



PREPARING TO TRAVEL WITH MYASTHENIA GRAVIS



myasthenia gravis association

MGA

serving missouri and kansas

Celebrating 50 years

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PLANNING THE TRIP

While living with a chronic condition like Myasthenia Gravis, you can tend to feel most comfortable in your own environment and near your physicians who know you and have your medical records at hand. But life can become more interesting when you are prepared to take a risk and travel out of your safe zone. The trick is to plan your trip while taking into consideration your Myasthenia Gravis, right down to the last detail. In that way you're prepared for any inconvenience or even a medical emergency. Being prepared can give you the sense of security you need in order to have a safe and rewarding vacation or trip to see friends or family. There may have been a time in your life when you could be more spontaneous and carefree with regard to travel, but living with a chronic disease and dealing with Homeland Security procedures at airports make careful planning a lot more practical. There's most likely no reason why long distance car travel, flying or going on a cruise can't become a reality. Hopefully, this guide will provide many helpful hints that will help make your trip one to remember. Achieving goals starts with a dream, progresses to the planning stage and ends with the satisfaction of success. If there's somewhere you've always wanted to go, start your planning process now and perhaps find the perfect traveling companion who understands and will accommodate some of your special needs.

WHAT, ME TRAVEL?

There are millions of Americans living with disabilities and chronic conditions, yet their conditions do not need to hinder their ability to travel. Since the passage of the Americans with Disabilities Act in 1990, most of the barriers to disabled travelers have come down and the emergence of this untapped market is even beginning to affect attitudes and willingness to comply abroad. However, even with federal standards for accessibility, travel accommodations for the disabled and for those with special medical conditions are generally acceptable but never particularly ideal. Seats on airplanes are still uncomfortable, finding a clean bathroom on the highway is unlikely and you are not going to be able to duplicate the ease of your home environment in a hotel room or a cabin on a cruise ship. But there are a number of steps you can take to make your trip a little easier.

There are three primary components of travel: the journey itself, accommodations (whether hotel or staying at a friend or family member's), and sightseeing or activities related to the visit. You need to plan for each stage of your trip in order to fully enjoy the trip and avoid problems or setbacks.

BECOME COMFORTABLE WITH DISCUSSING YOUR MG

Most of us like to minimize our limitations. We like to have others see us in control and resilient and so when someone says, “How are you doing?”, we often take it as a greeting and say, “Fine. How are you doing?” But becoming comfortable with disclosing and describing MG to those you encounter while traveling is essential. Since MG symptoms vary and can fluctuate from day to day, it is important that you can be vocal and clear about your needs. Perhaps one day you can pull your suitcase and the next, you cannot. Perhaps one day you can go to the beach and the next you must stay in an air-conditioned environment. Perhaps one day you can join the walking tour and the next, you must rest. How in the world will anyone know what you need or how you’re doing, unless you tell them? Remember that most people have never heard of Myasthenia Gravis and just because your friends or family know that you have MG, doesn’t mean that they understand what’s going on with you. No one is a mind-reader! It’s essential that you develop a short description of MG, so that you can explain to others why you may need assistance. Check out the next page for a quick explanation that you may want to use.



WHAT IS MYASTHENIA GRAVIS?

- Myasthenia Gravis means “*grave weakness*” and is an autoimmune, neuromuscular disease which causes fluctuating weakness in the voluntary muscles.
- Symptoms include fatigue, droopy eyelids, double vision, difficulty smiling, speaking, swallowing & breathing.

HOW MG AFFECTS YOU

- Be specific regarding potential symptoms you may have so that others will know what to expect and will know how to help if necessary. For instance, if slurred speech can sometimes occur, it is important for others to know, so that this particular symptom is not confused with stroke symptoms or inebriation.
- Let others know that you have to be the one to determine what activities you can participate in and which ones are not appropriate.
- If possible, travel with someone who knows your health condition and could serve as your advocate. If family or friends are having a difficult time accepting your limitations, have your traveling companion explain.

YOUR TRAVELING COMPANION

When planning your trip, involve your family, friends or other traveling companion and make sure they understand that you may not be able to do everything they want to do. The most stressful part of a trip can be trying to meet someone else’s expectations. Before you leave home, come to an agreement on how to handle the times you need to rest. Do you mind if they go somewhere without you one day? Are they willing to let you rest without making you feel guilty? Discuss possible scenarios and how you will handle them. Being clear enables you to relax and enjoy yourself.



