



## **Hitting the Road: Transportation and Travel Tips for People with ALS**

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# Today's Webinar

Happy Summer! This webinar will discuss items to consider when traveling with ALS and safety considerations when both home and away.

If you would like a copy of this presentation, please email me and I will gladly send you a copy

[abrownlee@alsa-national.org](mailto:abrownlee@alsa-national.org)

# Travel, Mobility & You

- Traveling offers many exciting opportunities: a chance to meet up with family and friends, see new places and experience different cultures
- It also requires that you leave your daily routine and comfort zone. If you have difficulty getting around, traveling offers additional challenges
- People traveling that have ALS need to find out from their physician if they are safe to travel
  - Are you safe to fly?
  - Air pressure is different in a plane and you may need a special test to see if you are safe to fly
  - ALWAYS CHECK WITH YOUR PHYSICIAN PRIOR TO ANY TYPE OF EXTENDED TRAVEL



# Travel Mobility Check List



- **Access your personal mobility**
- First, it's important to honestly assess how you get around. Think about the follow questions: How long can you comfortably walk? What kind of physical activities do you find difficult, i.e. stairs, hills or standing from a seated position? What do you currently do to improve your mobility?
- **What kind of trip will you be taking?**
- Next, closely consider your trip and the physical requirements you'll likely need to perform. Are you planning a trip that has you on the move? Will your trip require less activity, i.e. staying one spot with little walking?
- **Choose Your Tools:**
- Finally, you'll need to match the tools needed accomplish your travel goals with your physical abilities.

# Know Before You Go

- The first consideration in traveling with disabilities is the preparation you need to travel
  - If you don't travel much, speak to someone with a similar disability who has travelled abroad before
  - Think of questions you should consider if your disability requires additional assistance and write them
  - **Facebook Group called Traveling with ALS**  
<https://www.facebook.com/groups/1316912925029896/>
- If you use a wheelchair, what type of assistance will you need?
- Can you walk from the door of the plane to your seat or do you need an aisle seat?
- Can you transfer from your wheelchair to your seat or do you need assistance?
- If you will transfer planes, how much time do you need during the transfer?
- If you use a ventilator, are you sure the appropriate plugs are available?
- If you have special dietary needs, does the airline or hotel have the food/formula you need?

# Apps to help you in travel area

- Getting around with a mobility impairment is a challenge
- Many places are not wheelchair-friendly or accommodating of other disabilities requiring mobility aides. Too often those with mobility impairments requiring mobility aides such as wheelchairs end up extremely inconvenienced when they arrive somewhere where they can't find accessible parking, entrances or bathrooms
- You can do your own research on a place in order to find out whether it can accommodate wheelchairs or other mobility aides, but this information isn't conveniently housed in one place
- Thanks to modern smartphones, you can now download apps that will give you necessary information on different places regarding their accessibility as well as additional tips and tools to improve your quality of life
  - iAccess Life – Rating & Review Lifestyle App for the Mobility Impaired
  - Wheelmate
    - Source: <https://www.iaccess.life/best-apps-for-wheelchair-users-caregivers/>



# How will you get to your destination?

- Drive
- Rail
- RV
- Airline
- Durable Medical Equipment
  - Take you own?
  - Rent when you get there?
  - Wheelchairs, bathroom equipment, transfer equipment, breathing devices





# Renting a wheelchair accessible van

- By the way, week, month
- Know what type of place you will be driving in!
  - Do you need a smaller vehicle due to parking? Or a larger one for extra equipment?
- Wheelchair Getaways
- Accessible Vans of America
- Mobility Works
- There may be local companies – Google your destination city





