myasthenia gravis association

MGA

serving missouri and kansas

Celebrating 50 years

PREPARING FOR MEDICAL EMERGENCIES WITH MYASTHENIA GRAVIS

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THE WHOLE PERSON

Although this booklet is dedicated to your health and your relationship with medical providers, remember that you are more than your medical history. Our health is impacted by both subtle and complex realities, attitudes and perceptions. For instance:

- Do you see your health status as a disappointment or a challenge?
- Are you basically an optimist or pessimist?
- Do you have confidence in the medical professional that you've chosen to direct your health?
- Have you created a support group of loving people that are able to help you through a variety of difficult situations?

How we see ourselves can make a dramatic difference in our treatment outcomes. Respect for ourselves has to do with being informed, organized, following through and belief in the process. Our skilled physicians, medications and treatment options all play a part in our health potential, but there are other kinds of healing that lie within. Sometimes we forget that releasing upset feelings, expressing love and appreciation, offering prayer, meditation or deep breathing can actually reduce stress and promote healing!

As you read this booklet, try and focus your attention on the value of preparation; not misfortune. As they say, "*Better Safe Than Sorry*".

IT'S ALL ABOUT CHOICE

It's been said that one of the true indicators of intelligence is in the choices we make. Choosing to plan for contingencies or emergencies can give us peace of mind. Lack of preparation can exacerbate an already difficult or emergent situation. Not only do we make decisions about our personal health and our family's health, but we are also a health care consumer challenged with navigating and negotiating with the health care system. It can take research to find a doctor, rehab center, hospital or health plan that meets our needs, but it's all worth the time. Planning for your health is like buying insurance … you're glad you have it, but you hope you never have to use it. Honor yourself and your health condition by beginning your preparation today.

FACING YOUR FEARS

Eleanor Roosevelt said, "*You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face... The danger lies in refusing to face the fear, in not daring to come to grips with it... You must make yourself succeed every time. You must do the thing you think you cannot do."*

Being diagnosed with Myasthenia Gravis could make you feel like you've been punched in the stomach. Many of us have never heard of the chronic disease, but nevertheless, the fear of the unknown can cause a myriad of dreadful thoughts. Giving ourselves over to fear takes our power away and we forget about our abilities. In a step by step approach of becoming informed about MG, we lose the fear and move toward health. Living a healthy life means living in the present moment rather than investing yourself constantly into the future or the past or concentrating on your diagnosis.

Moving towards wellness and health while living with MG means a willingness to overcome your fears and to become your own health care advocate. Eating healthy, keeping a positive outlook, understanding how MG affects your body and how MG medications and other treatments work, are all valuable assets, but you must also learn how to communicate with your physicians.

YOUR MEDICAL HISTORY

At one time or another, you've probably filled out a health history form for a doctor. It can help your physician determine whether you have a higher risk for certain diseases and identify any early warning signs of those diseases. Also, families can share similar lifestyles and a common culture or live in the same area - exposing them to the same environmental factors. All of these things can affect your health. As useful as a health history is, the task of completing a separate health history for each doctor you visit can be inconvenient and redundant. Wouldn't it be nice if you could compile a single history that you could choose to share with each of your health care providers? Now you can do just that with a Web tool, "*My Family Health Portrait".* My Family Health Portrait is created by the Office of the Surgeon General and the U.S. Department of Health and Human Services. It is intended to be easy to use and private. Following the prompts, you enter health information about yourself and your family. You can save the file by downloading it to your own computer. After it's saved, it's up to you who you share it with. If you choose to share your health history, the tool is designed to be compatible with many electronic health record programs already in use by doctors and hospitals. If you have questions about how to use the tool or concerns about your privacy, "My Family Health History/Portrait" is equipped with "Get Help" and "Learn More" tabs. **http://**

