THE Sumaira FOUNDATION

What to KNOW about MG

The information on this page is designed to provide a patient-friendly overview about myasthenia gravis (MG).

Though MG is a rare disease, there are an increasing number of neurologists around the world who are now specializing in neuromuscular disorders. Furthermore, scientists are dedicating their time and efforts to better understand the epidemiology of MG while improving diagnostics and treatments to ultimately improve the quality of life for patients and their caregivers.

Below, you will find a list of important questions and answers with the goal of informing you and your loved ones about this condition. This guide includes important information covering diagnosis, symptoms and available treatments. Please be aware that the questions below are answered with general information about MG and may not fit your individual situation.

Information on this page is not intended to be used as a substitute for medical care and should not be relied upon for the diagnosis or treatment of myasthenia gravis. If you have questions or concerns regarding your health, please contact your healthcare provider.

What is MG?

Myasthenia gravis (MG) is a long-term condition where the body's immune system, which normally fights infections, mistakenly attacks the connection between nerves and muscles. This causes muscles to become weak, especially after activity, and to feel better after rest.

MG is considered rare, but it is more common than many people think. **Roughly 1 in 5,000 people live with MG**. It can start at any age, but it most often appears in younger women (20s–30s) and older men (60s–70s). The number of doctors who specialize in MG is growing, and new treatments are being developed every year.

What are the main types of MG?

By symptoms:

- **Ocular MG (OMG):** Weakness is limited to the muscles around the eyes, causing droopy eyelids and/or double vision.
- **Generalized MG (gMG)**: Weakness spreads beyond the eyes and can affect the face, neck, arms, legs, and the muscles used for breathing, chewing, and swallowing.

By age of onset:

- **Juvenile MG (onset at age 18 or younger):** MG in children is rare. Younger children are more likely to have the ocular form and may improve or go into remission on their own. Teenagers with MG tend to look more like adults with the disease. Treatments are generally the same as for adults, though doctors try to limit steroid use because of effects on growth.
- **Early-Onset MG (onset between ages 19 and 50):** More common in women. Patients usually have AChR antibodies and an enlarged thymus gland. Thymectomy is frequently recommended and has been shown to improve outcomes.
- **Late-Onset MG (onset after age 50):** The fastest-growing group, slightly more common in men. The thymus is usually normal in this group, though thymomas can still occur. These patients are more likely to have other health conditions (such as heart disease or diabetes) that can make treatment more complex.

If I have ocular MG, will it spread to the rest of my body?

This is one of the most common worries for people newly diagnosed with ocular MG. The good news is that many patients who remain purely ocular for the first two years are less likely to develop generalized weakness. However, it is important to know that spreading can still happen after the two-year mark in some patients. Continued follow-up with a neurologist is important regardless of how long symptoms have stayed in the eyes.

What is the cause of MG?

Just like other autoimmune diseases (such as Type 1 diabetes, lupus, or rheumatoid arthritis), the immune system makes a mistake and attacks the body's own healthy tissue. In MG, **the immune system produces proteins called antibodies that attack the spot where nerves connect to muscles, called the neuromuscular junction.**

What antibodies are associated with MG?

- **AChR antibodies** (the most common, found in about 85% of people with generalized MG): These attack the acetylcholine receptor, a tiny "docking station" on the muscle that receives signals from the nerve. When these receptors are damaged or blocked, the muscle gets weaker signals and cannot contract properly.

- **MuSK antibodies**: These attack a protein that acts like scaffolding, keeping the receptors organized in the right place. People with MuSK-MG often have more trouble with facial muscles, swallowing, and breathing.

- **LRP4 antibodies**: These attack another scaffolding protein that works alongside MuSK.

- **Seronegative MG**: In some patients, none of these antibodies can be found with current blood tests. This does not mean MG is not present — it just means science has not yet identified the specific antibody, or the levels are too low to detect.

How is MG diagnosed?

MG is usually diagnosed by a neurologist, ideally one who specializes in nerve and muscle diseases. Diagnosis typically involves a combination of:

- **Your symptom history:** Especially weakness that comes and goes and gets worse with activity
- **A neurological exam:** Testing how quickly muscles tire out
- **Blood tests:** Checking for AChR, MuSK, and LRP4 antibodies
- **Electrical nerve tests** (EMG):
    - ***Repetitive Nerve Stimulation (RNS)***: Small electrical pulses are sent to a nerve repeatedly. In MG, the muscle response gets weaker with each pulse.
    - ***Single-Fiber EMG (SFEMG)***: The most sensitive test for MG. A very thin needle measures the electrical activity of individual muscle fibers to detect delays in nerve-to-muscle communication (called "jitter").
- **Chest imaging** (CT or MRI): Used to check the thymus gland (see below).

What are bedside tests for MG?

