

GO FOR
Greater
with MG



Bryan
LIVING WITH MG

A Greater Everyday
Can Start Today

MG United
by argenx



Table of Contents

STEP 1:

Greater understanding

Symptom tracking with the MG-ADL scale	05
MG Activities of Daily Living (MG-ADL) Profile.....	06
Explaining MG in 3-D to your loved ones.....	07
MG-ADL scale collaboration activity.....	08
Advocating for yourself in the workplace.....	09

STEP 2:

Greater tools and resources

Quiz: Getting to know your healthcare communication style	11
Results: Getting to know your healthcare communication style	12
Helpful MG discussion guides for big conversations	13
Tell your doctor how your MG-ADL score affects your life	14
Let's Talk MG	15

STEP 3:

Greater treatment knowledge

Aiming for minimal symptoms	17
High 5: Talk to your doctor priority list.....	18
What's a "greater" treatment plan for me?	19
Handy discussion guides to use with your healthcare team.....	20

Making changes can be hard, especially while living with myasthenia gravis (MG). But with the right tools and support, you can aim for greater, from long-term goals to everyday tasks. Go for Greater gives you a 3-step action plan with resources that help you identify what you want—and go for it.

A greater everyday with MG means something different to everyone. Whether you want to get back to the gym, bake a new recipe or walk to the mailbox—you can make the journey your own.

This guidebook is designed to support you as you **Go for Greater**. It provides interactive activities to track symptoms, tips for better communication about MG, exercises for you and loved ones to work on together and much more.

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**

AIDEN-LEE
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Step 1

GREATER UNDERSTANDING

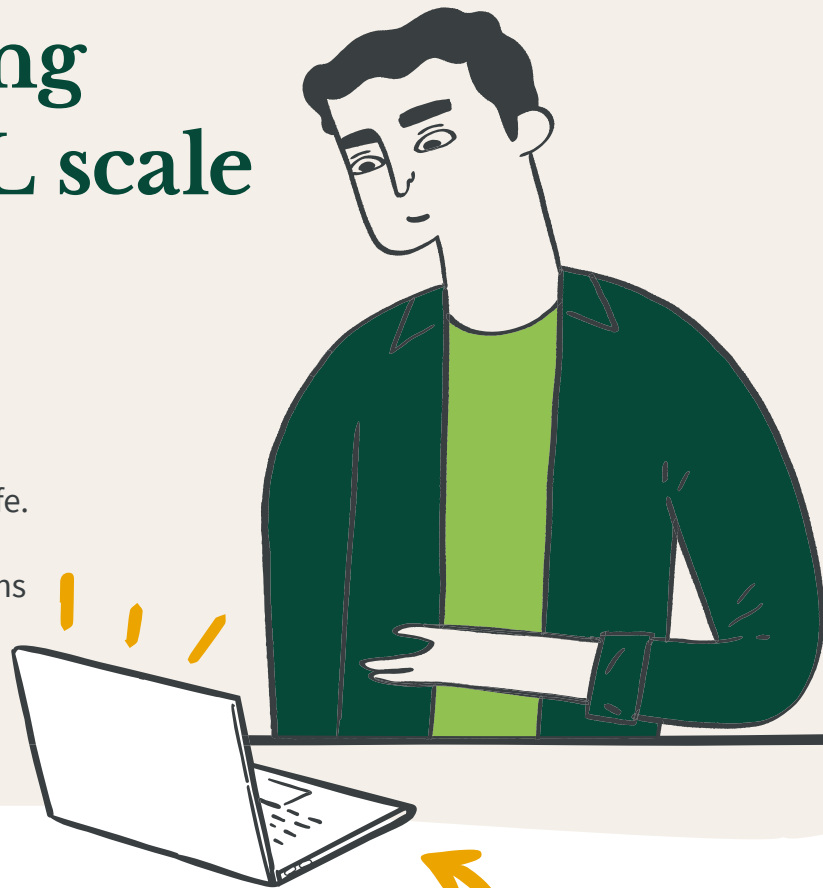
Even when family, friends and colleagues are highly supportive, it can still be hard for them to fully understand what it's like to live with MG. This step is about empowering yourself with the information to confidently explain how MG impacts you to help the people in your life understand what you're going through.

Symptom tracking *with* the MG-ADL scale

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.

