

EVERYDAY ENERGY Savers



A COLLECTION OF TIPS AND TRICKS
FROM THE MG COMMUNITY

MG United

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EVERYDAY ENERGY Savers

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If you're someone who is living with myasthenia gravis (MG), you're not alone.

And since MG symptoms can be as unique as each of us, daily activities that are doable for one person may not be so comfortable for another.¹ And that's OK.

MG United is dedicated to providing you with personalized, carefully selected resources that try to address the unique ways MG can affect your life.

As part of that mission, this eBook, written in partnership with a neurologist who specializes in MG, is intended to make your everyday tasks easier and more manageable as you progress through your daily routine. Here you may find support from members of the MG community to help you conserve your energy for the things you value most.

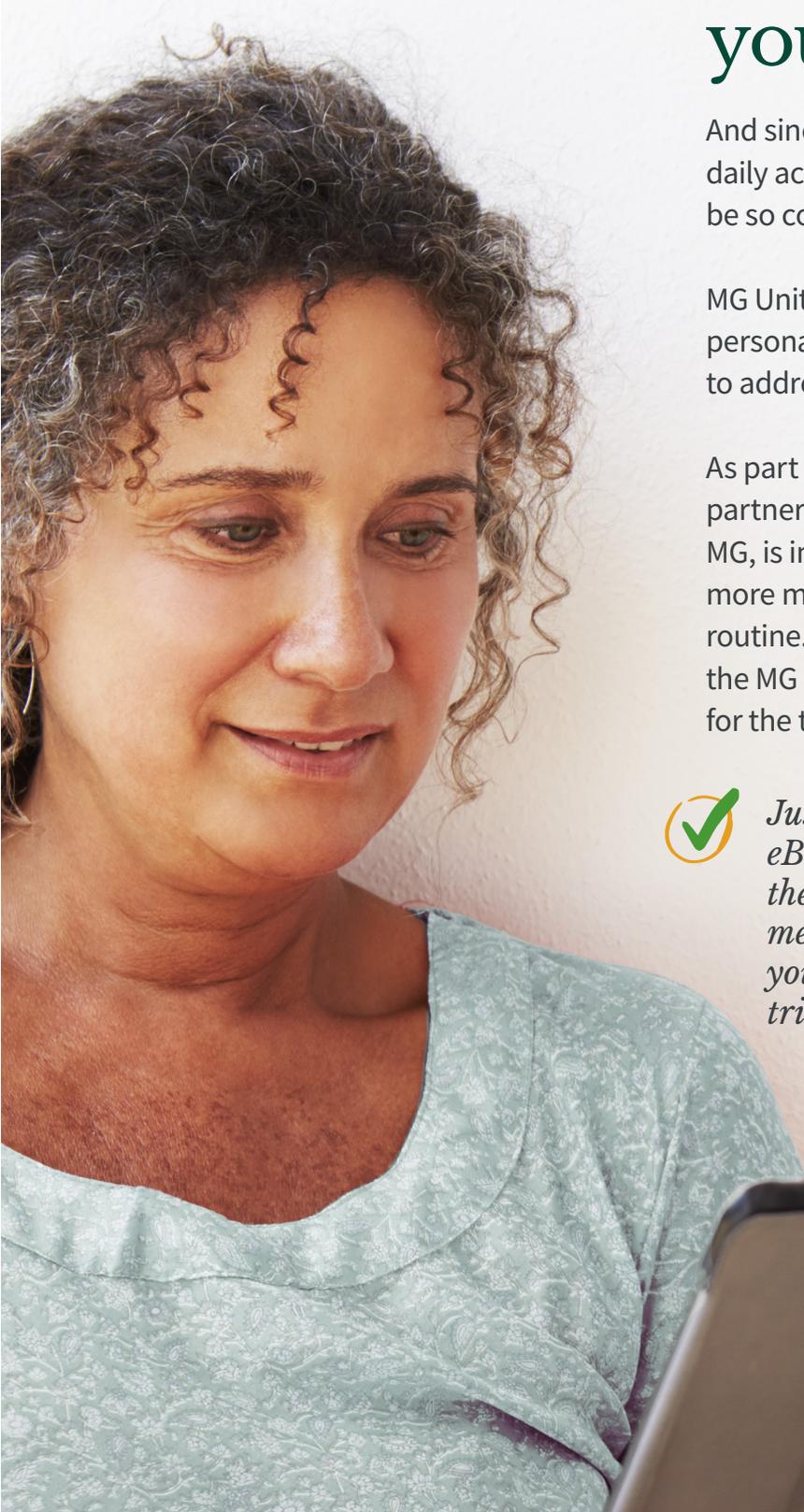


Just remember, the tips provided in this eBook are not professional advice, nor are they a substitute for treatment or professional medical care. Please ensure that you talk with your healthcare team about which tips and tricks might be right for you.



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Meet the Contributors

With the partnership of the people living with MG and clinical experts listed below, a collection of everyday tips and tricks has been pulled together to give people living with MG a resource to consider as part of daily routines.

This eBook was created for the MG community, by the MG community. ✨

MG COMMUNITY MEMBERS



RACHEL*

An education employee who was first diagnosed with myasthenia gravis in her early 30s and currently experiences mild symptoms



TOMMY*

A marketing professional who was diagnosed with myasthenia gravis when he was 12 years old and currently experiences primarily ocular, or eye-related, MG symptoms



VICTOR*

A fiction writer and retired computer programmer who is currently in remission, but was diagnosed with MG when he was 73

MG HEALTHCARE EXPERTS



**KATHLEEN*,
MS, CRC, LPCC**

A Licensed Professional Counselor who also lives with ocular myasthenia gravis



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An occupational therapist and certified hand therapist who also lives with myasthenia gravis



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**Paid contributor to MG United*

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Easing Eye Discomfort