ALL-NEW THEATER-STYLE LIGHTING  
ILLUMINATES THE CABIN INTERIOR





CONVERSION  
VAN DEALER

ARBOCAST

**RES**  
ASSOCIATION

# Accessible Rail Transportation-Amtrak

## Boarding and Detraining

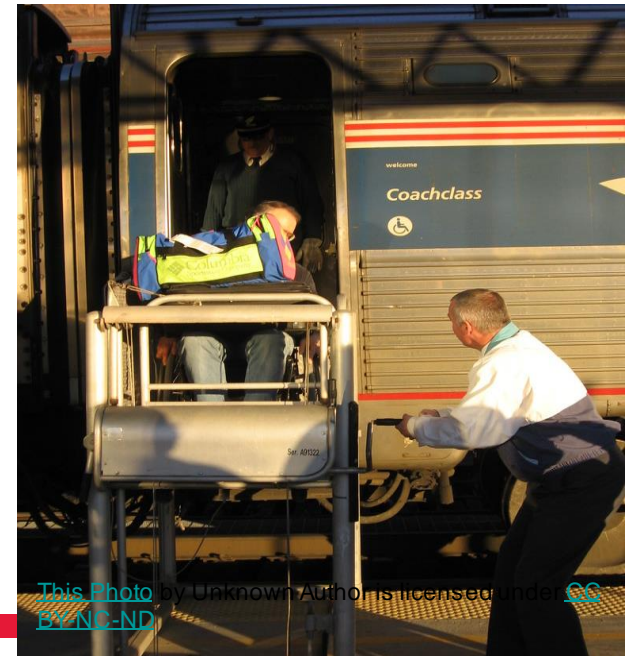
- Assistance to passengers traveling with wheelchairs in the following situations
- High Platforms: Amtrak will assist you across the gap between the platform and the train by using a bridge plate
- Low-Level Platforms: Amtrak will provide a level boarding through the use of station-board lifts
- Bi-Level Trains: Amtrak will provide a wheelchair ramp to help you board the lower level of the train

## Remaining in Your Wheelchair or Transferring to a Seat

- If you use a common wheelchair, including a battery-operated chair, you may remain in your wheelchair en route. When wheelchair lockdowns are not available, we request that you apply your wheelchair brakes
- Many First Class and Business Class cars also have accessible seating. If you choose to transfer to an accessible seat, you may stow your wheelchair nearby

## Wheelchair Restrictions

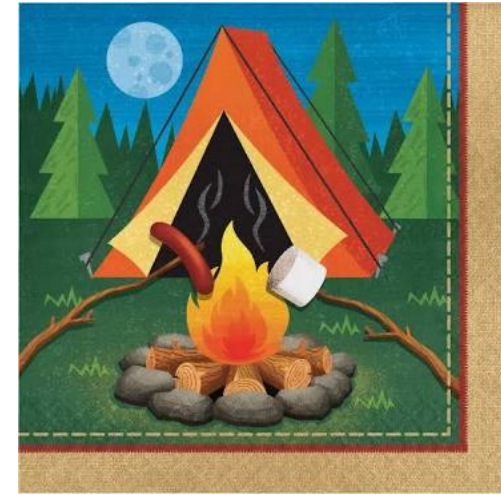
- Amtrak trains accommodate most wheelchairs in use today, provided they meet the ADA definition of a "common" wheelchair. Please note:
  - Dimensions: The chair should not exceed 30 inches (76 centimeters) wide, 48 inches (122 centimeters) long and 2 inches (5 centimeters) of ground clearance.
  - Weight: The weight limit for an occupied wheelchair is 600 pounds (273 kilograms).
  - Manual and battery powered: We permit both manually operated and battery powered



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# Accessible RV'ing

- RVing is the equal opportunity travel option where no one is precluded.
  - Allows folks to bring their accessibility with them
  - Accessibility issues that are often encountered in hotels and restaurants are solved with a comfortable traveling 'home-away-from-home' that can be thoroughly customized or modified."
- Accessible RV's have wheelchair lift, wide entrances and larger interior aisles to accommodate the wheelchair's girth
- Roll In Showers
- Larger so you can carry more equipment/people