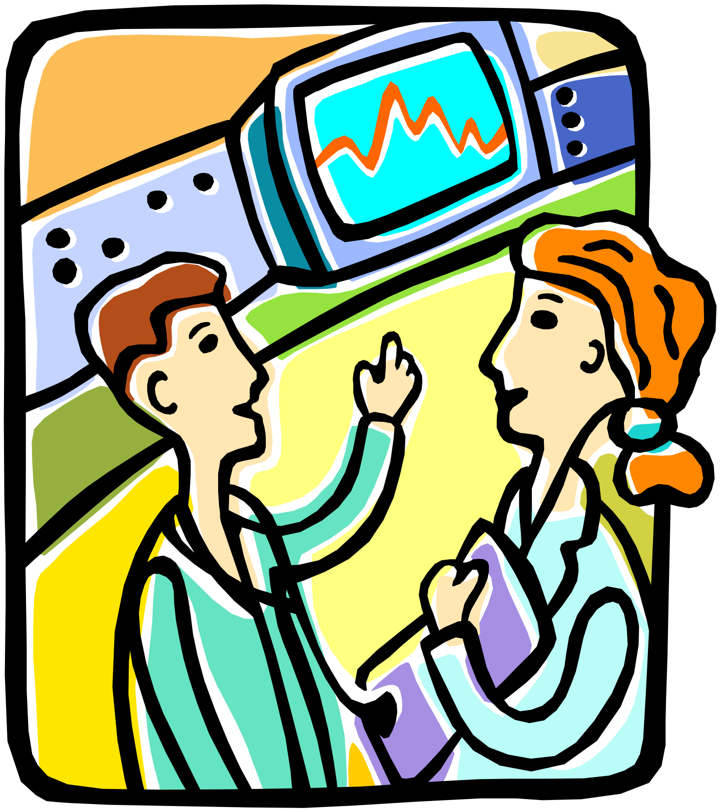
If you don't type, use a computer or the Internet, you can write down your pertinent health information and create categories of health concerns/surgeries with date of onset, treatment, and attending physician, allergies, current medications, etc. Have a trusted friend or family member create your medical history on a computerized document so that over time you can make changes or add information as necessary. Although most physician offices are glad to have your medical history in this form, they also want you to complete their own medical history form. Bringing yours with you to a new physician visit makes completing their medical history form much easier because you don't have to trust your memory for so much information.

Be sure and have a separate section to describe the ramifications of your Myasthenia Gravis. Since no two people experience MG in the same way, your physicians will need to know when you have symptoms, descriptions of symptoms, treatment, reaction to medication, IVIg or Plasmapheresis, hospitalizations, how your life changed regarding ability to work, participation in hobbies, social/family life, relationships, etc.

Make sure you have a few copies in case of emergency!

SPEAK THE MG LANGUAGE

Do you shut down when you hear your doctor talk about MG using medical terminology that you don't understand? Do you believe that you can't learn how to pronounce the names of your medications and so you refer to them by color and size? Many of us have preconceived ideas that we're not smart enough to accomplish a lot of things, but taking the time to understand MG is essential. Perhaps you don't need to grasp the scientific consequences of MG, but you can review the literature that MGA sends in our New Patient Packets, you can read our quarterly newsletters and go to the Myasthenia Gravis Foundation of America's website (www.myasthenia.org) to get a better understanding. Once you understand this neuromuscular, autoimmune disease, you can make better use of your physician appointments and benefit from clearer communication with your doctor. In case of an emergency, you will be more fully equipped to discuss your symptoms with the emergency medical services or with hospital personnel.



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.

A simple explanation:

Let's say you want to lift a piece of paper:

- Your brain sends an impulse that travels down your nerve endings to the muscles that will allow you to lift the paper. The nerve ending releases a chemical called acetylcholine that travels from the nerve ending to the receptor sites of the muscle.
- But for people with MG, the message gets blocked. Antibodies are normally a good thing & help keep us free of infection, but people with MG have too many antibodies & they actually attack the receptors that would have transmitted the message to lift the paper.
- People living with MG can have periods of remission & then "flare ups" that in extreme cases can result in a myasthenic crisis with hospitalization.

WORKING WITH THE NEUROLOGIST

People vary considerably in their expectations of doctors. Some patients call their doctor at the drop of a hat. Others are extremely reluctant to impose, hate to appear overly anxious and minimize their symptoms.

