



Taking an Active Role in Decision-Making

Empowering Yourself While Living With gMG



Take Steps, Big or Small, Toward Your Future

If you're using this workbook, you're interested in your future. What do you hope for?

The following pages can help you identify and take steps toward your goals. Each activity was designed to prepare you for what experts call *shared decision-making* with your healthcare provider. Using shared decision-making, you and your provider can chart a path forward that's based on you and your vision for the future.

What is shared decision-making?

It's a process used by people and their providers to make decisions. The process emphasizes partnership and involves 3 steps:

- 1** The person and provider recognize that a decision needs to be made.
- 2** The provider recommends options. The options are based on current medical science.
- 3** The person chooses the option that works best for them based on their stated goals, values, and preferences.

Shared decision-making between people and their providers may result in the best possible care plan and boost your confidence in the plan you make together.



How to Use This Workbook

This workbook is made up of several activities you can engage in to help you be an empowered partner in your care. Every person's journey is different, and your wants and needs may change at different times. Choose the activities that work best for you at a given time, and feel free to revisit activities as your needs change.

To help you plan, we've labeled each activity based on the effort required and the time they may take.

These labels are a guide. Take extra time or a break if needed, and write as much or as little as you prefer.



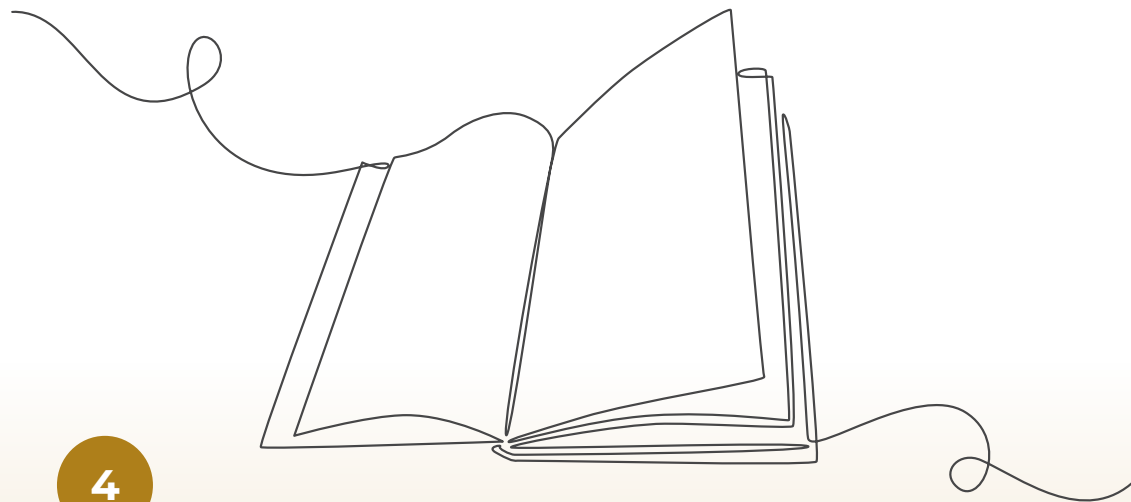
Quick



Moderate



Long



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To help track your progress, check off each activity on this page when you complete it.

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Imagine Your Future Self

Describe your past, present, and future self.

This activity can help you figure out what is most important to you. When you're done, you will be ready to set goals.



Example:

What was life like before your symptoms appeared?

