

Rare Disease Disability Toolkit



rare voices
A U S T R A L I A ®

Navigating Air Travel with Rare Disease Disability

Introduction

This guide is part of the nationally codesigned Rare Disease Disability Toolkit (the Toolkit). It is for people with rare diseases and their family, friends and carers.

The guide helps to make travelling with Australian airlines easier. It 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 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.

How to Use This Guide

This guide can help to make air travel with rare disease disability easier. Your family, friends, or carers can also use the guide to help plan air travel for you.

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

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There are

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rare diseases

About

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Australians live with
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Rare Disease Disability and Air Travel

Travel can be hard for people with rare disease disability. Higher support needs can make travel harder. Your health needs, the equipment you use, or how you need to communicate can be barriers. Along with how airports and airlines work, these barriers can make air travel challenging. Planning ahead can help.

Some common issues are:

- Trouble getting through security screening.
- Rules that change between airlines for using medical supplies on planes.
- Limits on battery-powered devices.

Getting on and off planes, finding your way through the airport, and being in new places can be hard without help.



Your Rights

People with rare disease disability have the right to travel safely and with dignity. Disability rights are human rights.

Australia has agreed to follow the [**United Nations Convention on the Rights of Persons with Disabilities \(CRPD\)**](#). This means the Australian Government will make sure people with disability have the right to:

- Be in the community, including when travelling.
- Access the same services and facilities as everyone else.
- Use assistive technology and support aids.
- Expect reasonable changes to be made to meet their needs.

These rights belong to you. It doesn't matter what disability you have, or if others can see it.

Discrimination means treating someone unfairly because of who they are. It includes being denied reasonable changes. The [**Disability Discrimination Act 1992**](#) makes it illegal to discriminate against someone because they have a disability.

Airports and airlines need to offer reasonable changes. For example, disabled toilets and boarding ramps at the airport.



Useful Links:

[**People with special circumstances**](#): Australian Government Department of Home Affairs

[**Advice for travellers with a disability**](#): Smartraveller

[**Passengers with disability and reduced mobility**](#): Civil Aviation Safety Authority

Help at the Airport and on Your Flight

Airports and airlines offer a range of supports to help make travel easier and inclusive. Supports can depend on the size of the airport and the type of plane.

When planning to travel, check with the airport or airline to see if you can use these supports.

Before Flying

Check if these supports are available **before flying**.

- **Accessibility and Sensory Maps** point out quiet zones, disabled toilets, ramps, and other supports.
- **Airline and airport guest services**, which you can use by phone and in-person. Most airports and airlines have staff who can help you. They can help with booking flights, getting through the airport, and boarding the plane. Talk to staff a few weeks out if you need to take anything with you like mobility aids. If you can't move around by yourself, airport staff cannot leave you alone for more than thirty (30) minutes at the airport. It's important that you **ask for this help when you book your ticket** and again **two (2) to three (3) days before your flight**.
- **Airport journey videos and audio navigation apps** show you what to expect at the airport and where to go. These guides can help to lower your anxiety when planning your trip.
- **Carer concession card discount flyer programs**. Some airlines offer cheaper plane tickets for carers travelling with you. Your carer must meet some requirements to get the discount.
- **Disability drop-off zones and curb side help** at the airport. If you ask beforehand, airport staff may be able to help you in these areas.
- **Seating supports and harnesses** may be able to be used if you have trouble sitting or staying upright by yourself. Speak to airline staff about these supports before flying.
- **Separate or private screening areas** are available at some airports. Ask the airline and airport guest services about this before you fly.

While You're At The Airport

Check if these supports are available **at the airport**.

- **Bathroom areas for support animals** for guide dogs and other support animals.
- **Disabled toilets and changing places** that are private with hoists, showers and adult change tables.
- **Hearing loops** that allow people using hearing aids to hear announcements at airport terminals.
- **Priority check-in and baggage drop** options so you can skip waiting.
- **Sensory or quiet rooms** to rest in, which are less busy rooms that aren't brightly lit. They can help with calming you down before or after a flight.
- **Therapy dogs and support animals** may be available at some airports to help if you are feeling stressed or anxious.
- **Visual tools and story-based guides** to help neurodivergent passengers.
- **Wheelchairs** may be available if you have trouble walking. Ask the airport if you can loan a wheelchair. Airline staff may also be able to help you if you are travelling alone.