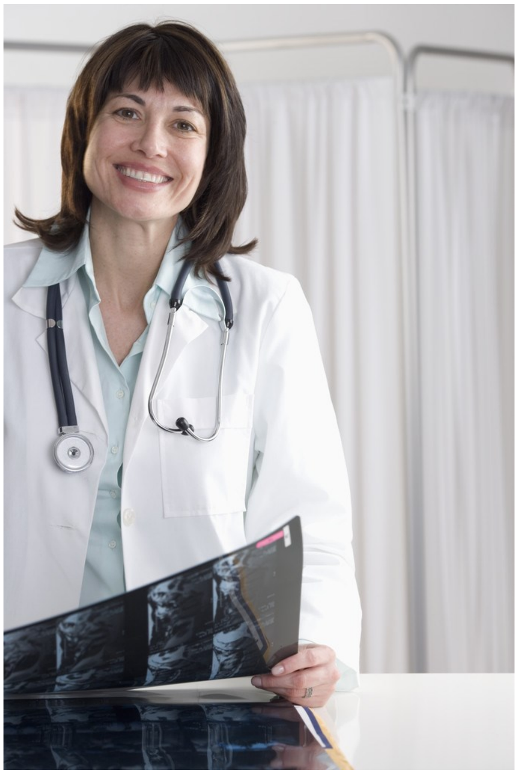
The doctor is a key member of the health team. If a trusting relationship does not exist, there are some steps you can take to improve the dynamics. Push past any notions you may have about doctor's ego and take a risk and bring up your concern. If the physician is unresponsive, ask for further clarification. It is less likely that you will summon help from a doctor if there is poor communication. If you do not believe that the doctor would go to bat for you during an emergency, think about making a change.

Most importantly, you need reassurance that the doctor has experience treating patients who have MG. Ask the physician to review his/her procedures for emergencies, ask questions about coverage, after hour procedures and the range of treatments available to avoid respiratory failure (such as plasmapheresis, steroids, etc.).

A physician who is familiar with MG understands the precarious nature of this illness and follows up with patients whose symptoms appear to be getting worse. Occasionally, a doctor may treat reported symptoms too casually. If you believe that you are not taken seriously, arrange for a consultation with another physician or go to an emergency room.

Over and above your relationship with the doctor you need to consider your own perspective on your Myasthenia Gravis and your health.

- Are you the type of person who minimizes symptoms and does not discuss changes in health with your doctor?
- Do fears about illness or hospitals prevent you from enlisting proper medical attention?
- Do you think it's okay to override a patient's resistance to treatment if it seems to be in the patient's best interest?
- As a patient, would you grant permission for your health care advocate to act on your behalf should you be too weak to accurately gauge the seriousness of the situation?
- Can you see yourself calling 911?



PROCEDURES TO ESTABLISH WITH YOUR NEUROLOGIST

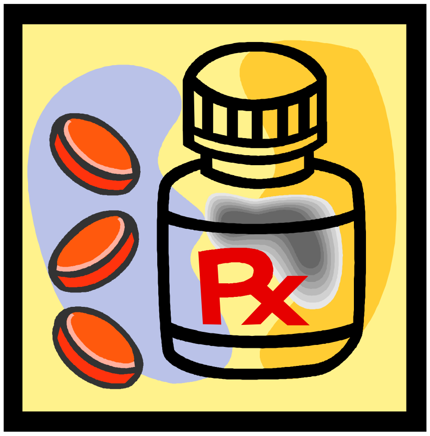
The procedures you jointly establish will become the guidelines to follow should an episode of increased weakness occur:

- What symptoms should I pay careful attention to?
- What might trigger a change in symptoms or a crisis?
- If my symptoms get worse, at what stage do you want me to call you and what number should I use to call you?
- Is there any way that I can check my own breathing?
- With which hospital(s) are you affiliated? Is this hospital equipped to provide plasmapheresis, IVIg, etc. or other treatments that can be employed in the face of an emergency?
- What should I do if I get sick at night or you are away? Is a doctor always on call? Do the covering doctors have experience treating MG patients?
- If I ever have to go to the emergency room, should someone call you to let you know that I am en route? Is it likely that you would be able to meet me there and oversee my treatment?
- When should I go to an emergency room or call 911?