Here's a video that brings the MG-ADL scale to life. It may help to answer some common questions, which may lead to more productive conversations with your healthcare team.

<https://bit.ly/3BbX9PX>



Use the MG-ADL scale to translate your symptoms into a number that you can explain to your loved ones and share with 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

Use the interactive MG-ADL scale and bookmark it on your device!

<https://bit.ly/3ZvzYtJ>

Good to know:

- ✓ Everyone's score may be different; it all depends on how it feels for the individual
- ✓ In general, the lower your score, the less severe your symptoms are and the less your daily activities may be impacted
- ✓ **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.

Explaining MG in 3-D to your *loved ones*

This exercise can help you identify concerns that your loved ones may need to know about, because sometimes, your score from the MG-ADL scale can be different from real life. You may have a lower score but feel like symptoms still get in the way.

Use the prompts below to break down how symptoms affect three dimensions of your life.

DIMENSION 1

Physical: “My MG symptoms limit my ability to...”

Ex: “Style my hair the way I want.”

DIMENSION 2

Social: “My MG symptoms get in the way of...”

Ex: “Going on golf trips with my friends.”

DIMENSION 3

Emotional: “My MG symptoms make me feel...”

Ex: “Less like myself, crummy a lot of the time.”

***** Share the scale and your MG in 3-D notes with your loved ones. Ask for their help in tracking and recording your symptoms. They may recognize some of the symptoms sooner than you do.



TIP: Take a picture or screenshot of this page after you’ve completed it and save it to your photo library favorites to look back on or share with loved ones.



MG-ADL scale *collaboration* activity

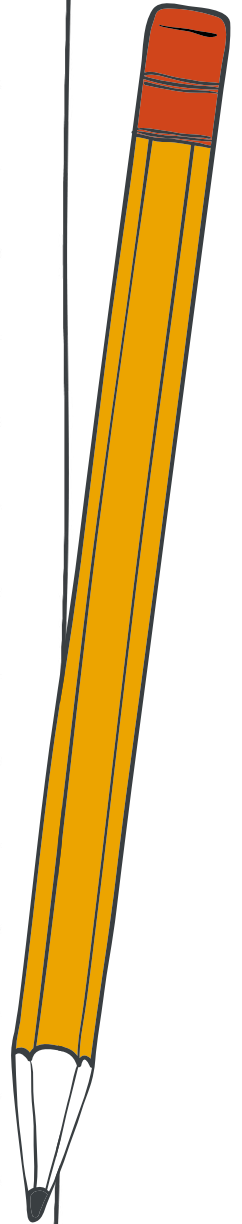
Share the MG-ADL scale with a close family member, friend or healthcare provider and ask them to fill it out on your behalf. Then, compare results—you might be surprised how their answers could differ from yours.

*** Sometimes, someone else might spot things you don't!**

Which areas did they rank HIGHER than you did, and why?

Which areas did they rank LOWER than you did, and why?

What did you learn about yourself from the score they gave you? Anything you can bring to your doctor?



Advocating for *yourself* in the workplace

Choosing to talk to your employer about MG is a personal decision and can be a difficult one. If you're living with MG, be sure to take your individual circumstances into account when deciding whether or not to disclose your health information with your employer.

✦ **Practicing what you're going to say with a loved one may help!**

CONVERSATION TIPS

If you are ready to talk with your employer about MG, you may find this resource helpful.

<https://bit.ly/47CesWy>

EXPLAINING MG

Consider sharing this link with your employer to help them better understand MG as a whole and how it impacts you.

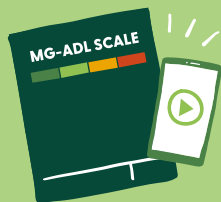
<https://bit.ly/47FDpjS>



KATHY
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**TOM
LIVING WITH MG**



Step 2

GREATER TOOLS AND RESOURCES

Having more ways to manage the ups and downs of MG and effectively advocate for yourself is game-changing. This step equips you to identify goals, understand your communication style and begin to discuss priorities with your friends, family and healthcare team.

Getting to know your healthcare communication *style*

What you share with your healthcare team may affect how much they can help you. Discover your healthcare communication style. Answer these quiz questions based on your own experience or with a loved one's experience in mind.

Or skip the math and find this quiz (along with many other handy resources) on mg-united.com.