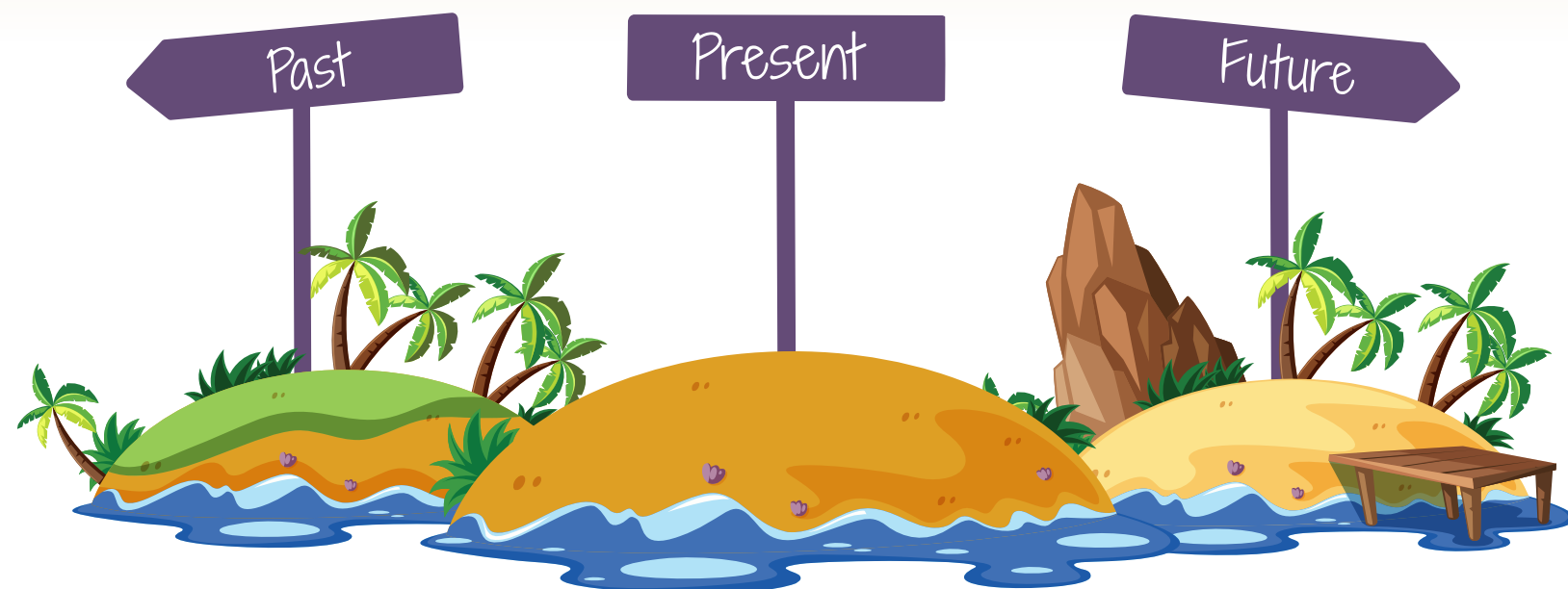
Three years ago, I worked full-time and sang in a choir. I enjoyed cooking meals with my husband, walking my dog, and going out with my friends.

What is your life like now?

I've cut back on work hours and stopped singing in the choir as my voice has changed. My husband and I cook less together, and I often cancel plans with friends. I still walk my dog, but not as far; on bad days, I just let her out in the yard. I often worry about my condition getting worse.

What would you like your life to be like in the future?

I want to work more, bring music back into my life, and maybe play keyboard again. I'd like more energy, a stable routine, daily mile-long dog walks, and to cook with my husband. I don't want to cancel plans or worry about my condition getting worse.



What was life like before your symptoms appeared?

What is your life like now?

What would you like your life to be like in the future?

2 Track Adaptations Needed for Your Daily Routine

Example:

Apply your adaptations to the chart below.

Morning	Afternoon	Evening	Daily Notes
Asked a friend to drive kids to school.	Napped instead of doing chores.	Couldn't eat steak, had yogurt instead.	

Week

Morning	Afternoon	Evening	Daily Notes
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Week

Morning	Afternoon	Evening	Daily Notes
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

Tip: Check in weekly
 Aim to fill out your tracker each day if possible, but don't worry if you miss some—try for at least one entry a week.

Share With Your Provider

Share your tracker and talk to your healthcare provider about the adaptations you needed to make to get through daily life.

There are additional calendar pages for you to use in the pocket folder inside the back cover.

Set Your Goals and Make a Plan

Create a blueprint for achieving the future life you imagined in Activity 1.



Moderate

Setting goals reminds you that you're more than your condition, offering hope and strengthening your partnership with your provider. When you share insights into your life with your provider, your care plan can go beyond managing gMG to improving your quality of life.



Identify a long-term goal and plan how to achieve it.



One helpful model for setting goals is to make them **S**pecific, **M**easurable, **A**chievable, **R**elevant, and **T**ime-bound. See the example below.

Example:

Long-Term Goal: Sophia's goal is to build enough stamina to walk her dog for 20 minutes each day.



Specific

Pick a specific thing you want to happen.

Sophia's specific goal is to go for a 20-minute walk every day.



Measurable

Decide how you will measure progress and success.

She can record walks on her calendar or track them in a phone app.