KEEPING A MEDICATION LOG

Severe MG symptoms can actually result from being under-medicated or over-medicated. During episodes of increased weakness, patients should keep an accurate log of medications taken, dosages and the specific times that they were taken. This step can be life saving. To administer the proper treatment, the neurologist or hospital staff must have an accurate picture of the exact medications taken. This information should be recorded on a separate piece of paper, brought to the doctor's office or hospital and handed directly to the treating staff.
Check out the "*Suggested Medication List*" on the next page to make your own.

If at all possible, bring your medications along with you to an emergency room. Should you have to wait to be seen, you will have your medication available for use.



SUGGESTED MEDICATION LIST

NAME OF MEDICATION	STRENGTH OF MEDICINE OR STRENGTH OF EACH PILL	WHEN TAKEN (TIME OF DAY)	#OF PILLS TAKEN AT EACH DOSE OR DOSE PRESCRIBED	PURPOSE OF MEDICINE	DATE STARTED	PHYSICIAN WHO ORDERED	DATE NEW SCRIPT NEEDED
DRUG A	*20 MG*	*1 PM & 5 PM*	*2*	*BLOOD PRESSURE*	*1/4/09*	*DR, X*	*6/30/09*
DRUG B	*80 MG*	*8 AM*	*1*	*MG SYMPTOMS*	*3/7/09*	*DR. M*	*6/7/09*
DRUG C	*50 MG*	*BEFORE BED*	*1*	*ALLERGY*	*3/7/09*	*DR. X*	*9/7/09*

REASONS TO BE HOSPITALIZED

Reasons for admission my include:

- Worsening of MG symptoms (dysphasia, dysarthria, respiratory compromise), infections or stress
- Surgery (thymectomy, appendectomy, hysterectomy, etc.)
- Emergent event (trauma, medical compromise)
- Labor and delivery

WHAT IS A MYSTHENIA GRAVIS CRISIS?

A Myasthenic crisis occurs when:

- Weakness from MG becomes severe enough that the patient is unable to breathe or swallow adequately
- 12– 16% of Myasthenic patients experience crisis
- A crisis most likely occurs in patients who have a history of previous crisis, oropharyngeal weakness or thymoma

EMERGENCY MEDICAL INFORMATION

Most people with MG are aware of the importance of accurate medical information. In urgent or emergency situations, the time you have available to get things together will be limited. The time and effort you spend beforehand gathering information and putting into handy, accessible form is a reasonable and valuable investment.

There are different options for keeping your medical history information updated and available. **Medic Alert®** or other organizations have identifying bracelets and necklaces with 24-hour phone numbers connected to centers that keep patient information handy. You can download your medical history from a document on your computer to a **flash drive** and hand it to personnel in the ER or you can just print out your medical history document and hand it to the personnel. It's amazing how many people come to the ER without even knowing the names of the medications they take and yet "current medications" are just the beginning of the information the nurses and doctors need to know as they plan the care and treatment they provide.

In your list of **medications**, include both prescribed and over-the-counter medications, as well as herbal or other supplements. Include medications that are taken by mouth, injected, inhaled, rubbed into the skin, put on patches and drops. Include date, mg, mcg or cc's, dosage and frequency.

Most hospitals have systems to alert staff when there are restrictions on taking medication, i.e., "on an empty stomach", "with food", etc., but it can help to remind staff to include this information in your chart as well. Remember to include the list of medications that should not be taken for people living with Myasthenia Gravis. You can get this list from the MGA of Greater Kansas City.

If you have multiple doctors prescribing medications, noting which doctor is responsible for which medication can be helpful too.

On previous pages we discussed creating a **Medical History**, but as a reminder be sure and include any diagnosed illness or condition, whether it is currently being treated or not, any significant past illness, surgeries and procedures. For major conditions and illness, include the date diagnosed if possible. Listing your most recent vaccinations, including your last tetanus shot, can help you get out of more needles than necessary.

