

Rare Disease Disability Toolkit



rare voices
A U S T R A L I A ®

Reasonable Adjustments in Healthcare: What Can I Ask For?

Introduction

This guide is part of the nationally codesigned Rare Disease Disability Toolkit (the Toolkit). It is for individuals and caregivers living with rare disability to use in healthcare settings. It may help you better understand what reasonable adjustments are, why they matter, and how you can ask for them.

Toolkit development was codesigned with people living with rare disease disability and facilitated by Rare Voices Australia (RVA). The Toolkit was funded by the Australian Government through the **Peer Support and Capacity Building grant** for the National Disability Insurance Scheme (NDIS).

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What Is a Rare Disease?

A disease is a condition with a specific pattern of clinical signs, symptoms, and findings, and is considered rare if it affects fewer than, or equal to, 5 in 10,000 people.

Rare Disease Disability

Nearly all of the estimated 2 million Australians living with a rare disease experience long-term impacts daily – impacts that meet the Australian Government's definition of a disability. The disability impacts of living with a rare disease often aren't recognised by policymakers. There are at least 7,000 known rare diseases, with new diseases being discovered regularly.

To address the challenge of responding to more than 7,000 different rare diseases, RVA has created the following 5 broad rare disease disability categories:

1. **Neurological/neurodevelopmental** – conditions that affect the brain, nerves, or how the brain develops.
2. **Progressive/degenerative** – conditions that get worse and more serious over time.
3. **Episodic/fluctuating** – the impacts come and go, and can change from day to day.
4. **Children with delayed development** – children who take longer to learn and do things.
5. **Undiagnosed rare disease conditions** – there is currently no name or explanation for the condition.

A disease is rare if it affects less than

5 in
10,000
people

There are

7,000+
rare diseases

An estimated

2 Million

Australians live with
a rare disease



How to Use This Guide

The guide can be used by individuals, families and caregivers to share with healthcare professionals, support coordinators and advocates.

It includes the following:



Guide

- **A Guide on Reasonable Adjustments in Health and Hospital Settings** – this describes your rights to reasonable adjustments and how to request them. This includes how to request concurrent supports from the NDIS.



Checklist

- Checklist - My Healthcare Reasonable Adjustments: What Can I Ask For?
- Checklist - My Hospital Reasonable Adjustments: What Can I Ask For?



Letter for Health Professionals

- Example Medical Practitioner Letter for Reasonable Adjustments in Hospital – for your general practitioner or medical practitioner to prepare in advance of any hospital stay.

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What Are Reasonable Adjustments in Healthcare?

'Reasonable adjustments' are changes to policies, processes, systems, or communication methods that help meet the needs of people with disability. They include inclusive practices and obligations and accessibility measures necessary to ensure equitable access to healthcare. Additionally, they help to prevent discrimination against people with disability.

These adjustments are supported by:

- Person-centred communication.
- Multidisciplinary teamwork.
- Inclusive pathways to healthcare.

They are sometimes referred to as 'adjustments' or 'reasonable accommodations'. The term 'reasonable adjustments' is used throughout this guide for consistency.



Why Are Reasonable Adjustments Important for People with Rare Disease Disability?

People living with rare disease disability often need a variety of reasonable adjustments in healthcare settings because many rare diseases affect multiple body systems. As a result, people may require communication, environmental, and system adjustments and additional supports.

If you live with a rare disease disability, you have the right to ask for reasonable adjustments in any healthcare setting. For example, when visiting your general practitioner (GP), attending a specialist appointment, or staying in hospital. These adjustments help to ensure the care you receive is safe, appropriate, and tailored to your needs.



Understanding Your Rights

Reasonable adjustments are not optional. Some of the documents that explain your rights are included below.

- The [United Nations Convention on the Rights of Persons with Disabilities](#) states that they are a human right, and that states are required to take all appropriate steps to ensure they are provided to promote equality and eliminate discrimination.
- The [National Safety and Quality Health Service \(NSQHS\) Standards](#) explains how making reasonable adjustments in healthcare creates inclusive environments, improves safety and quality of care and supports compliance.
- The [Australian Commission on Safety & Quality in Health Care](#) explains that under the [Commonwealth Disability Discrimination Act 1992](#), healthcare providers have a 'duty of care' to make reasonable adjustments to avoid discrimination, or where not safe or feasible to do so, they must explore alternatives. This duty is also reflected in the disability inclusion legislation of each Australian state and territory.

Reasonable Adjustments and Unjustifiable Hardship

The [Australian Human Rights Commission – Disability Rights](#) explain there are limited situations where a hospital may legally say no to a requested adjustment. This is usually based on the idea of significant and **'unjustifiable hardship'**, or because doing so is not feasible, or would create a serious risk to health or safety for the person with disability, other patients, or staff. If the hospital declines reasonable adjustments, it must still explore other options, explain their decision and keep records of their decision making and actions.

Complaints

If your request for reasonable adjustments is denied and you wish to make a complaint, you must first raise it with the health practitioner or health service. If you then wish to escalate your complaint, each state and territory in Australia has a government office that investigates complaints about health practitioners and services, which is sometimes referred to as the Health Complaints Commissioner or the Health Complaints Office.

Tools That Can Guide Inclusive Healthcare

Tools for Healthcare Providers

The Australian Commission on Safety and Quality in Health Care has developed the [Four Steps to Inclusive Health Care: With Me and About Me](#) to guide healthcare providers in providing inclusive care.

The Council for Intellectual Disability has a [Good Appointments Better Health reasonable adjustments checklist](#) that includes information about adjustments that help.

Tools That Help You Speak Up

The following tools can help you describe your rare disease disability impacts and speak up/advocate for reasonable adjustments:

- [Rare Disease and Disability Management Plan](#) – A plan that explains your condition/s, medical management plan, general disability impacts, and how to support you.
- [Example Medical Practitioner Letter for Reasonable Adjustments in Hospital](#) – A letter of support explaining your request for reasonable adjustments. Click here to access an example letter.
- **Health Passport** – A document that explains your needs, preferences, and how to support you.
- **Disability Health Profile** – A form used in hospitals to plan your care.



Who Can Help You?

People in different roles in the healthcare system may be able to guide you to request the necessary reasonable adjustments that can ensure your needs are being met. These may vary by location and may be offered in person or by telehealth.

These roles include:

- **Aboriginal Liaison Officer** – provides culturally safe support, advocacy, and help with navigating the hospital system.
- **Disability Liaison Officer/Nurse Navigator** – helps coordinate your care, ensure adjustments are made, and supports communication with staff.
- **NDIS Health Liaison Officer** – ensures timely communication with the National Disability Insurance Agency (NDIA), supports hospital discharge planning for NDIS participants, and helps coordinate access to necessary supports.
- **Pastoral Care or Spiritual Support** – helps with emotional or spiritual wellbeing.
- **Patient Liaison Officer** – helps resolve concerns or complaints and supports your rights as a patient.
- **Social Worker** – helps with emotional support, assistance with discharge planning, financial stress, housing, or family needs or NDIS supports.

How to Ask for Adjustments?

Here are some phrases you can use when speaking with your healthcare team about reasonable adjustments:

“I have a rare disease and disability. Can we talk about what adjustments I might need during my care?”

“I’d like to share my Health Passport with you. It explains how best to support me. Can you upload it on my patient record?”

“Can we make a personal care plan together that includes my disability needs?”

What You Can Ask For: General Categories

People living with rare disease disability may need access to a range of reasonable adjustments when accessing healthcare services. These are grouped in the following general categories:

1. Communication and Information Adjustments

Healthcare staff need to be able to communicate directly with the person and include them in any discussions about their care. This includes understanding their usual signs of pain or distress if they don't use words to communicate.

2. Environmental and Equipment Adjustments

You can ask for environmental and accessibility adjustments such as a quiet or low-stimulus space, flexible appointment times, accessible facilities, and tools like hearing loops to reduce stress and support sensory needs.

3. Support Inclusion

You can ask to have support people with you, including a carer, advocate, assistance animal, communication aide, or specialist health professionals who understand your disability needs.

4. Service Models and Procedures

You can ask for inclusive service options like telehealth, hospital tours to reduce anxiety, physical exam demonstrations to support informed consent, and pre-medication before procedures if needed.



Resources

- Use the [Checklist - My Healthcare Reasonable Adjustments: What Can I Ask For?](#) for a detailed list of reasonable adjustments.

What You Can Ask For: In Hospital

Reasonable adjustments during a hospital stay can take more planning and preparation. The hospital team may need additional evidence and information about your disability support needs to ensure that any requests for reasonable adjustments are appropriate and best provided by the hospital.

This section explains the process the hospital may use in determining your reasonable adjustments and the questions they may ask. It can help you gather the right information before you go to hospital.

Personalised Care Plan

If you are staying in hospital, staff should prepare a 'personalised care plan' or similar document that summarises your rare disease disability and support needs. This may also be called a 'disability health profile'.

This document will include:

- Your medical and disability support needs.
- What is available at the hospital.
- What you currently have in place.
- What disability-related support the healthcare service is required to provide.

You can ask for a multidisciplinary team to be involved in care planning, including allied health, social workers, and your support team.

The **Disability Health Profile** or plan should document the reasonable adjustments developed with you and what is going to be put in place during your admission.

You should request a written copy of the agreed reasonable adjustments for you to refer to throughout your hospital stay and to share with your support team.



What Will I Be Asked?

The type of information the hospital team will ask for includes the following:

- Personal care – level of assistance and equipment required.
- Eating and drinking – modified diet details, ability to swallow, risk of aspiration, ability to feed yourself, allergies, food preferences.
- Mobility – level of assistance and equipment required, how the person transfers, distance able to ambulate, falls history.
- Behaviour/emotional support strategies – triggers, comforters, level of supervision required (i.e. can the person be left unsupervised?).
- Environmental needs – assistive technology and special equipment needs.
- Communication needs and preferences – tools used, how the person expresses pain, hunger or thirst.
- Cognition – level of understanding, ability to read, level of education.
- Mental health – background information relating to supports required and any comorbidities.
- Medications and allergies.



