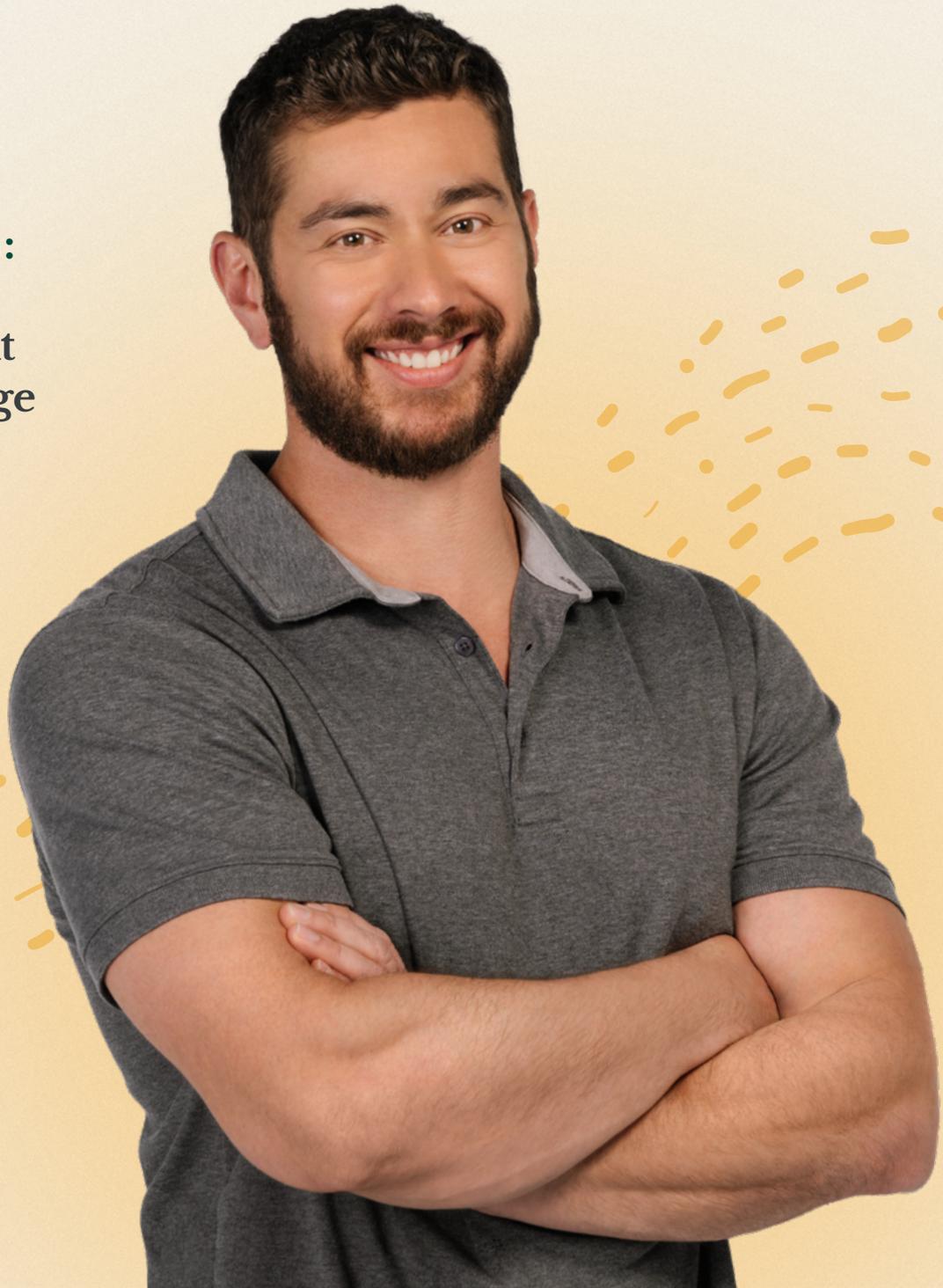


GO FOR *Greater* with MG

Discover your greater
Use the Greater Guidebooks to help you get there

GOAL #4:
Greater
treatment
knowledge



GOAL #4:

Greater treatment knowledge



You may have questions about MG treatment, especially when it comes to side effects and risks. This goal is about learning more about MG so you can make informed decisions about treatments.



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.**

Track how well MG treatment is working for you

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 so you can see how well treatment is working for you:

- * 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.

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 following pages to identify what minimal symptom expression could mean to you and the people who care about you.

Reference

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

What's a "greater" treatment outcome for me?

A little preparation can help you make the most of conversations with your healthcare team. Start by capturing what you know as of now and continue the exercise together at your next visit.

The form is a large circle divided into four quadrants by a vertical and a horizontal line. Each quadrant is connected to a green label box. The top-left quadrant is labeled 'My MG-ADL score' and contains two rows of horizontal lines. The top-right quadrant is labeled 'Current treatments' and contains two rows of horizontal lines. The bottom-left quadrant is labeled 'What can I do to feel better?' and contains four rows of horizontal lines. The bottom-right quadrant is labeled 'Treatments to consider' and contains four rows of horizontal lines. The top-left and top-right quadrants have handwritten labels: 'Current score:' and 'Side effects:' respectively. The bottom-left and bottom-right quadrants have handwritten labels: 'Goal score:' and 'How I'm feeling:' respectively.

My MG-ADL score

Current score:

Goal score:

Current treatments

Side effects:

How I'm feeling:

What can I do to feel better?

Treatments to consider

Ex: diet, exercise, stress relief, sleep

What could a minimal symptom score mean for you?

Just because you have MG doesn't mean you don't deserve more—like minimal symptom expression (i.e., a total MG-ADL score of zero to one)—so don't hesitate to have a conversation with your doctor. Let your healthcare team know you're interested in learning more.

What does day-to-day life look like with *your current score?*

My go-to activities:

My sometimes activities:

Things I struggle with:

How might things change if you reached *a minimal symptom score?*

Activities I could do more often:

New activities I could do:

Things I might still struggle with:



Reminder: Don't forget to discuss your thoughts with your healthcare team, so they can help you find a greater path forward.



GO FOR
Greater
with MG

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



“ I want autonomy, and I want
to be able to advocate for
myself. I think that’s really
important. ”

–Caitlin*
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!