Vision disruptions associated with MG symptoms may be causing some challenges during everyday activities.¹ Droopy eyelid (ptosis), double vision (diplopia), trouble focusing or blurred vision are all possible when the muscles controlling your eyes/eyelids become weak.¹ These symptoms might be short term or may stick around much longer than you'd like.¹



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INVEST IN AUDIOBOOKS

Book worms, fear not. If you love to read but have a hard time doing so because of unpredictable vision changes, look into getting audio versions of books, blogs, etc., to enjoy instead. Audiobooks provide an alternative to reading, and you can even close your eyes to give them a well-deserved break while listening.



ADJUST LIGHT SETTINGS

Sometimes the light from smartphones can cause your eyes to feel more strained.² Using blue light filter applications to adjust light settings may help with this.³ To find an app and see if it helps you, search for “blue light filter” or “night mode” within your smartphone’s app store, and different options will populate.



“I work on my computer often, and on days where my double vision is really bad, I can definitely benefit from screen readers that take the work out of reading for me and provide my eyes with some relief from the screen light.”

Tommy, living with MG

CARRY SUNGLASSES

If you’re sometimes sensitive to light, consider wearing sunglasses. Category 3 sunglasses protect against strong sunlight. For added protection, category 4 sunglasses should provide high protection against extreme sun glare—but because of the lens type, they’re not recommended to wear while driving.⁴

CONSIDER EYE DROPS

For some, eye drops can help to lubricate dry eyes and facilitate blinking.^{5,6} Talk to your ophthalmologist, or eye doctor, before starting a new eye routine and discuss whether eye drops are right for you.

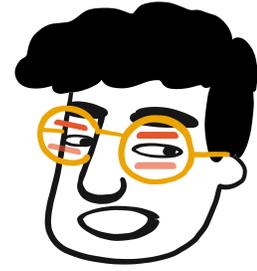
USE OF ACCESSIBILITY SOFTWARE

Consider letting technology help you work smarter, not harder. If your MG symptoms seem to get worse when using screens, like when you’re working long hours at a laptop or writing lengthy text messages, try using accessibility software. Screen reader programs to read text aloud and voice-to-text features that can type as you talk may help with some eye fatigue brought on by computers and phones. These features are built into some web browsers/smartphones or can be found by searching for “screen reader” and/or “voice-to-text.”