GENERAL TRAVELING TIPS

- Plan to do less than perhaps you did on past frantic or athletic journeys. Relax and smell the roses. Pace yourself.
- Avoid remote or exotic travel spots where Western style medical facilities may not be available.
- If your travel involves receiving vaccines to prevent communicable illness, **BE SURE YOU DO NOT TAKE A LIVE VACCINE!** Doing so can result in a myasthenic crisis and perhaps the need for hospitalization and now your trip will be delayed.
- Ensure flexibility in your plans in case of illness. In this way, plans can be changed if necessary without great loss of deposits and fees.
- Purchase trip cancellation insurance to cover your financial commitments just in case your health problems require cancellation of a trip. This insurance is available through your travel agent or private insurance companies. Cancelled airline tickets may be able to be rescheduled within 2 years after payment of a fine. Check with your airline.
- Take extra money with you on a trip to pay for additional taxi fares and other travel expenses. Subways and other inexpensive transportation options may be difficult for you.
- Download the disability license plate/parking pass application from your state's Department of Motor Vehicles website and take it to your doctor or ARNP for signature. Even if you occasionally have trouble walking, a handicapped license plate or a handicapped parking pass (displayed on your rear view mirror) can make a car trip so much easier. The pass can be used in any vehicle (rental cars, cars of friends, etc.). Most states accept plates and parking passes from other states. You can check online with the motor vehicle department for the state in question and for policies in other countries, check online for that country.
- If you're not able to participate in travel activities because of limited walking, don't hesitate to rent a power-scooter from a local medical supply store. They can deliver a scooter to a hotel, cruise ship, resort, etc. They are usually about \$50 per day.
- Try to pick a travel time not in the height of the flu season.
- Avoid crowds and coughing foreigners with new contagious bugs.
- Wash your hands frequently and pack anti-bacterial gel or wipes.
- Be careful of what you eat and use all the tourist dietary precautions. Do not eat raw or rare seafood or meat.

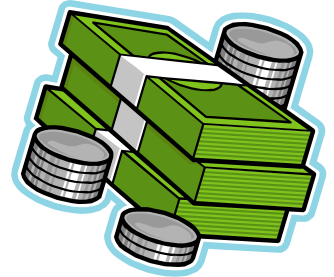
- Inquire about travel insurance that would fly you back home in case of serious medical issues so that you can be treated at home.
- For essentials you need now and again, purchase a small bag with wheels so you don't have to carry it. Many of these will fit under airplane seats.



A WISE OLD SAYING.....

~
GETTING READY FOR
YOUR TRIP:

Get your clothes ready
Get your money ready
Then take half of your clothes
And twice as much money



LUGGAGE

Take interchangeable clothes so that you don't need to pack so many. Only use luggage with wheels and a pull up handle so that you can easily tow it. The days of porters and redcaps are mostly gone, so basically, you are on your own. Use a brightly colored luggage tag or ribbon tied on the handle to identify it from all the others of the same color. Don't hesitate to ask a capable looking person to lift your luggage from the airport conveyor. Most people are happy to help.

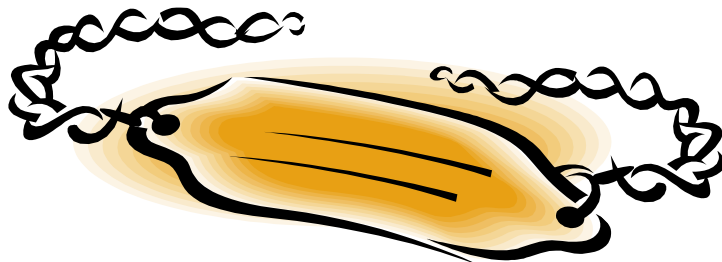
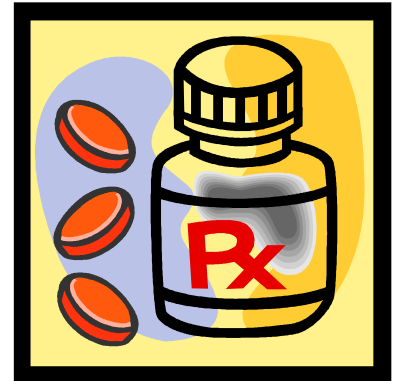


INFORMATION YOU SHOULD BRING ALONG

While we never like to think about a medical emergency, there's nothing like being prepared should one arise. Contact your physician or the local MG Association and get names of colleagues or contacts who could be called for emergency help in the area where you will be traveling. Obviously, the best prospects would be those involved in treating MG patients. If you cannot identify such physicians, contact local teaching hospitals, the local medical society or neurologists listed in the local yellow pages. How wonderful if you never need to use these contacts!

