

Travel Guide for MSA Patients and Families

Contributed by Patricia Libby Thvedt, former care partner to an MSA patient and member of the MSA Board of Directors.



“Travel is more than the seeing of sights; it is a change that goes on, deep and permanent, in the ideas of living.” – Miriam Beard

A diagnosis of MSA does not mean the end of travel for patients and their families. As outlined in this guide, it is possible, at many stages of MSA, to travel – from adventurous, overseas trips, to close-to-home vacation stays, and everything in between. The only limits are your imagination and, of course, your budget, but you don’t have to spend a lot of money to reap the many benefits of traveling. The experiences you have and the special time you spend with family and friends will buoy your spirits as you navigate your MSA journey.



Why should we think about traveling? How do we choose where to go?

MSA is a rapidly progressing disease, and it is therefore important to think about trips you want to take soon after receiving a diagnosis. Is there a bucket list destination you have always wanted to visit? Is it possible financially to make that happen? If so, start planning now and go as soon as possible. Because of declining mobility issues for most MSA patients, you can’t predict what you will be able to manage in six months or one year, so plan that trip and go soon.

Is there a bucket list destination you have always wanted to visit? Is it possible financially to make that happen?



A vacation doesn't have to be a bucket list trip to the Caribbean or Europe; it can also be a vacation rental at the beach, at a lake, or in the mountains an hour or two from home. Just getting away from the daily obligations of work and home can provide wonderful family time together. A change of scenery, a chance to play board games and laugh, spending beautiful days outside in nature, visiting museums, watching the sunset together — these are the special moments that a vacation creates for a family facing a disease like MSA.



Care partners, ask your loved one what they would most like to do for vacation. Where would they like to go? If they have trouble suggesting places (they may be scared or nervous that they can't manage a trip), do some research and make suggestions.

Make Beautiful and Lasting Memories

With a little (or a lot of) advanced planning, you and your family can travel and make wonderful memories together. Don't dwell on the things you can't do; focus on what you can do together while you explore your vacation destination.



Some Tips:

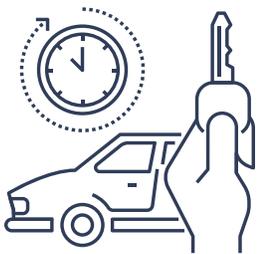
- *Take lots of photos and videos.*
- *Don't overplan activities.*
- *Go with the flow each day.*
- *You don't have to see or do everything.*
- *Enjoy yourselves and your loved ones.*
- *Be grateful for the chance to travel together.*



How can we plan a successful trip in the early stages of MSA?



Early on in the disease, you may be walking unaided, or may need a cane or a walker. These limitations do not have to constrain you in your travels. Careful planning about how you will get there, where you will stay, and what to do while at your destination will ensure a more successful trip.



Transportation

If you are driving, plan where you will stop for restroom breaks (most gas station and fast-food establishments have handicapped accessible bathrooms, and Starbucks often have clean, accessible facilities), bring appropriate snacks, lots of water to drink, and any medications you need during the drive, and make sure the cane or walker is easily accessible from the back of the car (not packed under lots of luggage.)

If you are flying, consider asking for wheelchair assistance when you check in for your flight (or when you book your flight – more about this below.) Even if you can walk on your own with a cane or walker, airports usually require passengers to walk extremely long distances. You will be less tired and less at risk of falling, if you allow the airline to provide wheelchair assistance. Sit down and relax and enjoy being pushed!



Where to Stay

If you are staying in a hotel, make a reservation for a handicapped accessible room. Even if you are fully ambulatory, you will find the bathroom much easier to maneuver if it has a walk-in shower, grab bars, and a raised toilet. If you don't want to (or can't) reserve a handicapped room, request a room with a separate shower if possible. It can be very difficult (and dangerous) for someone with balance issues to get in and out of a tub/shower combination. Look at the photos of the rooms online and/or call the front desk and ask what they offer.

Some older, historic hotels have very high beds which will be more difficult to get into and out of. Think about opting for a more modern hotel which may have lower beds. You can always call to ask if you can't find pictures online.