Larger aids, like manual wheelchairs, are typically checked in at the gate. Smaller aids, like canes, can be stored in cabin spaces.

On The Plane

Check if these supports are available **on the plane**. It's best to reach out to the airport about these supports **before booking your ticket**.

- **Aircraft aisle chairs** (a narrow wheelchair) to help you get to your seat if you have trouble walking.
- **Hoists** may be available on bigger planes to help transfer you from your wheelchair to the plane seat.
- **Mobile boarding ramps and bridges** to help with boarding the plane. If these supports are needed, always check with smaller and regional airports.
- **Slings, slide boards and/or mobility belts** may be available to help with getting on and off the plane, or if you need to get up during the flight. There are rules about what airline staff can help you with. A carer may need to travel with you to use this equipment.

Airline staff can help you on the plane with things like explaining meals, opening drinks, and going to and from the bathroom. **They can't help you eat, go to the toilet, or give you medical care during the flight.**

National Assistance Cards and Programs

- A [Hidden Disabilities Sunflower Lanyard](#) tells people you have a disability that may not be easy to see. Seeing a lanyard tells people to be patient, understanding and to offer extra support. You can get a lanyard from the Guest Services desk at participating airports.
- Having a [National Access Card and Lanyard](#) tells people you have a disability and what you may need help with.
- If you are autistic or have a brain injury, you can get a [National Assistance Card](#). The card tells people how they can help you and who to call in an emergency.

Before Travelling

Flying Alone

There are rules about travelling alone with rare disease disability when flying on a plane. For example, you need to be able to go to the bathroom alone, eat and drink without help, and take your medication.

If you can't do all the things in the airline rules, you will need to travel with a carer.

Before travelling alone, you can do a trial run to see if the supports you need are available.

Accessibility Planners

Before booking plane tickets, visit the Accessibility section of the airport's website to see what help is available. Accessibility webpages can help you to pre-plan your trip. They often include information and images of the airport and services.

Travelling with Equipment and Medical Needs

It's important to know what documentation and approvals you may need **before flying**. Airlines often need to know what equipment you are bringing before travelling. They may ask for supporting documents.

You may be asked to bring a letter from your doctor saying it's safe for you to fly. The letter may also need to explain any needs you have. For example, medication needs.

Checking what airlines need early means you have enough time to prepare everything.

Airline and Airport Guest Services

Tell the airline about any support you need when booking your ticket. **You can ask the airline and airport guest services team for help.** They may ask for more information.

It's a good idea to call the airline **two (2) to three (3) days before flying** to confirm your support needs.

Medical Clearance

Airlines will ask for a medical clearance if you are impacted by changes in cabin pressure and oxygen levels. For equipment, you may be asked for a **Medical Clearance Form**.

You may need to carry management plans for conditions like asthma or epilepsy.

If a condition is long-term, medically stable, and managed by your health team, you may need a **Long-Standing Medical Clearance**.



Baggage Allowance

Make plans with the airline before flying if you need to put medical aids and equipment into baggage.

Bring any medical items needed during the flight with you on the plane. Label everything clearly and keep them in the original packaging if you can.

Mobility Aids

Let the airline know as soon as possible about any mobility aids, like a wheelchair, that you need to travel. Devices with batteries must meet national and international safety rules.

You will need to provide the airline with information like battery type, if a device is collapsible, how it can be put together and taken apart, and measurements.

Airlines have size and weight limits for mobility aids. They can vary by airline.

Speak to your airline about your mobility aids before flying.

You won't be able to sit in your own wheelchair on the flight. You must be able to sit in a plane seat to fly. A carer can help you get into your plane seat if needed.

Airlines may have supports like plane aisle chairs, slings and hoists. Ask the airline before flying.

Insurance

Mobility aids can get damaged during travel. You are responsible for arranging insurance for your mobility aids.

Security Screening

Asking about other options for security screening can help you to prepare.

You can ask the airport about different supports for security screening. If you need supports, carry a letter from your doctor to explain your needs. You can also use the [Airport Screening Notification Card](#).

