ With support

☐ Not able; substituted decision-maker required

☐ Enduring Power of Attorney ☐ Guardian

☐ Nominee ☐ Other

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

d. My Support Team

These are members of my support team.

Role	Name	Phone	Email

These are the reasonable adjustments that my support team may need.

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

e. Rare Condition Overview

My rare disease diagnosis/diagnoses (and any associated disabilities, if known).

Other medical conditions I have (if relevant).

Web links to information and resources that are relevant to my condition(s).

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

Rare disease disability impacts. For example, what a good day looks like, my worst day, or a typical day.

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

f. Other Important Information

Other important information about me that may help someone support me.

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

Section 2: Support and Reasonable Adjustments

The reasonable adjustments I need when I am in an environment that is not my home or a familiar, safe location. For example, childcare settings, education settings, or employment settings.

Environment

Environment

Environment

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

Section 3: Baseline, Early Warnings and Emergency Action Planning

a. Baseline

This is how I am when I am generally well. It is what a typical good day looks like.

b. Early Warning Signs and Triggers

These signs may indicate I am becoming unwell, fatigued, overwhelmed, or at risk of escalation.

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

c. Support Required During Escalation or Medical Episodes

This is the specific support I need during escalation or emergencies, and how I want to receive support.

d. Emergency Action Plan

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

This is when I require emergency services to be contacted, and the information that should be shared with emergency responders.

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

Section 4. Disability Impacts

This is how my rare disease disability affects my daily functioning, and the types of supports or adjustments I need.

I note which NDIS impairment categories apply to me. For each one, I describe how it affects my functioning and the supports or adjustments I need.

NDIS Impairment Category	Functional Area(s)	How This Impacts Everyday Life	Supports, Equipment Or Adjustments That Help
Physical impairment			
Intellectual impairment			
Cognitive impairment			

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

NDIS Impairment Category	Functional Area(s)	How This Impacts Everyday Life	Supports, Equipment Or Adjustments That Help
Sensory impairment			
Impairment related to psychosocial disability			
Neurological impairment			

Rare Disease Disability Management Plan

Part 2. General Information, Supports and Adjustments

Section 5: Multidisciplinary Team and Key Contacts

These are my contacts, starting with the people I contact most often or who I need to be contacted urgently if something happens.

Role	Name	Organisation/Service	Phone	Email

Rare Disease Disability Management Plan

Part 3. Medications and Medical Management

This section describes when and how my medications are administered.

It must be completed by a medical professional (doctor or nurse practitioner). You can also refer to an existing signed Medication Authority Form.

a. Medication Review

The last medication review was conducted by

Date

b. Allergies and Adverse Reactions

I have known allergies or adverse reactions ☐ No ☐ Yes (if yes, complete the below information)

I carry an EpiPen ☐ No ☐ Yes (if yes, note where it is kept in the Management/Notes column below)

Allergen	Reaction	Severity	Management/Notes

Rare Disease Disability Management Plan

Part 3. Medications and Medical Management

c. Prescribed Medications

These are my prescribed medications (as prescribed by a health practitioner). These may be used routinely or as required.

Medication	Dose	Purpose	Special Instructions

Rare Disease Disability Management Plan

Part 3. Medications and Medical Management

d. Emergency Medications and Treatments

These are the medications I need during an escalation or emergency. This should be read alongside the Emergency Action Plan section.

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 and Schedule	Purpose	Special Instructions

Rare Disease Disability Management Plan

Part 3. Medications and Medical Management

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

These are the supplements I take regularly. They include supplements purchased from supermarkets, online stores, and from pharmacies.

Supplement	Dose	Purpose	Special Instructions

Rare Disease Disability Management Plan

Part 3. Medications and Medical Management

f. Therapy

These are the therapies I need. For example, physiotherapy, psychology, art therapy and exercise physiology. The notes include special instructions for my therapy sessions (e.g., positioning, equipment, fatigue management, communication support, and pre/post-session care).

Therapy	Schedule	Purpose	Special Instructions

Rare Disease Disability Management Plan

Part 3. Medications and Medical Management

g. Medical and Disability Management Plans

This table includes links to my detailed condition specific or disability specific management plans.

Management Plan	Prepared By	Date	Review by Date

Rare Disease Disability Management Plan

Medical Professional Declaration

This care plan has been developed in consultation with the individual and their authorised representative (where relevant). The information contained herein is accurate and reflects their current health and disability status and support needs.

Signature Block – Medical Practitioner

Medical practitioner's name

Professional title

Date form completed

Professional address

Contact details

Consent/Authorisation for Medication Administration

I, _____ hereby give permission and my full consent for staff appropriately trained and qualified to carry out the above medication support or assistance, as per the medical practitioner's instructions and medication packaging.

Signature Block – Medication Administration

Individual/Authorised representative name

Individual/Authorised representative signature

To sign, select Fill & Sign → Add signature, then place your signature here.

Date

Authorised representative role (if relevant)

☐ Parent ☐ Legally appointed guardian ☐ Nominee ☐ Other