# Accessible RV'ing Con't

- Can rent or purchase accessible RV's



[Handicap RV Rentals](http://handicappedrv.com/handicap-rv-rentals/)

<http://handicappedrv.com/handicap-rv-rentals/>



**ASSOCIATION**

# Booking Airline Travel

- When making airline reservations:  
Make your reservation as far in advance as possible.
- Tell the reservations person that you will be traveling with a wheelchair or scooter
- Inform them if you need assistance in boarding (an aisle chair to get to your seat)
- If it is a long flight and you are able to use a standard plane restroom but are unable to walk to the restroom ask that they make an aisle chair available to you during the flight
  - Some airplanes have a privacy curtain that includes the aisle that would allow a companion to assist you.
  - Keep in mind that airplane restrooms are quite small
    - » For males consider condom catheter or adult diapers
    - » For females, external female catheter (Purewick System) or a diapers



Condom  
Catheter

# Booking Airline Travel Con't

- On newer and refurbished wide body jets (the ones with two aisles) there is one accessible restroom. It is large enough to fit the aisle chair inside so making it possible to transfer to the toilet. These planes generally carry an aisle chair, but it is a good idea to confirm that one will be on board
- Always confirm that they have a record of your requests 48 hours prior to departure
- Some of the newer planes have lift up arms on some of the aisles. You can request to be seated there if they are available. It makes transferring easier. Some passengers prefer to request bulkhead seats that have more legroom, but the air rests on these seats do not lift up





# Airline Transportation

## Getting through security

- TSA shares tips for travelers with disabilities, medical devices, medical condition
  - Individuals with disabilities or medical conditions, and who use medical devices should not think of a Transportation Security Administration (TSA) checkpoint as a barrier to travel
  - All travelers are required to undergo screening at the checkpoint. Passengers with a disability or medical condition or their traveling companion may consult a TSA officer about the best way to relieve any concerns during the screening process. Individuals may provide an officer with a TSA notification
  - If a passenger with a medical device, medical condition or a disability is approved to use TSA Pre✓<sup>®</sup>, he or she does not need to remove shoes, laptops, 3-1-1 liquids, belts, or light jackets during the screening process. Persons with disabilities and medical conditions are not required to remove their shoes if they have a disability or medical condition. However, shoes must undergo additional screening, including in a discrete manner.



# TSA's 5 Top Resources for People with Disabilities



- TSA's toll free helpline, called **TSA Cares**, enables travelers or families of passengers with disabilities and medical conditions to call 1-855-787-2227 with any questions about screening policies, procedures and what to expect at the security checkpoint 72 hours prior to traveling. The helpline is staffed weekdays from 8 a.m. to 11 p.m. ET and from 9 a.m. to 8 p.m. on weekends and holidays.
- Passenger Support Specialists are highly trained TSA officers at airports who have special training in successfully engaging with, and screening, individuals who have disabilities or medical conditions, or who travel with medical devices
  - Travelers requiring accommodations to the screening process, or who are concerned about the security screening process at the airport may ask for a Passenger Support Specialist or a Supervisory TSA Officer who can provide on-the-spot assistance
- TSA's website has an entire section devoted to traveling with [disabilities, medical conditions and medical devices](#)
  - <https://www.tsa.gov/news/press/releases/2016/11/15/tsa-shares-tips-travelers-disabilities-medical-devices-medical#:~:text=TSA's%20Five%20Top%20Resources&text=TSA's%20toll%20free%20helpline%2C%20called,72%20hours%20prior%20to%20traveling>.

