

# GO FOR Greater with MG

**Discover your greater**


Use the Greater Guidebooks to help you get there

**GOAL #1:**  
Greater  
understanding  
from loved ones


# GOAL #1:

## Greater understanding from loved ones

---



Even when your family and friends are highly supportive, it can still be hard for them to fully understand MG. This goal is about empowering you with the information to explain exactly how MG affects you—in a simplified way—to help them really “get it.”



### 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

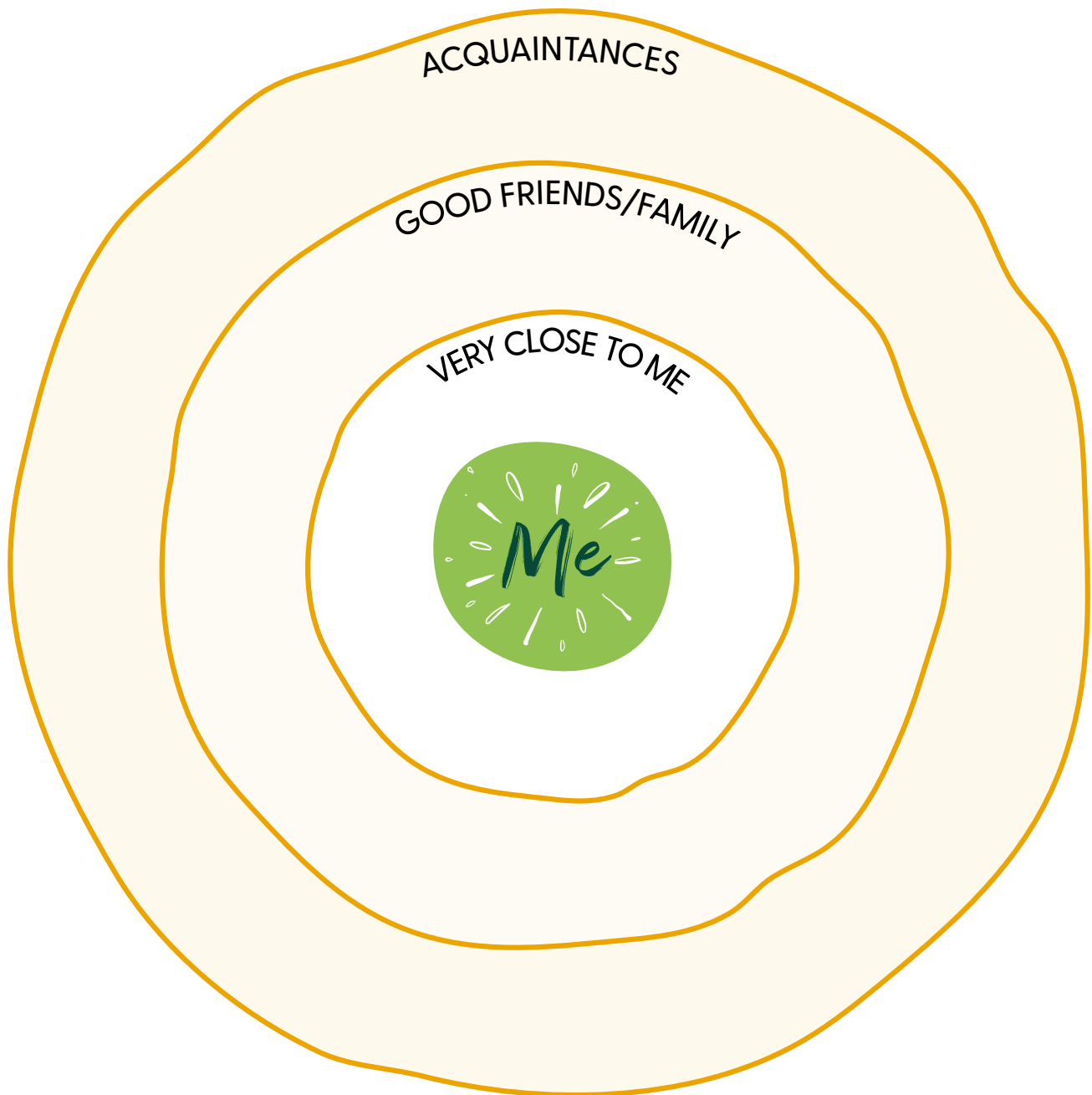
- \* The information contained in this guidebook is meant to be informative, but should not replace medical advice from your doctor.
- \* **It's important to talk to your healthcare team before making any changes you think could affect your MG.**

