

# Travelling with ALS

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

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

With local travel, it helps to plan your route and stops in advance, and to ensure you have packed the items you need for comfort. You can phone restaurants and other stops in advance to ensure they can meet your needs.

When flying, most of the preparation takes place when booking your ticket. At that stage, you'll make sure the airline can accommodate you, your support person, and your wheelchair, if necessary. You can plan things like toileting and eating before you start your trip.

Hotels vary in their accessibility, but by asking the right questions, you can find out if a hotel can meet your needs.

## GENERAL TIPS FOR TRAVELLING WITH ALS

People with ALS know they need to carefully plan their days and manage their energy when travelling, whether local or long-distance.

Here are some tips for managing your energy when out and about.

- **Space out tiring activities.** If your day involves more than one activity, it could help to plan for a break in between.
- **Consider using a more supportive mobility device for the day.** For example, if you usually use a walker, use a wheelchair instead. This can help you save your energy for the activities you are planning.
- **Communicate your needs to the people around you.** If you are travelling with others, make sure they understand what you will need in order to enjoy the day.

## LOCAL TRAVEL

Local travel might involve sightseeing, but these tips can apply to any prolonged period outside your home. This can be as simple as running an errand or visiting your specialist at the hospital.

It can help to plan all stops in advance, including restaurants. That way, you can phone ahead to all planned destinations to inquire about accessibility. 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 things to consider bringing with you when you leave your home.

- Adapted utensils or grips
- Straws
- Urinal
- Medications
- Food, snacks, and / or tube feeding formula
- Backup battery for BiPAP or wheelchair
- Cough assist and suction
- Communication device
- Backup low-tech communication device such as an alphabet board or book
- Change of clothing

## 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. 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, tell the person you're speaking with that you have specific accessibility needs and ask them if they can connect you with a colleague who will be able to provide detailed information.

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

## AIR TRAVEL

People with ALS can fly safely and smoothly with the right planning.

Almost everything you can do to improve your flight experience takes place at the planning stage.

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.

1) **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, as well as provide a letter to clear you for extra luggage, a support person, BiPAP use on board the plane, or medications you need to travel with.

2) **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.

3) **Plan around your mobility device.** If you are flying with a mobility device, ask about gate 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. 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.

4) **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 disposable undergarments (e.g. Depends).

5) **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 transit (e.g. WheelTrans). It is important to have a plan ahead of time, as accessible transit is not something that can be assumed.

6) **Bring important phone numbers.** Always travel with the phone numbers for your wheelchair repair department, important healthcare contacts, and the number for your BiPAP provider. It can also help to see if you can find a local repair option at your destination before leaving, just in case.

7) **Charge up.** Ensure all of your equipment (e.g. BiPAP, wheelchair, external BiPAP battery, suction, cough assist, communication device) is fully charged before leaving your home.

8) **Bring items to enhance comfort.** A gel pad or air cushion can help relieve pressure during long flights or car rides.

9) **Ensure your travel insurance is up to date.** It is important to have travel insurance in case you are not able to make the trip, and health insurance in case you need medical attention while abroad. Knowing about potential health care costs at your destination can provide peace of mind in the event that your insurance will not cover everything.

## HOTEL ACCOMMODATIONS

Knowing what you need before phoning a hotel can help make the process easier. It can help to think through a normal day, and all of the accessibility needs you encounter during the day: entering and leaving your home, toileting, bathing, eating, and other activities.

Here are some things to consider when evaluating potential accommodations:

- Do you need grab bars in the bathroom for transfers?
- Do you need a bed rail?
- Does the room/bathroom need to be able to fit a wheelchair?
- Do you need to be on the ground floor, or is there an elevator that will fit a wheelchair?
- Is the front door roll-in?
- Are the amenities (e.g. breakfast room) 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.

## SUMMARY

- While travelling with ALS presents unique challenges, good planning and preparation can ensure a smooth experience.
- Local travel can be easier when you plan your stops and bring the right items for comfort.
- When flying, most of the important preparation is completed before you get to the airport. It involves notifying the airline and ensuring they are able to accommodate you and your wheelchair if necessary.
- If you are staying in a hotel, it is important to verify the accessibility of the location before you arrive.
- It's also important to plan your transportation, whether it is by car or accessible taxi.
- The ALS Society may be able to connect you with an equipment loan program where you will be staying.

**KNOW THAT WE ARE HERE TO HELP!** For people and families living with ALS in Ontario, ALS Canada can assist in connecting you to support services, equipment, and ALS clinics. Whether you are a person living with ALS, a family member or a caregiver, we will strive to support you along this journey. If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region. Learn more at [www.als.ca](http://www.als.ca).

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