# At the Airport



When you get to the airport:

1. Arrive early
2. Always check your chair or scooter at the boarding gate and request it be brought back to you at the gate when you arrive
3. It is suggested that you use gel or foam filled batteries in your scooter or power chair. They are also known as dry cells. (NOTE: Standard acid filled batteries or wet cells will be removed by ground crew and packed in special containers for transport)
4. If you use a fold up manual wheelchair you can request that it be stowed in the on board coat closet. (NOTE: There is only room for one wheelchair and the service is available on a first come first serve basis, so you should arrive early to make your request. Plus not all planes have a coat closet)
5. Make sure your name and address is on your equipment and that it has a gate delivery tag if it is being stowed below
6. If you have to change planes request that your own equipment be returned for the layover. This not only assures your independence while in the terminal, it reduces the risk of it getting lost or damaged. Since wheelchair users are last off the plane make sure you allow enough time to make your connection. At least an hour and at big airports at least an hour and a half in smaller airports

# At the Airport

- 7. DAMAGE CONTROL - Remove seat cushions and any other parts that could easily become separated from the chair. Take these items into the cabin with you. Attach instructions on scooters or power chairs detailing how and where to disconnect the batteries, also *instructions for any other disassembly or prep that might be necessary for transport. If you have a large power chair, be aware that on some planes like the MD80's or Super 80's the cargo opening is only 26" high. Therefore some disassembly may be required.* You can ask what type of equipment will be used when you make your reservations. Having instructions on your equipment are very important because even if you are available to give the employees instructions, the crew at the other end didn't see how it came apart
- 8. If you need assistance transferring to the plane seat, take responsibility for yourself and tell the staff how to help you or pick you up, etc. Yes, they should be trained, but you are always safer not assuming anything
- 9. Before landing remind the flight attendant that you will need your equipment brought to the gate so they can radio ahead to make the arrangements. This can help speed things up
- 10. If you have any problems or damage ask to speak to the "Complaint Resolution Officer" (CRO). Each air carrier is required to have a CRO available by phone or in person at all times. This person is specially trained in dealing with problems that travelers with disabilities may encounter





# At the Airport

- If you are traveling with a scooter or power chair make sure you arrange for transportation that will be able to accommodate your equipment upon arrival.
- If you only need a scooter or wheelchair for distance you may prefer to rent one at your destination for a day or the entire trip. Also many theme parks and other attractions that require a lot of walking have scooters or wheelchairs available for rent or loan.
- US Air Carriers are not covered under the ADA. They are covered under the Air Carriers Access Act. To learn about your rights under the Air Carriers Access Act these free publications are available.
- A 28-page information booklet that is a wealth of information on the Air Carriers Access Act, what you can expect and what to do if you have a complaint. You can receive a free copy by contacting the Eastern Paralyzed Veterans Association, 75-20 Astoria Boulevard, Jackson Heights, NY 11370-1177. Phone: 718-803-EPVA.
- A 40-page booklet "New Horizons, Information for the Air Traveler with a Disability" is put out by the U.S. Department of Transportation and can be obtained by calling PVA Distribution Center at: 888-860-7244 (Order No. 2100-16)



## Airport Travel Tips

# How wheelchairs are loaded into cargo area





# Flying with a respiratory device

- It is highly recommended that you notify the airlines well ahead of time if you plan to use a respiratory device during the flight. Currently, all disability-related aids — including personal medical oxygen, ventilators, nebulizers, respirators, CPAPs, BiPAPs, Trilogies — are allowed through security checkpoints once they have undergone screening
- Unlike portable oxygen concentrators, positive air pressure devices like Respironics' CPAPs, BiPAPs, Trilogies, need not have a special label in order to be carried onboard
- To be screened, CPAPs/BiPAPs, Trilogies must be taken out of their carrying case, put in a plastic bag (which you must provide) and placed in a bin for X-ray screening. Face masks and tubing can remain in the carrying case
- Anyone traveling with battery-operated medical equipment should ensure they have sufficient battery power to cover preflight, in-flight and post-flight time — about 50 percent longer than the scheduled flight time
  - Only SOME airplanes have electrical outlets to plug in devices, so be prepared to use BATTERIES on your respiratory device should you need it during flight



