

LIVING WITH Myasthenia Gravis

Taken from the MGF of Illinois Web site

- Newly Diagnosed
- Healthy Living with MG
 - Safety at home
 - Helpful tools
 - Set your own pace
 - Exercise
 - Nutrition
 - Tips for eating and swallowing
 - Vision issues
 - Tips for getting dressed
 - Medical ID jewelry and services
 - Wallet card
 - Travel tips
- Staying Mentally Fit
 - Positive attitude
 - Coping with stress
 - Depression
- Family and Friends
- Local Support
 - Support groups
 - Community and government services
- Related Health Concerns
 - Other autoimmune diseases
 - Sleep problems
 - Medication side effects
- Personal Stories

Newly Diagnosed

“I have *myasthenia gravis*? What does that *mean*?”

If you or a family member has been diagnosed recently with MG, that question may echo in your head. How can you get a handle on the answer?

- **Learn about MG.** You'll want to know about the disease, what symptoms to look for, and how MG can affect your daily life. The MGF of Illinois can provide several resources, including:
 - MGF of Illinois *Conquer* newsletter
 - MG brochures and books
 - YouTube videos
 - Internet links to related Web sites, chat rooms and community services
- **Talk to someone who understands.** Call the MGF of Illinois office with questions and concerns. Our support groups meet several times a year in Chicago-area locations, Springfield and the Quad Cities area. We also sponsor two educational meetings a year.

- **Research treatment options.** It helps to know about medicines used to treat MG, surgical approaches, and other therapies. This way you're better equipped to talk with your doctor about treatment decisions.
- **Learn the lingo.** Your doctor might use words new to you when talking about the disease and your symptoms. The MGF of Illinois has a glossary of terms we would be happy to share that might be helpful to you.
- **Keep track.** Get a small pocket calendar or notebook. Identify which symptoms appear when, how long they last, and what events might have triggered them. Track when you start or stop a particular medication or change dosages. Bring this information when you're visiting doctors, dentists and eye specialists. Use it to discern what worsens your MG, or how long it takes to bounce back from certain events.
- **Be prepared.** In case of emergency, carry a wallet card that identifies your illness. The MGF of Illinois has one we can send you or you can print it off our website. Keep a list of your current medications in your purse or wallet at all times. And carry a list of drugs that myasthenics should avoid. Make sure someone other than yourself knows about your illness and where you keep your medication.
- **Decide who to tell.** You'll want to tell close friends and family members about your MG. Depending on the severity of your illness, you may need their help rebalancing home duties, getting to doctor visits, and moral support.

Beyond this inner circle? Ask why they need to know. For example:

- If you're in school, school administrators should understand your condition. Are there times when you lack the stamina for gym class or can't manage stairs? Do you need help carrying your books?
- If your symptoms could affect your work, you may want to explain that you have a medical condition. Can you identify accommodations that would help you, like a nearby parking space or computer adaptations to ease eye strain? Be honest, and be responsible about identifying what you can and cannot do.

Keep in mind that most people have never heard of myasthenia gravis. Be prepared for puzzled looks, curiosity, mispronunciations, and comments that range from "but you look fine" to "I'm so sorry." A sense of humor comes in handy.

Worth Noting

MGF of Illinois:

- *Fields multiple calls and emails each day from all over the country.*
- *Sends out new patient packets every week.*
- *Holds educational meetings twice a year, each drawing 40 to 70 people.*
- *Offers seven active support groups in the Chicago area, Springfield and the Quad Cities.*

Healthy Living with MG

There are many steps you can take to work with your illness. Depending on how myasthenia gravis affects you personally, there may be times when these ideas come in handy.

- Safety at home
- Helpful tools
- Set your own pace

- Exercise
- Nutrition
- Tips for eating and swallowing
- Vision issues
- Tips for getting dressed
- Medical ID jewelry
- Wallet card
- Travel tips

Safety at Home

Use your good judgment.

