



MG Management Discussion Guide

Healthcare appointments are so important! First, they are great opportunities for you to talk about the daily impacts of myasthenia gravis (MG). And second, you can use this time to assess your treatment plan with your provider.

This guide, developed in partnership with nurse practitioner Wilma Koopman,* provides some conversation starters that can help you get the most out of your time with your healthcare team.

*** Sometimes OK is not OK. Even if you feel “fine,” being an informed self-advocate is crucial.**

“I encourage patients to remember that they’re the expert in their own disease. Feel comfortable with your health practitioner to let them know what’s going on.”

- Wilma Koopman,* Nurse Practitioner

Managing MG, reducing symptoms and, if possible, aiming for minimal symptom expression (MSE)

Symptom tracking is a great way to get an overall picture of how you’re doing. It also may help your healthcare team assess how well your symptoms are being managed.

Used regularly, the Myasthenia Gravis Activities of Daily Living (MG-ADL) scale can help connect symptoms you experience with their impact on your day-to-day life. Over time, you may want to set a goal of reducing your MG-ADL score. A score of zero or one on the MG-ADL scale is considered MSE, and it indicates someone has no symptoms or is almost symptom free at the point of assessment.

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Below you'll find some useful questions all about symptom tracking and MSE to help get your conversation started with your healthcare provider.

Symptom tracking

1. What's the best way for me to track my MG symptoms so that I can easily share that information in our next visit?

2. When and how often should my symptoms be tracked?

3. Will tracking my symptoms indicate how well my treatment is working?

 Consistency is key! Symptom tracking is important even when you're feeling good.


"When you track symptoms, think about why it's a good or bad day. Elaborate in your diary. I tell this to patients all of the time."

- Wilma Koopman, * Nurse Practitioner

4. In addition to tracking my symptoms, what else can I do to decrease them, and, if possible, get closer to minimal to no symptoms?

MG treatments

When it comes to MG treatments, there's a lot to consider: effectiveness, safety, pre-treatment prep, when and how the treatment is received (orally, intravenous infusions, subcutaneous injections, etc.) and so much more. It's a lot to remember. Here are some valuable questions to support that important discussion.

 **TIP:** Be sure to think about what is most important to YOU when considering a treatment option.

Learning about treatments

1. How many available treatment options are there for MG?

2. Would I ever need to take more than one treatment? Why might I take more than one medication?

3. What can I expect in terms of symptom management with my treatment plan?

4. What does a treatment schedule based on my needs and symptoms look like?

5. What are the different ways that treatments can be given?

Considering a specific treatment based on a doctor’s recommendation

1. Why did you choose this particular treatment for me?

2. How effective is this treatment?

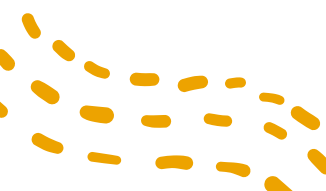
3. What possible side effects should I be aware of when taking this treatment? Is there anything from my medical history I should be mindful of?

4. Is a vaccination required before receiving this treatment? If so, how much time needs to pass until I can receive the treatment?

5. How often would I need to get this treatment? What circumstances (if any) would change my regimen?

6. Is there anything I can do to prepare for how I might feel after my treatment?

7. Does this treatment interfere with the current medications I’m taking?



*** TIP:** Remember to bring a list of any medications you are taking along with the dosages.

8. Are there any medications I should avoid while on this treatment?

9. (If applicable) Is this treatment safe for pregnant women or women planning to get pregnant?

Additional questions for your healthcare team about your MG treatment plan

1. How can I find out if my treatment is covered or if there are financial assistance programs to help cover the costs?

2. How will my primary care physician be updated on my condition, and what is their role in my MG care?

3. What travel precautions do I need to take with this treatment? Do I need a MedicAlert bracelet?

4. Is there anything I need to consider if I have a major surgery planned while on this treatment?

5. How can I reach you, and how often can I call you if I have more questions after my visit?

Notes and other questions:

