GENERALIZED MYASTHENIA GRAVIS

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WebMD LIVING WITH

FALL 2024

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THE LATEST ON

GENERALIZED MYASTHENIA GRAVIS

BREW ON THIS

The next treatment for myasthenia gravis (MG) may be found in your morning joe. In people with MG, a brain chemical called acetylcholine—a substance that helps with muscle movements—doesn't work as it should. Researchers already knew that caffeine could help to some degree with the acetylcholine problems seen in myasthenia gravis. Now scientists have boiled caffeine down to a few key byproducts that may be even more effective. These caffeine derivatives could one day be ingredients in MG drugs.

SOURCE: *ACS Chemical Neuroscience*

82,715 **Number of U.S. adults living with myasthenia gravis as of 2021.**

SOURCE: *Frontiers in Neurology*

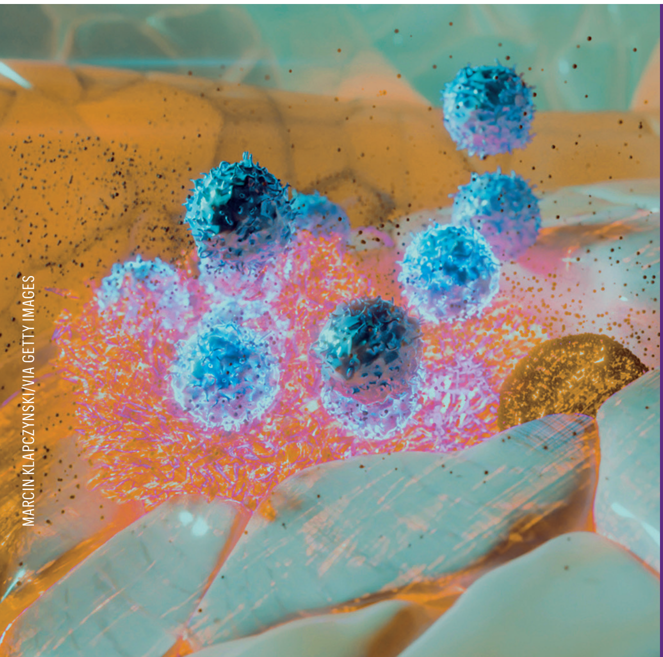
68.5 **Number of new diagnoses of myasthenia gravis in every million people in the U.S. every year.**

SOURCE: *Frontiers in Neurology*

COULD CURCUMIN END MG?

The gut bacteria in people with generalized myasthenia gravis is often off balance. Curcumin, found in the golden-colored spice turmeric, has gut-related benefits. New research explores whether it could make a difference in myasthenia gravis. It'll take more research to prove it helps humans, but when mice with myasthenia gravis were given this spice extract, their gut bacteria took a turn for the better and some of the cell processes that promote myasthenia gravis stopped. The finding could lead to new medicines containing the spice extract. In the meantime, it probably wouldn't hurt to add a daily dash of it to your diet. Curry, anyone?

SOURCE: *Cell*



MARCIN KLAPCZYNSKI/VIA GETTY IMAGES

IMMUNE CELLS RUN AMOK

As their name suggests, natural killer (NK) cells are born to kill. These immune cells obliterate infected or diseased cells like cancer cells. But they seem to go rogue in a number of immunological diseases, such as multiple sclerosis, Guillain-Barré syndrome, and generalized myasthenia gravis. New research teases out the unique havoc they wreak in each of these diseases. In myasthenia gravis, the study finds, rather than kill off disease-causing cells, NK cells activate the cells that promote myasthenia gravis flares. When scientists destroyed NK cells in animals with myasthenia gravis, it slowed the progress of the disease. This discovery could lead to new drugs that target NK cells directly.

SOURCE: *Biomedicine and Pharmacotherapy*

STATS & FACTS

By Sonya Collins

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

>60

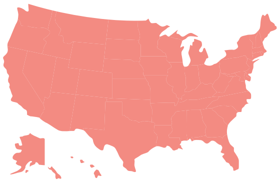
Ages when it's most common for men to get myasthenia gravis (MG).

up to 200

Number of people per million who have MG worldwide.

>70,000

Number of people in the U.S. who are diagnosed with myasthenia gravis.