- If you feel weak or unsteady, let someone else change the light bulbs. Skip the shower, and opt for sponge baths.
- If you live alone and feel very weak, ask someone to check in on you.
- Do what you can to avoid falls. Put away throw rugs. Keep walkways and stairs clear. Clean up spills promptly. Don't wax floors.
- In the event of a power outage, keep a flashlight handy. Also keep a working telephone available.
- Pay attention to the expiration dates of your medication. Throw out old medications.

Helpful Tools

When your MG is active, these items might be helpful.

Getting Around

- A lightweight cane can offer support.
- Use a city shopping cart or wheeled luggage cart for shopping at the mall. You can use it to bring things to and from the car, also.
- A handicapped parking sticker, decal or license plate makes your walk shorter when doing errands.
- Use the shopping scooters available at the grocery store.
- Consider a chair lift if your stairs keep you from getting around the house independently.

In the Kitchen

- Electric appliances such as an electric can opener and electric mixer can conserve your energy.
- Put the things you need within easy reach. Avoid getting down on the floor or up on a ladder to get what you want.
- Choose the medium or small containers at the store. Avoid the discount sizes that are too heavy to lift.
- Lightweight plastic dishes and lightweight silverware are surprisingly helpful.

In the Bathroom

- Install secured grab bars in the shower and bath. Not sure where to put them? Area building codes might give you guidance.
- Use a plastic shower chair. Check second-hand resale stores to reduce costs.
- Try a flexible hose attachment for the shower head, so you can sit while washing.
- Use railings for the toilet. Some attach to the toilet itself and can be used temporarily.

For Yourself

- A properly-fitted removable cervical collar can support your neck, for instance when you write, use the computer, prepare dinner or pay bills.
- Tape up your eyelids. Your eye doctor may have light-adhesive tape that temporarily keeps your eyelids from drooping. Or try silk tape that's used in hospitals.
- If your breathing is weak, your doctor may prescribe the use of a C-PAP (or Bi-PAP) machine. While you wear a mask, the C-PAP forces regulated puffs of air into your lungs, giving your breathing muscles a break. You can sleep with the C-PAP, and use it as needed throughout the day.

Set Your Own Pace

Physical stress and emotional stress can worsen MG symptoms. With this in mind:

- Don't rush. If you're going to be late, what the heck? Be late.
- Learn to ask for help when you need it. Be direct and specific. ("I need a ride on Tuesday at 10 a.m." "Please don't hold my arm; I'd rather hold onto you.")
- Get plenty of rest. You may need more sleep compared to pre-MG times.
- Build naps into your day without guilt.
- Rest your eyes regularly while reading or working on the computer.
- Learn what triggers your myasthenia. Can you avoid it? Can you rest before or after?
- Learn strategies to handle stress—for instance, special breathing or imaging techniques.
- Don't give up the things you love—yet. If myasthenia gravis is forcing you to stop gardening, golfing, biking, or whatever—it may be temporary. For example, can you focus on several planters instead of a larger garden?
- And hey, tomorrow is another day.

Exercise

"Exercise is the best doctor you can ever have!"

-- Speaker at an MGF of Illinois educational meeting

Most simply put, exercise *within your limits* is absolutely recommended if you are able. *Don't* exercise if you're weak.

Lack of exercise can actually cause fatigue; try something pleasant and nonstressful. Those who are able don't necessarily exercise for how it feels when they do it, but how it makes them feel afterward. Listen to your body. Start slow and short. *Always* heed your body's "NO" at its first hint.

Nutrition

When you're ill, good nutrition becomes even more important because it can have a bigger impact on your overall health. At the same time, your illness may pose new challenges. MG weakness can make it difficult to eat certain foods. MG medications may affect your appetite, your metabolism and your ability to exercise.

What Should You Eat?

According to the "Dietary Guidelines for Americans" from the U.S. Department of Agriculture and the U.S. Department of Health and Human Services:

- Eat a variety of foods.
- Maintain a healthy weight.
- Choose a diet low in fat, saturated fat, and cholesterol.

- Choose a diet with plenty of vegetables, fruits and grain products.
- Use sugars only in moderation.
- Use salt only in moderation.
- If you drink alcoholic beverages, do so in moderation.