## Identifying your support system

Who are the people in your life who you can rely on when it comes to your MG?

**Write down all the people you consider to be part of your support system.**

Sometimes it takes just one person to fill that void, and that's OK! Through this exercise, you may realize there are people close to you who should be more in the know about your MG.



# A tool to help your loved ones better understand your life with 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 that you can explain to your loved ones:**

- \* 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	
<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.

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



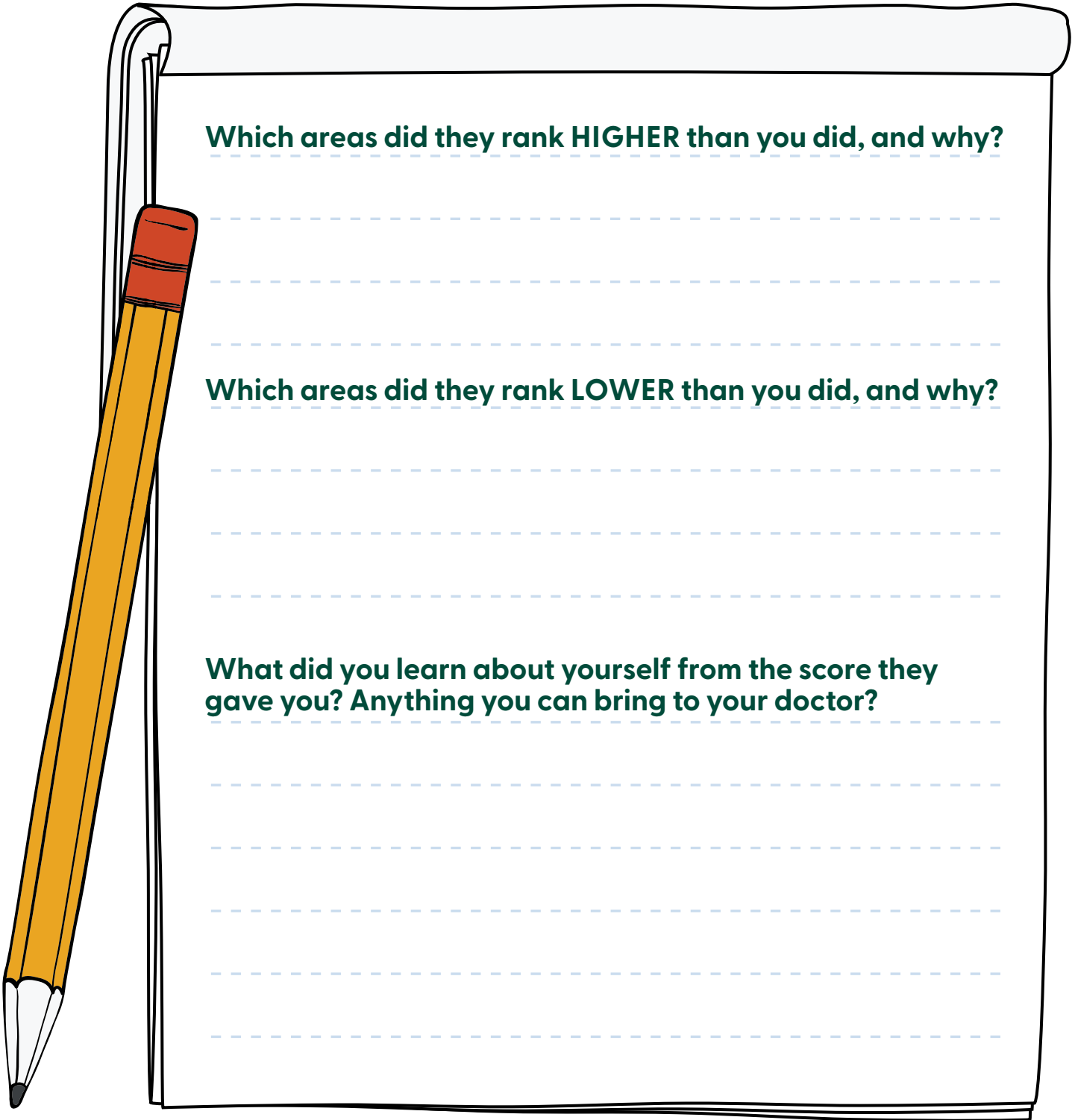
# Have your loved one fill out the MG-ADL scale for you