Having a MedicAlert bracelet or necklace is important, but you should have the following information with you in your wallet at all times:

- The Myasthenia Gravis Information Card which lists drugs to be avoided or used with caution in Myasthenia Gravis (if you don't have a card, ask the MGA office for one)
- Medication, dosage & frequency
- Medication & treatment contraindications
- Allergies to medication or to anything else
- Dietary supplements
- The name & contact info for your primary care physician, and your MG-treating neurologist.
- A brief medical history
- If traveling to a non-English-speaking country, create a card that says (in the language of origin) **I HAVE MYASTHENIA GRAVIS: AN AUTOIMMUNE NEUROMUSCULAR DISEASE. MY MEDICAL INFORMATION IS IN MY WALLET.** Should it be necessary, this card can be given by you or by your traveling companion, to EMS or other medical personnel. Print out a few of these.
- Telephone numbers of people you want notified in an emergency, such as family members and friends.



MY TRIP DIARY

As you plan for your trip, make notes regarding what's required in your mode of travel, accommodations, who you've spoken to and their title and phone numbers, friends/family or sights that you'll see. Make a list of what you need to bring, what needs to be packed and what needs to be in a bag that you carry, passport holder or wallet. Create a calendar with enough space to write in each detail of each day you'll be gone. Plan how much money you'll need and if anything has to be arranged at home, like a pet-sitter, mail hold, etc. Make a list of who needs to know your itinerary and how to reach you. The more prepared you are, the less stress for your wonderful trip!



MEDICATIONS

- Carry a full supply of all your medication for the entire trip and extra if possible.
- Ask your doctor and pharmacist if they will refill early as a one-time special consideration to meet your vacation schedule.
- Some national pharmacy chains allow you to refill wherever you are nationwide because their computers are linked. Ask your pharmacist.
- Don't assume you can get additional medications while traveling. Be totally self-sufficient. Always take 2-3 days of extra medication in case you drop or spill some or in case of delayed transportation. There could also be problems with local regulations for you to get a refill.
- Just in case, have a duplicate prescription(s) with you, written in generic terms as a back up and in the country's language if applicable.
- Don't put any medications in checked luggage where it could be lost. Hand carry all your medications and prescriptions and keep them in their prescription bottles including their labels.
- In times of heightened security, you may need to prove at airport check-in that the names on your prescription bottles match your identification.
- If you need to pack syringes, carry a copy of the prescription for the syringes and other information proving medical necessity.



- Most medications require a cool and dark environment for optimal storage. Do not store medication in your car glove compartment or in a sunny area or in the bathroom where humidity is higher.
- If you are carrying medications that require refrigeration, carry it in a small insulated cooler bag with an ice pack and wrap the bottles in a baggie or bubble wrap to avoid moisture. When traveling for more than a few hours, add ice to your cooler from another source by placing the ice in a baggie. Call ahead to your hotel and request a room that has a mini-refrigerator.
- Many medications cause photosensitivity. If you are going to a sunny destination, ask your doctor or pharmacist about your prescriptions. Bring the sun screen with the highest SPF (skin protection factor) and consider light-weight clothing which will cover you and protect exposed skin from the sun.
- If you are traveling through different time zones, ask your doctor for advice on when to change the time you take your pills, especially on the day of travel. It's important that you not skip doses nor take too much medication.
- Ask your doctor for a “standby” prescription for an antibiotic, cough medication, etc., in case you get sick while traveling. It may be easier than trying to find a doctor in an unfamiliar city.



RESEARCH & CREATE AN ITINERARY

Better safe than sorry, so research everything. Read what it says about medical emergencies on travel brochures, airlines, hotels, tours, etc. Find out if you can get your money back from a tour, cruise, flight or hotel. Print out copies of airline/hotel/cruise/tour policies to support requests if difficult interactions occur. Policies are available online or available by calling ahead to the “Special Services” departments. Request copies of policies on the rights of passengers with disabilities. If you have mobility aids such as cane, walker, crutches, wheelchair or power chair, find out about accommodations or restrictions.