1:1

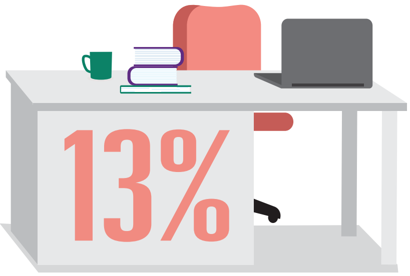
Number of women compared to men who get MG after age 50.

25

Maximum number of months after diagnosis that it takes most people to get their symptoms down to a level that's acceptable to them. Many people get symptom control sooner. For some it takes longer.

1 in 3

Number of people with MG who have depression or anxiety.



13%

Average amount of working hours employed people with MG miss. That's a little over 1 in every 8 work days.

SOURCES: Myasthenia Gravis Foundation of America, Rare Disease Advisor, *Brain and Behavior, Frontiers in Neurology, Muscle & Nerve*

FREEPIK.COM/GETTY IMAGES

VIROJT CHANGYENCHAM/VIA GETTY IMAGES

TAKE STEPS TO LIVE BETTER

ADD NEW HABITS TO YOUR MEDICAL TREATMENT TO IMPROVE YOUR SYMPTOMS

By Sonya Collins

Reviewed by Brunilda Nazario, MD,
WebMD Chief Physician Editor, Medical Affairs

With generalized myasthenia gravis (gMG), your immune system attacks the cells that carry out communication between your nerves and your muscles. Your muscles feel weak, and it's difficult to move your eyes, mouth, arms, and legs.

Besides medical treatment, "There are several things you can do that may help reduce symptoms and flare-ups," says John Morren, MD, a neurologist in the Neuromuscular Center at Cleveland Clinic in Ohio.

CONSERVE ENERGY

With gMG, the more you move, the weaker your muscles get. Budget your energy. Plan to take frequent breaks throughout the day. Divide tasks into smaller activities that you can complete separately, and rest in between. Only do today what must be done today—and ask yourself if it *really* needs to be done.

Work with your health care team to develop an effective yet manageable exercise program. You might get a referral to a physical or occupational therapist or a trainer with expertise in myasthenia gravis. "A tailored exercise program with mostly mild to moderate aerobic activity, such as walking or swimming, can help maintain muscle strength and overall fitness," Morren says.

Aim for 7 to 8 hours of sleep a night. If you can't get to sleep or stay asleep, tell your doctor.

BEWARE OF NEW MEDICINES

Some medicines and supplements can make gMG symptoms worse. Make sure that any health care provider who writes you a prescription knows that you have gMG so they prescribe safe medications.

"Before any new over-the-counter medication or supplement is started, discuss it first with your neurologist to get their clearance," Morren says.

Check the Myasthenia Gravis Foundation of America website for an up-to-date list, called "Cautionary Drugs," of medicines you should avoid or use with caution.

HELP FOR YOUR EYES

Some people with myasthenia gravis have double vision. An eye specialist can prescribe special corrective glasses, Morren says. "But even patching one eye can be a practical, simple and immediate way to alleviate double vision."

For droopy eyelids, Morren recommends tiny devices called "eye crutches," or ptosis crutches, that attach to your glasses and keep your eyelids lifted.

YOU'VE GOT THIS

You may be overwhelmed by your symptoms now, but you can handle this.

"Integrating MG drug treatment with personalized lifestyle changes, one can navigate this condition with great success," Morren says. "Leveraging tailored exercise, adequate rest, quality sleep, balanced nutrition, and social and psychological support, patients are able to not just live but thrive with MG."

WHAT YOU NEED TO KNOW

GET ANSWERS TO COMMONLY ASKED QUESTIONS ABOUT MG

By Rachel Reiff Ellis

Reviewed by Brunilda Nazario, MD,
WebMD Chief Physician Editor, Medical Affairs

Jaydeep M. Bhatt, MD, clinical professor in the department of neurology at NYU Grossman School of Medicine, answers common questions you may have about your myasthenia gravis diagnosis.

Q. What is myasthenia gravis?

Myasthenia gravis is a chronic autoimmune neuromuscular disorder that causes weakness in the eye and body muscles, which are responsible for clear vision, voluntary movements, and actions (those you make happen intentionally). Myasthenia gravis is not inherited, and it is not contagious. Autoimmune conditions happen when the body's immune system mistakenly attacks healthy tissues. MG happens when communication between nerves and muscles is disrupted due to the presence of antibodies that block or destroy the receptors for the neurochemical acetylcholine.