# Finding Accessible Transportation at your destination

- As a result of the growth of the Internet, finding accessible transportation in a strange and distance city is becoming easier. Even if you don't have a name of a company you can go online, find out who provides airport shuttle or taxi etc
- Most major cities have at least one company that runs an airport shuttle service between the airport and hotels. The majority of them either can provide accessible service or will provide accessible alternate service
- A good resource for finding transportation options that is often overlooked is the Center for Independent Living in that city. Most cities have one and they all have an information and referral person
- Public transit – buses, rails, subways



# Accessible Transportation Con't

- Paratransit
  - A door to door accessible service that must be provided by any city in the US that has a public transit system
    - It is available to passengers that are unable due to disability to use the normal public transit system or in many cases it is more broadly available when the regular bus or train system is not yet fully accessible. The hours and advance notice requirements for use varies widely from city to city so make sure to check it out in advance.
    - Some cities require travelers to provide proof of eligibility, while others do not. Even if you don't make use of paratransit at home it might be worthwhile to establish your eligibility to make use of it when you travel.
- UBER and LYFT
  - Depending on the city, may have accessible vehicles for hire
  - Check with each company and inquire about the availability of accessible vehicles in the city you are traveling to





# Hotel Accommodations

- Determine wheelchair access, to areas such as a swimming pool, public rooms, restaurants, bars, toilets, etc
- Find out if the equipment you may need is available for rent—such as back rests, bathing equipment, hoists, ramps, and special mattresses
  - Local Durable Medical Equipment Provider
- Ask for a ROLL IN SHOWER hotel room
- Determine if shopping and entertainment are accessible.
  - Determine voltage requirements in each country—whether an adapter is necessary, and what the plug configurations are.

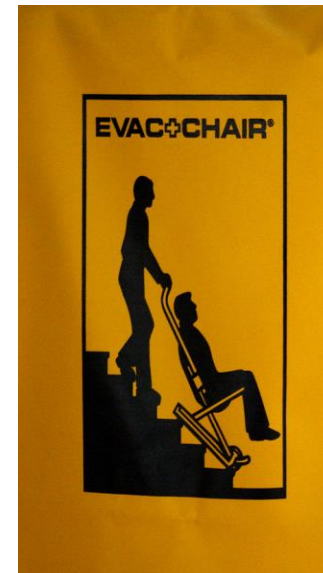


# Emergency Evacuation for High Rise Hotels/Condos

- The Americans With Disabilities Act (ADA) legislated equal access to facilities
  - One segment of the intent of the ADA that has been overlooked is equal exit during emergencies
  - It is essential that facilities that provide services to the general public such as hotels, motels, restaurants, nursing homes, hospitals, retirement centers and recreation facilities have a pre-planned procedure for evacuation of the disabled
  - Owners and managers have the legal and moral responsibility to provide emergency plans for their facilities. This includes having the proper immediate emergency equipment, emergency & evacuation plans and a properly trained staff. While most facilities have some sort of plan, either formal or informal, most do not provide for the special needs that will arise during evacuation of the disabled, elderly and children.

# Emergency Evacuation Con't

- Under the ADA, architectural barriers must be removed or redesigned to accommodate access for the disabled. Unfortunately, emergency routes have, in many cases, been neglected. While the use of elevators in multi-storied buildings are not safe emergency exit routes, stairwells and ladders cannot be navigated by disabled people without assistance. Additionally, to provide the required assistance, the facility employees must know where these people are and how to evacuate them safely without increasing the danger to them or to the people they are trying to assist
- Stairwells used in lieu of elevators present the largest obstruction for evacuation. Employees need to be trained in techniques for assisting the mobility impaired
- Adequate and proper emergency equipment should be staged at strategic locations throughout the facility to enable not only employees to assist the disabled but also for use by emergency professionals that may respond to the scene



# Renting an accessible home or condo

- Vrbo
- Airbnb
- VIP Vacation Rentals
- Gopher



## How to Find Accessible Vacation Rentals

<https://www.aplaceformom.com/caregiver-resources/articles/how-to-find-accessible-vacation-rentals>