Achievable

Ensure the goal is realistic based on your abilities and potential for change.

Sophia walks with a friend twice a week. Although it tires her, she aims to reach 20 minutes daily, with her provider's support.



Relevant

The goal should fit in with your values and other goals.

Reaching this goal will reassure Sophia she has the energy for a dog—and she loves being outside.



Time-bound

You should have a timeframe for achieving this goal.

Sophia and her provider expect it may take a few months to build up to 20-minute daily walks, with rest days as needed.

Once you write down a long-term goal, think about how you might break it down. Use the space below to break down your long-term SMART goal, if you choose to use that model.



Long-Term Goal:



Specific

Pick a specific thing you want to happen.



Measurable

Decide how you will measure progress and success.



Achievable

Ensure the goal is realistic based on your abilities and potential for change.



Relevant

The goal should fit in with your values and other goals.



Time-bound

You should have a timeframe for achieving this goal.

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List Questions You Wish Your Provider Would Ask

What do you want your provider to know before they try to help you?



Chances are, your providers ask you a lot of good questions that help them make decisions about your care. But there are likely other things you are feeling that they don't ask you about and you wish they would.

In this activity, you'll identify the questions you wish your provider would ask you. Sample questions are provided to get you started. Place a check mark next to the sample questions you like. Add any additional questions in the space provided.

Questions About Your Goals

- What more can I do to help you achieve the goals you've set?
- When you think about the future, what concerns you most?
- What do you hope to get back to doing?
- What are your goals for the next few weeks?

Your Questions:



Questions About Your Care

- Do you feel your care plan is working well, or do you want to discuss other options today?
- Do you see or need to see other providers to manage your gMG?

Questions About Your Daily Life

- How would you describe your best and worst days last week, from morning to night?
- What is your most bothersome symptom and how does it affect your daily routine?
- What new adaptations have you made to help you with daily activities?
- How many days a week do you change your plans because of symptoms?
- When you're not feeling well, what is your routine to help feel better?

Your Questions:



Create a Plan for Sharing Your Goals

Decide who to share goals with, when to share them, and what to say.

Review the goals and plan you made in **Activity 5, “List Questions You Wish Your Provider Would ask,”** on page 20. In this activity, you’ll create a plan for sharing those goals with other people.



Long

You will need to:



Identify who can support you in your goal



Decide how much you want to share and what you want to say



Figure out a good place and time to share your goals

My Goal:

By the end of the month, I want to return to working 3 days a week.

Example:

1

Supporter:
Husband

2

Supporter:
My Doctor

3

Supporter:
My tween child

How will I say it?

One of my new goals is to return to work part-time. I’m going to talk to my provider about adjusting my medication to try to get my symptoms under better control. These changes may be challenging, and I’m going to need your support. What do you think?

Shortly after I was diagnosed with gMG, double vision and fatigue forced me to quit my job. I want to return to work part-time. What changes can we make to my treatment plan to get these symptoms under better control?

I’m starting a new medicine that’s working well and feeling better, so I’m going back to work part-time. It’s a big step, and I’ll need your support. Some days, I might be too tired for my usual tasks. What do you think?

When and where will I say it?

Tomorrow when we walk the dog together

Next week at my doctor’s appointment

I’ll wait to share this until my treatment is working and I have a job. I’ll bring it up over a relaxed weekend dinner, so my child has time to ask questions.

Putting a plan in place can help you feel more confident and speak clearly about your goals and needs. And by planning when and where to talk, you help make sure the other person is able to listen and respond.



My Goal: _____

1

Supporter: _____

2

Supporter: _____

3

Supporter: _____

How will I say it?

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

When and where will I say it?

_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Overcome Barriers to Communication

Identify strategies to help you communicate more effectively with your provider.

This activity gives you specific ideas for ways to overcome communication barriers.



Moderate

1

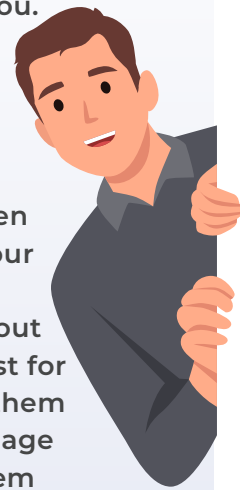
First, read through the communication barriers listed on this page. Select which barriers affect you and your provider the most.

2

Next, read through the menu of solutions. Choose the solutions that you feel will help you and your provider. Give them a try and see which ones work best for you.

