



TRAVELLING WITH ALS

While travel can present unique challenges for people with ALS, a comfortable travel experience is possible with planning and patience.

This fact sheet offers tips for planning a trip while living with ALS, whether it is a local day trip or a longer excursion including air travel. These tips may be helpful for things like running errands or visiting a specialist in another city, too.

Managing your energy

It can help immensely to carefully plan your days and manage your energy when travelling.

- Space out tiring activities. If your day involves more than one activity, it could help to plan for a break in between. Or consider alternating between busy days and days that are dedicated to relaxation.
- Consider using a more supportive mobility device for the day. For example, if you usually use a walker, you may choose to use a wheelchair or mobility scooter instead. An Occupational Therapist will be able to recommend the right equipment to suit your needs. Appropriate devices can help you save your energy for the activities you are planning.
- Communicate your needs in advance to the people you'll be travelling with. If you are travelling with others, make sure they understand what you will need in order to enjoy the day.

Local Travel

Local travel may include day trips, sight-seeing, running errands or medical appointments. It can help to plan all stops in advance, including restaurants, and to contact your

destinations before travelling to ensure their approach to accessibility will meet your needs and that no further arrangements are required. Some tourist attractions may have power scooters or transport wheelchairs available to borrow or rent.

Packing the right things can also make a day trip more enjoyable. Here are some items you may want to consider bringing with you when you leave your home:

Respiratory equipment and supplies:

- BiPAP with backup battery
- Cough assist and suction machines
- Toothettes

Mobility

- Accessible parking pass
- Backup battery for wheelchair
- Hoyer lift swing
- Other mobility devices as recommended by your Occupational Therapist

Nutrition/Feeding Supplies

- Food, snacks, and/or thickener packets
- Feeding tube equipment and formula
- Straws
- Adapted utensils or grips
- Bottles of water

Other considerations

- Fully-charged communication device (as well as backup low-tech communication device e.g. alphabet board or book)
- Extra clothing/blankets if outdoors
- Urinal and/or incontinence underwear, if unsure of availability of accessible washrooms
- Neck brace or travel pillow
- Tissues, washcloths and/or wipes
- Medications



ACCESSIBILITY TIPS

It is a good idea to ensure your destination is accessible ahead of time. This will help prevent arriving at your destination only to find it is not as accessible as advertised: just because a building has an accessible entrance does not mean you will be able to access the bathroom or other important areas. Ensuring accessibility often requires getting the answers ahead of time. You will likely need to be persistent, and to ask many questions. Phoning ahead, or asking someone to do so for you, can save you a lot of hassle.

When you first call, explain to the person you're speaking with that you have specific accessibility needs and ask them if they or a colleague can provide detailed information to help you plan.

Accessibility language and standards can vary widely across different regions of the world. For example, the terms barrier-free and accessible can have different meanings. Rather than using these terms, it can help to ask directly about the specific accommodations you require.

HELPFUL RESOURCES



AccessNow is a mapping application that ranks buildings for accessibility features and enables people to leave reviews. Visit www.accessnow.com or download the app.

AIR TRAVEL

Most people with ALS can fly safely and smoothly with the right planning.

Here are several things you can do to help prepare for air travel. Many of these tips apply to long trips of any form, whether by plane, train, or car.

- **Speak with your doctor about your trip before you book.** Your doctor will need to evaluate whether it is safe for you to fly, and what special needs you might have. They

can offer valuable advice and they may also be able to provide a letter to clear you for extra luggage, a support person, BiPAP use on board the plane, or medications and nutrition supplements you need to travel with.

- **Contact the airline.** Ask the airline about the accommodations that can be made at the airport and while in flight. Give as many details as possible about what you can and cannot do. It can help to assume people do not know anything about ALS, and to communicate your specific needs instead.

- **Plan around your mobility device.** If you are flying with a mobility device, ask about checking it. If you will have a power scooter or wheelchair with you, ask the airline if it can be accommodated in the cargo hold, and be prepared to tell them what type of batteries the chair has. This is important for security. It can also be helpful to have the make and model of your wheelchair written down in case the airline needs assistance identifying it, or if you need to call for repairs. You may wish to wrap the joystick in bubble wrap to protect it (the airline will be able to push the chair in manual mode). It's also a good idea to confirm that you will have access at the gate to your mobility device when you land.
- **Consider toileting needs ahead of time.** What strategies will give you peace of mind? Some options on board the plane include being transferred to the washroom using an aisle chair, using an external catheter, and using incontinence underwear.
- **Plan out accessible transit at your destination.** Some wheelchairs and scooters can easily be folded and placed in a standard car. Others require accessible transportation. Some accessible transit options include an accessible taxi, renting an accessible van, accessible rideshare such as Uber / Lyft, or public accessible transportation options. It is important to have a plan ahead of time, as accessible transit is not something that can be assumed.

- **Bring important phone numbers.** Always travel with the phone numbers for your wheelchair repair department, important healthcare contacts, and the numbers for your assistive devices service providers. It can also help to see if you can find a local repair option at your destination before leaving, just in case.
- **Charge up.** Ensure all of your equipment (e.g. BiPAP, wheelchair, external BiPAP battery, suction and cough assist machines, communication device) is fully charged before leaving your home.
- **Bring items to enhance comfort.** A gel pad or air cushion can help relieve pressure during long flights or car rides.
- **Look into travel insurance.** People with ALS may have difficulty in acquiring adequate travel insurance coverage, as ALS is typically considered a pre-existing and unstable condition. You may want to inquire about coverage with several different insurance companies and brokers. You may also require a letter from your doctor to support your application.



HOTEL ACCOMMODATION

Knowing what you need before contacting a hotel can help make the process easier. It can help to think through all of the accessibility needs you encounter during a regular day; for example, entering and leaving your home, toileting, bathing, eating, and other activities. Consulting with an occupational therapist can help you to determine what will be needed to make your stay safe and comfortable.

Here are some things to consider when evaluating potential accommodations. Do you need a walk-in or roll-in shower?

- Do you need grab bars or higher seat heights in the bathroom for transfers?
- Do you need a bed rail?
- Does the room/bathroom need to be able to fit your wheelchair, or other mobility device and/or bathroom aids?
- Do you need to be on the ground floor, or is there an elevator that will fit your wheelchair?
- Is the front entrance accessible?
- Are the amenities (e.g. breakfast room, swimming pool, etc.) accessible?

If you are staying for a long period of time, see if the hotel will allow you to rent specialized equipment (e.g. hospital bed, lift chair) from a local mobility store. Some cheaper accessible equipment (e.g. raised toilet seat) may be worth purchasing for a longer stay.

You can also ask your local ALS Society about loaning equipment. They may be able to connect you with someone locally where you are travelling, so you do not have to bring the equipment with you.

KNOW THAT WE ARE HERE TO HELP

The ALS Society of Canada can assist in connecting people and families living with ALS in Ontario to support services, equipment, and ALS clinics. We also invest in the most promising Canadian ALS research, advocate federally and provincially for the needs of people affected by ALS, and provide information to empower Canadians affected by the disease. Learn more at www.als.ca where you can also find more resources in the “What is ALS?” section.

If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region.

More information about travelling with ALS is included in the ALS Guide at www.als.ca/alsguide.

Thank you to occupational therapist Brianna Marshall for her contributions to this fact sheet.

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