- **Ice Pack Test**: An ice pack is placed over a droopy eyelid for a few minutes. Cold temporarily improves nerve-to-muscle signaling, so if the drooping gets better, it strongly suggests MG.
- **Edrophonium (Tensilon) Test**: An older test involving an IV medication that briefly boosts nerve signals. This is rarely used today because blood tests and EMG are more reliable.

Why do doctors check the thymus gland?

The thymus is a small gland in the upper chest that plays a role in the immune system. In many people with MG, the thymus is abnormal, it may be **enlarged or contain a tumor called a thymoma**. A CT scan or MRI of the chest is done to check for this. If a thymoma is found, it almost always needs to be surgically removed.

What is a thymectomy?

A thymectomy is surgery to remove the thymus gland. It is recommended for anyone with a thymoma. It is also often **recommended for AChR-positive patients even without a tumor.** A major clinical trial (called the MGTX trial) showed that removing the thymus, combined with medication, led to better outcomes and less need for immune-suppressing drugs over three years compared to medication alone.

What does a typical MG flare look like?

MG symptoms naturally go up and down, most people feel strongest in the morning and weaker as the day goes on or after physical effort. A short rest usually helps. This daily fluctuation is normal and is not a flare.

A flare (also called an exacerbation) is a significant, lasting worsening of weakness that does not get better with normal rest or regular medication. Symptoms may include worsening droopy eyelids, double vision, slurred or nasal-sounding speech, trouble chewing or swallowing, or weakness in the arms, legs, or neck.

If weakness spreads to the muscles that control breathing, it becomes a myasthenic crisis, a medical emergency. About 15% of MG patients will experience a crisis at some point, most often in the early years of the disease.

What triggers a flare?

Common triggers include:

- Stress
- Lack of sleep
- Illness or infections
- Surgery
- Extreme heat (hot tubs, saunas, prolonged sun exposure)
- Certain medications (see below)

What medications should I avoid?

Certain medications, both prescription and over-the-counter, can make MG much worse or trigger a crisis. Common ones to watch out for include:

- Certain antibiotics: fluoroquinolones (e.g., ciprofloxacin, levofloxacin), aminoglycosides (e.g., gentamicin), and macrolides (e.g., azithromycin, erythromycin)
- IV magnesium
- Beta-blockers (e.g., metoprolol, atenolol) ***Use With Caution***
- Calcium channel blockers (e.g., verapamil)
- Certain anesthetics and muscle relaxants used during surgery
- Quinine and quinidine
- Lithium
- Botulinum toxin (Botox)
- Cancer immunotherapy drugs called checkpoint inhibitors (e.g., pembrolizumab, nivolumab) — these can trigger severe MG or make existing MG much worse

Always tell every doctor, dentist and pharmacist that you have MG before starting any new medication. When in doubt, check with your neurologist first.

When should I go to the emergency room?

A myasthenic crisis is life-threatening. Call 911 or go to the nearest emergency room immediately if you experience:

- Shortness of breath, especially when lying flat
- Inability to swallow or clear saliva
- Severe difficulty speaking or chewing
- Extreme weakness in the neck ("dropped head") or limbs

Do NOT wait to call your neurologist's office. Once in the ER, make sure the doctors know you have MG so they can consult a neurologist and avoid medications that could make things worse.

How is a crisis or severe flare treated?

The first priority is making sure you can breathe safely, this may involve a breathing machine (BiPAP or ventilator). To quickly reduce the immune attack, doctors use one of two main treatments:

- **Plasma exchange (PLEX)/plasmapheresis**: A procedure that filters harmful antibodies out of the blood.
- **Intravenous Immunoglobulin (IVIg)**: An infusion of healthy antibodies from donors that temporarily blocks the harmful MG antibodies.

What happens after a crisis?

Recovery can take weeks to months. Rehabilitation, including physical therapy, occupational therapy and speech therapy, is often needed to rebuild strength and safe swallowing. Your doctor will also likely adjust your long-term medications to help prevent future crises.

How can I manage MG in my daily life?

- **Pace yourself**: Do demanding tasks when you feel strongest (usually in the morning). Take planned rest breaks before you become fully exhausted.
- **Avoid extreme heat**: Hot tubs, saunas, and prolonged sun exposure can temporarily worsen weakness.
- **Plan ahead:** Know your triggers, keep a symptom diary, and have a plan with your neurologist for when to call if symptoms worsen.
- **Stay connected**: Support groups and patient organizations can be a valuable source of information and encouragement.

How does MG affect pregnancy?

MG often affects women of childbearing age, so pregnancy planning is important. **MG symptoms can be unpredictable during pregnancy, some women improve, while others get worse.**

Key things to know:

- **About 10–20% of babies born to mothers with MG develop temporary weakness called Transient Neonatal Myasthenia Gravis.** This happens because the mother's antibodies cross the placenta. It is temporary and usually resolves completely within a few weeks as the antibodies clear from the baby's system.
- In rare cases, maternal antibodies can cause more serious effects on the developing baby, so close monitoring during pregnancy is essential.
- Some MG medications are safe during pregnancy (pyridostigmine, corticosteroids, azathioprine), while others must be stopped because they can harm the baby (mycophenolate mofetil and methotrexate are not safe during pregnancy). Rituximab should also be avoided.
- IVIg and PLEX are safe options if a flare occurs during pregnancy.
- Always discuss pregnancy planning with your neurologist well in advance.

