

GO FOR Greater with MG

Discover your greater

Use the Greater Guidebooks to help you get there

GOAL #2:

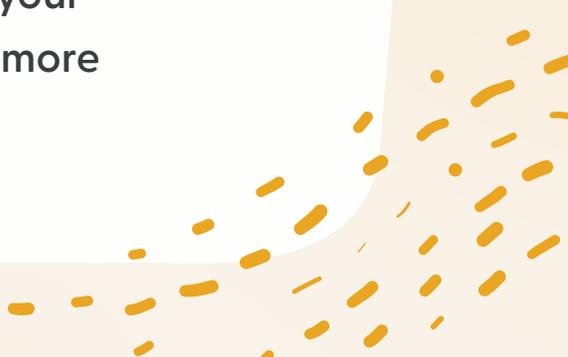
Greater
communication
with my
healthcare team



GOAL #2: Greater communication with my healthcare team



Better communication is mutually beneficial to you and your doctor. This goal is about having the right tools to help prepare for doctor appointments and explain your priorities clearly, so *both* sides get more value from those conversations.



How to use this guidebook

1. Print and complete at your own pace. **TIP:** Use a journal to take notes.
OR
2. Save this file on your smartphone and complete in your own time. **TIP:** Record a voice memo or selfie video, journal in your notes app and take screenshots.

Make this your own experience by using the tools that feel right to you.

Remember

- * The information contained in this guidebook is meant to be informative, but should not replace medical advice from your doctor.
- * **It's important to talk to your healthcare team before making any changes you think could affect your MG.**

Getting to know your healthcare communication style

What you share with your healthcare team may affect how much they can help you. Take a moment to think about the things you share and how you say them.

Which communication style matches you best?

#1

YOU'RE A BIG-PICTURE THINKER

You realize managing MG may be difficult. Tracking symptoms and preparing for appointments may feel like a lot, but the exercises in this guidebook are designed to help put your mind at ease.

#2

YOU'RE A DYNAMIC COMMUNICATOR

There's always room to grow. Use this guidebook's exercises to help you get the most out of your next healthcare appointment.

#3

YOU'RE AN MG-PREPARED PLANNER

You excel at communicating. The exercises in this guidebook may help you maintain your approach and learn even more.



What you say matters just as much as how you say it. Use this guidebook to find ways of expressing yourself more clearly to your healthcare team to help get the most out of every visit.



Help your doctor understand the impact of MG on your life

The Myasthenia Gravis Activities of Daily Living (MG-ADL) scale on the following page is a tool that helps identify the impact that MG has on your daily life.

Use the MG-ADL scale to translate your symptoms into a number that you can explain to your healthcare team:

- * The scale tracks eight key signs and symptoms that are commonly found in people living with MG
- * Each item is measured on a four-point scale, with a score of zero representing normal function and a score of three representing a lack of ability to perform that function
- * Your total score can range from zero to 24 points, with a higher score indicating more severe MG

NOTE: Ask your doctor if there is anything you can do to lower your MG-ADL symptom score.



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.

Tell your doctor how your MG-ADL score affects your life

Your doctor may ask if there have been any changes since your last visit. Looking at your MG-ADL score might make it easier to track any changes to your MG symptoms. But there's a lot more to your score than just the number! Use the area below to express what you can't do, can do and want to do as a result of your current score.



Can't

Can

Want



Discussing MG: Making the most of your words

Your version of “fine” is likely different than that of another person living with MG. That’s why it’s important to tell your doctor exactly how you’re feeling so there is no guessing! This exercise may help turn your feelings and goals into concise thoughts that you can share with your healthcare team.

- ✓ Be as descriptive and specific as possible
- ✓ Try using metaphors
- ✓ Don’t be shy!

Good

Ex, “I could brush my hair without getting tired!”

Fine

Ex, “I had trouble seeing during a meeting, but was able to follow along”

Tired

Ex, “It felt like someone kept tapping my eyelids shut.”

Struggling

Ex, “I stayed in bed all day and felt like I was on a deserted island.”

REMEMBER: YOU’RE NOT ALONE.

Many people with MG may struggle to communicate with their healthcare teams. Read more from people with similar experiences.

bit.ly/3cFpFuC

Aiming for minimal symptoms

How could tracking your MG-ADL score help you reach your personal goals?

Calculating your MG-ADL score may help you better understand just how much your symptoms are affecting your abilities, and it's valuable information to share with your doctor.

A higher score represents greater severity of 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. In fact, did you know that a score of zero to one is considered “minimal symptom expression” or MSE?¹ The lower the score, the closer you may be to reaching your personal goals.

Talk to your doctor about ways to lower your MG-ADL symptom score.



Going for greater may mean aiming for minimal symptom expression



Use the next page to identify what minimal symptom expression could mean to you.

Reference

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

Envision your version of greater

The exercise below may help you explain to your healthcare team what your ideal MG-ADL score would be and the positive effect it could have on your life.

Step 1

YOUR IDEAL MG-ADL SCORE

Choose an MG-ADL score that's meaningfully lower than your current score, but feels possible.

Ex: If your MG-ADL score is currently a nine, perhaps you could aim to get it down to a five. Work with your doctor on an attainable goal number.

Step 2

YOUR IDEAL ACTIVITY

Choose an activity that you believe you could do if you achieved your reduced MG-ADL score.

Ex: "If my MG-ADL score got down to a four, I'd like to take a weekend trip to visit my son."

Show the resulting combination of your ideal MG-ADL score and corresponding ideal activity to your doctor to help facilitate your next conversation.

GO FOR
Greater
with MG

A community-wide challenge
aimed to help achieve a
greater everyday with MG



“When you go to the doctor, **have a goal in mind of exactly where you want to be with MG.**”

—Mike*
Living with MG

*Paid contributor to MG United

Share your greater

How are you going for greater? Share a story or picture on social media with **#GoforGreaterWithMG** and encourage the MG community to join in!