Hotel Checklist:

- *Has handicapped accessible rooms*
- *Bathroom has walk-in showers*
- *Grab bars installed in bathroom/shower*
- *Bed heights are low and easy to get in and out of*

If you choose to stay in a vacation rental (Airbnb, VRBO), study the online photos of every room. Make sure there are no stairs or steps that may prove difficult for you. Look for a one level home without many internal steps. Check out the bathroom configurations. If you are unsure, you can email the owner and ask specific questions. It is better to know the layout before you arrive to avoid surprises.

What Activities Can We Do?

If you are visiting a city or other urban setting, you need to plan how you will get around. Public transportation may be very difficult if you are using a cane or walker. Subways require walking long distances and often have escalators and stairs that will make things difficult. Buses are designed to be handicapped accessible, but it may be challenging to board and get off the bus easily, especially if you are in a strange place. Walking short distances and taking taxis for longer distances may be the best way to get around. Of course, taxis are more expensive, and this will be an extra expense to add to your trip budget.

Museums and other larger venues usually have free wheelchair rentals (their websites explain where to go when you arrive to check one out.) Take advantage of this even if you are able to walk on your own. It will be easier for you to keep up with everyone if you are in a wheelchair and you won't get overly tired. It will also reduce your fall risk, which will put your companions at ease so they can enjoy the venue as well.

If you plan to eat out at a restaurant, call ahead to ask if they take reservations, and tell them you have a person using a walker. Reservations will be helpful to minimize wait times. Even though restaurants in the United States must be accessible, in reality, some are not as accommodating as others. Make sure there is a functioning elevator if the dining room is upstairs.

If you are in a more rural setting such as a lake or mountains, research where there are flat, paved paths for walking, or find a beach nearby where you can sit and relax. Research activities to determine which ones have easy parking and no stairs. You can always search for images of your destination (Google Maps, for example, can show you street view images) to get a better idea about activities that are easily accessible.



Where can we travel in the later stages of MSA when mobility is limited?



How can we still make the trip fun and memorable for all?

Being in a wheelchair does not mean you have to stay home! You can still travel many places throughout the world. Traveling in a wheelchair is very manageable (and still fun); it just requires more advanced planning.

Personal Tip:

When we were planning a winter trip to Iceland, I relied heavily on the Curb Free with Cory Lee blog which had wonderful tips for travel in Iceland in a wheelchair. It inspired us to overcome our concerns and take one of our family's most memorable trips ever.

Personal Tip:

We made it a priority to take nearly all of our trips with our three young adult sons. Not only did it provide wonderful family time together, but the boys were also invaluable in dividing up the work of pushing the wheelchair, transferring my husband to and from bed, and other daily tasks. We all enjoyed ourselves and no one person felt overwhelmed.

Where to Go

There are many options for travel in a wheelchair. Do some research online. Look for blogs about handicapped accessible travel for the places you want to go. Do you want to go to a city or to a quieter, more nature-oriented place? Do you want to leave the country or travel to another state? Do you feel more comfortable staying closer to home?

There are many excellent blogs regarding wheelchair travel that can spark inspiration and provide very practical suggestions for specific places you plan to visit. One of the most comprehensive blogs is Curb Free with Cory Lee (curbfreewithcorylee.com). You can get many destination ideas from Cory's travels throughout the United States and overseas, so start there and explore places you may want to go. Another popular blog is Simply Emma (simplyemma.co.uk) which covers mostly European travel.

Who Will We Travel With?

This is one of the most important considerations for the care partner when planning travel. It can be very difficult for a care partner to travel alone with a loved one in a wheelchair. It is physically challenging and just plain exhausting to manage everything on your own. Strongly consider bringing family members – adult children, siblings, nieces and nephews – or close friends who would be helpful and fun. Think about who in your circle will jump in and assist without being asked. Some family members and friends are uncomfortable pushing a wheelchair, transferring someone to and from a bed, or assisting in the shower. Those people will not provide the kind of help you need. Figure out who will be a true partner in helping the trip go more smoothly.

What to Bring/ Planning Ahead

The unfortunate reality of MSA is that many patients have medical issues, such as orthostatic hypotension (which can cause balance issues) and incontinence, that require extra supplies and planning when you are away from home.

If you are traveling by plane and staying in a vacation rental, ask the owner or rental company if you can send a package ahead of time. You will be able to travel lighter if you mail extra supplies ahead of your arrival. Send more than you think you will need; you can always bring home the extra items in your suitcase.