Evaluate where you’re going and what you’ll be doing. Do not set unrealistic expectations for yourself. Choose a destination where you will be physically comfortable with the weather and environment. Be realistic about how much activity you can handle everyday, how many stairs to climb or distance to walk. Often advertisements for guided tours include the level of physical activity required. You might want to book your trip through a travel agent and have them do all the research regarding walking distance, number of stairs, location of elevators, etc. It is natural to want to see and do all you can with the few vacation days you have available, but if you try to do too much, you will not enjoy any of it. Schedule rest periods into your itinerary and if it is not possible to return to your hotel room/cabin, etc., at least allow yourself time to sit down in a quaint café and leisurely sip your favorite beverage while your body rests and revives. Avoid scheduling any sightseeing or family reunion the day you arrive. Traveling is tiring at best, so just settle in, rest and have a nice dinner.

TRAVELING BY TRAIN

Amtrak has an online section for services for people with disabilities and special needs. Do not book a reservation online, but call so that you can make your needs known. Inquire if train personnel will be able to offer assistance. Some trains may have sleeping accommodations for people with disabilities that may be more comfortable. Ask for a seat assignment in a car that is easily accessible to the restroom and club car. Be sure and hang on to the seats and grab bars as you travel from one car to another, as trains tend to rock as they move along.



TRAVELING BY CAR

As you plan your trip and how many miles you'll need to travel to reach your destination, consider just how long you're comfortable driving or being a passenger. Try not to restrict yourself to a timetable, as that may create unwanted stress; stress on you and stress on your relationship with your traveling companion. Besides the usual precautionary car maintenance before a trip, consider your own precautionary health maintenance. Schedule a physician appointment before your trip to make sure you're in condition for travel and have current prescriptions that will not expire while traveling; and during cold & flu season, a current flu vaccine. Despite air-conditioning, keep your prescriptions away from the car window and direct sunlight and when you leave the car, bring them with you. Plan to stop for a few minutes every hour or two. Get out of the car and stretch and walk around a little. Staying in one position too long will cause you to become stiff, increasing pain. If you're in the passenger front seat, push it back as far as you can so your legs have room to stretch out. If there is room in the car, make a comfortable spot in the back seat so you can put your feet up and recline. Try out a variety of sitting positions and note how many pillows you will need to take to keep you as comfortable as possible. If you are the driver, you can put a pillow under your left arm and a few under your right arm to provide comfortable support. Don't forget to bring a cooler for water and healthy snacks and a cell phone in case of emergency.

Bring a recent map, use MapQuest or a GPS device and have your route planned out well so that you don't waste time and get stressed from taking a wrong turn. If you do lose your way, don't be reticent to stop and ask for directions, as it will minimize your stress in the long run.

Be aware, if you're driving alone and have trouble pumping your own gas, many large chain gas stations will display a sign indicating the availability of refueling assistance. Pull up in front of the station, beep the horn and wave your handicapped parking pass. As soon as the attendant comes out, move your car to an available gas pump.



TRAVELING BY BUS

Although more reasonable in price, a long distance bus trip may be one of the most uncomfortable means of travel. Unlike a train, you can't get up and walk around and there is no way to insure a seat will be available in the front of the bus. Walking to the restroom is a bumpy and unsettling experience as well as using the restroom. So hang on to the top of each seat as you make your way through the bus. Buses make infrequent rest stops, unless a chartered bus has a schedule to do otherwise. Schedule trips when fewer people are traveling such as mid-week; avoid too many transfers to other buses; and bring a pillow, tissue in case there's no toilet paper, snacks and water for a more comfortable trip. Call for reservations and inquire for best times to travel and any special accommodations you may need.

Buses can be warm and stuffy, but can be over air-conditioned as well, so it is best to dress in layers. Be aware that in some foreign countries, some buses don't have air-conditioning and the bus may be so crowded that there are people standing in the aisles and there may be a goat or two along for the ride!



