Living Well with Myasthenia Gravis (MG)

COPING WITH MG

A guide from the Myasthenia Gravis Association

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MGA
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Receiving an MG Diagnosis

Hearing the words *"You have myasthenia gravis"* can bring a flood of emotions. You may feel relieved to finally have answers after months—or even years—of unexplained symptoms. You may also feel scared, frustrated, overwhelmed, or uncertain about what comes next.

There is no "right" way to react to an MG diagnosis. Every person's experience is different, and your emotions may change from day to day.

While MG is a chronic autoimmune neuromuscular disease, today's treatments have changed what living with MG can look like. Many people successfully manage their symptoms, continue working, travel, exercise, raise families, and enjoy the activities that matter most to them.

Your journey with MG is unique, and you do not have to navigate it alone.

Understanding Your Emotions

Living with a chronic illness often involves an emotional adjustment as well as a physical one. It's common to experience:

- Shock
- Fear
- Anxiety
- Anger
- Sadness
- Grief
- Relief after finally receiving a diagnosis
- Hope as treatment begins

Some days may feel easier than others. Give yourself permission to experience these emotions without judging yourself.

If feelings of anxiety or depression begin interfering with daily life, talk with your healthcare provider. Counseling, peer support groups, and mental health professionals can all be valuable parts of your care team.

Remember

Seeking help is a sign of strength—not weakness.

Learning About MG

Learning about MG empowers you to make informed decisions and become an active participant in your care. Start with reliable sources of information and don't hesitate to ask questions.

Reliable resources include:

- Myasthenia Gravis Association (MGA)
- Myasthenia Gravis Foundation of America (MGFA)
- Muscular Dystrophy Association (MDA)
- Your neurologist or neuromuscular specialist
- Your pharmacist
- Educational webinars and support groups

Remember

Online discussion groups can be helpful for support, but not every recommendation shared online is medically appropriate for you.

Becoming Your Own Healthcare Advocate

One of the most important things you can do is become an active partner in your healthcare.

As you begin to get used to the day-to-day management of MG, consider keeping a notebook, binder, or digital app to track:

- Symptoms
- Medications
- Side effects
- Infusions or injections
- Questions for your providers
- Test results
- Hospitalizations
- Symptom triggers

Before each appointment:

- Write down your three most important questions.
- Bring an updated medication list.
- Track any changes in symptoms.
- Consider bringing a family member or friend to help take notes.

The more information you can provide, the easier it is for your healthcare team to understand how MG is affecting your daily life.

Communicating with Family and Friends

One of the most difficult parts of living with MG is that symptoms often aren't visible.

Family and friends may not understand why you can feel well one day and exhausted the next. This is because MG causes **fluctuating muscle weakness**, meaning symptoms can change throughout the day or from one day to another.

Open communication helps others better understand your experience.

Instead of assuming others know what you need, try being specific.

For example:

- "I'm having a difficult MG day today."
- "I have the energy to visit, but not to go shopping."
- "Thank you for helping with dinner tonight. It really makes a difference."

Allow yourself to accept help when you need it, and remember that asking for support does not mean giving up your independence.

Managing Fatigue and Conserving Energy

Fatigue is one of the most common and frustrating symptoms reported by people living with MG.

Learning how to conserve energy can help you accomplish more while reducing symptom flare-ups.

Helpful strategies include:

- Pace yourself throughout the day.
- Prioritize the most important tasks.
- Schedule rest breaks before you become exhausted.
- Break large tasks into smaller steps.
- Use adaptive equipment when appropriate.
- Ask for help when needed.

Exercise can also play an important role in overall health. Many people with MG benefit from regular physical activity, but exercise should always be individualized and discussed with your healthcare team.

Understanding MG Triggers

Everyone's MG is different.

Not everyone experiences the same triggers, but many people notice worsening symptoms during certain situations.

Common triggers include:

- Illness or infection
- Lack of sleep
- Emotional stress
- Physical overexertion
- Hot weather
- Hot tubs or saunas
- Surgery
- Hormonal changes
- Certain medications

Some individuals also notice worsening symptoms with:

- Alcohol
- Dehydration
- Strong chemical fumes
- Extreme temperatures

Learning your own triggers can help you better manage symptoms over time.

Medication Safety

Some medications can worsen MG symptoms.

Before starting any new prescription, over-the-counter medication, or supplement, discuss it with your healthcare provider or pharmacist.

Examples of medications that may require extra caution include:

- Certain antibiotics
- Magnesium-containing medications
- Beta blockers
- Some muscle relaxants
- Certain heart medications

Never stop or change medications without speaking with your healthcare team.

Find a full list of Cautionary Drugs here. This list was composed by the Myasthenia Gravis Association's Medical Advisory Committee.

Finding Your "New Normal"

Life with MG may look different than it did before your diagnosis. That doesn't mean it can't still be fulfilling. Many people discover new hobbies, adjust their routines, strengthen relationships, and develop resilience they never knew they had. Rather than focusing on what you've lost, try to recognize what remains possible.

Your diagnosis does not define you. You are still the same person—with your talents, relationships, dreams, humor, experiences, and goals.

Financial and Workplace Considerations

Living with a chronic illness can affect employment, insurance, and finances.

If needed:

- Learn about workplace accommodations.
- Review your insurance benefits.
- Keep organized medical records.
- Save receipts for medical expenses.
- Explore disability benefits if appropriate.
- Meet with a financial planner or social worker if needed.

Planning ahead can reduce stress and help you prepare for future needs.

Caring for Your Emotional Well-Being

Taking care of your mental health is just as important as managing physical symptoms.

Healthy coping strategies include:

- Spending time with supportive friends and family
- Joining a support group
- Practicing mindfulness or relaxation techniques
- Journaling
- Engaging in hobbies
- Speaking with a therapist

Remember that it's okay to ask for help.

Building Your Support Network

Support can come from many places:

- Family
- Friends
- Healthcare providers
- Local support groups
- Online support communities
- Patient organizations
- Mental health professionals

Connecting with others who understand MG can provide encouragement, practical advice, and hope.

Helpful Resources

Myasthenia Gravis Association (MGA)

The Myasthenia Gravis Association provides:

- Support groups
- Educational webinars
  - Video Library of previous webinars
- Patient education
- Resource library
- Advocacy opportunities
- Connections to others living with MG

Website: https://mgassociation.org

Additional Resources

- Your neurologist or neuromuscular specialist
- Licensed mental health professionals
  - Give an Hour
- Social workers
- Physical and occupational therapists
- Pharmacists familiar with MG
- Other MG Organizations
- Rare disease organizations
  - National Organization for Rare Disorders (NORD)
  - Global Genes / Allies in Rare Disease
  - EveryLife Foundation for Rare Diseases
  - Genetic and Rare Diseases (GARD)