Q. How will this disease affect my daily life?

Myasthenia gravis typically causes muscle weakness that worsens with activity and improves with rest. It commonly affects muscles that control eye movements, facial expressions, chewing, swallowing, and speaking. You can also have weakness in the arms, legs, and neck muscles. You should consult a neurologist if you have these symptoms. If you can't get a quick appointment, set up a telehealth visit so you can discuss what's going on and plan next steps.

Q. What are the most common symptoms?

Everyone with MG has their own unique combination of symptoms.
The common ones are:

Eye problems: About half of all people with MG experience drooping eyelids or double vision. These symptoms occur because the muscles that control eye movement are weakened.

JAYDEEP M. BHATT, MD

PHOTO COURTESY OF NYU LANGONE HEALTH

Speech and swallowing difficulties: Some people with MG may have difficulty speaking clearly or swallowing food and liquids. This can lead to choking or aspiration pneumonia.

Limb weakness: Weakness in the arms and legs is also common in MG. This can make it difficult to perform daily activities such as lifting objects, climbing stairs, or getting up from a chair.

Fatigue: People with MG often feel tired or fatigued, especially after physical exertion.

Q. What are my treatment options?

MG does not have a cure, but there are several options to treat your symptoms. These treatments work on your immune system to decrease your autoimmune response and improve symptoms. These include oral medications, intravenous infusions, subcutaneous injections, hospital procedures, and chest surgeries for some people. Not everyone with MG is eligible for every treatment option; your doctor will help guide you to the most appropriate option. It is important to tell your doctor about all of your symptoms during an office visit.

It's key to also listen to your body and stop your activities and rest when you are tired. This will help to conserve energy until you can start to exert yourself without symptoms. There is no proven diet to clinically improve MG.

Due to the wide variety of treatment options, myasthenia gravis has a great prognosis for most patients who see treatment providers in the office … or [patients who need to go to] the hospital if symptoms progress before an office visit can be arranged.

HOW MYASTHENIA GRAVIS IS DIAGNOSED

Your doctor can usually diagnose your disease based on symptoms, but may also:

+ **See how you respond to treatment.** If an anticholinesterase medicine improves your muscle weakness, it's likely you have MG.

+ **Test your blood.** Your doctor can look for certain antibodies that can confirm an MG diagnosis.

+ **Perform a nerve conduction study.** Your doctor may give you a test called repetitive nerve stimulation to see how well your nerves are communicating with your muscles.

+ **Measure the electrical activity of your muscles.** An electromyogram (EMG) can detect abnormal electrical muscle activity to provide clues about an MG diagnosis.

RYSTIGGO®
(rozanolixizumab-noli)
Injection For Subcutaneous Use
140 mg/mL

REACH HIGHER
with RYSTIGGO*

RYSTIGGO is a targeted **GENERALIZED MYASTHENIA GRAVIS (gMG)** treatment for adults who are anti-AChR or anti-MuSK antibody positive

*Based on MG-ADL and QMG results at Day 43 vs placebo in the MycarinG clinical trial. Results may vary. No head-to-head trials were conducted.

AChR=acetylcholine receptor; MG-ADL=Myasthenia Gravis Activities of Daily Living; MuSK=muscle-specific tyrosine kinase; QMG=Quantitative Myasthenia Gravis.

IMPORTANT SAFETY INFORMATION AND INDICATION

WHAT IS RYSTIGGO?
RYSTIGGO is a prescription medicine used to treat adults with a disease called generalized myasthenia gravis (gMG) who are acetylcholine receptor (anti-AChR) antibody positive or muscle-specific tyrosine kinase (anti-MuSK) antibody positive.

Please see the Consumer Brief Summary on the following pages and full Prescribing Information at www.RYSTIGGO.com, and talk to your healthcare provider about your condition or treatment. For more information, go to www.RYSTIGGO.com or call 1-844-599-2273.

In a clinical trial, people taking RYSTIGGO saw **significant improvement in activities of daily living, as measured by MG-ADL scores.[†]**

Over 25% of participants taking RYSTIGGO in the trial achieved Minimal Symptom Expression (MSE).[‡]

MSE is sometimes used as a treatment goal for gMG, and is defined as a total MG-ADL score of 0 or 1. People who reach MSE experience minimal symptoms as assessed by the MG-ADL scale.