<https://bit.ly/3ZvA0Sn>



Questions about your healthcare communication style

1. **Do you track your MG symptoms?**
 - A. Yes, I track daily (1 point)
 - B. Yes, I track weekly (1 point)
 - C. Yes, I track occasionally (1 point)
 - D. No, I don't track my symptoms (0 points)
2. **Have you shared goals with your healthcare provider?**
 - A. Yes (1 point)
 - B. No (0 points)
3. **True or false: My doctor understands the impact MG has on my daily life and my ability to do the things I love.**
 - A. True (1 point)
 - B. False (0 points)
4. **True or false: I want tools to help my doctor understand the impact MG has on my daily life and my ability to do the things I love.**
 - A. True (1 point)
 - B. False (0 points)
5. **Do you prepare for appointments with your healthcare provider ahead of time (ex: bring questions, symptom-tracking journal, etc.)?**
 - A. Yes (1 point)
 - B. No (0 points)

TOTAL SCORE

Results on next page



Getting to know your healthcare communication *style*

Which communication style matches you best? Add up your points and discover your result below.



**You're ready
for greater**

(0-1 point)

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 you feel better equipped for conversations with your healthcare team.



**You're on the
right track**

(2-3 points)

You've made great strides and you're open to new strategies. Use this guidebook's exercises to help you get the most out of your next healthcare appointment.



**You're an MG-
prepared planner**

(4-5 points)

You excel at communicating. The exercises in this guidebook may help you feel prepared to aim for better symptom management and learn even more.

**What you say matters just
as much as how you say it.**

Use this guidebook (and the healthcare provider discussion guide on **page 20**) to find ways of expressing yourself more clearly to your healthcare team during appointments to help get the most out of every visit.

Helpful MG discussion guides for *big* conversations

Opening up about MG isn't always easy.

Explore the following resources that may make having big conversations with your loved ones easier, more effective and less stressful.



- * Learning to discuss MG clearly and simply with others can help make your day-to-day life with MG a little easier for you and them. Start the conversation with the discussion guide: **Talking to Family and Close Friends About MG**
<https://bit.ly/3zgl5js>



- * Whether you're in a relationship while living with MG or a partner to someone who is, communication may help you both. For tips and suggested conversation starters when checking in with each other, download the discussion guide: **Talking to Your Partner About MG**
<https://bit.ly/3ZtJZYw>



- * Explaining MG to children can be tricky. Explore communication tips and strategies that may help these important conversations go more smoothly. Get the discussion guide: **Talking to Children About MG**
<https://bit.ly/3ZCsJQK>



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

Your doctor or healthcare team may ask if there have been any changes since your last visit. Using the MG-ADL scale 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.

I CAN'T

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



I CAN

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



I WANT

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



Let's *support* each other. Let's Talk MG.

What is it? Let's Talk MG is a mentorship program where you can virtually connect one-on-one with someone who *gets it*—an MG Guide, a person living with or supporting someone with MG.

Who's it for? People living with MG or MG supporters.

Why sign up? Share the challenges of your MG experience and hear personal insights that may help you better manage life with MG. You can also share your thoughts on the activities in your Greater Guidebook with your MG Guide.



**CHRIS
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Sign up for Let's Talk MG and speak with an MG Guide who understands what it's like to be impacted by MG. Plus, get valuable resources to help have meaningful conversations with loved ones and your healthcare team.

<https://bit.ly/47ArhAk>



Led *by* the MG community,
for the MG community

<https://bit.ly/3ZpRxvs>



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Step 3

GREATER TREATMENT KNOWLEDGE

Keeping up with the evolving MG treatment landscape can feel daunting. This step helps you set personal goals and advocate for yourself with your doctor.

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 daily life. And it's valuable information to share with your doctor so they can help you work toward your goals.

