

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 Rare Disease Disability Toolkit (the Toolkit). It is for people with rare disease and their family, friends and carers to use in healthcare settings. It can help you to better understand:

- What reasonable adjustments are.
- Why they matter.
- How you can ask for them.

The guide was designed with people who live with rare disease disability.

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 September 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.

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. 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.

How to Use This Guide

This guide is for individuals, families and caregivers. You can share it with your health care team, support coordinators and advocates.

There are checklists and an example letter at [RVA's website](#) to help. More detailed information is in the [full guide](#). You may need support to use these resources.

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

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What Are Reasonable Adjustments in Healthcare?

'Reasonable adjustments' are changes that help meet the needs of people with disability. These changes may be to rules, ways of working, systems or how information is shared. They help to prevent discrimination against people with disability.

Discrimination means treating someone unfairly because of who they are. It includes being denied reasonable changes.

Reasonable adjustments are sometimes called 'adjustments' or 'reasonable accommodations.'

We only use 'reasonable adjustments' in this guide.

Why Reasonable Adjustments Are Important for People with Rare Disease Disability

Rare diseases can affect many bodily systems. This can make the care needed more complex. People living with rare disease disability often need reasonable adjustments in healthcare settings. This helps them get the care they need.

You have the right to ask for reasonable adjustments in any healthcare setting. For example, when staying in hospital or seeing your general practitioner (GP).

Reasonable adjustments help to make sure the care you receive is safe, appropriate and suits your needs.



Your Rights

Reasonable adjustments are not optional.

The [United Nations Convention on the Rights of Persons with Disabilities](#) states that they are a human right.

For more Australian-specific information, see the:

- [National Safety and Quality Health Service \(NSQHS\) Standards](#)
- [Australian Commission on Safety & Quality in Health Care](#)

You may need support when reading these resources.

Healthcare providers have a 'duty of care' to make reasonable adjustments. This responsibility is included in the disability inclusion laws of each Australian state and territory.

There are some situations where a hospital may legally say no to a requested adjustment. This is usually based on the idea of '**unjustifiable hardship**' or because the changes requested:

- Are not possible.
- Will create a serious risk to health or safety for the person living with disability, other patients, or staff.

If this is decided, hospitals must:

- Explore other options.
- Explain their decisions.
- Keep records.

Complaints

You can complain if reasonable adjustments are denied. You need to talk with the health worker or service first. If you aren't happy with their reply, you can take it further.

Each Australian state and territory has an office for complaints about health workers and services. This is sometimes called the Health Complaints Commissioner or the Health Complaints Office.

Tools to Help Make Healthcare More Inclusive

Tools for Healthcare Providers

- [Four Steps to Inclusive Health Care: With Me and About Me](#) – Australian Commission on Safety and Quality in Health Care
- [Good Appointments Better Health reasonable adjustments checklist](#) – The Council for Intellectual Disability

Tools That Help You Speak Up

- [Rare Disease Disability Management Plan](#) – A fillable form to help explain your condition and how to best support you.
- [Example Medical Practitioner Letter for Reasonable Adjustments in Hospital](#)
- **Health Passport** – 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

Different health workers can support you in requesting reasonable adjustments. What's available may depend on the location. This help may be given in person or by telehealth.

Health workers in the following roles may be able to help you:

- **Aboriginal Liaison Officer** to help with the hospital system.
- **Disability Liaison Officer/Nurse Navigator** to help coordinate your care.
- **NDIS Health Liaison Officer** to speak to the National Disability Insurance Agency (NDIA). They can support hospital discharge and coordinate access to supports.
- **Pastoral Care or Spiritual Support** to help with emotional or spiritual wellbeing.
- **Patient Liaison Officer** to help with your rights as a patient.
- **Social Worker** to help with things like emotional support, NDIS supports or housing.

Some Examples of How to Ask for 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

- **Communication and information adjustments** so health workers can talk with you about your care. If you don't use words to speak, this includes health workers understanding signs of pain or distress.
- **Adjustments to the space around you and equipment.** For example, a quieter room or access to tools like hearing loops.
- **Support people or animals** to help you. For example, a carer, assistance animal or health worker who understands your needs.
- **Inclusive service options** like telehealth and hospital tours to reduce anxiety. You can ask to be shown the physical exam process to support informed consent.

