

# GO FOR *Greater* with MG

**Discover your greater**


Use the Greater Guidebooks to help you get there

**GOAL #5:**  
Greater empathy  
in the world




## GOAL #5: Greater empathy in the world

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Discovering meaningful reasons to have a positive outlook can make a big difference. This goal is about finding ways to raise awareness and understanding among others, so we can all look forward to a world with more compassion for those with MG.



### 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.

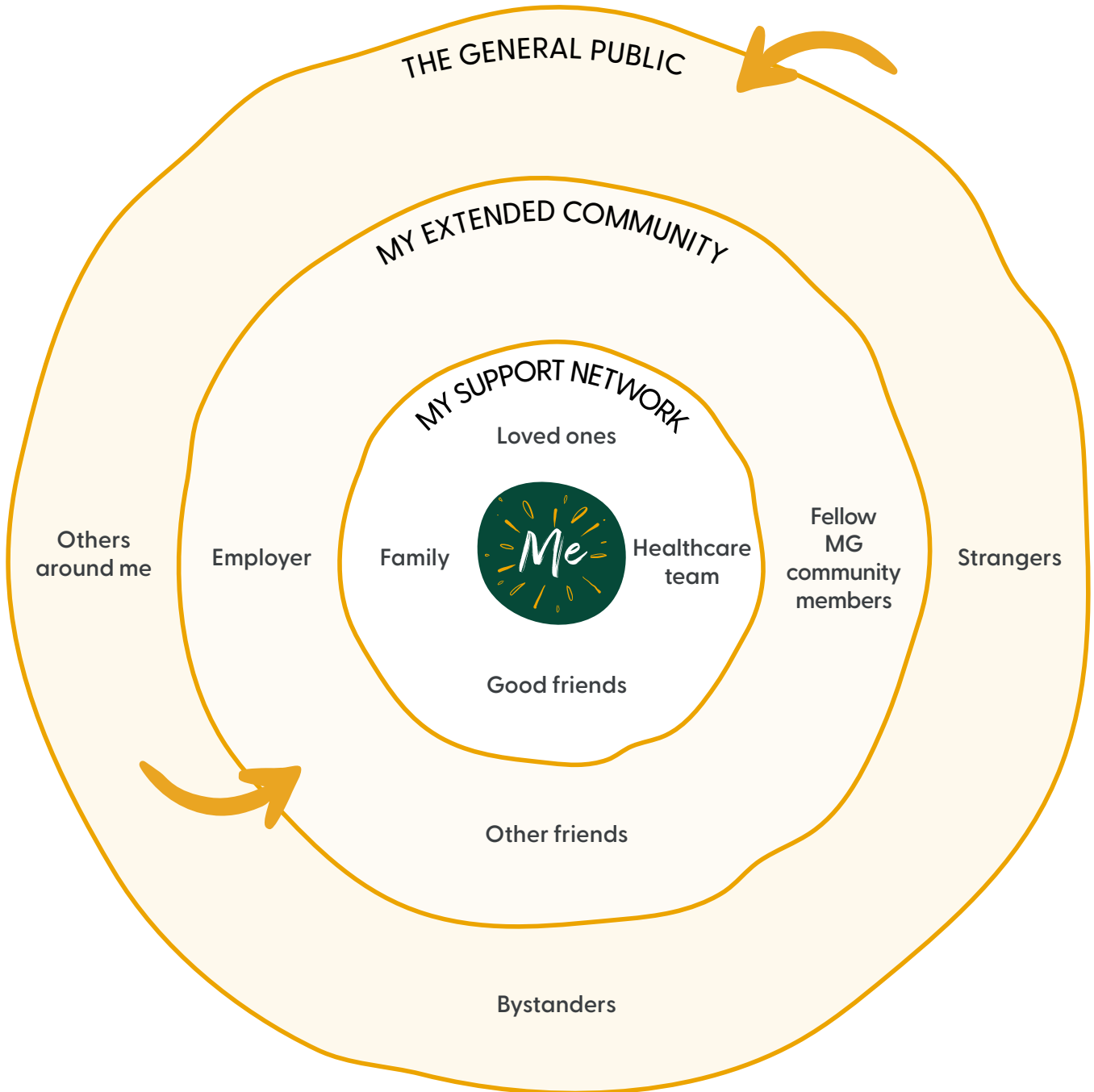
**Make this your own experience by using the tools that feel right to you.**