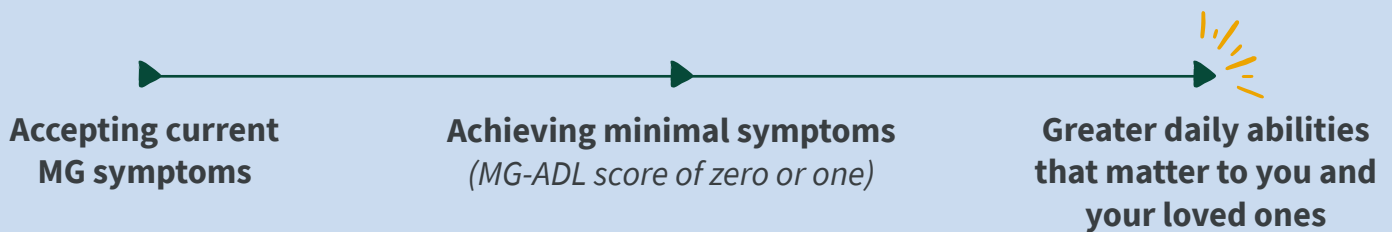
A higher score represents greater severity of symptoms that can get in the way of your daily life, whereas a lower score may mean having fewer symptoms—and being able to do more of what you want in your everyday life. In fact, did you know that a score of zero or one is considered “minimal symptom expression” 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.



KATHI
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Going for greater may mean aiming for minimal symptom expression



No matter how you're feeling, MG United has resources that may help support your hobbies and daily activities.

COOKING

Let's Cook has MG-friendly recipes and step-by-step cooking videos—many of which you can meal prep and freeze.

<https://bit.ly/47vmXmb>

EXERCISE

Getting started with a gentle stretching routine may be a good way to move your body while keeping your symptoms and energy levels in mind.

<https://bit.ly/3ZrfhiP>

Reference

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

High 5: Talk to your doctor priority list

There can be some pressure going to doctor appointments, making sure you're using your time wisely and remembering everything you wanted to discuss. This worksheet with five important topics can help you prepare for your appointments.



SYMPTOMS	<p>What are your main symptoms? Ex: "Trouble breathing, brushing your hair."</p>	
SEVERITY	<p>How severe or concerning are your symptoms? Ex: "Can't sit up without help, must lie down to brush hair."</p>	
FREQUENCY	<p>How often are your symptoms happening? Ex: "Every morning."</p>	
IMPACT	<p>How are symptoms affecting you and your life? Ex: "People need to help me every day."</p>	
GOALS	<p>What do you wish you could do? Ex: "Wish I could get out of bed more easily."</p>	

COURTNEY
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What's a "greater" treatment plan for me?

Building off of the last activity, let's dive a bit deeper! A little preparation can help you make the most of conversations with your healthcare team. Start by capturing what you know as of now—describe your long- and short-term goals and review your current treatments—and continue the exercise together at your next visit.

GOALS

Short-term (this year):

Ex: "Attend my niece's wedding."

CURRENT TREATMENTS

Date of first treatment:

Side effects:

How I'm feeling:

QUESTIONS FOR MY HEALTHCARE TEAM

- What's new in the MG treatment landscape?
- What type of targeted treatments may help me?
- Is there anything going on in MG research I should know about?
- How can I be proactive in educating myself on the treatment landscape?



MY MG-ADL SCORE

Long-term (next 5 years):

Ex: "I want to hike again."

TREATMENTS TO CONSIDER

Handy *discussion guides* to use with your healthcare team

Start the conversation (or keep it going) with your healthcare team about managing your MG. While it may be difficult to discuss how your MG symptoms are affecting your lifestyle, it's important. Check out the following discussion guides to help you with your next conversation.



The MG treatment landscape is constantly evolving and changing. Check out this discussion guide that may help you feel more prepared for your next appointment with your doctor:

<https://bit.ly/47yfsRE>



Discussing your MG symptoms and how they impact your daily activities may help your healthcare team better understand what's going on in your life. Get the discussion guide, **Talking to Your Healthcare Team About MG**

<https://bit.ly/47wEMRI>

ZACH
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**A Greater Everyday
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Everyone's experience with MG is unique, so when you're going for a greater everyday with MG there is no one-size-fits-all. Through exercises, resources, discussion guides and more, **Go for Greater** was created to support you on your own personal journey.

“Go for Greater is something you can do on your own or with others. It can be the next right step for anyone!”

**RACHEL
LIVING WITH MG**



“It can give you tips and ideas that you didn't think about to help with MG or daily life.”

**AIDEN-LEE
LIVING WITH MG**

“We hold the future in our own hands. So do your part, take personal action and Go for Greater.”

**VICTOR
LIVING WITH MG**