MSE was an exploratory outcome in the clinical trial, not a primary or secondary outcome. Caution must be used when interpreting as conclusions cannot be drawn. Results may vary.

[†] The trial included 200 adults with gMG (66 received 7 mg/kg of RYSTIGGO, 67 received 10 mg/kg of RYSTIGGO, and 67 received placebo). Improvement in MG-ADL score from baseline on Day 43 of the trial; –3.4 points in the RYSTIGGO-treated group (133 people) vs –0.8 in the placebo group (67 people). Individual results may vary, and not all people taking RYSTIGGO will experience improvements.

[‡] 26% (17 out of 66 people) in the 7 mg/kg group and 28% (19 out of 67 people) in the 10 mg/kg group, compared with 3% (2 out of 67 people) in the placebo group.

Have questions about RYSTIGGO?

Visit RYSTIGGO.com or scan code to learn more

WHAT IS THE MOST IMPORTANT INFORMATION I SHOULD KNOW ABOUT RYSTIGGO (rozanolixizumab-noli)?

RYSTIGGO may cause serious side effects, including:

- **Infection:** RYSTIGGO may increase the risk of infection. In clinical studies, the most common infections were upper respiratory tract infections, COVID-19, urinary tract infections, and herpes simplex infections. Your healthcare provider should check you for infections before starting and during treatment with RYSTIGGO. Tell your healthcare provider if you have any history of infections.

Visit **RYSTIGGO.com** or scan code to learn more

Tell your healthcare provider right away if you have signs or symptoms of an infection during treatment with RYSTIGGO. Some of the signs and symptoms may include fever, chills, frequent and/or painful urination, cough, runny nose, wheezing, shortness of breath, fatigue, sore throat, excess phlegm, nasal discharge, back pain, and/or chest pain.

- **Aseptic Meningitis:** RYSTIGGO could cause aseptic meningitis. Tell your healthcare provider right away if you develop any signs or symptoms of meningitis during treatment with RYSTIGGO such as severe headache, neck stiffness, drowsiness, fever, sensitivity to light, painful eye movements, nausea, and vomiting.
- **Hypersensitivity Reactions:** RYSTIGGO can cause swelling and rash. Your healthcare provider should monitor you during and after treatment and discontinue RYSTIGGO if needed. Tell your healthcare provider immediately about any undesirable reactions you experience after administration.

Before taking RYSTIGGO, tell your healthcare provider about all of your medical conditions, including if you:

- Have a history of infection or think you have an active infection
- Have received or are scheduled to receive a vaccine (immunization). The use of vaccines during RYSTIGGO treatment has not been studied, and the safety with live or live-attenuated vaccines is unknown. Administration of live or live-attenuated vaccines is not recommended during treatment with RYSTIGGO. Completion of age-appropriate vaccines according to vaccination guidelines before starting a new treatment cycle with RYSTIGGO is recommended.
- Are pregnant or plan to become pregnant or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

WHAT ARE THE POSSIBLE SIDE EFFECTS OF RYSTIGGO?

RYSTIGGO may cause serious side effects, including:

- See "**What is the most important information I should know about RYSTIGGO?**"

The most common side effects of RYSTIGGO include:

- headache
- infections
- diarrhea
- fever
- hypersensitivity reactions
- nausea

These are not all the possible side effects of RYSTIGGO. For more information, ask your healthcare provider or pharmacist. Tell your healthcare provider about any side effect that bothers you or that does not go away. Call your healthcare provider for medical advice about side effects.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. You may also report side effects to UCB, Inc. by calling 1-844-599-CARE [2273].

Please see the Consumer Brief Summary on the following pages and full Prescribing Information at www.RYSTIGGO.com, and talk to your healthcare provider about your condition or treatment. For more information, go to www.RYSTIGGO.com or call 1-844-599-2273.

Consumer Brief Summary

RYSTIGGO®
(rozanolixizumab-noli)
Injection For Subcutaneous Use
140 mg/mL

Consumer Brief Summary

RYSTIGGO (rozanolixizumab-noli) injection, for subcutaneous use
RX Only
Brief Summary of Full Prescribing Information (See Package Insert for Full Prescribing Information)

This information does not take the place of talking to your healthcare provider about your medical condition or your treatment.

What is the most important information I should know about RYSTIGGO?

