

Myasthenia gravis 🝷

Understanding myasthenia gravis: a guide for patients

An essential guide to myasthenia gravis: understanding what it is, treatment options and steps towards empowerment and hope

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Introduction

Myasthenia gravis is a chronic autoimmune disease [1]. In simpler terms, this means your body's defense system, which normally protects you from illness, mistakenly attacks healthy parts of your body [2]. In MG, this attack targets the connection between your nerves and muscles [2].

To understand this better, imagine your nerves sending messages to your muscles, telling them to move. These messages travel through a special messenger called acetylcholine [1]. In MG, your body creates antibodies that block or destroy the areas where these messages are received by your muscles [3]. This disruption leads to muscle weakness, which is the hallmark of MG [3].

What is Myasthenia Gravis?

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Breaking Down the Medical Terms

Let's clarify some of the terms you might encounter when learning about MG:

- **Neuromuscular junction:** This is the point where your nerves and muscles meet and communicate. It's like a tiny bridge where the nerve sends its message (acetylcholine) to the muscle.
- Antibodies: These are proteins produced by your immune system to fight off infections. In MG, they mistakenly attack the receptors on your muscles that receive nerve signals.
- Acetylcholine: This is the chemical messenger that carries signals from your nerves to your muscles, telling them to contract.
- **Thymus gland:** This gland, located in your chest, plays a role in your immune system. It can sometimes be larger than normal or have abnormal growths (thymomas) in people with MG [2].
- **Autoimmune disease:** This is a condition where your immune system mistakenly attacks your own body's tissues.
- **Chronic:** This means the condition is ongoing and long-lasting.
- **Skeletal muscles:** These are the muscles that you control voluntarily to move your body.

Symptoms of Myasthenia Gravis

MG can affect different muscles in your body, leading to a variety of symptoms. These symptoms often fluctuate, meaning they can be better some days and worse on others [5]. This fluctuation can make it challenging to plan activities and manage daily life, as the intensity of muscle weakness can change from day to day, even hour to hour [6]. Most people with MG find they feel strongest in the morning and weakest at the end of the day [6]. Some common symptoms include:

- **Eyelid drooping (ptosis):** One or both eyelids may droop, making it difficult to keep your eyes open. This can interfere with daily tasks like reading, watching TV, and driving [3].
- **Double vision (diplopia):** You may see two images instead of one, which can also make activities like reading and driving dangerous [3].
- Facial muscle weakness: This can make it difficult to smile, frown, or make other facial expressions. It can also affect your ability to close your mouth completely, potentially leading to drooling. These changes in appearance can sometimes cause difficulty expressing emotions [8].
- **Difficulty chewing and swallowing:** You may find it hard to chew food thoroughly or swallow liquids [7].
- **Slurred speech:** Your speech may become unclear or difficult to understand [2].
- Weakness in the arms, legs, or neck: This can make it challenging to lift objects, walk, or hold your head up. It can impact your ability to perform everyday tasks, such as getting dressed, climbing stairs, or even holding a cup [2].

• **Shortness of breath:** In some cases, MG can affect the muscles involved in breathing, leading to difficulty catching your breath or feeling short of breath during physical activity [2].

It's important to remember that everyone experiences MG differently. You may have some of these symptoms or others not listed here.

Potential Complications

One of the most serious complications of myasthenia gravis is a **myasthenic crisis**. This is a condition of extreme muscle weakness, particularly of the diaphragm and chest muscles that support breathing [5]. Breathing may become shallow or ineffective, and the airway may become blocked because of weakened throat muscles and a build-up of secretions [5]. A myasthenic crisis may be caused by a lack of medicine or by other factors, such as a respiratory infection, emotional stress, surgery, or some other type of stress [5]. In a severe crisis, a person may have to be placed on a ventilator to help with breathing until muscle strength returns with treatment [5].

Treatment Options

While there is no cure for MG, various treatments can help manage your symptoms and improve your quality of life. These include:

• Medications:

- **Anticholinesterase inhibitors:** These medications help improve communication between your nerves and muscles by increasing the amount of acetylcholine available [9].
- **Immunosuppressants:** These drugs help reduce the activity of your immune system, which is attacking your neuromuscular junctions [9].
- Corticosteroids: These powerful anti-inflammatory drugs can help control symptoms, but they may have side effects with long-term use [10].
- **Thymectomy:** This surgical procedure involves removing the thymus gland, which can improve symptoms in some people with MG [11].
- **Plasmapheresis and intravenous immunoglobulin (IVIg):** These therapies help filter out the harmful antibodies from your blood [11].

Your doctor will work with you to determine the best treatment plan based on your specific symptoms and needs.

Living with Myasthenia Gravis

Living with a chronic illness like MG can be challenging, both physically and emotionally. It's important to remember that you are not alone. Here are some tips for coping with MG:

- **Pace yourself:** Avoid overexertion and take breaks when needed. Listen to your body and don't push yourself beyond your limits.
- **Get enough rest:** Fatigue can worsen MG symptoms, so prioritize sleep. Aim for 7-9 hours of quality sleep each night.
- Eat a healthy diet: Proper nutrition is essential for overall health and well-being. Focus on a balanced diet with plenty of fruits, vegetables, and whole grains.
- **Manage stress:** Stress can trigger or worsen symptoms, so find healthy ways to cope with stress, such as exercise, relaxation techniques, or spending time in nature. Consider activities like yoga, meditation, or deep breathing exercises.
- **Connect with others:** Join a support group or online forum to connect with other people living with MG. Sharing your experiences and learning from others can be incredibly helpful. You can find information about local support groups and online forums through organizations like the Myasthenia Gravis Foundation of America (MGFA) [5].

In addition to the physical challenges, MG can also take an emotional toll. You might experience frustration, anxiety, or even depression due to the unpredictable nature of the disease and its impact on your daily life [8]. It's important to acknowledge these feelings and seek support when needed. Consider talking to a therapist or counselor who can help you develop coping strategies and manage the emotional aspects of living with MG [8]. Engaging in creative outlets, such as painting, writing, or music, can also be a helpful way to express your emotions [8].

Resources and Support

Here are some organizations that can provide valuable information, support, and resources for people with MG:

- Myasthenia Gravis Foundation of America (MGFA): (<u>www.myasthenia.org</u>)
- Muscular Dystrophy Association (MDA):(<u>www.mda.org</u>)

These organizations offer a wealth of information about MG, including research updates, treatment options, and coping strategies. They also provide resources for finding local support groups and connecting with other people living with MG.

Conclusion

Myasthenia gravis is a chronic condition that can present unique challenges, but with the right information, support, and treatment, you can live a full life. This guide has provided a starting point for understanding MG and its medical terminology. Remember to work closely with your healthcare team to develop a personalized treatment plan and find the resources that best meet your needs. By actively participating in your care, practicing self-care strategies, and connecting with others, you can navigate the challenges of MG and live well with this condition.

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