If you have heart problems, consider obtaining a copy of an EKG (electrocardiogram). Besides allergies to medications, don't forget to list

Listing your current weight is important because some medication doses are based on weight. Also, if someone needs to be flown by medical helicopter, the flight crew always inquires about weight.

Any **medical equipment**...inside or outside your body...is helpful for medical staff to know. Be sure to note the settings for the medical equipment that have them, like Bi-PAP or CPAP machines and oxygen, and routine maintenance procedures/ schedules for such medical equipment. Hospital personnel like to know about glasses, contact lenses, dentures, whether you routinely use a walker, cane, crutches or wheelchair.

Dietary restrictions as far as salt intake, calories, diabetic or lactose-intolerant, can be an issue even in the ER. Include food allergies and thickening agents for liquids and food consistency needs, (soft or ground foods).

CALLING AN AMBULANCE

When developing a plan for emergency care, it is advisable to contact your local "first responders" or First Aid Squad to introduce yourself and learn about their procedures. Ask to speak to the Captain and explain that you have Myasthenia Gravis and might possibly require an ambulance in the future. It is useful to know how long it generally takes for the emergency squad to respond to the call, the hospitals that generally service area residents and whether they can keep a record of your condition on file. If you live in a hard-to-find residence, make sure that they have specific directions to your home. Some MG patients who prefer to be taken to out-of-area hospitals need to contact private ambulance services. For a fee, they generally can take a patient to his or her hospital of choice. Whatever advance research you can do to familiarize yourself with local emergency services will greatly ease the process of calling for an ambulance should one ever be needed.

If the day ever comes that you need an ambulance, you may not be in a condition to make the call yourself, but you'll be relieved in one respect; that you've trained your spouse/ significant other/health advocate how to make that call and be prepared for a successful transition to the hospital.

Whoever calls 911 or the designated private ambulance company, don't panic. Speak clearly and slowly so that you do not have to repeat your information. The dispatcher will ask you to identify the patient, their age, presenting problem and address. It would be at this point that the caller would also mention that the patient has Myasthenia Gravis and any other chronic diseases that could play a part in treatment and care. The dispatcher may also ask how long the current symptoms have been occurring. Unlock the front door and if evening, turn on the porch light. If you have pets, make sure they are secure in a room that will not need access by the EMS team. The EMS personnel will knock and then just walk in and will want a clear walkway to the patient; clear enough to roll a gurney.

Once at the side of the patient, the EMS personnel will begin asking questions of the patient, but if she or he cannot speak, the advocate must be ready with pertinent information such as:

- When did the patient start feeling poorly?
- What symptoms exist?
- Has the patient been exposed to a cold or other contagious illness?
- Did the patient take all their meds today?
- What time was the last MG medication and did it help? Did it make symptoms worse?
- They will ask to see all current medication.
- Although it may be evident that the patient is having trouble breathing, the EMS personnel may ask the patient, "Are you having trouble breathing?" "Does your breathing get better if you relax yourself so you won't hyperventilate?" Do you want to go to the ER?"
- The advocate may think that time is being wasted by asking these questions, but they are routine and necessary.
- The EMS staff will tell you to which hospital they will be transporting the patient. Before they leave, go to the file where you keep the patient's medical history information and give them a copy. They can look it over in the ambulance and call the ER to alert them of any special circumstances.
- Before they leave, take off patient's jewelry including wedding ring and put in a safe place.

Your advocate will not ride in the ambulance with you, but will follow by car and park in the area indicated for Emergency Services. But before they leave the house, they need to get another copy of your medical history to be included in your hospital chart. Don't assume your medical history got transferred from EMS to the chart. In fact, don't assume anything.

Next, the advocate will call the ER and ask for the Triage Nurse or Doctor in charge and state that ___________ will be arriving shortly and cannot swallow, breathe, move or whatever the crisis situation reveals.

Now, the advocate should place a call to your neurologist and if necessary, should leave a clear and carefully stated message stating patient's name, date/time, symptoms, EMS transferred to which hospital. If you have a cell phone, leave that number as well as a home phone.