RYSTIGGO may cause serious side effects, including:

- **Infections.** RYSTIGGO may increase the risk of infection. In clinical studies, the most common infections (at least 5% frequency) were upper respiratory tract infections, COVID-19, urinary tract infections, and herpes simplex.
  - Your healthcare provider should check you for infections before starting and during treatment with RYSTIGGO.
  - Tell your healthcare provider if you have any history of infections.
  - Tell your healthcare provider if you have any signs or symptoms of infection during treatment with RYSTIGGO, including fever, chills, frequent and/or painful urination, cough, runny nose, wheezing, shortness of breath, fatigue, sore throat, excess phlegm, nasal discharge, back pain, and/or chest pain.
- **Aseptic meningitis.** RYSTIGGO could cause aseptic meningitis.
  - Tell your healthcare provider if you have any signs or symptoms of meningitis during treatment with RYSTIGGO including severe headache, neck stiffness, drowsiness, fever, sensitivity to light, painful eye movement, nausea, and vomiting.
- **Hypersensitivity reactions.** RYSTIGGO can cause hypersensitivity reactions (swelling and rash). Your healthcare provider should monitor you during treatment and after treatment.
  - Tell your healthcare provider if you are experiencing any undesirable reactions after administration.

Call your healthcare provider right away if you have any serious side effects listed above.

What is RYSTIGGO?

RYSTIGGO is a prescription medicine used to treat adults with a disease called generalized myasthenia gravis (gMG) who are acetylcholine receptor (anti-AChR) antibody positive or muscle-specific tyrosine kinase (anti-MuSK) antibody positive.

Before starting RYSTIGGO, tell your healthcare provider if you:

- Have a history of infection or have an active infection.
- Have received or are scheduled to receive a vaccine (immunization). Administration of live or live-attenuated vaccines is not recommended during treatment with RYSTIGGO.
- Are pregnant or plan to become pregnant or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medications you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements.

What are the possible side effects of RYSTIGGO?

RYSTIGGO may cause serious side effects, including:

- See **"What is the most important information I should know about RYSTIGGO?"**

The most common side effects (reported in at least 10% of patients treated with RYSTIGGO) include:

- Headache
- Infections
- Diarrhea
- Fever
- Hypersensitivity reactions
- Nausea

These are not all the possible side effects of RYSTIGGO.

Consumer Brief Summary continued

For more information, ask your healthcare provider or pharmacist. Tell your healthcare provider about any side effect that bothers you or that does not go away. Call your healthcare provider for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I receive RYSTIGGO?

- RYSTIGGO is a subcutaneous infusion, administrated by a healthcare professional using an infusion pump.
  - Most people will receive RYSTIGGO at an infusion center or at their doctor's office.
- RYSTIGGO is available in 3 recommended doses, based on body weight. Preparation and infusion time may vary by patient dosage, infusion provider, and/or provider location.
- RYSTIGGO is administrated in the lower abdomen below the belly button. Do not receive RYSTIGGO in areas where the skin is tender, bruised, red, or hard.

You will be monitored while you receive RYSTIGGO, and for 15 minutes after your infusion is complete.

- RYSTIGGO is administrated once weekly in 6-week cycles.
  - You will receive 6 doses of RYSTIGGO in total, spaced 1 week apart.
  - Every 6-week cycle is followed by a break in your RYSTIGGO treatment.
- Most people may require repeated cycles of RYSTIGGO to manage their gMG symptoms. After you finish a treatment cycle it is important to:
  - Monitor your progress and track any symptoms.
  - Work with your healthcare provider to determine if or when another cycle is needed.

Ask your healthcare provider for more information about subcutaneous infusion and what to expect on infusion days.

What are the ingredients in RYSTIGGO?

Active ingredients: rozanolixizumab-noli 140 mg/mL (2 mL, 3 mL, 4 mL, and 6 mL vials)

Each single-dose vial contains 280 mg, 420 mg, 560 mg, or 840 mg of rozanolixizumab-noli at a concentration of 140 mg/mL with a pH of 5.6. Each mL also contains histidine (1.05 mg), L-histidine hydrochloride monohydrate (4.87 mg), polysorbate 80 (0.30 mg), proline (28.78 mg), and water for injection, USP.

For more information see the Patient Counseling Information section in the FDA-approved Full Prescribing Information at www.rystiggo.com or contact UCBCares at 1-844-599-CARE (2273). UCBCares is a helpline offered by UCB to people living with chronic diseases on a UCB medication, and their healthcare professionals.