3

Once you have chosen and implemented your solutions, take a moment to think about which ones work best for you and why. Write them down on the notes page and refer back to them when needed.



☆☆☆ Barriers Menu ☆☆☆

Identify your communication barriers

- Feeling nervous** or anxious during office visits and forgetting what I want to discuss
- Difficulty in describing symptoms and needs,** not knowing exactly how to describe what I feel physically or emotionally
- Feeling rushed** or running out of time during an office visit
- Feeling misunderstood** by my healthcare provider
- Feeling brushed off,** like certain symptoms or side effects are being minimized or ignored by my healthcare provider
- Wanting to not be bothersome,** avoiding asking questions or bringing up concerns so as not to “bother” my healthcare provider
- Feeling embarrassed** by sharing important information or talking about challenges



☆☆☆ Solutions Menu ☆☆☆



Prepare to share. Look back to Activity 5. What questions do you wish your provider would ask? Try to pick the 2 or 3 most important to you. Write down your answers and have them ready to share with your provider.



Bring support. Take a trusted person with you to appointments. Another person can provide emotional support and ask questions. They can also take notes and help you understand and remember what the provider says.



Write down your symptoms, how bad they get, how often you experience them, and what triggers them. Writing down your symptoms helps ensure you won't forget or leave out details.



Use decision aids. Use Activity 9 to compare the pros and cons of a treatment option with your provider. Decision aids like this one can help you and your provider have honest, in-depth conversations.



Use pictures and videos. Use your phone to take pictures or videos of your symptoms at their worst. Do the same for symptoms that are new to you. That way, your provider can see your symptoms even if you're not experiencing them during the appointment.



Use “I” statements. To avoid feeling brushed off or misunderstood, practice using clear “I feel” statements, such as “I feel worried that my symptoms are not improving, and I'd like to understand why that might be.”



Talk about your adaptations. Your provider may not be aware of how much gMG affects your life. Share the information from Activity 3. Explain how often you must make adaptations and how they may get in the way of reaching your goals.



Use different words to describe your symptoms. Use the Glossary on page 35 to find the specific words to describe how you are feeling. Using medical terms may help your provider better understand your symptoms and take them seriously.



Practice role-playing. Consider practicing talking to your provider with the help of a friend or family member. This practice can help you feel more comfortable answering and asking questions. It can also help you make sure you present your concerns clearly.



Arrive relaxed. Before your appointment, take a few minutes to imagine it going well. Prepare to arrive early so you don't feel rushed. Listen to relaxing music on the way to your appointment.

Define Your and Your Provider's Roles

What should you expect from yourself and from your provider? Try saying it out loud.



Quick

You and your provider are partners in shared decision-making. You both have important roles. In this activity, you'll read descriptions of these roles out loud. You can even try doing it while looking into a mirror.

This activity can help you embrace your role as a patient partner. It can also help you spot when you or your provider could be doing more. If this happens, you can call attention to it and try to address it right away.



Read the descriptions below out loud.

It is my provider's role to:

As a patient, it is my role to:



Give me their respect and attention



Understand my disease and current treatment options



Make medical recommendations based on what they believe is best for me



Provide access to my medical records



Ensure my privacy and confidentiality



Tell me about any conflicts of interest that may affect my care



Work with the rest of my healthcare team to coordinate my care



Understand that I may get a second opinion



Treat my provider with respect and listen to what they have to say



Be honest with my provider—including sharing information that may affect my care, even if it feels embarrassing



Consider my provider's recommendations before making decisions



Make Choices: Weigh the Pros and Cons

Write down what might happen if you make a change to your care plan.



Moderate

Sam's Choice

Sam was diagnosed with gMG 3 years ago. He quit his job shortly after that. Today, his symptoms are under better control. He'd like to return to work, but he's worried that working several hours each day will make his symptoms worse.

Sam talked to his provider. They discussed options and possible outcomes. Based on their conversation, Sam filled out this pro and con list.

No Change	Pros (advantages)	Cons (disadvantages)
Continue not working	I can continue with what is familiar. I won't risk making my symptoms worse due to extra activity.	I will not get the paycheck or satisfaction that comes with holding a job.
Make a Change	Pros (advantages)	Cons (disadvantages)
OPTION 1		
Return to my job as a store manager	I will return to a job I like, earn a paycheck, and get benefits.	Being on my feet all day at work may make my fatigue worse and I'll be too tired after work to do the things I enjoy, like cooking or visiting with friends.
OPTION 2		
Work part time as a store clerk or cashier	I will get to work and be at a lower risk for developing fatigue and muscle weakness.	While better than not working at all, a part-time job will pay less than a full-time one and won't provide benefits.

