TRAVEL TIPS

for patients with

Myasthenia Gravis

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Myasthenia Gravis (MG) is a chronic neuromuscular disease that affects the strength and stamina of voluntary muscles. Symptoms within muscle groups can vary from person to person. The symptoms can fluctuate by the day or month. Sometimes the illness can worsen for no apparent reason. Unexpected changes in a patient's condition present a special challenge for patients who need or wish to travel. This leaves individuals and families of people who have MG question, "Is it safe to travel with MG?" and if so, "What do I need to consider before travelling?"

Travelling is not out of the question however it will require thoughtful planning. In general, travel requires planning and an itinerary. People with MG may need a more advanced level of preparation. There are helpful tips that can assist persons with MG to arrange trips and special activities. You may find some of these "helpful tips" common sense however you may discover some new information you weren't aware of. These are intended to help you travel wisely, remain safe and ensure you enjoy your time away.

PLANNING

First, it is recommended to think about your overall medical condition and treatments. Consider how stable your myasthenia gravis has been in the last year. Are you prone to fluctuations in symptoms? How sudden and severe are these? Have you required a change in medications or treatments? It is important to realize that psychological stress, infections and changes in weather conditions may exacerbate MG symptoms. Answering questions about your overall health, your MG condition, your response to changes in conditions may prove to be helpful in planning your trip.

Consider discussing your travel plans with your family physician and/or MG specialist. They may be able to provide you with a realistic comprehensive medical view on your condition. They can assist you with a careful risk assessment based on where and how long you plan to travel and environmental factors such as weather and infectious diseases that can challenge persons with MG.

Ask your physician(s) for a copy of the most recent consultation note that summarizes your MG condition and includes a list of your medications, dosages and other treatments. This will be helpful to health care providers should you require assistance while travelling.

MG is a relatively rare disease. While there are hospitals and medical clinics accessible in foreign countries, the health care professionals may not be well trained in caring for persons with MG. Advanced treatment options may be unavailable. It will be prudent to research these health care facilities in advance and to establish exactly what services are available, the location and hours of operation. Consider the following questions - How far away is the medical facility from where you are staying? Do they have adequate medical facilities to manage MG and provide the care you need should symptoms worsened?

- Ask your MG specialist at home about possible medical contacts they may have in or around your travel destination. They may know of physicians who specialize in MG or neurology who may be contacted for emergency services.
- It may be helpful to contact the local Embassy or Consulate at your destination. They may be able to offer contact information of medical providers who practice Western style medicine and are familiar with MG and standard treatments.
- Research websites such as the International and Overseas Medical Clinics or the International Association for Medical Assistance for Travelers (IMAT) for medical contact information

Another option is to consider discussing your destination and plans with a travel medicine physician. Many cities have Travel Clinics that are staffed by Travel Medicine physicians and nurses who specialize in travel medicine. Some are infectious disease specialists. They are aware of current conditions and travel warnings for foreign countries. Depending on your destination, they will be able to provide answers to specific travel concerns. They may charge a small fee for their services.

There may be some areas of the world that will not be safe for you. If your MG is active and you are taking immunosuppressive drugs, a risk assessment by trained health care professionals may advise you not to travel to a particular area. This is intended to reduce potential harm especially if it is "absolutely contraindicated and the patient is at high risk of infection or when the clinical condition of a patient may worsen because of travel." (Travel Medicine and Infectious Disease 2007 5, 7-17)

It is advised to closely research your destination. Location, duration, reason for travel and accommodation should be considered. It is important to remain realistic about what you can and cannot do.

Is your travel for business purposes or pleasure? How will the trip challenge your abilities for activity? Will it allow for rest periods? Travel plans should be realistic. Perhaps going for a relaxing cruise will be a better choice than an excursion requiring more physical exertion. Travelling to exotic areas away from medical facilities or areas that require certain immunizations may not be possible. How long do you intend to be gone? Will this interfere with regular treatments for MG? By asking in-depth questions in advance you will have a better chance for a safe and enjoyable travel.

HELPFUL SUGGESTIONS

Once you have determined your travel itinerary there are some additional "helpful hints" that can make your trip successful.

- **Documents**
  Think about purchasing a small resource book on MG in case health care professionals are not familiar with the condition or treatments.

In addition to a medical consultation note with a synopsis of your medical history and current medications, it may be helpful to have the telephone number of your MG specialist or family physician who can be contacted in case of emergency.

Take a list of telephone numbers with you of persons that you want to notify in case of emergency.

Take a list of medications that *may exacerbate* MG.

It may be helpful to make a list of medical terms in the language of the country you will be visiting.

- **Medications**
  Plan for the possibility that you may get separated from your medications. Travel with your medications in your carry on luggage.

  It is best to keep medications in a cool, dark, and non-humid place when possible.

  "Never leave home without it". Consider keeping a few days worth of medications in your tote bag/purse during day excursions. There is always a possibility of missing a bus or train or a transportation vehicle breaking down.

  If your medications are lost, stolen or damaged you will need to have them replaced. Don't assume that the medications you take will be readily available while traveling. Please remember that a written prescription from your doctor here will not be accepted in another country. Try to be as self sufficient as possible.

- **Cash or credit cards**
  Take additional cash with you to pay for additional taxi fares or travel expenses. Subways and other inexpensive transportation options could be challenging from a physical activity perspective. Credit cards may be necessary to pay for possible hospital or medical bills.