Product manufactured by:
UCB, Inc. Smyrna, GA 30080

MY JOURNEY WITH gMG

I'M GRATEFUL FOR TREATMENT

By Thomas Bartlett

Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

I was very athletic for most of my life. I played tennis and was in national tournaments. I also played baseball for 20 years and golfed. One day in July 2019, I was in a tennis tournament, and I noticed something was wrong.

A RARE DIAGNOSIS

While playing tennis, I noticed the ball coming over the net, but I just couldn't react. My muscles wouldn't cooperate. I shrugged it off and went on a work trip the next day. While traveling, I noticed an issue with my eye. My eyelid was pulling up. I called my doctor and he suggested I be seen right away. When the nurse saw my eye, she went to get the head doctor for the practice right away. He asked questions and ran tests to rule out Lyme disease, diabetes, and Bell's palsy. I got an MRI and my doctor called me that same night. I was used to waiting a few days for these types of results. He told me all the things I did not have but said I'd have to wait for blood work. He suspected I had a rare condition called myasthenia gravis (MG). An appointment with a neurologist confirmed this.

LIFE WITH MG

As I was reeling from this new (and rare) diagnosis, I was scared. I didn't know anyone with this. I've since learned that only about 80,000 people [as of 2021] have MG in the United States. For comparison, about 29 million people in the U.S. [as of 2021] have been diagnosed with diabetes.

Thankfully, I found some help and support from the Myasthenia Gravis Foundation of America. It was through that group that I found a neurologist who specialized in MG. That has made such a huge difference in my health.

MOVING FORWARD

A lot has changed in my life. I get tired and have to lie down. I had to resign from a job that I loved to focus on my health. I was getting brain fog and I just couldn't do my job like I wanted to.

Fortunately, I have been able to work as a writer and consultant from home. I've moved up the line in therapy from early treatment that wasn't effective to an FDA-approved drug for MG. I read that only about 5% of rare diseases have an FDA-approved treatment, so I was lucky. Now, I'm getting infusions once a week for 4 weeks followed by a break for 4 weeks. So far, it's going well. I have taken prednisone since my diagnosis in 2019 as well as medications for digestive issues. I'm happy to see more medications coming out for MG.

I also have made several lifestyle changes. I have to alter how I travel now—whether by car or plane. I've done my best to remove certain foods that are difficult to swallow due to my MG. I try to do an anti-inflammatory diet.

While I can't play tennis or baseball anymore, I'm grateful that I can still play some golf. I might only be able to do a few holes, but it's worth it to keep going.

THOMAS' TIPS

- + **Be persistent.** Because MG is rare, you may have to push for answers.
- + **Be aware.** Listen to your body. Rest when you need to.
- + **Be flexible.** Life may not look the same as before MG, but life can still be good.

YINYANG/VIA GETTY IMAGES; INSET PHOTO COURTESY OF THOMAS BARTLETT

YOUR MENTAL HEALTH

LEARN HOW TO TACKLE FEELINGS OF ANXIETY, DEPRESSION, OR GRIEF THAT MAY COME WITH YOUR gMG

By Kendall K. Morgan

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

WESTEND61/VIA GETTY IMAGES

When you have generalized myasthenia gravis (gMG), you may have changes in your vision, strength, energy, appearance, and more. These physical symptoms take a toll on your mental health. About 1 in 4 people with any chronic medical problem will face mental health challenges. In gMG, it may be even more common, with one study showing more than 1 in 3 people had either depression or an anxiety disorder.

COMMON SIGNS

“We often find that people with myasthenia gravis do struggle with different symptoms related to anxiety or depression,” says Alaina Carr, PhD, a licensed clinical psychologist specializing in chronic illness at the National Center for Health Psychology in Chevy Chase, MD. “There are a lot of different symptoms that are difficult to manage, like trouble with swallowing, mobility, dexterity, and speech. By the time I see an individual in therapy, they’ve often been to multiple providers. They may have been misdiagnosed along their care journey. They often feel understandably overwhelmed and anxious about finding the right care team as well as really understanding what symptoms they can attribute to myasthenia gravis versus anxiety or depression.”