Find a ziplock bag and gather all medications and whatever the patient needs to swallow them, (yogurt, pudding) because you won't want to wait for the hospital pharmacy to order them—this can take several hours. In another bag, bring patient's eyeglasses, dentures. When you get to the hospital, be sure and alert the nurse in charge that you have ________'s medications. Ask the nurse if she understands Myasthenia Gravis and hand her the patient's medical health history and draw her attention to the medication section. It's important that she sees the medication schedule and is mindful of the significance of timing.

Try and make sure that your appointed advocate is not panic-prone. Your upset advocate will only make your symptoms worse and take attention away from your MG issues.

PLANNING AHEAD FOR A HOSPITAL STAY

The very idea of surgery is scary, but you can minimize some of the fear if you are prepared. Here are some ways to get ready.

Basic Information:

Before entering the hospital, ask your doctor who will be providing care for you. Learn which specialists may be involved, particularly if you develop a complication. Expect anyone who comes into your room to be wearing an ID badge. You can ask to meet with the anesthesiologist before surgery so that you can reinforce your concern for difficulties related to your Myasthenia Gravis.

The most important part of preparation is making sure that you've thoroughly read up on your condition and MG, including the test or procedure you are having. You should be as informed as possible about what is going on in your body. After all, you are the key partner of your health care team.

What To Bring:

- As stated before, you'll want to bring your complete medical history document. Don't assume that your primary care physician or neurologist will transmit all the details related to your Myasthenia Gravis.
- Your insurance cards, driver's license and social security number
- Copy of Advanced Directive and Medical Power of Attorney
- A ziplock bag with your medications in their original containers and give them to the nurse. Also do the same with any over-the-counter medications or supplements. These can have potential interactions with prescribed medications and may even cause you to bleed more.
- Phone numbers of persons you want to be able to receive medical information about you for the HIPPAA form (Health Insurance Portability & Accountability Act)
- Personal hygiene items: including toothbrush, shampoo & comb, lotion, lip balm, etc.
- If you don't want to wear a hospital gown, bring your own pajamas, robe and slippers with rubber soles. Make sure your sleepwear is loose-fitting so as not to rub against potential stitches or staples.
- Eye glasses, eye glass case, dentures and denture cup.
- Paper and pen, magazines, books, listing of your favorite TV programs, channels and times.
- Bring a list of questions for your doctor and a checklist of questions related to medications you will be prescribed after your procedure.

What Not To Bring:

- Money, credit cards
- Jewelry
- If you're admitted as an emergency, ask the ER to lock your valuables in the business office safe until someone can take them home.

If You're Admitted By A Specialist

If possible, notify your primary care physician prior to admission or ask your specialist to write an order for your primary care doctor to be notified.

Having Problems During Your Hospital Stay?

Depending on the severity of the problem, you can contact the head nurse, patient advocate or patient representative, social worker, nursing supervisor or administrator or hospital administrator.

DETERMINING INSURANCE COVERAGE

Although there are many types of hospitals available to meet the needs of different patients, the patient's choice may be limited by his or her insurance plan. If the patient receives care from a facility that is not approved by the health plan, the patient may have to pay for most or all of the medical expenses related to the hospital stay.

Managed care insurance plans often require pre-certification before any hospital stay, except for emergency situations. Usually, the patient's doctor has to authorize the hospital stay and some types of care provided in the hospital require insurance clearance. If the patient has Medicare (for patients over 65) a semiprivate room, meals, general nursing, hospital services and supplies are covered. Services not covered by Medicare include private duty nurses, private room (unless medically necessary), TV and telephone fees.

The patient may desire to seek a second opinion to confirm the doctor's treatment recommendations. The patient needs to contact his or her insurance provider to determine if the second opinion consultation is covered.

For patients who do not have insurance coverage, other payment options and sources of financial aid can be discussed with the hospital's financial counselor.

HOSPITAL SERVICES

When the hospital stay will be for more than one day, the patient usually receives information about the hospital from the admitting office regarding parking, lodging information if the patient is from out of town, types of rooms, etc.