TRAVELING BY AIR

If you are traveling by air, call the airline well in advance of your trip and tell them of your special needs and if you will be flying with a companion. Ask for the name and title of each person you speak with and record this information. Unless you are flying first class, request a bulkhead aisle seat (first seat in coach). This is the easiest seat to get in and out of and has the most leg room. But beware, this may be an exit row with extra requirements. If you have to change planes, allow yourself extra layover time so that if the flight is running a little late, you will be able to make your connecting flight without rushing. Even if you do not normally use a wheelchair, you may want to request that one be waiting for you at curbside and at the gate of each stop on your trip. Save your energy for sightseeing and other fun activities. You and your companion will be able to be in the first group to board. Get your boarding pass online to minimize the number of times you have to wait in line. Curbside check-in saves on pulling luggage through the airport and long lines. Make sure that the skycap checks all your luggage through to your final destination. As mentioned, only use luggage with wheels and do not attempt to bring it onboard. Finding an open bin close to where you sit and trying to lift it overhead can be difficult. Only carry what you absolutely need including (prescription labeled medication) and perhaps a change of clothes on board, as it will have to be stowed under your seat for take-off and landing.

In the event your luggage is lost, you will still have the medicine you need. Check with your carrier for what items and size are allowed. Lugging heavy bags through airports will leave you exhausted before you ever arrive at your destination.

Allow extra time to get to and through the airport. If you have a wheelchair or walker, you can check it in with your luggage and arrange for wheelchair transport through your airline. If you take advantage of that service, airport personnel must push you in the wheelchair, even if your companion is prepared to do so. A tip is expected. In larger airports, roving electric carts provide transport on an unscheduled basis - just flag them down. If you have a power chair, there are specific procedures for storage. Before you call your airline for instructions, make sure you have all the specifications regarding the chair (measurements, weight, movable parts, what kind of battery, etc.) If you want to use your own wheelchair or walker in the airport and check it at the gate, make arrangements at check-in with the skycap or at the ticket counter. It can be stowed in the luggage compartment at the last minute and then brought to you when the plane lands. Just tell the check-in person that you want to “gate check” your appliance.

Airlines in other countries have significantly different policies regarding service for people with disabilities. Some European airlines have excellent reputations for being cooperative, but others may have virtually no experience with people with disabilities. If you must fly with a non-U.S. airline, find one that is a partner with a U.S. airline, as they often have similar policies. No matter what airline you fly, don't be reticent to speak up regarding your needs. Alert a flight attendant as soon as you board instead of after take-off, when they will be busy with required tasks and with other customer requests.



AIRPORT SECURITY

Everyone must undergo the same security screening process, including removal of shoes. Therefore, you might want to consider what are your easiest shoes to take off and on. You might also want to consider how much jewelry you wear, since substantial jewelry will set off the screening alarm. Check online for what can be contained in your carry-on bag or on your person. Anything found that is not permitted will be confiscated. If you have had a hip or knee replacement or have a pacemaker, make sure you tell the security officer, so they will expect the alarm to sound. Often people with hip or knee replacements must undergo pat-downs, which take a considerable amount of time. If you bring an assistive device like a cane or walker and it sets off the screening alarm, then it will be subject to further screening. The limit of one carry-on bag and one personal bag (purse or briefcase) does not apply to medical supplies and/or assistive devices.

There are rules prohibiting liquids and gels, but liquid prescription medicine with a name that matches the passenger's ticket, liquid nutritional supplements, (including a doctor's note), liquid or gel low blood sugar treatment, saline solution eye care products, etc. are allowed, but must be declared to the security agent. Toiletries such as shampoo, lotion, toothpaste, etc., must be in 3 oz. containers and be packed in a one quart baggie.

FLYING WITH PORTABLE OXYGEN

Check with your airline carrier for policies when making reservations and be sure and state what kind of portable oxygen system you will be bringing on board. Oxygen containers must be x-rayed by security and you must produce a doctor's letter verifying your medical need. Keep in mind that not all airlines offer supplemental oxygen service. Airlines do not provide oxygen for in-terminal use. If you are making a connection, or need to spend time at an airport before or after a flight, those oxygen arrangements must be made through an outside supplier.



