A Guide to MG

Managing the Financial Crutch
Coping with a chronic illness can result in loss of income, not to mention the increase in medical bills and medication. If you’ve been the major earner in the family, you may feel an extra burden of responsibility for making the mortgage payment or saving for children’s education. Keep in mind that financial planning is a joint activity. Be sure to include as many family members as possible. Consider these ideas for lightening the load:

- **Know your options**
  Look at what eventualities you'll need to plan for and what resources (savings, insurance benefits, Medicare) are available. You may want to meet with a financial adviser and lawyer. Be sure and read the fine print on insurance and disability policies your family has so you understand what benefits are needed and when you're eligible.

- **Keep careful records**
  It's a good idea to keep copies of all letters and forms concerning insurance, bills, hospital records, and prescriptions. Some medical expenses are tax-deductible, while others may be reimbursed through your insurance plan.

- **Consider at-home earning**
  If you can’t work at a full-time job, you may be able to continue working from home. Consider home-based work such as phone sales or consulting jobs. Volunteer work, as well as being emotionally rewarding, can sometimes lead to a paid job.

- **Extend your caring power**
  Trade services with other parents or caregivers. You might offer a service for someone who can do shopping or chores for you. Be creative.

- **Know the limit**
  When you have only so much money, you will need to economize. Learn the limits and don’t apologize for what you need to do to take care of yourself.

Create Your Own Health History
Your primary physician has gotten to know you over time and you probably thought it wasn’t necessary to create a one or two-page version of your health history, but you’ll be seeing a neurologist now who needs to get up to speed regarding your health status. Although every physician’s office asks you to complete a health history before you see the doctor, it is a good idea to create your own. Once you have your health history it is much easier to complete the medical history form in your doctor’s office. Here are some tips on what should be included. No need to use complete sentences; just the facts, dates, tests, medications, etc. and you’ll want to make a few copies. -Name, address, phone, cell, email, date of birth, insurance plan and ID, who to call in case of emergency, relationship, address, and phone at the center top. List the current date on the far right: -Name of primary physician, address, phone, FAX and email -Current medications you are currently taking with the dosage -Blood type -Issues regarding
anesthesia: MYASTHENIA GRAVIS - Allergic to medications - Allergic to anything else - Last flu, pneumonia and tetanus shots - Current conditions and what doctor is treating you for each condition - Surgeries, date and surgeon - Injuries: - Any historical conditions that may be pertinent to your care: - Current health issues: - Current Living Will available:

Your personal health history is an asset if you have to go to in an ambulance, to an ER or for hospitalization. You may not be in any condition to notify medical personnel regarding your treatment, so handing them your medical history can save precious time, avoid mistakes and be lifesaving. Remember that hospital staff may not be familiar with myasthenia gravis, so either you or your family/friends may have to educate staff regarding the importance of understanding MG, especially when it comes to requiring anesthesia.

Keep an MG Diary
Your neurologist will want to know the details about your symptoms, when they occur and if there’s anything you can determine that might bring on the symptoms. S/he will want to know what reduces your symptoms, whether it’s medications, rest or something else. Your doctor will want to know about side effects that you might experience from taking medications as well. You might think that you can remember all this to tell your doctor, but the reality is that your appointment goes fast and there isn’t time for you to tell a long story. Before your neurologist appointment, review your diary to select the most important issues to discuss with your doctor. There won’t be time for the doctor to read your diary so create notes to take with you.

Speak Up and Be Prepared
You may never have thought of yourself as an assertive person, but your health depends on your willingness to speak up. There was a time when a trip to the doctor was not only a time for tests and results, but a time when you could actually get information related to your health and your questions would be answered. Due to tightly scheduled appointments, much of that has changed. Given the fact that you will have somewhere between 5-10 minutes with your doctor and you may see him/her only a few times a year, you must prepare. Besides issues related to your symptoms or medication side effects, write down questions related to how MG relates to other conditions you may have. Make sure you present all your questions before your doctor leaves the exam room. This is your appointment and you and your insurance company are dearly paying for it. You will never get all the information you need about Myasthenia Gravis from your physicians. Read about MG through various websites including the Myasthenia Gravis Foundation of America at www.myasthenia.org, and the Mayo Clinic at www.mayoclinic.com/health/DiseasesIndex/DiseasesIndex.