### 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 world

Living with a rare disease like MG means many people may never have heard of it (or learned to understand it). While you may not be able to expect everyone to empathize, there are plenty of people who might! **Circle the people below who you wish had a better understanding of MG, as well as an appreciation for how it impacts your life.**



## Simplifying your MG for others using numbers

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

**Use the MG-ADL scale to translate your symptoms into a number that others could understand:**

- \* 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.

## Aiming for minimal symptoms

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

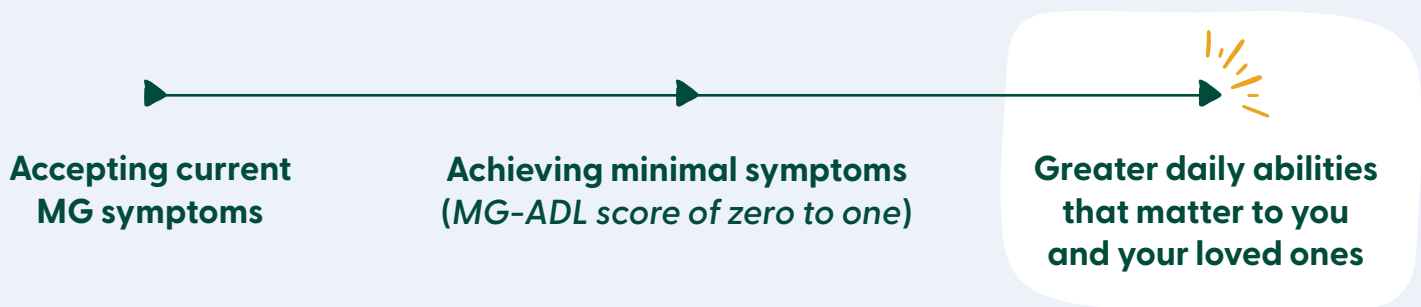
Calculating your MG-ADL score may help you better understand just how much your symptoms are affecting your abilities, and it's valuable information to share with your doctor.

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



**Refer back to this guidebook's exercises to identify what minimal symptom expression could mean to you.**

**Reference**

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



## Explaining the impact of MG in your words

If you're having a bad day with MG, that likely means something different to you than it does to those who don't realize its effect on you. To create more empathy with friends, acquaintances or even strangers, think about different ways to express how you're feeling. This exercise may help turn your feelings and goals into concise thoughts that you can share with your world.

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

Good

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Ex, "I could brush my hair without getting tired!"

Fine

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

Tired

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Ex, "It felt like someone kept taping my eyelids shut."

Struggling

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Ex, "I stayed in bed all day and felt like I was on a desert 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.

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

# Advocating for yourself in the workplace

Choosing to talk to your employer about MG is a personal decision and can be a difficult one



## CONVERSATION TIPS

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

<http://bit.ly/3KJ3btJ>

## EXPLAINING MG

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

<https://bit.ly/33jnF5U>



# Discover advocacy organizations dedicated to supporting the MG community

See what these different organizations are doing and how you can get involved! By working together, we can strive for greater empathy in the world.



Bookmark this page to learn more about these organizations:

<https://bit.ly/3c2Scwn>



# GO FOR *Greater* with MG

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



“ I call it the snowflake... The symptoms can be different from day to day—it could be my arms, my legs, could be my eating. I think that it’s pretty hard. I wish they would understand that it’s not like a broken bone where you know exactly what it is. ”

—Chris\*  
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!