Special Concerns for Myasthenics

Maintaining a **healthy weight** is extra challenging and extra important. If you're weak and unable to exercise, or if you're taking a corticosteroid like prednisone, extra pounds can show up. But doing everyday activities with extra weight is a bigger drain on your strength. Keeping your weight in check is worth the effort.

Prevent excessive **bone loss** (osteoporosis) that happens with age and with prednisone usage. According to the National Osteoporosis Foundation, adults under age 50 need 1,000 mg of calcium and 400 to 800 IU of vitamin D daily. Adults age 50 and over need 1,200 mg of calcium and 800 to 1,000 IU of vitamin D daily. An 8-ounce glass of milk contains about 300 mg of calcium. Ask your doctor about taking a calcium/vitamin D supplement.

If your MG medication causes **diarrhea or stomach upset**, avoid foods that are fatty, spicy or high in fiber. Avoid dairy foods, except for yogurt which can sooth digestive problems. Good choices include mild foods like bananas, white rice, eggs and chicken.

Diarrhea can lower **potassium** levels. Foods rich in potassium include orange juice, bananas, potatoes, avocados and apricots.

If prednisone use causes **fluid retention**, you'll want to avoid salt. Use a salt substitute. Avoid frozen meals, canned soups and vegetables, smoked and cured meats, and salty snacks.

Tips for eating and swallowing

MG can weaken your lips, tongue, jaw or throat. You might:

- Spill liquid from your lips
- Have trouble clearing food from your mouth
- Tire when chewing tough meals
- Have to swallow several times to get food down

Something to Chew on

If you do find yourself with a mouthful that you're unable to swallow, spit it out. A little embarrassment is better than choking.

End of sidebar

To reduce residue in your throat:

- *Moisten solid foods with gravy, sauce, broth, butter, mayonnaise, sour cream or yogurt.*
- *Choose chicken or fish instead of tougher meats.*
- *Avoid dry crumbly food such as crackers, rice, cookies, nuts, chips or popcorn.*
- *Avoid bread products such as sandwiches, bagels and muffins.*
- *Focus on the swallow. Hold your head in a different position to try a different swallow pathway.*

To reduce fatigue:

- *Eat several small meals during the day.*
- *Chop or mince solid foods (like meat).*
- *Eat your largest meal earlier in the day when you have more energy.*

- *Take anticholinesterase medication (for example, Mestinon) shortly before mealtimes.*

To reduce the risk of food accidentally going into your lungs (called “aspiration”):

- *Thicken all fluids to the consistency recommended by your doctor or speech pathologist.*
- *Remember that ice cream and popsicles melt into a thin fluid in your mouth, and that once you chew fruits, the juice released is also a thin liquid.*
- *Be careful swallowing mixed-consistency foods, for example, cereal with milk, soups (like chicken noodle or vegetable), and fruit salad mixed in juices.*

To reduce nasal regurgitation:

- *Limit each swallow to half a teaspoon.*
- *Sit upright and don’t tilt your head forward when swallowing.*

Beware!

Warm liquids, like coffee, tea or soup, can relax swallowing muscles. If you’re having trouble swallowing, try sipping on ice chips periodically as you eat.

End of sidebar copy

This information was abstracted from “Myasthenia Gravis and Swallowing Difficulty,” by Angela Colton-Hudson, M.CL Sc., Speech Language Pathologist, University Campus, London Health Science Chapter, published in *Conquer* newsletter, MGF of Illinois, April 2006.

Vision Issues

MG vision problems include

- *Double vision*
- *Droopy lid(s)*
- *Dry eyes*
- *Focusing problems*
- *Cataracts from medications*

Here are ways to handle MG vision issues:

- If you have a problem with double vision or droopy lids, think carefully before you drive. This also applies if you have cataracts (for instance, from medication), or your neck is so weak it makes your head extremely heavy.
- Use an eye patch while reading or watching TV to relieve double vision. Alternate the eye patch from one eye to the other to avoid eye strain.
- Use sunglasses and sun visors to reduce glare.
- Tape up your eyelids to cope with droopy lids. Ask your eye doctor for light-adhesive tape. Or try silk tape that’s used in hospitals.
- If reading is difficult, contact your local library. The librarian may be able to direct you to books on tape and CD, print enlargement machines, and computers with special screen magnifying software like ZoomText.
- Have your eyes tested regularly. This is especially important if you’re taking a steroid medication like prednisone, which can cause glaucoma or cataracts. Early detection can prevent blindness.

