Limb Weakness with Myasthenia Gravis (MG):

Discussion Guide and Tips from Experts

Here is your guide for discussing, managing and symptom-tracking limb weakness with MG. **This guide was made in partnership with Julia,* an occupational therapist (OT) living with MG, and Liz Plowman,* a physical therapist (PT) living with MG.** Bring it to your next doctor's visit to help drive a productive conversation!

THE MG DIAGNOSIS STORIES OF AN OT AND A PT

Julia was in college and already pursuing occupational therapy when she was diagnosed with MG. Her diagnosis led her to focus on specifically becoming a certified hand therapist, which helps her limit her own movement at work and continue to support her patients.

Liz was a physical therapist in the Navy before getting diagnosed with MG. Her symptoms came on just a few months after having a baby, meaning she was unfortunately unable to return to the Navy. So instead, she focused her professional efforts on providing virtual physical therapy exclusively to people living with MG.

Check out more MG tips from Julia and Liz in this article!

> "Discussing goals is one of the most valuable, impactful conversations to have. That way, your physical therapist can see, 'This is what this person wants. Let's work together.' And then it becomes a really good partnership."
>
> **Liz Plowman**
> Physical therapist living with MG

IDENTIFY YOUR GOALS

Tell your healthcare team exactly what you want to achieve—big or small. And be specific!

Goals I want to achieve

1. Ex: Carry the laundry by myself
2. Ex: Take my kids trick-or-treating
3. Ex: Go on a light hike
4.
5.
6.

Not sure what your goals are? Think about your challenges and go from there.

Current challenges

1. Ex: Cooking my favorite meal
2. Ex: Loading the dishwasher
3. Ex: Playing catch with my kids
4.
5.
6.

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EXERCISES

Always consult your healthcare team before changing or starting an exercise routine. The following exercises are optional and meant to be done at your own pace, based on your unique symptoms and conversations with your doctor.

- Test your grip strength with a handheld dynamometer (ask your occupational or physical therapist for one!) and note how many repetitions you can do
- Make snow angels in the air to work on strengthening your arm muscles
- Practice your balance by standing on one leg, with something to grab onto nearby (consider standing on a foam mat if you'd like an added challenge)
- Sit on a yoga ball to work on strengthening your core muscles
- Try these MG-friendly stretches and exercises

TRACKING AND COMMUNICATING ABOUT SYMPTOMS

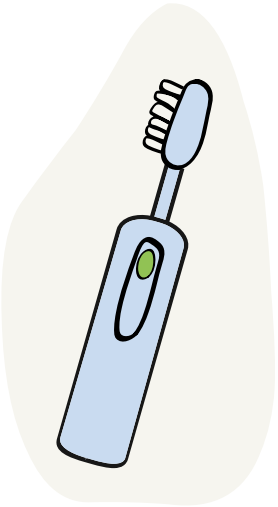
Both Julia and Liz emphasize the importance of being specific when it comes to documenting and explaining your symptoms. Below are some tips to help do this:

- If you try any of the exercises above, write down the duration of time it took you to complete them or the number of repetitions you did
- Rate your energy level and/or the severity of your limb weakness on a scale of 1 to 10, and repeat that morning, afternoon and night to identify any patterns
- Keep notepads around your house so you can easily document symptoms when they hit you, wherever you are
- Use the Myasthenia Gravis Activities of Daily Living (MG-ADL) interactive tool to gather quantifiable data on your symptoms that you can share with your doctor

This discussion guide is intended as educational information. It does not replace a doctor's judgment or clinical diagnosis.

ADAPTIVE TOOLS

Julia and Liz recommend the following tools that may help you complete everyday tasks while managing limb weakness:



For your upper body

- Electric jar opener
- Food processor
- Electric mixer
- Wide-grip utensils
- Rotating curling iron
- Hairdryer stand
- Electric toothbrush

For your lower body

- Shower grab bar
- Cane
- Walker
- Stools (use while cooking, washing your face, etc.)
  - Bring a collapsible stool for when you're traveling

PRO TIP: *Your environment matters! Keep items that you use frequently out on countertops, rather than storing them in cabinets or drawers you have to open and dig through.*

CHECK OUT MORE MG DISCUSSION GUIDES!

- Talking to Your Healthcare Team About Symptom Management
- Talking to Your Family and Close Friends
- Talking to Your Children
- Talking to Your Partner

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