Share the MG-ADL scale with a close family member or friend 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, a loved one can spot things you can'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?**



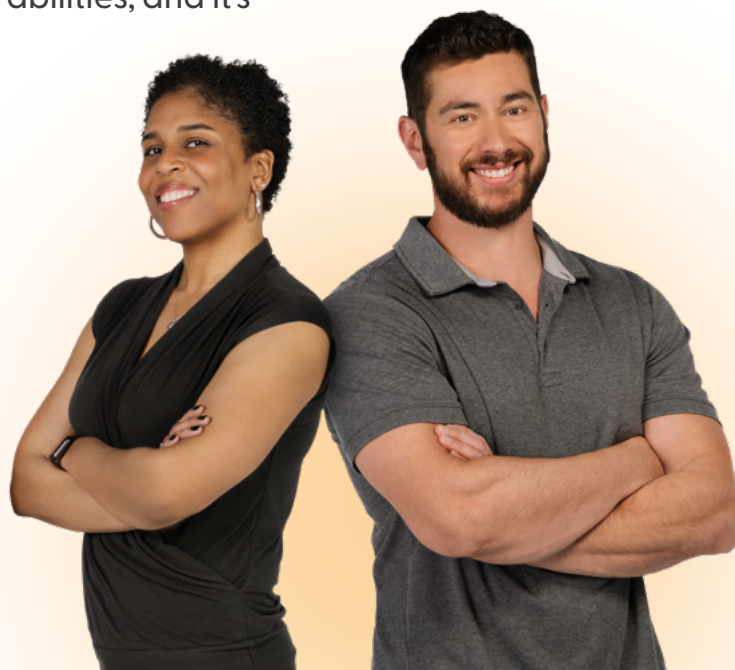
## Aiming for minimal symptoms

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

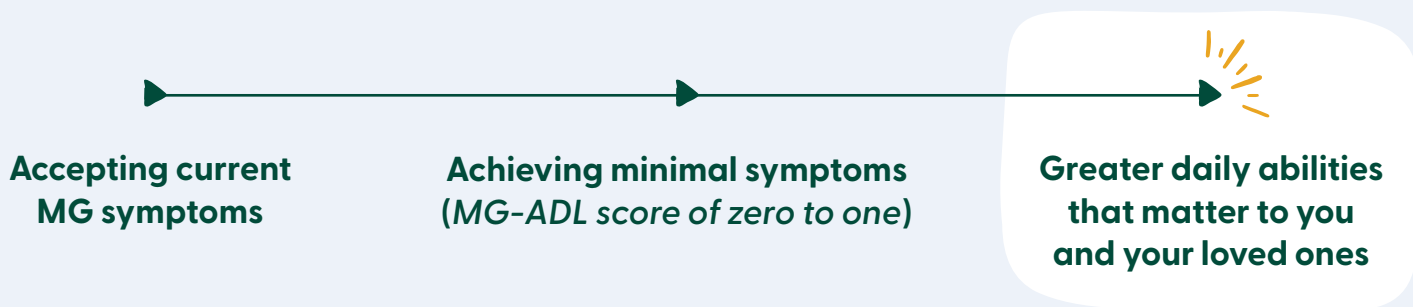
Calculating your MG-ADL score may help you better understand just how much your symptoms are affecting your abilities, and it's valuable information to share with your doctor.