- **Medical alert bracelets and cards**.
  Emergency physicians and nurses are trained to look for these identifiers at the time of admission to a health care facility. An Alert Card in your wallet or a Medical ID Bracelet will identify you as an MG patient and immediately assist health care professionals. Several companies supply medical alert bracelets. Some companies offer supportive services including translators who can work with health care providers in other countries.

- **IVIG treatments**
  If you are receiving IVIG treatments, plan to have your treatment just a few days before leaving. If you are planning an extended visit, there may be neurologists in other countries who can assist in arranging for treatments. These treatments would not be covered by travel insurance.

- **Immunizations**
  Travel medicine clinics will know what immunizations are necessary for your destination.

  Some immunizations have been known to aggravate MG. If immunizations are necessary, please consult your MG specialist (neurologist) to discuss if these are safe for you. It may not be beneficial for you to be immunized when your disease is active. The answer is not clear cut. The decision to receive immunization will depend on your past medical history, current condition, the medications you take and type of immunization.

  When possible you may want to consider updating routine immunizations when your disease is stable. Immunizations such as Diptheria, Pertussis and Tetanus (DPT) do not last a life time and require "booster" shots. These must be discussed with your MG specialist.

  Also, immunosuppressive drugs such as prednisone, azathioprine (Imuran), mycophenolate mofetil (CellCept), cyclosoporine (Neoral) may decrease the response of immunizations and may put patients at risk of not achieving full immunity.

  Live vaccines or partially inactivated vaccines such as polio, Herpes zoster (shingles) should not be given to MG patients who are on immunosuppressive medications.

  Yellow fever vaccine must be used with extreme caution and contraindicated in MG patients who have a history of a thymic disorder, thymoma, or thymectomy. An in-depth risk assessment may be considered if a patient is stable and not on prednisone. The Center for Disease Control (US) recommends that if travel to endemic areas is necessary then significant precautions are needed against mosquito bites. There are several countries where yellow fever immunization is required for entry into the country. It is best to check prior to purchasing flights and hotels.

- **Travel insurance**.
  Ensure you have adequate medical travel insurance. Some plans do not cover pre-existing conditions. It is important to ask if your plan will cover medical and extended costs for Myasthenia Gravis. Be aware that some insurance companies will not cover you if your medications have changed within 30 days of travel. Does your provider cover evacuation insurance?

  Flight insurance for trip cancellation will allow for some flexibility in travel arrangements and help to avoid loss of deposits and fee.

- **Supplies**
  Consider taking a small first aid kit with you. Avoid insect bites by using insect repellent and mosquito nets and wearing light colored clothes that cover your legs and arms. Use unscented make-up, deodorant, soaps because some insects are attracted to perfume.

- **Other thoughts**
  Factors such as infections, fatigue, stress, and environment can aggravate MG. Are you traveling to hot weather areas? The symptoms of MG can be exacerbated by heat. The following tips may help you in hot weather.

a. Consider taking a small battery operated fan with you
b. Cool showers or baths may help to reduce symptoms
c. If you experience problems with swallowing and chewing, some MG patients report that ice and cool cloths on your face and neck can help until you reach a healthcare facility

Travel with someone who knows about your MG and can advocate for you in an emergency situation.

Hand washing is the single best way to prevent the spread of infection. Hand wash frequently. Take an antimicrobial hand sanitizer with you.

Take advantage of airport services such as handicap transports. Call your airline carrier in advance and arrange for pre-checking of luggage and wheelchair services. Don't hesitate to use these helpful services. Airports are vast and may require long walking distances.

If traveling locally, persons with MG often will choose not to travel during the peak flu season or when there is an outbreak of other contagious diseases.

Don't leave other symptoms such as cold/flu like symptoms, diarrhea, nausea for too long. Seek medical attention as soon as possible. Sudden infections can quickly exacerbate MG.

It is important not to depend completely on vaccines to prevent disease. There are things to know about drinking water, eating food and swimming in both ocean and fresh water while in foreign countries. Ask the travel clinics if there are any specific concerns in the country where you will be traveling.

Make sure to follow common sense health practices like avoiding unclean eating places, drinking tap water or using dirty toilet facilities. Be especially careful with drinking water. Make sure you break the seal on the bottle yourself. It is usually safe to drink liquids that have been boiled like tea and coffee. Use only ice cubes that are made from sterilized water. Use bottled water or sterilized water for brushing teeth.

Consider the foods you are eating and the preparation in local restaurants. Fresh vegetables and fruits may be washed with unsterilized water.

Use luggage with wheels that are easy to tow. Airport porters are still available in small more remote areas however busy metropolitan airports leave you pretty much on your own.

When traveling you may be in contact with different conditions that may make you more prone to infections. If you are taking immunosuppressive medications, remember that these make you more at risk for infections**.** Avoid crowds and persons who are coughing.

Flying across time zones may cause a change in normal wake and sleep cycles. Jet lag can be diminished by cutting down on alcohol consumption, eating light meals and sleeping as much as possible. It will help to sleep and eat according to the local time as soon as you reach your destination.

Finally, MG is not without its' challenges but by planning well in advance and considering all the characteristics of your final destination, specific activities and potential risks will ensure a safe, enjoyable and successful trip.

Additional Travel Resources

a. Public Health Agency of Canada - Information for Travellers
b. BC Centre for Disease Control - Travelers Health
c. Centre for Disease Control (USA) - Travelers Health
d. World Health Organization - Information for Travellers
e. Travel Health Online - TripPrep.com

PLEASE REMEMER TO PLAY IT SAFE … and