Hospital services offered may include:
- Ethics consultations
- Barber or beautician (will incur a fee)
- Complementary techniques such as relaxation tapes, massage therapy or aromatherapy
- Home care (arranged by a discharge planner)
- Nutrition therapy: Registered dietitians available
- Ombudsman: Health care personnel available to address concerns about medical service and nursing staff
- Pastoral care: Hospital staff that provides religious support and services. Small inter-faith chapels provide a quiet retreat for patients and family
- Patient education: A variety of services are available to teach patients and family about medical conditions and procedures
- Pediatric services: Most hospitals have dedicated services and programs available for children and teens
- Social work: Social workers are available to help patients manage the changes that may occur as a result of their hospitalization and provide links to community resources

PATIENT RIGHTS AND RESPONSIBILITIES

All hospitals have a list of patient rights & responsibilities, established by the American Hospital Association and posted throughout the hospital. They include:

- Considerate and respectful care
- Complete information about diagnosis, treatment and expected recovery in terms that the patient can understand
- Knowledge of the name and function of any health care professional providing care
- Informed consent
- The right to refuse treatment to the extent permitted by law and be informed of the medical consequences

Each patient should obtain a list of his or her rights and responsibilities prior to a hospital admission.

HOSPITAL CAREGIVERS

Sometimes the patient's primary physician or neurologist is not the attending physician who is in charge of the patient. The attending physician may be a doctor on the hospital staff, called a "*hospitalist*". You may also be provided care from residents and interns. Nurses work closely with doctors to supervise the care provided. Nurses take the patient's vital signs and teach patients how to care for themselves. The head nurse, also called the clinical care nurse manager, coordinates your care.

Other health care providers include medical technologists, radiographers, nuclear medicine technicians, physical and occupational therapists, speech therapists and dietitians.

SPEAK UP!

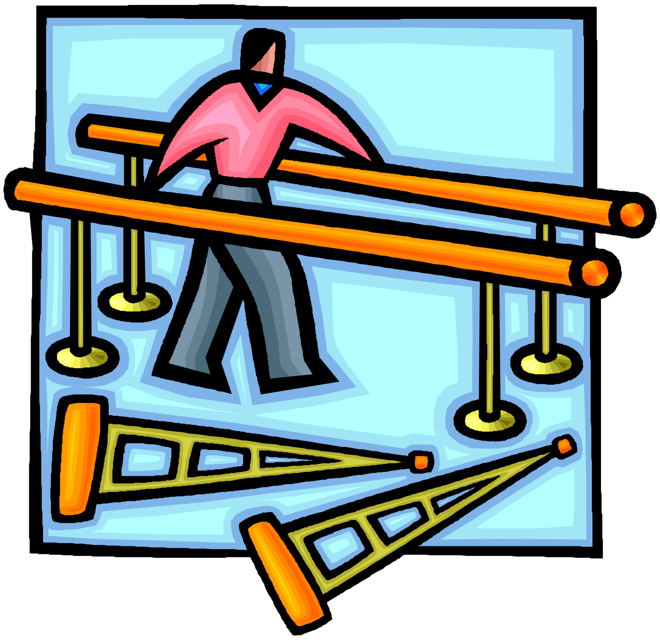
If you have a need, problem, concern or question, SPEAK UP. Don't assume that hospital staff know your needs or should know what you're thinking! If you are not assertive, it may be helpful to select a spokesperson from your family or friends designated to communicate with the health care providers as well as to other family members or friends. Make sure that this person is listed in your chart.

REHAB & SKILLED NURSING FACILITIES

Injuries happen and you may find yourself with a referral to an outpatient or inpatient rehabilitation facility. Physical therapists will be focused on their training to get you back into shape, but may not be educated regarding the muscle weakness associated with MG. The task of weight training may be very hard to balance since if you do too much, you risk aggravating your MG and if you do too little, then you may not strengthen the muscles necessary for recovery. For this reason, it is best to contact your neurologist and ask him/her to arrange for a consultation with the rehabilitation specialist to discuss rehab options. The rehab specialist can then instruct the physical therapy team to develop a healing plan that is appropriate for your needs. Do not be hesitant to tell a physical therapist about your MG and what you perceive to be too much activity. You can also give informational materials on MG to your therapists and other medical professionals or call the MGA at (816) 256-4100 and we'll send materials to whomever you designate in KS & MO.

