

Travel Support and Tips

Travelling with EDS, whether it's a short or long journey, can have a big impact on our health. We have put together this guide for you which includes nationwide services that you may be eligible for, as well as some handy tips and tricks from EDSer's around NZ in helping make your journey more comfortable.

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MOBILITY PARKING PERMIT

The Mobility Parking Permit allows the holder to park in designated mobility parking spaces around the country. These parks are usually wider and closer to the entrances of shops allowing people with limited mobility greater freedom in going out. The wider parks allow for ease of access in getting in and out of vehicles. There are two types of permits; the Long-Term Permit which is for people with a long-term disability, this permit lasts for 5 years, and the Short-Term Permit which is for people who need mobility help for a temporary condition such as recovering from a hip replacement, this permit lasts for a minimum of 3 months with a maximum of 12 months.

The Mobility Parking Permit is applied to through CCS Disability Action, who work in combination with Waka Kotahi New Zealand Transport Agency, who manage legislation around parking requirements and fines, Local Councils, who monitor on-road parking spaces, and Doctors and GP's around the country who assess people to determine their eligibility.

Eligibility

Just having a medical condition or a disability does not automatically entitle you to a mobility parking permit, there is criteria that must be met to be eligible which must be confirmed by your doctor. The criteria is as follows:

1. You are unable to walk and always require the use of a wheelchair, or
2. Your ability to walk distances is severely restricted by a medical condition or disability. If for example, you require the use of mobility aids, experience severe pain, or breathlessness, or
3. You have a medical condition or disability that requires you to have physical contact or close supervision to safely get around and cannot be left unattended. For example, if you experience disorientation, confusion, or severe anxiety.

Applying for A Mobility Parking Permit

There is an application form which will need to be filled out by both yourself and one of your doctors which you can download from [here](#). Alternatively you can contact your [local CCS branch](#) and they will send you out a form.

There is a fee for the Mobility Parking Permit. This fee differs depending on what type of permit you are applying for, with the 5-Year Permit costing \$50. Payment for your Mobility Parking Permit is included in the application.

Once completed, the application is then sent to CCS for processing. This information, along with contact information for CSS is also on the application form.

For more information about the Mobility Parking Permit –

[CCS Disability Action – Mobility Parking Permit](#)

NATIONAL TRAVEL ASSISTANCE

The National Travel Assistance scheme may be available to you for help in travelling to and from hospital and specialist appointments. This scheme reimburses you for money spent on travelling costs such as petrol, public transport, or flying, even accommodation costs, if you are regularly travelling long distances for health appointments.

There are many different criteria that need to be met in order to be eligible for this assistance, which includes distance travelled, frequency of travel, what type of appointments you are travelling for, and even where in the country you are located. You can use the Ministry of Health's [National Travel Assistance Eligibility Checker](#) to see if you qualify for this assistance.

The National Travel Assistance scheme is run by the Ministry of Health, there are support staff located at most hospitals who can assess you for eligibility and help you fill out the necessary forms needed. Each time you attend an appointment, you will need fill out the form and have it signed off at the reception of the hospital department you are visiting.

For more information, including Region specific information, please read the Ministry of Health's page about the [National Travel Assistance Scheme](#).

TOTAL MOBILITY SCHEME

What is the Total Mobility Scheme? The Total Mobility scheme is a provided service throughout New Zealand that subsidises door-to-door transport for all disabled people who cannot independently use regular public transport services, either for all trips, or some trips. The Total Mobility scheme provides users with a 50% discount using selected services, such as taxis, including wheelchair accessible services. This is provided as either an electronic card or a book of vouchers.

Eligibility

You may be eligible for the Total Mobility Scheme if you have a long-term or permanent disability that stops you from using one or more of the following 5 aspects of a journey by yourself using public transport –

- Getting to the place where the transport departs
- Getting onto the transport
- Riding securely
- Getting off the transport
- Getting to your final destination point.

Applying for the Total Mobility Scheme

Total Mobility is a joint venture between local councils and central government, including Metlink, Auckland Transport and Waka Kotahi NZ Transport Agency. This means you will need to contact a local agency about applying for the Total Mobility Scheme. Waka Kotahi NZ Transport Agency have provided a very detailed brochure which you can [find here](#).

This brochure breaks each region down, with details on who you need to talk to about applying for the Total Mobility service, as well as a list of operators who accept Total Mobility vouchers/cards within each region, their contact details and whether they are wheelchair accessible or not.

As part of the application process you will need to sit through an assessment which takes between 20-30 minutes, and includes the assessor taking a photo of you for printing onto your Total Mobility identification card. You can have the assessment at your own home or at the support agency office.