Some medications, aids and medical devices should not go through X-ray scanners. Wheelchairs, mobility aids, and vision support canes cannot pass through body scanner screeners. Let screening staff know if you can't be separated from these items.

You may also be separated from other personal belongings during screening. You can ask airport staff to look after your items until you've been through screening.

Percutaneous Endoscopic Gastrostomy (PEG) Feeding Pumps

Airlines follow procedures for using Percutaneous Endoscopic Gastrostomy (PEG) feeding pumps while flying. Most airlines will need you to:

- Organise approval with the airline **at least five (5) days** before travel.
- Send a **Medical Clearance Form** completed by a medical practitioner confirming you can fly.
- Follow their rules for using feeding pumps while on the plane.

PEG feeding pumps should be packed in carry-on luggage if needed during the flight. Check when they can be used on the flight when booking.

Onboard Oxygen Pumps

There are safety rules for using oxygen equipment like portable oxygen concentrators (POCs) or oxygen cylinders while flying.

Airlines don't provide oxygen concentrators. Some airlines may have oxygen cylinders for a fee on some flights.

It's important to make sure you have enough oxygen and battery power for your entire trip. In general, bring only what you need for the flight, but allow for delays.

POCs are generally allowed if they meet safety and battery rules. Most airlines will need you to:

- Arrange approval with the airline **at least five (5) days** before travelling.
- Send a **Medical Clearance Form** to the airline. This must be completed by a medical practitioner to confirm you can fly.

More helpful information

CPAP machines and oxygen devices must be airline-approved and labelled with manufacturer safety information.

If you need help using your devices, you will need to travel with a carer. Carry a copy of the device manual with you and always follow the instructions.

Airline staff can't provide medical support when you are on the plane.

Flying with Assistance Animals

You can bring some assistance animals onboard if they meet the airline's rules. For example, guide dogs.

Let the airline know you'd like to bring an assistance animal onboard when booking. You should confirm your assistance animal is coming with you **at least fourteen (14) days** before flying.

If they think it may be a safety risk, the pilot or airline may refuse to allow your assistance animal onboard the plane. The decision made needs to meet the rules of the [Disability Discrimination Act 1992](#).

Blind or Vision Impaired Passengers

Safety cards in Braille are available on most planes. After the safety briefing, you can request a Braille card from the flight attendant.

Airline staff can also read the meal menu aloud and describe the placement of food items on your tray upon request.

Deaf or Hearing-Impaired Passengers

Let airline staff know how you like to communicate. They can provide written information if asked.

Some planes will have subtitles and captioning on in-flight shows and movies.

Airport Transfers and Connections

Connecting flights can be hard with medical needs. Having issues with moving from place to place or using the bathroom can make connecting flights challenging. Speaking with airline staff can reduce stress and avoid missing connecting flights.

Plan Ahead

Tell the airline about connecting flights when booking and confirm them at check-in.

Ask airline staff for help to transfer between gates. If you have trouble walking, you can ask for an airport buggy or wheelchair.

You can also ask staff to call the next gate, so they know you are on your way. If boarding has started, this can stop your seat being given to someone else.

Getting on a Connecting Flight

You may not be able to get on the plane before other passengers on a connecting flight. Ask airline staff if they can help. Let them know what support you might need to get on the plane if everyone else is already onboard.

Hygiene and Supplies

There may be extra time between flights at the airport. Plan for a bathroom break before getting on the next plane. Use the airport map or ask airline staff where the closest disabled toilets are.

If you need medical or feeding supplies between flights, tell airline staff as soon as you can. Tell them what you need and the time it takes so that they can help.

Tips for Reducing Stress

- Carry essential items (for example, medications) in your cabin baggage.
- Keep airline and assistance contact numbers handy in case of delays or gate changes.
- Ask staff for help if you need to rebook your tickets because of a missed flight or gate changes.

Speaking Up for Yourself

Tell the airline if you feel unhappy with how you've been treated while flying. You can find out how to send a complaint on their website.

If you're unhappy with the response you receive, you can go to the Airline Customer Advocate (ACA). They can help you to resolve the issue with the airline. The ACA has a complaint form on their website.

You can also complain to the Australian Human Rights Commission (AHRC). They can help with disability discrimination.



References

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