

GO FOR *Greater* with MG


Discover your greater

Use the Greater Guidebooks to help you get there

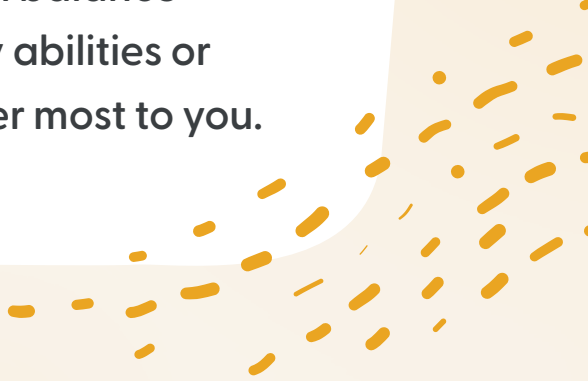
GOAL #3:
Greater tools
and resources



GOAL #3: Greater tools and resources



There may be more to learn when it comes to advocating for yourself or managing and tracking symptoms with MG. This goal is about feeling better equipped to maintain balance with MG, helping you improve daily abilities or pursuing whichever priorities matter most to you.



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.**

A tool to help you better understand the impact of MG

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 explain to others how you're doing:

- * 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?

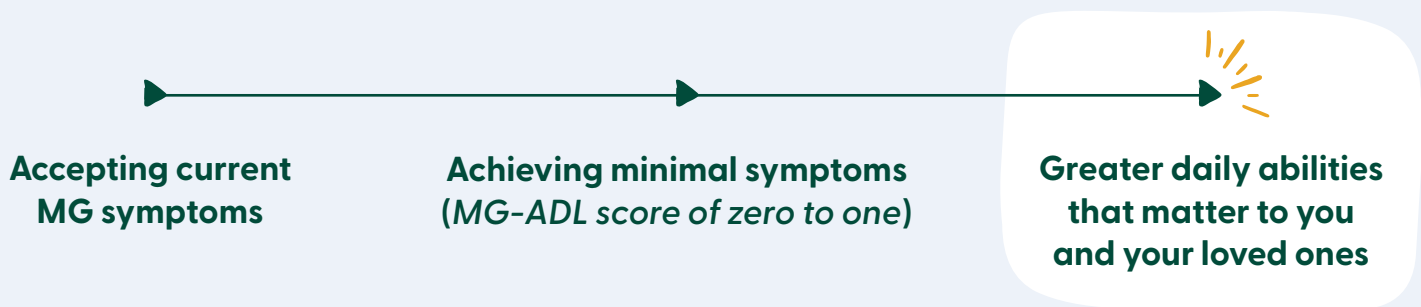
Calculating your MG-ADL score may help you better understand just how much your symptoms are affecting your abilities, and it's valuable information to share with your doctor.

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

Reference

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

A pin for your thoughts


It can be easy to forget all the questions and points you want to share with your doctor at each visit. Use this page to jot down notes on your smartphone or in a physical journal about how your MG-ADL score has evolved. If you really like this exercise, consider writing on real post-it notes at home and creating your own board of thoughts!




When did the symptoms start, and how did they change throughout the day, week and/or month?



Is there anything that makes the symptoms better or worse?



How would your supporter describe the changes?



If you've had an improvement in symptoms, what goal(s) could you reach that you couldn't before?

MG crisis planning tool

Hopefully the day never comes, but it may feel good to know you have a plan in place. In the event of an MG crisis, you and your support system may benefit from having a card that includes your doctor's information, current medications, where your MG crisis kit is located and other important details. Consider printing it out and keeping it in your wallet for easy access, wherever you are.

MG Crisis Card

Print and cut out this card and leave one in a common location in your home, like on the refrigerator. Carry another one on your person and one in the car. Should a crisis occur, you can give this card to get assistance, share important medical information and help your support person find your kit.



If it looks like the cardholder is having an emergency, please dial 911 right away, and notify their emergency contact below.

MG CRISIS CARD

Myasthenia gravis (MG) may sometimes cause struggles to stand, talk and/or breathe, as well as problems with muscle weakness.¹ Double vision and drooping eyes may also occur.¹ If breathing or swallowing problems are heightened, the person carrying this card may be having an MG crisis and need immediate emergency medical help.¹

If it looks like the cardholder is having an emergency, please dial 911 right away, and notify their emergency contact below.

Name: _____

Birthdate: _____

Address: _____

Phone: _____

Emergency contact name: _____

Relationship: _____

Emergency contact phone: _____

Medical conditions in addition to MG: _____

If I am struggling to breathe, it is very important to call 911 immediately.

Current medications: _____

Additional notes to know in the event I cannot communicate: _____

MG Crisis Kit Location

In the event of a myasthenia gravis (MG) crisis, please dial 911 and find my MG Crisis Kit here: _____

This information is intended as educational information for patients and their healthcare providers. It does not replace a doctor's judgment or clinical diagnosis.



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Reference

1. Wendell LC, et al. *Neurohospitalist*. 2011;1(1):16-22.



Download the MG Crisis Card
<http://bit.ly/43dmfHz>

My MG Care Team: Contact Card

It's great having help on your MG journey. But keeping track of all that contact info may be overwhelming! Fill out this contact card to have all your care team members' info in one place—from neurologist to therapist to trusted family members. Then, snap a picture or print out copies to share with loved ones. Consider this your MG team roster.

Name	MG Care Team Role	Phone Number	Email	Address	Notes
<i>John Doe</i>	<i>Physical Therapist</i>	<i>(123) 555-1234</i>	<i>john.doe@domain.com</i>	<i>12345 Doe Rd. City, State 54321A</i>	<i>Unavailable between 1-3pm CST on weekends</i>

GO FOR *Greater* with MG

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



“ I think just having the resources to fully understand: 1) What is an autoimmune disease? And then: 2) Okay, what exactly is MG? Because I know for a fact, it took me a very long time to understand what my body was doing to itself. ”

–Courtney*
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!