# Cruising

- Cruising has long been a viable and convenient option for disabled travelers
- Cruise lines making an increased effort to accommodate passengers by closely adhering to the guidelines of the Americans With Disabilities Act, cruising has become the vacation of choice for many travelers with mobility issues
- New ships are being designed with the needs of travelers with disabilities in mind
- Newer ships offer roll-in showers with drop down benches, raised toilet seats, plenty of grab bars, closets with pull-down rods, and wheelchair-level placed desks, sinks, and outlets
- Seek the assistance of a travel professional that is trained or certified to work with travelers who have a disability



# Health and Safety Information

- Key resource for health information is the Travelers' Health page of the Centers for Disease Control and Prevention (CDC) website at <http://www.cdc.gov/travel>
- Discuss with your health care provider the activities you have planned, your general physical condition, any immunizations, and medications—whether prescription or over the counter—that you might need for your trip
- Consider any effects the local topography or climate may have on you. For example, if you are sensitive to altitude or humidity, consult with your health care provider
- Carry a letter from your health care provider, preferably on letterhead, which describes your medical condition, medications, potential complications, and other pertinent medical information. CARRY YOUR LIVING WILL WITH YOU

*International Travel: Determine health care availability in the location where you will be traveling. Your doctor, health care provider, insurance company or the local U.S. embassy can provide the names and contact numbers of health care facilities at your destination. Make sure to carry medical alert information, preferably in a place that a health care provider or anyone who assists you will find easily (wallet card, necklace)*

# Go Bag



## Content suggestions

- Copy of your Medical Insurance Cards
- Medical Card with ALS specific information
- Written list of phone numbers: doctors, pharmacy, and family contacts
- Written list of medications
- 7 days worth of medication
- Written directions on how to communicate with the person with ALS
- Letterboard
- Advance Directive
- Style/Serial number of medical devices
- Reading Glasses (dollar store will do)
- Wipes
- 10 FOOT Phone Charger / Ear Buds
- Socks
- Pen and paper

# Medical Information Packet

- The ALS Association website
  - [www.alsa.org](http://www.alsa.org)
- <http://www.alsa.org/als-care/resources/publications-videos/medical-information-packet>
- Allows user to fill out information regarding communication, swallowing, nutrition, mood, and respiratory issues, and others
  - Walks the user through all aspects

[illegible]

# Communication Considerations

- Make sure your Medical Information Card explains the best method communication for you
- Store writing materials/letter board/key phrases in your emergency kit
- Determine how you will communicate with emergency personnel if you do not have your communication device
- Obtain an alternate power source for electronic means of communication

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# Communication Bards

- I can email you a link for you to print out
  - [alisa@alsphiladelphia.org](mailto:alisa@alsphiladelphia.org)
- Website offering free downloadable communication boards
  - Patient Provider Communication
    - <https://www.patientprovidercommunication.org/supporting-communication-covid-19.htm>
      - Bilingual available

# FREE communication tools for patients with COVID-19



# EMS/Emergency Room Considerations

*I can not verbally speak but I understand everything you are saying.  
Consider translating this information if you are traveling abroad where  
English is not the standard language.*

*I say YES by moving my eyes to MY RIGHT*

*I say NO by moving my eyes to MY LEFT*

*I say MAYBE by looking up*

## SHORTNESS OF BREATH:

If I display shortness of breath or low SpO<sub>2</sub>, do not give me oxygen unless I have another respiratory condition that requires it. I may need noninvasive positive pressure ventilation to expel CO<sub>2</sub>.

## OXYGEN MAY NOT HELP AND MAY MASK RESPIRATORY FAILURE:

My lungs are healthy, but my muscles including diaphragm are weak. IF I am using a BPAP at home, the settings should be the same as those. IF NOT, a BPAP with a pressure of 12/6, backup rate of 10 with titration as needed may help.