Your mental health challenges may show up in unexpected ways, Carr says. For example, your depression or anxiety may present as anger or irritability. Especially if your gMG has led you to a traumatic or life-threatening experience, such as difficulty breathing, she says symptoms of posttraumatic stress disorder (PTSD) also may arise. PTSD symptoms include recurrent memories of a traumatic event, flashbacks, nightmares, and emotional distress when something reminds you of an awful event.

THERAPY CAN HELP

“Anxiety and depression are most common, but there may also be grief,” says Tameeka Hunter, PhD, a counselor at Palo Alto University in California. “You may be having trouble sleeping as you face the fear of the unknown. Many

EASE YOUR STRESS

Stress may cause your physical symptoms to flare. To tackle stress, try:

- **Meditation**
- **Reading or listening to music**
- **Guided imagery**
- **Exercise**
- **Hobbies**
- **Practices for spiritual growth**

times people isolate because they can't function the way they used to."

Your condition may be affecting your ability to work, which Hunter notes is not only stressful but can also lead to changes in the way that you see yourself given that our identities are often tied to our professions. Hunter says it's important to recognize that these are significant losses you'll need to work through.

She recommends looking for a therapist with special training, such as a licensed mental health professional who is also a certified rehabilitation counselor (CRC). CRCs will have training in chronic illnesses and disabilities and their impact on mental health. They also should feel comfortable talking to you about how your chronic illness is affecting you without worrying they'll say the wrong thing. To get the help you need, you may first have to overcome some mental barriers. Hunter says this can be especially true for men.

"Men are taught to be independent providers and so they are not socialized the same way as cisgender women to talk about their feelings," Hunter says. "Talking about feelings can be seen as weakness. It's really important we try to destigmatize men seeking help and normalize that more."

WARNING SIGNS

Get help if you notice these or other troubling changes in your mental health:

- + **Worrying constantly**
- + **Excessive sadness**
- + **Trouble concentrating**
- + **Unusual mood swings**
- + **Avoidance of friends or family**

If you or a loved one is in crisis, call or text 988 or chat 988Lifeline.org to reach the 988 Suicide & Crisis Lifeline.

YOUR COMMUNITY

GOOD INFORMATION AND PEOPLE WHO UNDERSTAND gMG MAKE ALL THE DIFFERENCE

By Kendall K. Morgan

Reviewed by Neha Pathak, MD, WebMD Lead Medical Editor

A couple of years after Kathleen Timothy, community outreach coordinator for the Myasthenia Gravis Foundation of America (MGFA), found out she had MG, she ended up next to the co-leader of a local MG support group during an infusion.

"That's how I got involved," Timothy says. "I ended up leading that support group about a year later."

MEET OTHERS WITH MG

While family and friends are essential, Timothy says meeting other people with MG was a turning point.

"To try to get somebody to understand that brushing your teeth is arduous—it's hard for anyone to understand that if they haven't gone through it," Timothy says. "The connection with other people with MG is truly what turned my attitude around. I was letting MG rule my life before that."

CARE TEAM

It also helps to find a neurologist or neuromuscular specialist who understands the disease and its treatment, Timothy says. The MGFA offers a search tool for doctors who are part of the MGFA's MG Partners in Care network, including ophthalmologists, psychiatrists, and more.

GET INFORMED

Timothy says local or regional organizations also are a great place to go to learn everything you can about the disease and resources in your community.

"Education is a huge part of what we do," Timothy says. "When a newly diagnosed patient calls looking for a support group, I'll offer to send them a new patient packet that has all kinds of information in it. We just want to make sure that all their needs are taken care of and not just what they think they need."

BETTER DAYS AHEAD

Timothy still remembers thinking early on that she'd be stuck in a recliner all her life, unable to work. The MG community showed her a new life and career path ahead. Today, she's the experienced voice letting others know there's hope.

"If somebody had told me the first 2 years were going to be my hardest, I think I would have dealt with those first 2 years a lot better," she says.

SUPPORT GROUP 101

Virtual or in-person support groups can offer:

- **+ Resources**
- **+ Educational programming**
- **+ Connection with people who understand**
- **+ Caregiver support**
- **+ Specialty groups for Spanish speakers, young people, families, and more**

To find a support group in your area, contact the Myasthenia Gravis Foundation of America at 800-541-5454 or mgfa@myasthenia.org. You can also search by city, state, meeting dates, and more at Myasthenia.org/MG-Community/Find-MG-Support-Groups.

COURTNEY HALE/VIA GETTY IMAGES