For more information on the Total Mobility scheme –

[Wellington Metlink](#)

[Waka Kotahi NZ Transport Agency](#)

TRAVEL ADVICE

Flying

There is no indication against being on an aeroplane with a diagnosis of EDS, but it is worth considering the risk associated with long haul flights. If a medical emergency were to happen mid-flight there would be a considerable delay before any medical assistance would be available.

Assisted Travel

Book special assistance at the airport for your outbound and inbound journey. Most airports provide this service and a patient diagnosed with EDS is no exception. Special assistance is also provided by most train operators including wheelchair ramps.

Please note: It is advisable to check with your operator/airport and book in advance.

Airport Sunflower Lanyards

By wearing one of the airport's Sunflower Lanyards, it will discreetly indicate to staff that you have a hidden disability, and you would like additional support. Airport staff have been trained to recognise these lanyards, and to provide you with any help you may need at various stages at the airport.

The lanyard also "permits access to the family and priority lanes at security as well as the use of special assistance lanes on arrival at the airport." It will also allow you priority boarding on to the aircraft and special assistance at the onward destination airport.

Please note: Please contact the airport customer service team directly who will be able to provide you with information on their current services and a lanyard, if available. As of December 2020 this initiative is being [launched in New Zealand](#), so may not currently be available at all airports.

Travel Plans

We recommend planning for your vacation, making travel plans will not only help to ensure your safety, it will also ensure you maximise your time away so you can enjoy your break.

- Where is the nearest hospital with emergency care?
- Wear your MedicAlert bracelet if you have one.
- Purchase travel insurance.
- Communicate with travel providers before departure to find out what extra support they can give.
- Communicate with accommodation providers so you know what facilities are available, can request a room location that might be easier (floor access etc).
- Most importantly, make memories which will last a lifetime!

Travel Insurance

Travel Insurance is essential and should not cost you significantly more because of a diagnosis of EDS. It is well worth shopping around and visiting comparison websites to get the best package at the right premium.

Medications

Have a letter from your GP itemising all of your medication (prescription & over the counter), have all of these medications in your carry on in a clear bag, take enough for the length of your trip + some extra incase of delays, you will need to show all your medications at both departure and arrival of each country so prepare for this (be friendly and nice, customs will sometimes just wave you through if they see you have your medications bag and letter ready to show them).

Other tips for flying

If you can, try to start a conversation with the flight attendants. These are the people who are there to help you during your flight, and they are the best people to get on your side. Be friendly and kind with them, for passengers they like they will provide extra pillows and blankets - Don't be afraid to ask for these, there is no shame in asking or disclosing that you may need more assistance, extra pillows can help you get more comfortable on the flight which may enable you to feel better on landing. Alternatively, buy a neck pillow and carry that on board with you. Bonus, the neck pillow can also be used when travelling by car!

Traveling by Car

If you are long-distance travelling via car, there are steps you can take to mitigate the effects of travel. Try to travel outside of peak hour traffic, preferably early morning to avoid traveling during the heat of the day.

We recommend taking a pillow and a lap blanket so while traveling you can rest comfortably; the pillow will allow you take the strain off any sore joints as you can pop it under your knees, use it to rest your arms on, or even use it as a pillow to get some sleep, while the blanket can block out sun, or keep you warm. Take frequent breaks on long-distance journeys, stop in towns to use the pit-stop facilities, and have a stretch and walk around a little to clear any stiffness in the joints. Pit-stops are also a fantastic time to grab a bite to eat and hydrate. If it's a route you haven't taken before, prepare in advance by choosing pit stops that will suit your needs, including knowing where toilets are along the way, and eateries that suit any particular dietary requirements you may have.

Take snacks with you in the car which are easily reached from your seat. If you have Postural Orthostatic Tachycardia Syndrome make sure you have plenty of water on you to stay well

hydrated and consume with a salty snack like popcorn or rice crackers, so you aren't needing to stop too frequently to use pit-stop facilities.

Try to share the driving load, if possible, between multiple people so you aren't too fatigued or sore when you get to your destination. Once at your destination, find some time to rest. Traveling can be taxing on healthy people, let alone people with chronic health conditions like EDS. It is important to make sure you get sufficient rest once at your destination so you can enjoy any activities you have planned without overdoing it, even if this means when planning your trip you head off a day early.

Take something to do during the journey, a good book or an easy craft project such as knitting or crochet, maybe a tablet with some games or access to watch a movie or tv show. Don't overdo it with your chosen activity, take frequent breaks to avoid strains and headaches. Make a fun music playlist that you can play while traveling.

Where possible, bring aides. A walking stick, crutches, or a foldable stool in the boot as a "just in case", can mean the difference between enabling yourself to enjoy your day for longer/with less fall out, vs being in pain for days. Aides help enable us to do more, not less.