HOTELS

While most large hotel/motel chains have 800 numbers and online reservations, it is worth the extra money to call the hotel directly to make your reservations. This gives you the opportunity to ask specific questions about the actual facility in which you'll be staying and to be clear about your special needs. Ask for a room that is on the main floor or near the elevator to minimize the distance you'll have to drag your luggage or arrange for a bellhop to assist. If you've pre-arranged for a power-scooter to be delivered to the hotel for your trip, be sure and alert the hotel when it will be delivered. Specify the accommodations you need (wheelchair accessible, shower grab bars, etc.). You can ask for a shower chair to be delivered to your room to use in the shower or to use outside of the shower to sit down and dry off. It can give you stability. Upon arrival, if you find the hotel bed uncomfortable, don't hesitate to ask for additional pillows or to even change rooms. Many hotels have actual rooms designed for a variety of disabilities and may include whirlpool tubs. Remember that although a hot bath may initially feel great after a long day of sightseeing, prolonged soaking in hot water can cause fatigue related to your MG!



CRUISING

There are no official regulations according to the Americans With Disabilities Act that apply to cruise ships. Which means that cruise ships that carry a foreign flag are not required to adhere to minimal standards. However, cruise lines know what a big market the disabled are and so it is realistic to think that, whatever the medical issue, the cruise line will accommodate.

Whether you book your cruise through a travel agent or through the cruise line reservation agent, tell them about Myasthenia Gravis and your condition. Don't be shy about requesting a cabin designated for those with disabilities as they will be located closer to elevators. Check your medical insurance provider to see if visits to the ship's infirmary are covered. If not, take out a travel insurance policy that does reimburse. Ask for a ship's map and locate the infirmary so, if necessary, you will know how to get there. Feel free to introduce yourself to the ship's doctor.

Depending on the size of the ship and the weather, the motion of the ship can make some people feel uneasy, but with Myasthenia Gravis, the feeling may be intensified. Speak with your doctor before you take your trip and discuss a motion sickness medication that will be safe for you to take with you. Dramamine is available over the counter and so are motion-sickness-wrist-bands. Ginger tablets and ginger teas are available at health food stores and are a good alternative to motion-sickness medication.

Shore excursions are a thorny subject. Don't be afraid to pin down the ship's expert shore excursion staff and ask which specific trips are appropriate if you have a walking, step-climbing or wheelchair challenge. Remember that some ports, particularly foreign ones with ancient cities, may not be disabled-friendly (no curb cuts, narrow sidewalks, uneven streets, steep steps and cobblestones).

Most cruise ships are owned by foreign countries. On the ship and on-shore, protect yourself from contaminated or bacteria laden water, by always drinking bottled water. Make sure that the cap is still attached to the ring. To ensure the water bottle has not been refilled, always open it yourself! Remember that many fresh beverages include water. Inquire about how your coffee is made and how your favorite mixed alcoholic beverage is made. You don't want to spend your precious cruise on the bathroom floor.

Check with your cruise line and cell phone company about being able to make or receive calls on your cell phone. Even if you bring your own laptop, some cruise lines charge for Internet usage.

Each cruise line has different guidelines for passengers who require oxygen. Before making a reservation check for your ship's requirements.



THEME PARKS

Most U.S. theme parks and large tourist attractions are well designed to accommodate special needs. Even if you never use a wheelchair in your daily life, consider renting a wheelchair or scooter at theme parks. You don't want to wind up on the opposite side of the park and unable to walk back. At most attractions, if you are in a wheelchair, you and those accompanying you can go right in without waiting in line. You will be able to do a lot more and suffer a lot less. Remember to prepare for sun exposure and drink a lot of water.



FOREIGN TRAVEL

Where possible, locate MG contacts in the country you intend to visit. MGFA (The Myasthenia Gravis Foundation of America) has a limited list of these available upon request. Contact your travel agent, the local embassy or consulate for help finding doctors or hospitals that practice Western style medicine or contact a local teaching hospital. The International Association for Medical Assistance to Travelers can provide general information and lists of physicians that speak English. Ensure you have adequate health insurance in effect while you are on your trip and always check with your insurance company that you are in fact covered in a foreign country. You may find that you need to purchase supplemental insurance.

Please read the information provided about drinking water and beverages under CRUISING on the previous pages. In addition and for obvious reasons, be careful about buying food from street vendors. A case of dysentery can not only ruin your trip, but can result in hospitalization.

Check with your cell phone provider to see if you will be able to make or receive calls.

