

Your role as a caregiver A GUIDE TO CARING FOR A LOVED ONE WITH gMG

gMG
NEVER
RESTS

SATURDAY

Walk outside

Good day!

Patient Portrayal

Understand the critical role you play as a caregiver in advocating for and supporting someone with uncontrolled generalized myasthenia gravis (gMG)



“ My wife and I are most involved in my care. It's nice to have a support system.

– Greg, on the importance of a support system after living with gMG for 18 years

YOUR UNIQUE ROLE AS A CAREGIVER

As a caregiver, you play an important role in the lives of those with gMG. It can be difficult to track and monitor the impact that gMG may have on your loved one's life. But **you can help your loved one recognize uncontrolled disease in their day-to-day life.**

During this time, your loved one may come to rely on you even more. Instead of allowing them to accept symptoms as their new normal, you can help by:

- **Listening** to their needs and help them to understand that they're not alone
- **Tracking** their symptoms over time
- **Encouraging** your loved one to use their voice and share their experiences
- **Assisting** in ongoing conversations with their doctors



Patient Portrayal

“ I don't like gMG, but I have learned more with having this disease. You have to deal with the deck you have been given and just play.

– Michael, on the lessons he's learned living with gMG for 30 years

UNDERSTANDING THE UNCONTROLLED

As a reminder, gMG is a chronic, autoimmune, neuromuscular disease that may be present in your loved one's life for years.

gMG is a more severe form of MG and may result in debilitating symptoms that cause weakness throughout the entire body.

For many people with gMG, their condition may be **uncontrolled**. This means that they experience debilitating symptoms that impact daily life—even if they are on treatment.



gMG symptoms can be **unpredictable**, happening without warning no matter where they are in the disease experience. gMG symptom fluctuations can change by the person, the day, or the hour.



For many people, gMG can feel **unexpected** because the symptoms can be caused by triggers that can't always be controlled, including stress, changes in weather, infections, and certain drugs.



Patient Portrayal

If your loved one is dealing with uncontrolled gMG, there are many ways to help provide much-needed support. Encourage them to keep track of symptoms and help share changes with their healthcare team.

[LEARN MORE](#)

SUPPORT. SPEAK UP. SHARE.

gMG can impact many aspects of daily life—**physically, personally, and professionally.**

It's important to recognize when this is happening and help your loved one best communicate their experience with their healthcare team.

Here are some symptoms to look out for in your loved one's day-to-day life and address during their next doctor visit.



Have you noticed a change in their **ability to walk**?

7 out of 10 people with gMG have difficulty walking, which can affect things like climbing stairs



Are you or another caregiver **helping them with more activities**?

gMG symptoms can cause those living with gMG to rely more on a caregiver to help with daily activities



Have they had **difficulty working**?

Over a quarter of people experienced unemployment due to the condition or treatment



Do they regularly **make modifications**?

This may include using special tools like a blow dryer stand due to arm weakness, or eating foods with softer textures due to trouble chewing or swallowing

While these aren't all the experiences to monitor, you can start to keep track of how your loved one copes with the daily impact of gMG. Be sure to look for changes over time, as your loved one may accept worsening weakness and difficulty with activities they didn't have before as their new normal.



Patient Portrayal

The **Doctor Discussion Guide** can help you clearly communicate with your loved one's doctor on the impact of uncontrolled gMG, so they can best help to manage their condition.

[GET THE GUIDE NOW](#)

“ I'm the one with gMG, but my whole family has it in a way.

– Greg, on how gMG affects his family after living with the condition for 18 years

FIND RESOURCES. CONNECT WITH THE COMMUNITY.

gMG can take a toll on the whole family. It is important to seek care for not only physical health, but also mental and emotional well-being.

Just know that you and your loved one are not alone.

There are support groups, as well as resources to help you and your loved one each step of the way.

Click to discover resources curated specifically for caregivers, to better take care of yourself and your loved one.

WATCH VIDEOS TO SEE HOW OTHER PEOPLE ARE LIVING WITH gMG



FIND HELPFUL WEBSITES FOR CAREGIVERS AND PEOPLE WITH gMG



DOWNLOAD HELPFUL RESOURCES



SEE THE ANSWERS TO FREQUENTLY ASKED QUESTIONS



Patient Portrayal

UNDERSTAND HOW YOU CAN HELP SOMEONE LIVING WITH gMG

If you are taking care of someone living with generalized myasthenia gravis (gMG), their symptoms may be impacting many aspects of their lives—even if they are on treatment.

Use this guide to learn how:

- gMG can be **uncontrolled, unpredictable, and unexpected**
- To be the **voice** for your loved one
- To find **resources** for taking care of yourself

Find more information on uncontrolled gMG at **[gMGNeverRests.com](https://www.gMGNeverRests.com)**

REFERENCES: **1.** Cutter G, Xin H, Aban I, et al. Cross-sectional analysis of the Myasthenia Gravis Patient Registry: disability and treatment. *Muscle Nerve*. 2019;60(6):707–715. **2.** Juel VC, Massey JM. Myasthenia gravis. *Orphanet J Rare Dis*. 2007;2:44. **3.** Grob D, Brunner N, Namba T, Pagala M. Lifetime course of myasthenia gravis. *Muscle Nerve*. 2008;37(2):141–149. **4.** Blum S, Lee D, Gillis D, McEniery DF, Reddel S, McCombe P. Clinical features and impact of myasthenia gravis disease in Australian patients. *J Clin Neurosci*. 2015;22(7):1164–1169. **5.** Twork S, Wiesmeth S, Klewer J, Pohlau D, Kugler J. Quality of life and life circumstances in German myasthenia gravis patients. *Health Qual Life Outcomes*. 2010;8:129. **6.** Nowak RJ. Myasthenia gravis: challenges and burdens of disease. *Neurology Reviews*. March 2018. https://www.neurologyreviews-digital.com/neurologyreviews/nord_supplement_0318/MobilePagedArticle.action?articleId=1361082#articleId1361082 **7.** Nagane Y, Murai H, Imai T, et al. Social disadvantages associated with myasthenia gravis and its treatment: a multicentre cross-sectional study. *BMJ Open*. 2017;7(2):e013278.



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