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USE OF ADAPTIVE EYEWEAR

Seeing double? If double vision is putting a damper on your everyday activities, there are a few tips that may provide some relief. **Depending on your surrounding environment and specific symptoms, consider discussing these options with your eye doctor⁷:**



Wearing an eye patch

AND/OR

Adding a piece of masking tape behind one side of sunglasses or eyeglasses



AND/OR

Speaking with your eye doctor for a prescription for prism glasses



WEAR AN EYE MASK

We all need our beauty sleep. If eye discomfort is making it hard to fall asleep and get a good night's rest, try wearing an eye mask at night. Even if the muscles that are used to close your eyes are fatigued, an eye mask may help improve your quality of sleep.



A cooling eye mask may be helpful to wear for a few minutes during the day to give your eyes a break and help relieve some discomfort.

If you're someone who may not be so comfortable wearing an eye patch in public, putting some masking tape behind the lens on one side may be a discreet way to block out the view from one eye, helping to reduce the frustrations brought on by double vision.⁷ Prism glasses may work for some people who have a consistent prescription, but for those whose double vision changes throughout the course of the day, an eye patch or using masking tape may offer better help.⁷

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Prioritizing Health & Well-being

Give yourself permission to be kind to yourself. Optimizing MG management can mean listening to your body, **practicing self-care** and taking the steps to build strong relationships with your healthcare team.⁸



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PRACTICE BELLY BREATHS

Deep breath in. Deep breath out. **Focus on stress management** by practicing deep belly breaths.⁹ To do this, place one hand on your stomach, then breathe into the space where you can feel it expanding. Try taking three breaths and smiling on each exhale.

This activity can help you de-stress during any time of day, whether it's as soon as you wake up, before sitting down at your desk for work or at a time when you're feeling overwhelmed. Kathleen, a mental health expert who lives with ocular MG, suggests exhaling for a longer count than you inhale to engage the parasympathetic nervous system, which helps the body conserve energy.

USE ADAPTIVE DEVICES

If muscle weakness causes difficulty opening medication bottles, consider asking your pharmacy not to use childproof lids or use an adaptive device, like a gripper made of a flexible non-slip material.

* *Note: If you have children at home, please be sure all medication bottles are out of their reach.*

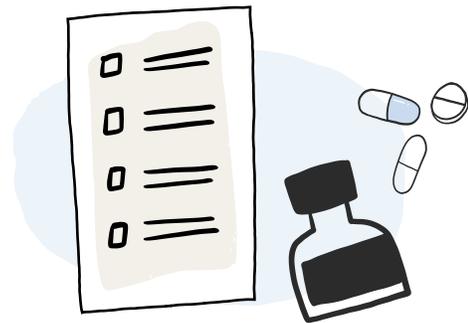
“ There are so many things to worry about at times when you are getting ready for the day or preparing to leave the home. I set reminders on my smartphone calendar so I remember to take medicine on time. ”

Victor, living with MG



OPTIMIZE YOUR NIGHT ROUTINE

If you’re having a hard time sleeping, think about your usual pre-bedtime routine. Do you scroll social media or watch a favorite TV show? Our bodies detoxify and repair during deep sleep, so consider avoiding blue light before bed, creating a “wind-down” time or doing some deep breathing to help you get a good night’s rest.^{3,9,10}



BUILD A LIST OF MEDICATIONS BEING TAKEN AND THOSE TO AVOID

Partner with your healthcare team to create a list of medications that you’re currently taking, as well as those that may not be OK for people living with MG or for people with your specific symptoms.¹¹ Print that list, and keep it with you. This may be especially helpful if you meet with a new doctor who doesn’t know your medical history.

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CONSIDER TALKING TO AN OCCUPATIONAL THERAPIST

For additional support with activities of daily living and lifestyle adjustments, think about asking your primary care provider for a referral to an [occupational therapist](#) (OT).



“OTs can help people with MG make changes to their environment, like re-organizing a home in a more MG-friendly way, and we can also partner with you to adjust your mindset and **approach activities in a way that works for you.**”

Julia, OT who lives with MG



Check out these [MG-friendly exercises](#) created by Vanetta*, a personal trainer who is living with MG.

TRY AT-HOME EXERCISES

Don't get bent out of shape. If your symptoms allow for exercise, look for options online that can be done at home. Whether it be an app or streaming service, save the segments that look interesting so you can reference them quickly and pause or come back to them when needed. Look for a variety of classes, including some that can be done from a chair.



* *Note: It's important to consult with your healthcare team before beginning any exercise program. Check with your doctor to make sure that any exercises you want to try are safe and suitable based on your physical condition and where you are in your MG journey.¹*

**Paid contributor to MG United*

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TRACK YOUR SYMPTOMS

Jot that down! Between doctor’s appointments, [track your symptoms](#) and goals to make note of any questions that come up. Keep that info handy and ready to discuss with your doctor. Being well-prepared may help you make the most of your time.

Fill out and bring along this [discussion guide](#) that was designed to help you prepare for your next appointment.



“ Making a list of questions and writing down notes between doctor’s appointments can definitely help organize your thoughts to cover what you have been through since your last appointment.”

Tommy, living with MG



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TAKE PRECAUTIONS BEFORE TRAVELING

[Planning a trip or outing?](#) Take precautions before traveling, such as planning with your healthcare provider to make sure you have enough supply of any necessary medications and that you're up to date on vaccines. [Download the travel checklist](#) for extra trip reminders.



* ORGANIZE MEDICATIONS

To help you stay organized and reduce the risk of missing a medication dosage, consider using a weekly pillbox.



“We have a little checklist on the door so we can double-check we have the essentials before leaving the house. Listing things like your phone, keys, wallet and purse—it just helps you so you don't have to really think about these things, especially because you can't remember everything all the time.”

Victor, living with MG



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Improving Mobility in the Bathroom

Your bathroom at home may be tricky to navigate, depending on your symptoms. So why not make a few adjustments that may help improve your routine?

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ADD NONSLIP AREA RUGS

To help prevent fall injuries if you're experiencing leg fatigue, try adding nonslip area rugs or choosing floor surfaces that are less slippery.¹²

Julia, an OT who lives with MG, suggests ensuring any areas where you have rugs are well lit to help prevent falls, and she notes that it's important the rug is secured in place and in good condition, so the edges aren't curling.

INSTALL A BIDET

If your budget allows, you may want to consider installing a bidet. Search online for "portable bidets" to learn more and find an option that can be added onto your existing toilet.

CONSIDER CONTRASTING COLORS

If your depth perception is impacted because of your MG symptoms, you may want to consider using color-contrasting counters, walls and/or floors in your bathroom space. You may also consider color coding different areas, like your countertops, shower and toilet.

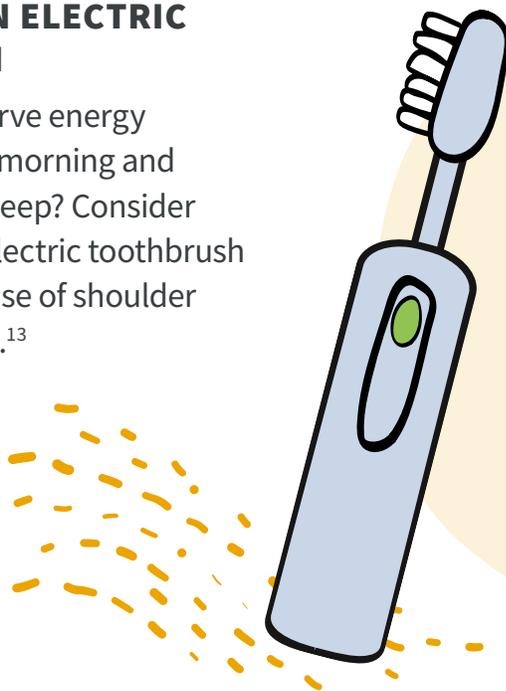


Is it time to redecorate?