HERE IS A LIST OF ITEMS THAT CAN BE SENT AHEAD IN ONE OR TWO BOXES:

- *Incontinence briefs*
- *Personal wipes*
- *Extra pairs of underwear*
- *Waterproof bed pads*
- *Small trash bags*
- *Portable grab bars for the shower and toilet area*
(suction shower grab bars are available on Amazon and at medical supply stores)
- *Special cups for swallowing issues*
- *Weighted utensils to assist in eating*

DON'T SEND AHEAD (PACK IN SUITCASE):

- *Prescription medicines*
- *CPAP machine*
- *Prescription glasses*
- *Handicapped placard*
(look up the rules for using handicapped placards where you are going.)
- *Anything you would not be able to replace easily*

Where to Stay

If you are going anywhere for more than one or two nights, it is often easier and more convenient to stay in a vacation rental. You will have access to a kitchen, more space for the wheelchair, and likely a more comfortable place to relax if you decide to “hang around” for a day. Vacation rentals usually have washers and dryers which can also be useful.

TIPS FOR FINDING A SUITABLE VACATION RENTAL:

- *Vacation rental sites like Airbnb and VRBO have search filters that allow you to find accessible rentals. Airbnb, for example, has an “Accessibility Features” section with 28 different filters you can click on for requirements like “no stairs or steps to enter” and “step-free shower.” VRBO has two filters, for “elevator” and “wheelchair accessible.” Whatever site you use, look at the search filters and narrow down your search to places that are more likely to be suitable. If you are unable to find any places, you can remove the filters and look for one-story rentals without significant stairs in the photos. You can always contact the owner through the messaging feature on the site and ask about stairs/steps before you book.*
- *It is also useful to read the reviews for any place you plan to rent. Sometimes you can gather additional information about the rental or its location that can help you decide if it would work for a disabled person.*

What to Do/Activities

If you are going to a beach area, call ahead and ask whether there is a beach wheelchair available. Many beach resorts have beach wheelchairs for rent, and this can be a fun way for you to experience sitting on the beach and even dipping your feet in the ocean. Also check with the county where you are going to the beach as many municipalities offer free beach wheelchair rentals at lifeguard stations. For example, dozens of California beaches offer such service (check out this map: coastal.ca.gov/access/beach-wheelchairs.html).

Many public swimming pools have a lift chair or sloped ramp designed to assist the disabled to enter the water. Ask about pool access when you book your hotel or vacation rental.

Call ahead at restaurants and ask to reserve a table that works for someone in a wheelchair so they will set up an accessible table before you arrive. In other parts of the world, access is not always as available as it is in the United States, so especially if you are in another country, it's a good idea to call or even stop by during the day, if possible, to check it out before making a dinner reservation.

Consider Hiring A Caregiver

If it has become difficult to transfer from wheelchair to bed or shower, consider hiring a caregiver at your destination to assist while you are there. This can make the vacation more relaxing for the care partner. You can search for homecare agencies at your destination and call to ask whether they have someone available for some or all of the days you plan to be there.

Be Prepared for the Inevitable Complications

MSA is an unpredictable disease, especially in the more advanced stages. Planning ahead for issues that may arise will provide peace of mind as you leave home. One of the most common problems is a urinary tract infection that can cause significant issues, especially for an advanced MSA patient. There are ways to be prepared while hoping you never have to take advantage of your advanced planning.

SOME THINGS TO DO BEFORE YOU LEAVE HOME:

- *Research local hospitals. Whether you are going to a large, urban area or a more rural location, figure out where you would go to the Emergency Room if you have an urgent problem while traveling. There are online reviews of most hospitals and emergency rooms, and you can get a sense of which ones might be better than others. It's better to know ahead of time rather than trying to figure it out in the moment.*
- *Bring printouts about MSA to provide to ER doctors (print at home and bring with you as you may not have access to a printer.)*
- *If you frequently get UTIs, ask your doctor if you can take antibiotics with you just in case. Often MSA patients and their care partners know pretty quickly if a UTI has developed, and you can make arrangements with your doctor to call them immediately if you suspect an infection. If you have the antibiotics that typically work for you on hand, it saves a lot of time and effort if they tell you to go ahead and start. Similarly, if you are on palliative care, ask your nurse or doctor before you go if they can prescribe antibiotics to take with you just in case. In addition, most doctors are happy to look at photos so if you have concerns about medical issues that can be captured in a picture, take photos and send them to your doctor before you talk on the phone.*
- *Bring a UTI test kit with you (AZO makes one, and pharmacies such as CVS have their own brand.) If you suspect a UTI, you can do the test to see what it shows, although be aware they are not always accurate.*

Traveling by Plane



Traveling by airplane is very manageable in a wheelchair. As with everything else, doing some research and planning will help the trip go smoothly.