Make sure you know how to say **“HOSPITAL or EMERGENCY”** in the language of the country in which you are traveling:

Emergencia = <i>Spanish</i>	Urgenza = <i>Italian</i>
Nosokomio = <i>Greek</i>	Crise = <i>French</i>
Beit holim = <i>Hebrew</i>	Byouin = <i>Japanese</i>

DINNER & DRINKS

It's your vacation and you want to have a good time. So much of our sociability revolves around eating and drinking alcoholic beverages. So, before you embark on your trip, discuss with your doctor what amounts of rich foods and alcohol are reasonable for you. Although people around you may encourage you to have another slice or take another drink, remember that you don't want your vacation to be spoiled because of illness. When you or someone else wants to make a toast, drink water or a soft drink. Remember that mixing alcohol with your medications can cause negative reactions.



AVOIDING HOLIDAY HASSLES

Going on a trip at holiday time can be a huge hassle for the most hearty of travelers let alone for someone with mobility problems. Overcrowded roads, planes, weather delays, etc. can make you want to stay home, but if you want to bite the bullet and share the season with friends and family, there are some ways to help ensure the smoothest transit possible.

Schedule your traveling days for days that the rest of the world isn't traveling. Slide your traveling plans forward or back a day to avoid a travel crunch. If you plan on flying, try to book non-stop flights as they cause the least problems. Connections can cause a missed flight. Flights that leave first thing in the morning are less likely to have delays and of course, arrive at the airport extra early.

Airlines often cut carry-on limits to a single bag during the heavy holiday season, but equipment necessary for a disabled traveler does not count against this limit.

If you're thinking about Amtrak, trains do fill up and delays aren't uncommon. However, the trade-off for the slower speed of travel is an often more comfortable trip.

For those planning on braving the freeways, try to leave either very early or very late so as to avoid as much traffic as possible. Because of oncoming headlight glare, many drivers find traveling at night unpleasant, but for those living with Myasthenia Gravis, night driving may be dangerous. Even if you're the passenger, the glare of oncoming lights may be unsettling. You may want to map out alternate routes in case you run into unexpected traffic or road closures. Don't forget your cell phone and emergency car kit!



EMERGENCIES

Use your imagination and plan for every possible thing that could go wrong. Sure, it sounds like you're taking all the fun out of the trip, but in fact....it's your own personal insurance. Always determine a place that you and your companion, friends or tour will meet if you get separated. Read everything you can to provide for a safe and interesting trip. Your health always comes first and second is having a marvelous time!



PLAN YOUR RETURN HOME

If possible, plan at least one day of rest after you return home before going back to work or resuming other activities. While a trip can be enjoyable, rewarding and even thrilling, it can also be exhausting. No need to unpack the second you return home. Give yourself a break and when you feel relaxed, then unpack. If you received extraordinary service from a hotel, airline, tour, cruise ship, etc. and if you feel inclined, email or write a letter stating your appreciation (especially related to your MG) and mention the names of those that offered services or kindness. Expressed appreciation helps to maintain services related to serving those with disabilities.

RESOURCES

Able To Travel

Website that has services & useful tips & will actually book your trip for you
www.abletotravel.org or (888) 311-3635

Travelers With Disabilities & Medical Conditions: Medications

The Transportation Security Administration (TSA) has a helpline for travelers with disabilities and special medical circumstances. The helpline provides specific information on security procedures at airports. If a traveler is asked to submit to a full-body scan he/she can undergo a pat-down instead, which includes agents using their hands to check sensitive areas of the body. You can call TSA toll free at 1-855-787-2227 before you travel to learn about screening policies, procedures and what to expect at the security checkpoint. If you call 72 hours before your trip, TSA will coordinate checkpoint support with a TSA Customer Service Manager located at the airport when necessary.

www.tsa.gov/travelers/airtravel/specialneeds/editorial_1059.shtm

Airline Travel With Oxygen

<http://www.portableoxygen.org/flyingwitho2.html>

Travel With Chronic Fatigue

<http://chronicfatigue.about.com/od/copingstrategies/a/travel.htm>

Real-time Airline Access Hotline

A toll-free hotline is available seven days a week
 7am - 11pm EST to provide assistance on the spot or for upcoming trips and can be a great resource
 if and when difficulties arise.

Voice (800) 778-4838 or TTY (800) 455-9880

Just GOOGLE *Traveling With Disabilities* and you'll find hundreds of websites!

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