



# Conversation Guidebook

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



Tom, Let's Talk MG Guide

## What's Inside

About this guidebook .....	2
→ Making the most of your time with your MG guide .....	3
→ Tracking MG's impact on daily life .....	4
→ MG activities of daily living (MG-ADL) profile .....	5
→ Reflecting on daily life with MG .....	6
→ Setting meaningful goals .....	7
→ Resources: support and practical tools .....	8



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

## About This Guidebook

This guidebook is meant to be just that—a guide. Whether you're reading this for yourself or on behalf of someone you care for, you do not need to follow every detail. The information within is meant to help you identify what matters most in your life with MG. It also provides tools to talk with an MG Guide and healthcare team about how to work toward meaningful 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 B., Let's Talk MG Guide who has lived with MG for 10+ years



*MG Guides are not medical experts. Please reach out to your healthcare provider for medical advice and information about diagnosis and treatment.*

# Making The Most Of Your Time With Your MG Guide

Everyone's journey with MG is unique, so start by sharing yours. Be honest about what you want from each conversation and the things you wish could be better in your or your loved one's life with MG. Your time with your MG Guide offers an open, safe and understanding space to talk about MG. The goal is to make you 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 symptoms that get in the way of everyday life. In the next call, you may want to focus on how to talk to your or your loved one's healthcare team.



## 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 healthcare team and loved ones.

“

*Let's Talk MG is a great resource for learning how to talk with your healthcare team and loved ones about your experience with MG.*

”

**-Ben, Let's Talk MG Participant**

# Tracking MG's Impact on Daily Life

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

1

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

The first step is to track your or your loved one's symptoms regularly using the MG-ADL scale. Consistent tracking helps you spot changes over time. It also prepares you for more informed conversations with your healthcare team.

2

## Understanding your or your loved one's MG-ADL score may help you recognize the impact of MG

The MG-ADL uses a scale from zero to three to help you measure the impact of MG symptoms. The lowest score of zero reflects minimal impact, while a score of three shows the greatest effect.

3

## Use your MG-ADL score to talk with your healthcare team about what's next for your or your loved one's treatment plan

Understanding this score is a key step toward building a treatment plan that supports daily abilities and helps you or your loved one work toward meaningful goals.

### MG-ADL Scale



Minimal Symptoms  
& Less Impact

Severe Symptoms  
& Greater Impact

Ask your MG Guide how tracking and reducing symptoms may have helped improve their daily abilities and supported progress toward their goals. Then, talk to your healthcare team about what that could mean for you and your life with MG. [Learn more about the benefits and how to use the MG-ADL Scale.](#)

# 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	
					<b>MG-ADL score total (items 1-8) =</b>

**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.

## Reference

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



## Reflecting on Daily Life with MG

This exercise aims to help you and your MG Guide evaluate your or your loved one's MG-ADL score and explore how MG symptoms may be impacting daily life. Use the space below to reflect on what you or your loved one can't do, what's still possible, what goals you hope to reach and what support might help along the way.

### ⊗ I CAN'T

Ex: "I can't eat some of my favorite foods without choking."

### ★ I WANT

Ex: "I want to take my dog on longer walks."

### ✔ I CAN

Ex: "I can cook a recipe without having to sit down."

### 🎯 I WILL

Ex: "I will talk to my doctor about adjusting my treatment."



# Setting Goals for the Future



## ✓ REVIEW

Take a moment to reflect on 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

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

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

## ✓ MAKE A PLAN

Talk to your healthcare team and loved ones about these goals, which may include how to minimize symptoms. 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 healthcare team at your next visit?



Take a look at the next page for helpful resources to support you or your loved one on your MG journey.



# Support and Practical Tools for Navigating Everyday Life with MG

## GO FOR *Greater* with MG

Join [Go for Greater with MG](#) to get tools and resources to reach a greater everyday with MG.



Find helpful discussion guides to aid in your conversations about MG

- \* [Talking to Your Doctor](#)
- \* [Discussing MG with Your Family](#)
- \* [Explaining MG to Your Kids](#)
- \* [Speaking to Your Partner about MG](#)

Want to discover an FDA-approved treatment option?

Talk to your doctor to learn more about this [treatment option](#) and discuss if it may be right for you.