MAKING THE RESERVATION:

- Airlines are required by federal law to provide assistance to passengers with disabilities. You can access information about what airlines must offer here: https://www.transportation.gov/sites/dot.gov/files/2022-07/508_Airline_Passengers_with_Disabilities_Bill_of_Rights_07132022_ADA.pdf
- When making a reservation online, look for information on passengers needing special travel assistance and request wheelchair assistance or make other more specialized requests (such as using oxygen on board.) The airlines handle this differently. Some require you to call or email with your request, while others have an online form to fill out when you make your reservation.
- It is very important to make a seat reservation near the front of the plane. Even if you are still able to walk down the aisle, it can be challenging to walk a long way down the aisle, especially if people start boarding behind you. If there are no seats available near the front, call the airline and request one for a disabled passenger and companion. They usually can accommodate you if you do this far enough in advance as they typically reserve some seats near the front for disabled passengers.

ARRIVING AT THE TERMINAL AND GOING THROUGH SECURITY:

- When you arrive at the terminal, alert the ticketing agents (where you check your luggage and get your boarding passes) that you requested wheelchair assistance (even if you haven't previously requested it, they will still provide it if you ask.) You will then be asked to wait for a transport agent to bring an airport wheelchair to you. If possible, it is easier to transfer to the airport wheelchair and check your wheelchair with your luggage (there is no charge for this.) The transport agent will help you navigate the most accessible route to TSA security. Your party will be allowed to go with you to the front of the TSA line with the transport agent.
- At security, you will be asked if you can stand to walk through the metal detector. Just say no and they will push you through and allow the TSA Agents to use a handheld wand to do the security check. It is helpful for the care partner to try to stay close to the patient as they go through security because they sometimes need to advocate or speak for a loved one who may have speech issues.
- Once through security, the transport agent will take you to the gate (ask to stop at the restroom before you get there and use a family restroom if you need assistance from your care partner) and they will usually leave.

BOARDING AND DURING FLIGHT:

- Make sure the gate agents are aware that you need to pre-board; don't rely on the transport agent to make that happen; have your care partner remind them.
- The transport staff or gate agent will wheel you down the ramp to the plane, but your travel companions will have to assist you once you reach the door of the airplane. Your entire party should go with you so they can help you get seated and with any carry-on bags.
- Decide ahead of time if you are able to walk from the wheelchair to your seat. This will depend on how well you can take a few steps and how close your seat is to the front of the plane. If you are concerned and want additional assistance, tell the gate agent you will need an aisle chair. The airline staff will transfer you to a little rolling chair that fits in the aisle.
- Once you are settled in your seat, ask the flight attendant if you can use the First Class restroom. It will usually be the closest restroom to you, assuming you are sitting near the front of the plane. They will often allow you to do so (and just ignore the occasional grumblings from other passengers.)
- Once in flight, the flight attendants will usually offer extra assistance with things like getting your carry-on bag down from the overhead bin.
- Bring your own food (either from home or buy in the terminal.) Flights do not provide a good variety of healthy food these days and what they do provide, such as nuts and chips, may be difficult for someone with swallowing issues.
- After the flight lands, stay in your seat until everyone deplanes. The staff at the arrival gate will be there with a wheelchair to help you once you get to the door of the plane (or, again, you can request the aisle chair.)

IN THE ARRIVAL TERMINAL:

- The transport personnel can assist you to stop in the restroom before you get to baggage claim so be sure to ask.
- If you are renting a car, it is easiest to have one of your travel companions board the shuttle bus to rent the car while you wait (hopefully with someone) for them to circle back to get you in front of the terminal.
- If you are taking a taxi, ask at the taxi stand if there are minivans available as they will be easier to get in and out of and will accommodate your wheelchair more easily.