## LAYING ME ON MY BACK:

May be difficult for me because of the possibility of CO<sub>2</sub> retention due to diaphragmatic weakness and aspiration due to poor ability to protect my airway. I may be able if using a BPAP or non-invasive mechanical ventilation.

## AVOID:

Paralytic or general anesthetics, narcotics or muscle relaxants unless absolutely necessary. If used, the ability to rapidly assist ventilation non-invasively or invasively should be available.

**If I have a gastrostomy tube, please use that for administration of “oral” medications.**

# Medications

- If you take prescription medication, make sure you have enough to last during your entire trip, including extra medicine in case you are delayed
- Make sure to ask your pharmacy or physician for the generic equivalent name of your prescriptions in case you need to purchase additional medication abroad
- Physicians and pharmacists abroad are more likely to be familiar with the generic name (also known as the chemical name) of medications
  - Pack your medication in your carry-on bag, since checked baggage is occasionally lost. Always carry your prescriptions in their labeled containers, not in a pill pack. Take a copy of your immunizations records along in your hand-carry luggage.

# Health and Evacuation Insurance for International Travel

- Make sure you have adequate and up-to-date health insurance coverage while abroad, including coverage for medical evacuation (not covered by most domestic policies)
- Medical treatment and hospital care abroad can be expensive, and medical evacuation to the United States can cost more than \$100,000
- Check with your health insurance provider to see whether you will be covered overseas, in which countries you will be covered, and under what circumstances
- Your health insurance provider may also require you to provide notification of your travel before you depart the United States and pre-approval may be necessary for some treatments
- Ensure that anyone traveling with you also has adequate insurance coverage. Note that U.S. Medicare and Medicaid programs do not provide payment for medical services outside of the United States
  - <https://travel.state.gov/content/travel/en/international-travel/before-you-go/your-health-abroad.html>

# Smart Traveler Enrollment Program (STEP)

## Benefits of enrolling in STEP:

- You'll receive the latest safety and security information for your destination country, so you can make informed decisions about your travel.
- The information you provide enables the U.S. embassy or consulate to contact you in an emergency.

## Stay Informed

- When you enroll in STEP, you will receive current information about your destination country, including:
- [Alerts from the U.S. Embassy about safety and security](#) situations.
- Updates to the country's [Travel Advisory](#).
- Messages about U.S. embassy events and services, such as town hall meetings, voting information, [federal benefits](#), and U.S. citizens' legal obligations (taxes, selective service registration, etc.).
- Set up one account, and then add trips later for all your future travel plans!

## Stay Connected

- Enrolling in [STEP](#) will help the U.S. embassy contact you and provide assistance during an emergency overseas. And, if your family or friends in the U.S. are having difficulty contacting you with urgent news while you're traveling, we can use the information in STEP to try and reach you.

<https://travel.state.gov/content/travel/en/international-travel/before-you-go/step.html>



# Useful Links

## Wheelchair Users' Guide to Air Travel

<https://wheelchairtravel.org/air-travel/>

## Center for Disease Control -- Travel Guidelines

<https://wwwnc.cdc.gov/travel/yellowbook/2020/travelers-with-additional-considerations/travelers-with-disabilities>

## Traveling with a Disability – US Department of Transportation

<https://www.transportation.gov/individuals/aviation-consumer-protection/traveling-disability>

## Tips on Traveling with a Ventilator or Breathing Machine

<https://www.miusa.org/resource/tipsheet/ventilator>

# ALS Specific Resources

- Helpful Tips for Traveling With ALS
  - <https://www.als.org/blog/helpful-tips-traveling-als>
- **On the Road: Tips for Traveling with ALS**
  - <http://www.alsa.org/als-care/resources/als-insight/articles/may2015-on-the-road-tips-for.html>
- Traveling with ALS
  - <https://www.youralsguide.com/travel.html>
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