Tips for Getting Dressed

If getting ready to face a new day wears you out, try these ideas:

- Choose an easy-to-manage hairstyle. Skip the blow-drying, if possible.
- Try an electric toothbrush.

- Avoid hot baths and hot showers.
- Sit to brush your teeth, blow dry your hair, or shave.
- Get ready in stages.
- Choose lightweight, comfortable shoes—ones that are easy to put on, and help you keep your balance.

Medical ID Jewelry and Services

Here are two services that offer medical ID emblems.

- **MedicAlert®** 1-800-ID-ALERT (1-800-432-5378) <https://www.medicalert.org> This nonprofit healthcare organization sells engraved jewelry indicating your medical condition and offers a service that emergency responders can call for complete medical information you provide. MedicAlert also offers products for summoning emergency aid.
- **Medic Assist™** <http://www.medicassist.com> Medic Assist™ offers medical identification cards and custom-engraved medical identification jewelry. You can specify the information to be engraved—medical conditions, allergies, family or doctor names and telephone numbers. They also offer an Assist a Medic product that will automatically call up to 4 numbers you program into the system and play your pre-recorded message. Medic Assist also offers products for summoning emergency aid.

Wallet Card

Carry an MG information card with you in case you have a medical emergency away from home. This will save valuable time when you're treated by doctors and emergency personnel. The MGF of Illinois has a printable copy that you can keep in your wallet. You can find it on our website, or you can contact our office and we will send you one.

Travel Tips

Traveling when your myasthenia is active can be a challenge. Here are some suggestions:

- Wear a medical identification emblem.
- Keep this information in your wallet: a list of current medications, medical history, allergies, doctor contact information, and family contact information.
- Keep your medication with you, not packed in baggage that you check.
- Whenever possible, plan and book flights in advance. Talk to an airline representative in advance if you need help checking in, or if you need ground transport to get from one place to another in the airport.
- Call ahead to find out if hotels have handicap accessible bathrooms.
- Keep your luggage minimal, especially if you need help with it. Consider sending some things ahead to limit what you have to manage.
- Maintain your medication schedule.

Staying Mentally Fit

Do you see a glass half full? Half empty? Or simply holding four ounces?

For the most part, MG won't change your unique view of the world. Still, when you see life through the prism of illness, that view can be altered by your attitude. When facing illness, can

you be positive? Can you feel hope, gratitude and humor? Sometimes we have to intentionally choose *and practice* a positive attitude.

A positive attitude helps you get through each day, manage your worries, and maintain relationships. With or without MG symptoms, it allows you to feel better mentally.

You can improve your positive thinking, even if it doesn't come naturally. Try these steps:

- Practice. Can you think of something you appreciate right now?
- Put it in your daily schedule. Express something positive when you brush your teeth, at mealtime, or before you sleep.
- Hang out with optimistic people. If a group conversation turns petty or whiny, maybe it's time to excuse yourself.
- Research. Try the library or a book store for books that discuss how to live with illness. To get started, read *Hoping, Coping & Moping, Handling Life When Illness Makes It Tough* by Ronna Jevne, Ph.D.

Purposefully insert positive thoughts and affirmations into your day.

Coping with Stress

Stress is a primary MG enemy. It can affect MG in a snap, as the mind and body can't be separated, so be prepared.

Seek and use what works for you. Here are some ideas:

- meditation
- recreational reading
- listening to music
- visualization/guided imagery
- prayer
- exercise (if possible)
- reading for inspiration or spiritual growth
- hobbies

Purposefully insert positive thoughts and affirmations into your day.

Depression

Many people who are diagnosed with a threatening medical condition can develop depression. Depression is very real and can be debilitating. It can keep you from reaching out for help when you need it most.

