

## Coping with MG

*The following document was prepared by the Myasthenia Gravis Association.*

You never fully appreciate your health until you have to face the fact that now you've been diagnosed with an illness that is not going away. You may feel angry and depressed and dwell on questions like, "Why me"? Reactions to learning of one's chronic illness are varied, but they are always powerful. Emotions may range from shock to relief, and everything in between. Even when symptoms have been present for a long time, the diagnosis can be upsetting.

### **Feeling a spectrum of emotions**

While shock may be the first reaction to learning of your Myasthenia Gravis diagnosis, denial is also common, as are anger and grief over the loss of health. Since most have not heard of this neuromuscular, autoimmune disease, even the name can be scary. All reactions are normal.

An acute illness like pneumonia may be serious, but it can be diagnosed, treated and resolved. A chronic illness is different. Receiving the diagnosis is only the beginning. You may have seen numerous specialists, taken endless tests or even been hospitalized before your diagnosis was certain. Your friends and family have become aware of your struggles and are worried about you and your future.

Although Myasthenia Gravis cannot be cured, it can often be controlled with carefully followed dietary, exercise and medication regimens. Once past the shock and disappointment, people with chronic illness often find that their condition requires that they live healthier, more health-conscious lives. As people are living longer, chronic illness is affecting nearly every American family and everyone is learning about the changes and strains that come with long term illness.

### **Regaining Control**

You and your relatives and friends will need to learn how to become your own health care advocates by learning as much as you can about the condition. The more information you have the more in control you will feel. Resources online can provide essential information and studies show that support groups and counseling can improve one's ability to cope.

A chronic illness changes your frame of reference; secure plans for the future may suddenly be overturned. You may not be able to depend on your body or livelihood. It's a good idea to avoid making major decisions at the initial diagnosis and during acute stages of dealing with Myasthenia Gravis symptoms.

### **Identify the challenges**

As you begin to get used to the day-to-day management of MG, consider activities and stresses that affect your ability to maintain a practicable quality of life. Take stock of what you can do and not do and try not to

push yourself beyond good judgment. Learn how to relieve tensions To keep tensions at bay, acknowledge how you feel and determine reasonable and preferred hobbies or activities that give you a pleasant diversion or create joy. Enhance your relationships with friends and family and remember that it is important to have fun. Create private time for self-reflection.

### **Understand your own coping process**

With the ongoing changes that can occur with chronic illness, adjusting to the changes is a challenge. Trying to manage with less money, fighting for health insurance benefits, form completion, etc., can require patience and skill. If you're a social person, joining a support group may help or if information helps you feel more in control, read all you can about Myasthenia Gravis.

### **Consider your attitude**

Despite the strain of living with Myasthenia Gravis, you may find unexpected pleasures, such as meeting joint challenges with your family members. Developing a sense of humor is a great survival tool.

### **The importance of good communication**

Family and friendship relationships shift over time as roles and responsibilities change. Some of the people who are closest in your life may be so uncomfortable with your diagnosis that they may deny the illness. They may feel overwhelmed and cut off communication at a time when you really need them. It is not uncommon for family members and friends to feel hopeless, isolated and trapped under these circumstances. 3 Some well-meaning loved ones may fret over minor issues while holding back their pain, anger or resentment over your diagnosis. While you have a lot on your plate and it is not your responsibility to help everyone understand how living with Myasthenia Gravis has changed aspects of your life, your clear communication can help to normalize your important relationships.

- Identify your own needs
- Recognize that life is more than Myasthenia Gravis
- Learn to send "I" messages: "I really appreciate your willingness to do the laundry, since that gives me more energy to do other things."

You must organize the medical aspects of your life so that your care is consistent and accurate. Don't assume that all of your medical information is in your medical records in your physician offices. Test results, x-rays, reports, current medications and changes in symptoms need to be front and center in order for your physicians to determine your best care. Keep an MG Diary and record changes in medications, your response to medications and treatment, symptoms and potential rationale for symptoms; dates tests were taken, etc. Prepare for your physician appointment by reviewing your MG Diary and take notes to your appointment. Engage your physician in conversation and ask questions related to the management of your MG. Make the most of your appointment by being prepared and speaking up.

### **How to help family members understand Myasthenia Gravis**

The loving support of a family is a great comfort when living with a chronic disease, but your friends and family are not mind-readers. They do not know what you're thinking or feeling unless you tell them. It does not show a sign of weakness to reveal what you're going through....it actually shows a sign of strength and a step towards improving communication with those who are about you.

If your MG began with a sudden, perhaps even life-threatening event, it will have been quite a scare for everyone. At first family will gather around you and help in any way they can. But as time goes by, they may not realize how weak you still are. Each time you exhibit some energy they may see this as a sign that you are better and they may not understand that Myasthenia Gravis is a "fluctuating muscle weakness" so that muscle weakness may come and go.

In cases where MG comes on slowly, it can be even harder for you and your family. There may seem that there is no one point in time when the MG begins. It may have taken your doctor a long time to identify your condition and you may have been misdiagnosed several times. During that period, some family members may be sympathetic, but others may wonder if you have become a hypochondriac. You may have tried to keep up a cheerful front because you didn't want to be seen as a complainer. All this can result in a confusing time and you may wonder if your family really cares. It isn't a lack of caring, but their wanting you to be well and happy.

### **Finding the balance between dependence and independence**

Most of the time, you will be able to live your life without accommodations to Myasthenia Gravis, but there will be times when you require some assistance. Learning to work together is possible when you develop and maintain mutual respect and communication. Not everyone does things just like you do, so you might have to allow for a variety of methods, messes and even mistakes. Go with the flow. Managing the financial crunch 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.

### **Redefining your identity/your new normal**

In a society that often identifies us by what we do for a living or by our standard of living, Myasthenia Gravis can throw you into a no-mans-land where you are no longer sure who you are based on your health.

Nevertheless, you can gain back some of your identity through activities or you may have to develop new interests to replace old ones. Even these new activities may have to be adjusted depending on how you feel from day to day. Do not define yourself by your Myasthenia Gravis. You are a whole person with accomplishments, history, relationships, interests, skills, personality, intelligence, creativity, humor, etc.

### **Taking charge of your Myasthenia Gravis**

You can't eliminate your condition, but you can understand the illness and your options and then take steps to adapt along the way. Be sure to take the time to step back, share feelings and consider what type of help you could use and how you can support your family and friends in their quest to be there for you. Make use of resources in your own community that may be of value and become your own health care advocate.

### **Myasthenia Gravis Triggers**

- Stress (good or bad)
- Intense negative situations
- Anxiety (good or bad)
- Certain medications
- Alcoholic beverages
- Hot or cold weather
- Hot tubs, hot baths, or saunas
- Quinine or tonic water
- Insecticides, flea sprays, and fumes
- Infections
- Low potassium level
- Diarrhea
- Low thyroid level
- Lack of sleep
- Household cleaners