Research has shown that increasing color contrast, such as red-to-grey, can be particularly impactful in helping depth perception.

SWITCH TO AN ELECTRIC TOOTHBRUSH

Looking to conserve energy first-thing in the morning and before going to sleep? Consider switching to an electric toothbrush to minimize the use of shoulder and arm muscles.¹³



CLEAN WITH USED TOOTHBRUSHES

Save those used toothbrushes! They can be used to clean around faucets and other hard-to-reach places. Rachel, a person living with MG, shared that by allowing the brush to do part of the work for you, it may save you some energy.



“In the morning when I’m getting ready, an electric toothbrush helps me because it’s less arm movement. Any opportunity to save some energy makes a big difference later in the day.”

Rachel, living with MG

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SECURE GRAB BARS

Grab bars are another feature that could be added to your bathroom to help prevent falls and provide stability if you're feeling tired. Consider installing grab bars near your toilet to help when standing up and sitting down.¹⁴

USE A REACHER TOOL

To help conserve energy, use a reacher/grabber tool that will eliminate the need for you to bend down to grab things off the floor and put them in a laundry basket or washing machine.¹⁴



“We had reachers in our bathroom for many years and it was very convenient.”

Victor, living with MG



If heat worsens your symptoms, consider taking shorter or less hot showers.



INVEST IN A SHOWER CHAIR

For times when you are feeling up for a shower, consider investing in a shower chair with support to pull up or arms to push off, or a bench, to conserve energy. If falls are a concern, adding one of these accessibility accessories can decrease the chance of you falling by providing a more secure area in an otherwise slippery shower.¹⁴

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Getting Dressed to Feel Your Best

Does the start of the day often leave you feeling fatigued? Getting prepared to take on the day ahead can be hard for many, but by preserving the energy it usually takes you to get ready, you may find yourself with more energy reserved for running errands, spending time with loved ones or practicing a hobby.



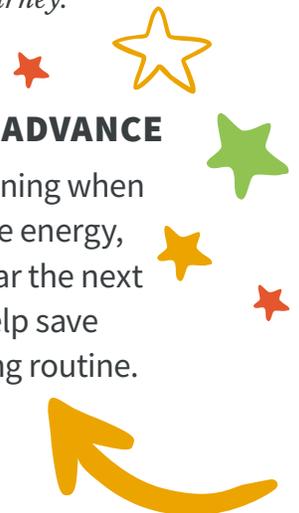
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TRY A UNIVERSAL CUFF

If your hair can take too much time and effort to style, try a universal cuff to brush it and a stationary or domed hair dryer, rather than a hand-held dryer. A universal cuff is a tool that fits tightly around your hand to provide grip strength and control with utensils—like a hairbrush, pen or fork.

CHOOSE CLOTHES IN ADVANCE

At a point in the day or evening when you find yourself with more energy, choose your clothes to wear the next day and lay them out to help save energy during your morning routine.



USE A SOCK AID

Knock your socks off. Or on. If you can benefit from compression socks, or if you're having difficulty with your socks in general, try a sock aid for easier on-and-off. There are a lot of different types of accessories available online that can be found by searching "sock helper."



“A lot of people with MG have comorbidities that may require them to wear compression socks, and one of the helper devices can definitely make it easier to put those on.”

Julia, OT who lives with MG

**CARRY ONLY NECESSITIES**

Travel lightly. Use pockets or a backpack to help evenly disperse the weight of your necessities, like a wallet and keys. If you do carry a purse or tote bag, clean it out often to make sure it is as light as possible and you're only carrying the items you absolutely need.

CONSIDER VARIOUS SUPPORTIVE RAILS

Looking for extra support when you first wake up? Consider installing a rail or a pole by your bed to help ease mobility and make standing up easier.¹⁴ Another option is to place a rail between your mattress and box spring.

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TRY BUTTON HOOKS

A button hook is a tool that might be helpful to use while putting on a button-up shirt. It has a hook fixed with a handle, so it can be more easily held and eliminate some struggle that may happen while getting dressed.

