



Conversation Guidebook

A tool to help you make the most of one-on-one conversations with your myasthenia gravis (MG) Guide



ABOUT THIS GUIDEBOOK:

This guidebook is meant to be just that—a *guide*. Although there are important topics covered here, you do not need to follow everything line by line. The information found within is meant to help you open up to your MG Guide about ways your life could be better and learn how to talk to your doctor about your goals.

I want everyone with MG to know they have someone who can relate and understands what we go through—*someone who can listen and be supportive* in a way family, friends and community sometimes cannot be.

—Bryan, Let's Talk MG Guide who has been living with MG for 10+ years



TIP: Before your first call, closely review this guide and consider completing the exercise, so you can make the most of your time with your MG Guide.

MG Guides are not medical experts. Please reach out to your healthcare provider if you have questions about treatment.

Making the most of your time with your MG Guide

Everyone with MG has a unique story, so start by sharing yours! Remember to be honest about what you want from each conversation and things you wish could be better in your life with MG. This is an open forum for communication and a safe, understanding space to talk about MG—so you can feel empowered to take the next step and share these learnings with your healthcare team and loved ones.



SET AN INTENTION OR GOAL

What do you want to learn and be able to do after each conversation?

For example, you may want to talk about certain symptoms that get in the way of everyday life. In the next call, you may want to focus more on how to talk to your doctor more effectively.



TAKE NOTES TO SHARE WITH YOUR DOCTOR AND LOVED ONES

Get ready for lots of helpful tips, resources and information from your MG Guide. Have a physical notebook or digital note-taking app ready for one-on-one conversations. Refer back to these notes when talking about your concerns and goals with your doctor and loved ones.

**Looking to continue the momentum in your everyday life with MG?
Join Go for Greater with MG, a community-wide challenge aimed to help achieve a greater everyday with MG.**

MG Activities of Daily Living (MG-ADL) Profile

Answering these eight questions with your doctor can reveal how MG affects you every day.

Grade	0	1	2	3	Score (0, 1, 2 or 3)
1. Talking	Normal	Intermittent slurring or nasal speech	Constant slurring or nasal, but can be understood	Difficult to understand speech	
2. Chewing	Normal	Fatigue with solid food	Fatigue with soft food	Gastric tube	
3. Swallowing	Normal	Rare episode of choking	Frequent choking necessitating changes in diet	Gastric tube	
4. Breathing	Normal	Shortness of breath with exertion	Shortness of breath at rest	Ventilator dependence	
5. Impairment of ability to brush teeth or comb hair	None	Extra effort, but no rest periods needed	Rest periods needed	Cannot do one of these functions	
6. Impairment of ability to arise from a chair	None	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance	
7. Double vision	None	Occurs, but not daily	Daily, but not constant	Constant	
8. Eyelid droop	None	Occurs, but not daily	Daily, but not constant	Constant	
					MG-ADL score total (items 1-8) =

This information has been provided for educational purposes only and is not meant to be a substitute for professional medical advice. Patients should not use this information for diagnosing a health condition. Patients should always consult a healthcare professional for medical advice or information about diagnosis and treatment.

Source: Wolfe GI, et al. *Neurology*. 1999;52(7):1487-1489.

Aiming for minimal or no symptoms

Here are three things to know when discussing this with your MG Guide:

1

The MG-ADL scale is a helpful tool to track symptoms

The first step is to track your symptoms using the MG-ADL scale regularly, and then talk to your doctor about your score and what it means to you. This is important because symptoms and how they affect you can change over time.

2

Aiming for a lower MG-ADL symptom score may help improve daily abilities

A score of zero or one out of 24 on the MG-ADL scale is considered “minimal symptom expression” or MSE.¹ The lower the score, the less impact MG has on your daily activities. A higher score represents more severe symptoms that can get in the way of daily abilities, whereas a lower score may mean having fewer symptoms—and being able to do more of what you want in your everyday life. But remember, MSE is not an end destination, as symptoms can change. You can work with your healthcare team to find a goal that works for you.

3

Aiming for minimal or no symptoms is worth a conversation with your doctor

Keeping track of your MG-ADL score may help you better understand just how much your symptoms are affecting your daily abilities. It’s important to remember that pursuing greater symptom control is a journey. That’s why regular symptom tracking and reporting can help you have more productive conversations with your doctor to inform your treatment plan.

Ask your MG Guide how reducing symptoms may have helped improve their daily abilities. Then, talk to your doctor about what that could mean for you and your life with MG. Specifically, what could you do after achieving a lower score that you couldn’t do today?

Reference

1. Albazli K, et al. *Front Immunol.* 2020;11:917.



MG in 3-D: Expressing your MG symptoms in numbers and words

This exercise is designed to help you and your MG Guide better understand what minimal symptom expression could mean for you in real life. Use the MG-ADL scale found earlier in this guidebook to calculate your score. Then, think about how your score translates to how you feel and what you can do.

When my MG symptoms are **bad**, my score is a _____ and I feel

When my MG symptoms are **mild**, my score is a _____ and I feel

On my **best day**, when I have no/very few MG symptoms, my score is a _____ and I feel

Share this scale and your MG in 3-D notes with your MG Guide.

TIP: Take a picture of this page and share it with your doctor during your next appointment.

My MG in the moment

Right now, my score is a _____ and I feel

Setting goals for the future



✓ REVIEW

what you learned today from the conversation with your MG Guide.

- * Refer back to notes taken in your journal or note-taking app on your phone

✓ IDENTIFY

if another call may help you achieve your goals. Consider asking yourself:

- * Did this call help you determine what to talk to your doctor and loved ones about, so they may help you reach your goals?

✓ MAKE A PLAN

to talk to your doctor and loved ones about your goals, which may include minimal symptom expression. If there is anything in the way of you taking this step, consider asking yourself:

- * Are there any resources that may help you remember the learnings covered today or that may help you open up to your doctor at your next visit?



SUPPORT FOR EVERYDAY LIFE WITH MG

- * Join **Go for Greater with MG**, a community-wide challenge aimed to help achieve a greater everyday with MG

GO FOR
Greater
with MG

- * Find helpful discussion guides to aid in your conversations about MG

- [Talking to Your Doctor](#)

- [Talking to Your Kids](#)

- [Talking to Your Family](#)

- [Talking to Your Partner](#)