

# Breathing Symptoms with MG:

## Discussion Guide and Tips from an Expert



Meet Ashley,\* a respiratory therapist (RT) who lives with myasthenia gravis (MG).

Ashley shares her experience as an RT *and* as a person living with MG. She's joined by other members of the MG community to provide tips for saving energy with MG breathing symptoms in mind.

### AN RT'S MG DIAGNOSIS STORY

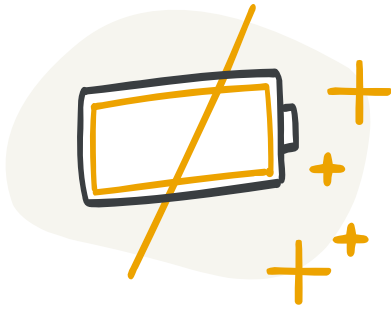
“When I was in school for respiratory therapy, we were learning how to identify MG by certain symptoms such as droopy eyelids, slurred speech, choking on your saliva, slow/difficulty walking. Through my education, I was able to help diagnose myself. I started to notice that something wasn't right with me. I went to the doctor and told them I thought it was MG and they were able to diagnose me relatively quickly.”

### WHAT DOES A RESPIRATORY THERAPIST DO?

“As a respiratory therapist, I'm a nurse for your lungs and your heart. I'm there with a patient at the head of their bed. I manage the ventilators, set the settings, do bloodwork, ensure the patient is comfortable. 'Is this patient getting air into their lungs? Is it sufficient?' I'm there to help patients maintain, ventilate and oxygenate, so that their body is getting vital oxygen to all their organs.”

### RT RECOMMENDATIONS

- \* **Top tip:** “If you're experiencing breathing issues, seek immediate help from a healthcare provider!”
- \* **Asking for an RT:** “I think if you're newly diagnosed with MG, you should be advocating to have a respiratory therapist in the room with you at the ER.”
- \* **Emergency information:** “I keep a folder—I call it my emergency binder—with my medications, my procedure history, my doctors, and a list of medications that I cannot have and make sure I bring it with me if I need to go to the hospital.”
- \* **Support system:** “My sister knows my preferences, she's very mindful. She'll advocate for me if I can't speak up. A support system is your voice when you cannot talk, so it's super important that they know what's going on, what medications you're on and any other necessary information.”
- \* **Knowing your normal:** “Know your normal and know your baseline. Paying attention and being able to identify changes in what's typically normal for you can make a world of difference.”
- \* **Being prepared:** “I'm always telling people, 'Advocate for yourself.' MG is a rare disease, so I do prepare for appointments as if the person I'm meeting has never heard of MG.”
- \* **Saving energy:** “Trying not to overexert yourself and preserving your energy when you can, may be helpful.”



## ENERGY SAVING TIPS FROM THE MG COMMUNITY

- \* Ask your support system for help
- \* Build time for rest into your schedule whether that's day-to-day or while traveling
- \* Don't push yourself too hard. If you have a busy day, figure out which tasks/activities are a lower priority and wait to tackle them another day
- \* At the store, use an electric shopping cart and skip self-checkout
- \* Park close to a building's entrance, use curbside pickup or apply for accessible parking
- \* Consider hiring a service (landscaping, cleaning, laundry, food delivery, grocery delivery) to help regularly with chores or as a one-off during a time when you're feeling particularly low energy
- \* Skip the stairs and use the elevator or escalator

## TRACKING AND COMMUNICATING ABOUT SYMPTOMS

Try these tips from people living with MG to help articulate your symptoms to your healthcare team:

- \* Text yourself or take photos/videos with your smartphone to document what's happening (this automatically timestamps your experiences)
- \* Keep notepads around your house so you can easily jot down 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 how your daily activities are being impacted by certain symptoms like having difficulty with breathing

Be sure to talk with your neurologist regularly about your symptoms so you can discuss the potential severity of your symptoms and what may be an emergency.

You can also talk to your neurologist to see if you can improve your breathing symptoms with the right treatment plan.

**Remember, any shortness of breath should be discussed with your doctor. And it's important to note that there are cases where crisis symptoms are brought on more quickly, possibly due to a physical or environmental trigger. Weakness may develop within minutes to days, and it may feel difficult to breathe.**

## 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](#)

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