Resources

You can prepare for these questions ahead of time. You may like to use the following tools to communicate your needs and preferences:

- [Rare Disease and Disability Management Plan](#)
- [Example Medical Practitioner Letter for Reasonable Adjustments in Hospital](#)
- **Health Passports**

Use the [Checklist - My Hospital Reasonable Adjustments: What Can I Ask For?](#) for a detailed list of reasonable adjustments.

In some cases, these documents can be uploaded into the hospital system for future reference but procedures for doing so may vary across hospitals.

Other Hospital Support Services

Other patient support services may also be appropriate, but their availability may vary from location to location. These supports may not be automatically offered, so it is important to ask. If you're unsure who to speak to, ask a nurse or doctor to refer you to a social worker or liaison officer to ask about:

- Access to a fridge or microwave for personal food storage (if needed).
- Day leave or temporary leave from the ward (where medically appropriate).
- Laundry services for personal clothing.
- Access to personal care items (e.g. toiletries, continence aids).
- Discounted or free hospital parking for you or your support person.
- Meal vouchers or subsidised meals for family members or carers staying with you.
- Accommodation support for family or carers (e.g. hospital-provided or nearby options).



What Is Not a Reasonable Adjustment in Hospital?

While hospitals and healthcare services are required to make reasonable adjustments to ensure equitable access to care, some supports do not fall under this obligation.

They include services that are part of standard clinical care or are the responsibility of other systems, such as the NDIS.

Healthcare Responsibilities

The following services are considered part of the hospital's core duty of care and are not optional:

- Medical care and treatment, including:
 - ▷ Diagnosis and management of health conditions.
 - ▷ Medication administration.
 - ▷ Wound care and pressure injury management.
 - ▷ Dysphagia (swallowing) management.
 - ▷ Complex bowel care.
 - ▷ Catheter care.
 - ▷ Enteral feeding (e.g. PEG tube management).
 - ▷ Suctioning and respiratory support.
- Personal care during admission, such as:
 - ▷ Showering and hygiene.
 - ▷ Toileting and continence care.
 - ▷ Bed transfers and mobility assistance.
 - ▷ Pressure care and repositioning.
- Allied health services provided as part of acute or post-acute care (e.g. physiotherapy, speech pathology, occupational therapy).
- Hospital-provided equipment (e.g. hoists, commodes, hospital beds).

National Disability Insurance Scheme Responsibilities

The following services are considered part of NDIS responsibilities. In coordination with the hospital, you can ask for:

- Training for hospital staff to understand your disability-specific needs (e.g. communication strategies, behaviour support).
- Assistive technology that is not part of clinical care (e.g. communication devices, environmental controls).
- Access to support coordination to help plan for discharge and post-hospital supports.

- Planning for home and living supports (e.g. Supported Independent Living or Specialist Disability Accommodation) for discharge.
- Health Liaison Officer (HLO) support to coordinate between the hospital and the NDIS.

The NDIS will not fund support workers to provide personal care or clinical care during your hospital stay or allied health services that are part of your medical treatment.

You can continue to access funded social and community supports while in hospital.

National Disability Insurance Scheme Concurrent Supports

While in hospital, some NDIS participants may also be eligible for a support worker to assist them due to their significant behavioural and/or communication support needs. These supports are referred to as 'NDIS Concurrent Supports'.

Requests for these supports must be made by the hospital to the NDIS, through the HLO for consideration by the NDIS. Requests can only be made after all reasonable adjustments have been considered.

If support workers are approved to provide support in hospital, they must always follow the rules of the hospital or health service.

If you are a NDIS participant and are admitted to hospital:

- Inform your NDIS Support Coordinator or Local Area Coordinator (LAC) as soon as possible.
- Ask the hospital to notify the NDIS HLO for your region.

If you are not yet a NDIS participant, hospital staff can help you begin a NDIS Access Request. You can request a [**Discharge Assessment Template**](#) from the NDIA to help plan for supports after discharge.



Resources

General Resources:

[Queensland Government: Support persons in health settings](#)

[Government of Western Australia South Metropolitan Health Service: Disability Health Profile Form](#)

Easy Read:

[Council for Intellectual Disability: Reasonable adjustments Easy Read](#)

Health Practitioners:

[Australian Commission on Safety and Quality in Health Care: Intellectual disability and inclusive health care](#)

[Council for Intellectual Disability: Resources for Health Practitioners](#)

[Council for Intellectual Disability: Good Appointments, Better Health](#)

[New South Wales Health: Appendix 1: Examples of Adjustments - Responding to the health care needs of people with disability](#)

NDIS:

[National Disability Insurance Scheme: Hospital discharge](#)

[National Disability Insurance Scheme: Our Guidelines](#) - Mainstream and Community Supports Overview

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