In Hospital

Hospitals use a process to determine the reasonable adjustments needed. You will likely be asked questions about the disability support you need. **It can be helpful to gather the right information before going to hospital.**

Personalised Care Plan

Hospital staff should create a document for you while you're in hospital. It may be called a 'personalised care plan'. It could also be called a '[disability health profile](#)'. It will include:

- Your medical and disability support needs.
- What is available at the hospital.
- What is currently in place.
- The disability-related support the healthcare service must provide.

You can ask for a team of health workers to be involved in care planning. For example, social workers and your support team.

Your personalised care plan should state:

- The reasonable adjustments developed with you.
- What will be in place during your hospital stay.

You should request a written copy of reasonable adjustments agreed to. You can then use this document during your hospital stay and share it with your support team.

Example Questions That the Hospital May Ask You

Questions About Your Daily Needs

- How much help do you need daily with tasks like eating?
- Can you swallow without the risk of choking?
- What foods do you prefer?
- Do you have a special diet?
- Can you be left alone?
- How do you communicate?
- How do you show you are in pain, hungry or thirsty?
- Do you need any help understanding what's happening?

Questions About How You Move

- Can you move around by yourself?
- Do you need help in situations like getting in and out of bed?
- Have you had any falls?

Questions About the Tools and Equipment You Use

- What equipment do you use?
- Do you use any tools to help you communicate?
- Do you have any other special equipment needs?
- Do you use any assistive technology?

Questions About Health

- Are you taking any medications?
- Do you have any allergies?
- What's your mental health history?
- What helps when you're feeling overwhelmed?

Other Hospital Support Services

Other supports may also be available in hospital. These supports may vary. It's a good idea to ask about other supports, as they may not be suggested without asking. You can ask a nurse or doctor for help if you don't know who to speak to. They can connect you with a social worker or liaison officer.

Other support services to ask about:

- Using the fridge or microwave for food you bring in.
- Leaving the ward for the day or short periods, if it is medically safe to.
- Laundry services.
- 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.
- If there is a place to stay for your family or carers. For example, a place provided by the hospital or somewhere nearby.



What Is Not a Reasonable Adjustment in Hospital?

Not all supports fall under the category of reasonable adjustments. Some supports are the responsibility of other systems, like the NDIS.

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

Medical care and treatment, including:

- Diagnosing and managing health conditions.
- Giving medicines.
- Caring for wounds and pressure injury management.
- Swallowing (dysphagia) management.
- Complex bowel care.
- Catheter care.
- Enteral feeding (e.g. PEG tube management).
- Suctioning and breathing support.

Personal care in hospital. For example:

- Showering and hygiene.
- Using the toilet and continence care.
- Helping you get in and out of bed and move around.
- Pressure care and helping you change positions.

Allied health services, like:

- Physiotherapy.
- Speech pathology.
- Occupational therapy.

Equipment the hospital provides, like:

- Hoists.
- Hospital beds.

National Disability Insurance Scheme Responsibilities

In coordination with the hospital, you can ask for:

- **Training for hospital staff** so they understand your needs. For example, how to best communicate with you.
- **Assistive technology** you use daily, like communication devices and environmental controls.
- **Support coordination** to help with planning to leave the hospital and supports needed after your hospital stay.
- **Planning for home and living supports** for when you leave the hospital. For example, Supported Independent Living or Specialist Disability Accommodation.
- **Health Liaison Officer (HLO)** support to coordinate between the hospital and the NDIS.

The NDIS will not fund:

- Support workers for personal or clinical care when you are in hospital.
- Allied health services that are part of your medical treatment.

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

National Disability Insurance Scheme Concurrent Supports

Some NDIS participants may be able to get a support worker to assist them with behavioural and communication support needs. These are called '**NDIS Concurrent Supports**'.

The hospital's Health Liaison Officer (HLO) needs to ask the NDIS for this support. All reasonable adjustments must be considered beforehand.

If you can get a support worker while in hospital, they need to follow the rules of the hospital or health service.

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

- Tell your NDIS Support Coordinator or Local Area Coordinator (LAC).
- Ask the hospital to contact the NDIS HLO for your region.

If you are not a NDIS participant, hospital staff can help you begin a NDIS Access Request.

You can also ask for a [**Discharge Assessment Template**](#). This can help you plan for supports after you leave the hospital.

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