Example:

Sam's Decision

Although Sam would like to work full time, his doctor advised him to ramp up his work hours slowly. After weighing the pros and cons, Sam spoke with his family and his manager, who agreed to have him work up to his full-time schedule over time.

Below is an empty table for you to fill out. Try using it the next time you talk to your doctor about a decision related to your goals or care plan.

Considerations for your pros and cons list

When you create a pros and cons list, you consider how a choice might affect your physical health, mental health, loved ones, time, productivity, sense of self, and finances.

You might have other considerations. Every person and decision is different.

Your Choice:

No Change	Pros (advantages)	Cons (disadvantages)
Make a Change		
OPTION 1		
OPTION 2		

Your Decision:



Helpful Organizations

While your healthcare provider is a trusted source of advice and medical information, you might need other support along your journey. The organizations below can help if you have questions about living with a chronic disease, your rights as a patient or employee, paying for treatment, and more.

Autoimmune Association

The Autoimmune Association website offers information, ideas, and resources to people with gMG and other autoimmune diseases.

www.autoimmune.org/

The Assistance Fund

The Assistance Fund helps people who are insured pay for medical care that may have high out-of-pocket cost.

(855) 845-7608 | www.tafcares.org

Caregiver Action Network (CAN)

CAN provides resources and help to people who care for family members with chronic conditions, disabilities, and diseases.

(855) 227-3640 | info@caregiveraction.org | www.caregiveraction.org

Job Accommodation Network (JAN)

JAN staff answer questions and offer advice about getting workplace accommodations under the Americans with Disabilities Act.

(800) 526-7234 | www.askjan.org

Rare Disease Diversity Coalition (RDDC)

RDDC helps address challenges often faced by people who have been diagnosed with rare diseases and who belong to historically under-represented populations.

www.rarediseasediversity.org

PAN Foundation

PAN improves healthcare access to patients through financial assistance and healthcare advocacy.

(866) 316-7263 | www.panfoundation.org/disease-funds/myasthenia-gravis

Patients Rising

Patients Rising helps patients advocate for themselves, access patient resources, and get the care they need.

(202) 750-1186 | info@patientsrising.org | www.patientsrising.org

The National Organization for Rare Disorders (NORD)

NORD's patient assistance program, RareCare, helps qualified patients get medication they need and helps pay health insurance premiums, copayments, and expenses related to necessary diagnostic tests and travel.

(203) 571-3167 | mg@rarediseases.org | www.rarediseases.org/patient-assistance-programs/financial-assistance



Learn the Lingo

Whether you were just diagnosed with MG or have had it for several years, there may be some words or terms you don't know. This glossary can help you understand the language you may encounter throughout your treatment journey.



Acetylcholine (ACh): a type of neurotransmitter that delivers messages from the nervous system to muscles and tells them when to contract. When the body functions normally, ACh is released by nerves and binds to receptors located on muscles.

Acetylcholine receptor (AChR): receptor molecule located on the surface of muscle fibers at the neuromuscular junction. AChR provides a place for ACh to attach and allows ACh to deliver messages to muscles.

Anti-AChR antibodies: proteins that attack the AChR and stop it from working normally. As many as 9 in 10 people with MG have AChR antibodies in their blood. AChR antibodies are part of a larger class of antibodies called IgG antibodies.

Adaptive immune system: the immune system's second layer of defense after the innate immune system. It provides specialized protection by recognizing and targeting specific disease-causing bacteria, viruses, and other agents.

Antibodies: an essential part of the adaptive immune system. Antibodies in the blood recognize and defend the body against disease-causing bacteria, viruses, and other agents. In some people, antibodies attack their own cells, which can be fatal.

Autoimmune disease: a disease that occurs when the immune system attacks healthy cells. MG is one of more than 80 autoimmune diseases.

Autonomic muscles: muscles you cannot control. Examples of autonomic muscles include your heart and muscles that move food through your digestive tract. Autonomic muscles are usually not affected by gMG.



B cells: white blood cells that are part of the body's adaptive immune system.