Symptoms may include a lack of joy, magnified sadness, feelings of emptiness or isolation, persistent pessimism, loss of interest in daily life, difficulty making decisions, loss of appetite, gloominess or thoughts of suicide.

Because the mind and body are so closely connected, depression can make your myasthenia gravis worse. Working to overcome depression is essential to improve your overall health. There is no shame in seeking help from a trusted, skilled, competent therapist.

Myasthenics face a catch-22: many antidepressant medications can worsen MG, or may not be effective. If you see a mental health professional, make sure that person knows your full medical history.

Family and Friends

Most myasthenics put a high value on support from friends and family. If that's you, know that your help is appreciated—whether you bolster an MG patient's spirits or offer much-needed physical aid.

First, try to understand.

- It takes time for a person to accept that he or she has an illness. A person may face loss of health, limits on activity, body image changes from medication and more. These losses may prompt anger, denial, fear, and confusion before acceptance sets in.
- Uncertainty is stressful. When MG symptoms appear, your friend may be on pins and needles wondering, "What's next?"
- There's a ripple effect. It takes time to figure out how MG affects a person's place in the world, for instance, with:
 - Relationships, including marriage, friendships, parenting.
 - The ability to work, attend school, run a household, care for children.
 - The ability to pursue activities, hobbies and travel.
- It's difficult for a previously able-bodied person to ask for help.

What can you do?

- Listen. *Accept* what the person has to say. Try to listen without diminishing or making light of their concerns. (Avoid responses like these: "I feel tired, too." "It could be a lot worse." "Everyone's eyesight gets worse with age.")
- Be patient. A person talks when he or she is ready.
- Be flexible. Plans may have to change from day to day depending on how a person with MG feels.
- Offer help. Repeatedly.

A Helping Hand

Can you help with any of these tasks?

- Rides to doctor visits*
- Rides to hair appointments*
- Lawn mowing*
- Driveway shoveling*
- Grocery shopping*
- Preparing a meal*
- Help with insurance or other paperwork*
- Housecleaning*
- Laundry*
- A weekly phone call*
- A trip to the movies or social event*
- Babysitting*

Local Support

Your doctors can be a great resource of information about MG as a disease. But how about what it's like to live with MG?

- Support groups. Sometimes it helps to talk to others who are facing similar issues.
- Community and government services. There are many services available to disabled individuals.

Related Health Concerns

If you have myasthenia gravis, it's not uncommon to have additional medical problems, too.

- Other autoimmune diseases
- Sleep problems
- Medication side effects

Other Autoimmune Diseases

People with MG are more likely to suffer from another autoimmune disease as well. These can include thyroid disease, lupus, rheumatoid arthritis and diabetes. With thyroid disease, an episode of hypothyroidism may trigger a flare-up of MG weakness.

Sleep problems

Myasthenics often have sleep problems, either with the quantity or quality of sleep. You might experience insomnia, or symptoms of sleep apnea such as loud snoring, daytime sleepiness, and repeated stops in breathing as you sleep. Your sleeping partner may be aware of such problems before you are.

MG doesn't necessarily cause these symptoms directly. Instead, the culprits can be MG medications, depression, or inactivity that leads to being overweight.

Be sure to discuss sleep problems with your doctor to rule out other, more serious causes. Many sleep concerns can be treated easily with improved sleep habits.

Medication side effects

When MG patients gather, first they compare symptoms, then treatments. Inevitably, talk next turns to medication side effects.

Almost every medication has side effects—effects on the body that are not intended and are not helpful. Which side effects you experience depends on your individual makeup, the dose, the length of time you take the medication, other drugs you're taking, and so on. Simply put, everyone is different.

It's important to discuss the side effects of every medication you take with your doctor. Your doctor may prescribe extra medications and vitamin supplements, for example, to ease digestive problems or prevent bone loss.

Corticosteroids like prednisone are worth a special mention here. They are used often as a first line of defense with MG because they work more quickly than other immunosuppressant drugs. But the side effects can be numerous. And sometimes a "side effect"—even from medications for another condition—can become more serious and life-changing than your MG. Read the fine print that comes with your medication. Keep up with regular blood tests, eye exams and other recommended checks.