Although hydro-therapy (spa or hot tub) treatments may initially feel good, remind physical therapists that prolonged hot water therapy can exacerbate MG symptoms.

If you find yourself in a skilled nursing facility for reasons other than your MG and you're rehabilitating from illness or surgery make sure that everyone attending to you knows that you are living with Myasthenia Gravis. It is important that your medications have been prescribed for you and that they are administered in a timely manner.



CHALLENGES FOR FAMILY & FRIENDS

Family and friends can find themselves caught between wanting to respect their loved one's fears and knowing how important it is to act decisively. Illness can upset the customary roles and expectations in a family. Loved ones worry about being intrusive or inflicting additional stress on a person who is ill. The desire to protect, comfort and support is genuine, but the best ways of helping are not always clear. Denial is human, but not helpful when the need for medical attention is urgent. For instance, potential respiratory failure scares us all, but having a well-thought prevention plan in place is a protective measure that can save lives.

MG is a trying illness; no one should have to bear it alone. Just as patients require support, so do health advocates. If you are going to become a health advocate, you will need accurate information about MG. You'll be better prepared to handle an emergency if you fully understand the fluctuating nature of this illness. For example, breathing and swallowing difficulties commonly intensify when a patient gets ill. If the patient cannot speak and does not have the proper legal documents (power of attorney, for instance), the hospital can do whatever it wants. Without a POA (sometimes called a health care directive), a relationship with an unmarried partner does not exist in medical emergencies. You are just another stranger. Although laws are changing to protect the rights of gay and lesbian people, having the appropriate documents can protect against prejudice during a time when essential health decisions are required.

It's a mistake to believe that patients, family and friends can ward off escalating symptoms or receive better care by having a good attitude, but a willingness to be accommodating and friendly to hospital staff can take the pressure off. There is an art to working with a person who is sick. There is no need to take charge or override a patient's wishes when symptoms are not severe. Try to elicit as much input as possible from the patient so that you are seen as an ally, not an adversary. Try to frame things in a way that feels supportive, i.e., "I know you have been through a lot. I can see why you are reluctant to call the doctor. Perhaps there are some things the doctor can recommend that do not require hospitalization."

If it is possible for you to develop a relationship with the treating physician, this can be of considerable help. With early intervention, you may never have to deal with a full-blown crisis. If your loved one cannot call the doctor, you may need to inform the neurologist that symptoms are escalating. There is the possibility however, that one day you will be needed to take charge and enlist emergency medical services. If you encounter patient resistance, trust your own judgment. Do not hesitate to call 911 if severe breathing or swallowing difficulties are evident.

Becoming a health advocate is both a privilege and a responsibility. Despite the conflicts that may arise from time to time, people who care about one another seem to be able to cope with occasional differences. Sharing the burden of an illness engenders appreciation and closeness—this carries its own rewards.

PLAN FOR THE WORST, HOPE FOR THE BEST

The recommendation to prepare for an emergency in no way implies that life-threatening situations are inevitable; in fact, with the newer treatments that exist today, MG is more controlled than ever before.

Many patients live with MG and never experience extreme respiratory difficulties or complications due to surgery. Yet to deny that this possibility exists leaves one needlessly unprotected. The best hope for all of us is to live fully and safely. Prevention plans are suggested because they offer peace of mind and added safety.

myasthenia gravis association
MGA
serving missouri and kansas
Celebrating 50 years

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THANK YOU TO THE FOLLOWING FOR THEIR HELP IN COMPILING THIS BOOKLET

Carolyn Cooperman,
NJ MGFA Chapter, *Newsletter Nov.* 2009

Susan C. Winters, "*The Nutmeg*"
NJ MGFA Chapter, March 2009 January 2009

Kathleen Kluger, *OK MGFA Chapter*. March 2004

www.healthatoz.com

Answers.com: Planning A Hospital Stay

Jennifer Johnson, ARNP
MGA Board Member