For added ease, look for shirts that have snap closures or magnetic buttons. If you have weak fingers or poor dexterity, these can help eliminate the stress of standard buttons.

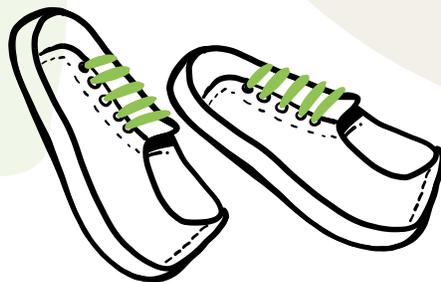
UTILIZE ADAPTIVE NAIL CUTTERS

Use nail clipper adaptive equipment if your pinch is too weak or your hands won't allow you to safely trim your nails. There are even automatic nail clippers available now that can trim nails without any manual effort.

CHOOSE THE RIGHT FOOTWEAR

Shoes that require laces may be too much effort for certain moments. Instead, try hook and loop closures or supportive slip-on shoes with a heel strap. Be sure to avoid flip-flops, as they may cause slips.

Try using an extended shoehorn to make it easier to put footwear on.



“Some people have more energy at nighttime and some do in the morning, so meal prepping, laying your clothes out for the next day, etc., when you have the most energy makes sense. Get things done while you can to give your mind a mental break when you need it.”

Rachel, living with MG



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Keeping Up in the Kitchen

Are you learning new ways to fuel your body while making adaptations to your diet? If preparing a meal sometimes feels like more of a chore than a joy, there are helpful tips you can implement around your kitchen that may save you time and energy.



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ORGANIZE APPLIANCES

Put the most used appliances and/or the heaviest appliances within arm's reach around your kitchen. This will help ensure you aren't wasting your energy frequently getting those out when cooking.

USE ADAPTIVE TOOLS

Use gripping material or a damp towel in the kitchen when you need to open a jar or hold a bowl and stir.

MIX UP SOME SMOOTHIES

Smoothies are a great way to sneak in vegetables and are a nutritious option that is easy to eat. Add nut butter into your [smoothies](#) if your diet allows. Since they're blended in, it may take away some of the swallowing struggles that sticky food can bring.

CONSIDER THIS RECIPE:

- **1 cup liquid** (milk, water or plant-based milk, coconut water, etc.)
- **1 serving fruit** (1 piece or 1/2-1c serving)
- **1 handful or cup of leafy greens**
- **1-2 tbsp nut butter**

✦ Combine all ingredients in a blender until smooth.

BUY PRE-CHOPPED FOODS

Let someone else do the heavy lifting. If cooking is fatiguing, buy pre-chopped foods when preparing your favorite recipes. You may also consider using an apple slicer to cut pears, cheese, onions, etc., to save your arm and hand some energy.



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SAUTÉ VEGGIES

Cook or sauté vegetables to make them softer and easier to eat. Cooking vegetables also allows for more nutrients to be released. For example, you can absorb more iron and calcium from eating cooked spinach instead of raw.¹⁵

PREPARE FOODS AHEAD OF TIME

Want to make a [breakfast of champions](#) or prepare snacks for the week ahead? Why not prepare as much as possible before mealtimes, like when you're feeling your most energetic. For instance, squeeze the lemon juice or measure out the dry ingredients ahead of time and there'll be less to do when you put it all together.

“At the beginning of the week, make a big batch of grains or roasted vegetables that you can incorporate into meals or eat as snacks throughout the week.

Think about your schedule and find pockets of time where you can devote to [meal prepping](#). ”

Jen, registered dietitian



SWAP OUT STICKY FOODS

Nut butter, candies and even sticky rice can more easily get caught in your throat or dry out your mouth. Potatoes and squash might be a better option than rice or quinoa for starches, as rice and quinoa have tiny particles that can get caught in the throat.¹⁶

CREATE A FOOD JOURNAL

If you think certain foods may be impacting your MG symptoms or overall mood, start tracking what you're eating by creating a food journal. For best results, write down what you eat and how you are feeling energy-wise, stress-wise and mood-wise. Then, look back and see where you may want to make diet changes or have a follow-up discussion with your doctor.