What are the treatment options for MG?

There is currently no cure for MG, but it is highly treatable. Treatment is aimed at several goals:

Treating symptoms directly?

Pyridostigmine (brand name: Mestinon) is the most commonly prescribed first-line medication. It does not stop the immune attack, but it prevents the breakdown of acetylcholine, the chemical messenger between nerves and muscles, so that signals get through more effectively.

Important note: Pyridostigmine does not work well for patients with MuSK-MG and can actually make symptoms worse or cause serious side effects in those patients. If you have MuSK-MG, your doctor will likely use different treatments.

Treating acute flares?

IVIg and PLEX (described above) are used for rapid, short-term relief during severe worsening or before surgery.

Long-term immune treatments to prevent flares?

These are medications that calm down the immune system to reduce the production of harmful antibodies. Because they affect the immune system, they may increase the risk of infections, and patients need regular monitoring.

Traditional medications:

- **Prednisone (a steroid):** Fast-acting and effective, but long-term use can cause side effects including weight gain, sleep problems, mood changes, bone thinning, cataracts, and diabetes. Doctors try to use the lowest effective dose.
- **Azathioprine**, Mycophenolate Mofetil, and Tacrolimus: Daily pills that broadly suppress the immune system. They can take several months to become fully effective and require regular blood tests to monitor liver, kidney, and blood cell counts.
- **Rituximab**: An IV medication given periodically that targets specific immune cells (B-cells) responsible for making antibodies. While used off-label for AChR-MG, it has been shown to be especially effective for MuSK-MG, over 80% of MuSK-MG patients achieve significant improvement, and many reach remission faster than with other treatments. It is now often used early in the course of MuSK-MG rather than as a last resort.

B-Cell Depleting Therapies:

B cells are a type of immune cell responsible for making antibodies, including the harmful antibodies that cause MG. B-cell depleting therapies are medications that specifically target and remove these cells from the body. By reducing the number of B cells, these treatments lower the production of the antibodies attacking the neuromuscular junction. There are two main types, based on which marker on the B cell they target:

- **Rituximab (targets CD20)**: An IV medication given periodically that removes B cells carrying the CD20 marker. While used off-label for AChR-MG, it has been shown to be especially effective for MuSK-MG, over 80% of MuSK-MG patients achieve significant improvement, and many reach remission faster than with other treatments.
- **Uplizna (inebilizumab) (targets CD19):** A newer, FDA-approved IV infusion given every 6 months. Unlike rituximab, inebilizumab targets CD19, a marker found on a wider range of B cells, including the more mature cells that are actively producing harmful antibodies. Newer targeted biologic medications:

Recent scientific breakthroughs have led to the approval of several new targeted therapies for generalized MG. These fall into two main categories:

Complement Inhibitors: These stop a specific part of the immune system (the "complement cascade") from damaging the neuromuscular junction. Currently approved for AChR-antibody positive generalized MG:

- **Soliris (eculizumab)**: IV infusion. Also approved for children aged 6 and older.
- **Ultomiris (ravulizumab):** A longer-acting IV infusion given every 8 weeks.
- **Zilbrysq (zilucoplan):** A daily injection under the skin.

Important: Complement inhibitors carry a risk of serious meningococcal infections (a type of bacterial meningitis). Patients must receive specific meningitis vaccines before starting these medications.

FcRn Antagonists: These work by speeding up the removal of harmful antibodies (including MG antibodies) from the bloodstream:

- **Vyvgart (efgartigimod)**: Available as an IV infusion or injection under the skin, given in treatment cycles based on symptoms. Approved for AChR-positive generalized MG.
- **Rystiggo (rozanolixizumab):** Injection under the skin. Approved for both AChR-positive and MuSK-positive generalized MG.
- **Imaavy (nipocalimab):** A newer option given as a continuous, regularly scheduled IV infusion (not in cycles).

Approved for both AChR-positive and MuSK-positive generalized MG in adults and adolescents aged 12 and older.

Surgery

Thymectomy (removal of the thymus gland) is recommended for patients with a thymoma and is often recommended for AChR-positive patients even without a tumor, as clinical trials have shown it improves outcomes and reduces the need for medications over time.

A note about cancer treatment and MG

If you are ever diagnosed with cancer, it is critical that your cancer doctors know you have MG. A class of cancer drugs called immune checkpoint inhibitors (such as pembrolizumab and nivolumab) can trigger severe MG flares or even cause MG in people who did not have it before. Your neurologist and oncologist should work closely together.

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