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?<sup>1</sup> 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.

# 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 got in the way of...”  
[Ex: “going on golfing trips with my friends.”]



---

---

---

**Dimension 3** | **Emotional:** “My MG symptoms made me feel...”  
[Ex: “less like myself, crummy a lot of the time.”]

---

---

---



# MG in 3-D: Expressing your MG symptoms in numbers and words

When my MG symptoms are **bad**, my score is a \_\_\_\_\_ and I feel \_\_\_\_\_

---

---

---

When my MG symptoms are **mild**, my score is a \_\_\_\_\_ and I feel \_\_\_\_\_

---

---

---

On my **best day**, when I have no/very few MG symptoms, my score is a \_\_\_\_\_ and I feel \_\_\_\_\_

---

---

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.

## My MG in the moment



Right now, my score is a \_\_\_\_\_ and I feel \_\_\_\_\_

---

---

---




# Keep the conversation going

Whether you're in a relationship while living with MG or are the partner of someone who is, communication may help you both. Use the discussion guide linked below for tips and suggested conversation starters when checking in with each other.

DISCUSSION GUIDE:

## Talking to Your Partner About Myasthenia Gravis




Whether you're the one living with myasthenia gravis (MG) or your partner is, this discussion guide may help you navigate your journey together. Consider setting regular check-ins on a cadence that works for you (weekly, monthly, etc.) and use the sample questions below to maximize each conversation. Then reference the second page for tips to keep check-ins productive and for space to take notes.

**QUESTIONS TO ASK YOUR MG Supporter**

- What are some things I can feasibly do to support you?
- What are some things we've accomplished recently that make you happy?
- How are you feeling about the extra responsibilities you've taken on to support me?
- What are some effective ways I've communicated my MG challenges to you?
- How can I better communicate ways you can support me when I'm symptomatic?
- What can we do to maximize our quality time together?
- What can we do to ensure you're getting enough time to yourself?
- What has helped us work well together in the past?

**QUESTIONS TO ASK YOUR Partner with MG**

- What are some things I can do to better support you?
- What are some things we've accomplished recently that make you happy?
- What are some ways I've supported you that are working well?
- What are some ways I've been trying to support you that aren't working or could be improved?
- How have your symptoms been affecting you lately?
- What can we do to maximize our quality time together?
- What can we do to ensure you're getting enough time to yourself?
- What has helped us work well together in the past?

 For U.S. audiences only.  
©2023 argenx US-NON-22-00161 V1 03/2023

## Tips and Notes for Your Next Check-In

Check out the following tips to help keep your discussions constructive. Then, ask yourself: What were the biggest lessons from your most recent conversation? Is there anything you'd like to revisit? Write your thoughts below!

**TIPS FOR A Productive Check-In**



- ✓ Acknowledge and celebrate wins in addition to working through challenges
- ✓ Approach the conversation as a team working together
- ✓ Focus on qualities that have helped you work successfully together in the past
- ✓ Keep an open mind
- ✓ Be empathetic
- ✓ Give context to your statements (e.g., "Due to my MG symptoms this week, I need...")
- ✓ Ask follow-up questions if you need clarity on something your partner shares

**Takeaways:**  
Important ground you and your partner covered  
*Example: I need to be more up front about how my symptoms affect me.*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Goals:**  
Topics to cover in your next conversation  
*Example: How I can contribute to household chores while being mindful of fatigue.*

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

 For U.S. audiences only.  
©2023 argenx US-NON-22-00161 V1 03/2023

→ Download the guide at <http://bit.ly/40QX0ZU> ←

# GO FOR *Greater* with MG

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



“I think there is a  
difference between  
understanding  
and getting it.”

—Kathi\*  
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!