Learn the Lingo



Care plan: a written plan for medical care that is based on a person's disease, treatments, and goals. The plan describes how providers will share information and coordinate care. Some care plans also state how long a treatment will last, how to reduce or avoid possible side effects, and what to do for follow-up care.



Diplopia: double vision. gMG can cause what doctors call binocular diplopia, which occurs when the eyes are not aligned.

Dysarthria: a speech disorder that may occur when MG affects the muscles you use for speech. Dysarthria may cause a person to talk slower or sound different.

Dysphagia: difficulty swallowing. gMG may cause weakness in the muscles that control swallowing.



Generalized myasthenia gravis (gMG): myasthenia gravis that may or may not cause eye symptoms and causes other symptoms, such as head droop, dysphagia, or weakness in the limbs.



Head drop: muscle weakness in the neck that causes the head to droop forward. About 1 in 10 people with MG experience head drop at some point.



Immunoglobulin G (IgG) antibodies: antibodies that typically help prevent infections but can be responsible for disease and symptoms. There are different types of IgG antibodies. For example, most AChR antibodies are IgG1 or IgG3, and most MuSK antibodies are IgG4 antibodies.

Immune system: a network of cells, tissues and organs that work together to protect the body against infections and disease-causing changes in cells, like cancer. The immune system is divided into innate (nonspecific) and adaptive (specific).

Innate immune system: the immune system's first layer of defense. It provides a fast, nonspecific immune reaction. The innate immune system can alert and work with the adaptive immune system.

Involuntary muscles: involuntary muscles are muscles we cannot control. Examples of involuntary muscles include the heart and the muscles that help move food through the digestive tract.



LRP4: a protein that is involved in helping muscles to work normally. LRP4 is involved in helping MuSK and AChR function in the neuromuscular junction. Experts are unsure how many people with MG have LRP4 antibodies.



Muscle-specific kinase (MuSK): a protein that is needed for muscles to work normally. MuSK helps AChR function in the neuromuscular junction. MuSK antibodies, which attack MuSK, affect fewer than 1 in 10 people with MG.

Myasthenic crisis: a potential medical emergency that occurs when breathing muscles become weak. A crisis usually lasts a few weeks and may require hospital care. In serious cases, patients are put on a ventilator until breathing becomes normal again. About 20% to 30% of people with gMG experience a myasthenic crisis.

Myasthenia gravis (MG): an autoimmune disease that prevents nerves and muscles from working together normally. Although there are several subtypes of MG, clinicians generally distinguish between 2 main categories: ocular MG (oMG) and generalized MG (gMG).



Neuromuscular junction: the location where a nerve sends signals to a muscle, telling it to move.



Ocular myasthenia gravis (oMG): MG that causes symptoms limited to the eyes, particularly ptosis and diplopia. Many people who are diagnosed with oMG develop gMG within 2 years. About 1 in 5 people with MG only ever get oMG.



Ptosis: drooping of the eyelid. Ptosis may occur alone or with diplopia.



Shared decision-making: a process used by patients and doctors to make health-related decisions together. When the patient and doctor face a medical choice, the doctor provides the patient options based on medical expertise and the patient's stated values and preferences. The patient can make an informed choice based on the recommended options.

Learn the Lingo



Thymectomy: a surgery to remove the thymus gland. Thymectomy is common treatment for certain people with MG, particularly those with thymomas.

Thymic carcinoma: a potentially fast-growing tumor that occurs on the thymus gland. Thymic carcinomas tend to spread to other parts of the body, which can make them difficult to treat.

Thymoma: a typically slow-growing tumor that develops on the thymus gland. Thymomas are linked to MG. Although thymomas tend not to spread, they can develop into thymic carcinomas. This process often takes 10 to 14 years.

Thymus: a gland located behind the top of the sternum. The thymus plays an important role in the development of the adaptive immune system during infancy and childhood.



Voluntary muscles: the muscles we can control. gMG affects voluntary muscles.



Great job. You did it!

You've taken action and completed activities that may help you take a more active role in your care. Even the small steps you take every day can make a big difference in your future.



To request extra copies of this workbook,
call UCBCares at 844-599-2273 or
email us at UCBCares@ucb.com

1 Record Your Daily Routine

Morning	Afternoon	Evening	Notes

2 Track Adaptations Needed for Your Daily Routine

Week _____

Morning	Afternoon	Evening	Daily Notes
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			