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Recharging for Out & About Activities

Whether you're leaving home to run errands or walking to the neighbor's house for a game night, keeping up with your hobbies and routines may sometimes feel difficult. Consider maximizing your energetic moments by planning ahead.



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PLAN OUTINGS AHEAD OF TIME

Look into parking options, handicap access, access to wheelchairs, seats or benches available, shady stops and benches in hot/outdoor venues, rooms to accommodate coats and other heavy items, access to drinking water and restrooms, etc.

An hour of planning can save you several hours of doing. When considering a visit to a museum or other large tourist attraction, do your research ahead of time based on your needs.

ORDER GROCERIES IN ADVANCE

Trips to the grocery store can leave anyone feeling exhausted. Order groceries online for delivery to your home or curbside pickup so you can save time, wait in your car and avoid lifting bags out of the shopping cart.



WEAR A COOLING TOWEL

If you find that your MG symptoms are worse in the heat, a neurologist suggests that a cooling towel or vest may be an inexpensive way to lower your body temperature quickly and help you to be less uncomfortable in warm or humid environments.

ORGANIZE SHOPPING LISTS

Planning a day of running errands? Keep shopping lists based on stores you're visiting. Consider organizing grocery lists by aisle and list out all items needed from other stops you plan to make, such as the hardware store, library, pharmacy, dry cleaning, etc.

MAKE USE OF ADAPTIVE HOLDERS

Need a hand? Use holders—such as a card holder, cell phone holder and/or magnetic eyeglass holder—to prop your necessities, saving hand and arm energy.

CONSIDER PARKING PLACES CLOSEST TO ENTRANCES

Consider talking to your doctor about getting a handicapped parking tag for your car, if you haven't already, and use it for close parking wherever possible. Those fewer steps may be the energy you need to finish the day!

“Having an open and honest conversation with my household to compare what things we valued was an important part of my MG management. We said, What do we *have* to do and how can we **prioritize** so that we can spend more time on things that are important to us? ”



Julia, OT who lives with MG

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Try to board the plane early and sanitize your seat, tray and anything else you will be touching, to help prevent germ spread.

OPTIMIZE TRAVEL EXPERIENCE

Hey jetsetter, when you're [planning a trip](#) that requires air travel, put as many things as you can into your checked bag to avoid wheeling heavy carry-on luggage around the airport and having to lift it into the overhead bin on the plane. Keep any necessities, like medication, on you at all times.

WEAR GLOVES WITH GRIP

When you're out and about and need to open doors, use nitrile gloves for help with grip. Bare hands can be slippery, especially on warmer days, so some extra grip may help minimize your effort.



“ If I'm out running errands and begin to feel fatigued, I head home and lie down to take a little nap. We always try to schedule the nap every day in the afternoon or late afternoon.”

Victor, living with MG



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Building a Strong Support System

Don't be afraid to phone a friend when you need one. Communicating effectively and honestly with yourself and others may help you find a network of trusted supporters who you can reach out to on good days and bad. Try leaning on your loved ones and seeking out clinical experts as well as others living with MG to help support your MG journey.

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JOIN A SUPPORT GROUP

Join an MG support group to connect with others who are living with MG. Share experiences, resources and tips within the MG community.



Discover some of the [patient advocacy organizations](#) dedicated to MG.

PRACTICE HOBBIES

Carve out time each week to do something you enjoy with the people you love to help you re-energize and lift your spirits. Try something creative, like painting or writing, if you have the energy for it, or simply listening to a favorite song.

KEEP A JOURNAL

At least once a week, write something positive about yourself or a family member or friend, like personal accomplishments, goals reached, kindness either given by or provided to you, etc. This can be something you look back on later to help boost your spirits if you're having a bad day.



CONSIDER COUNSELING SUPPORT

Consider speaking to a counselor, life coach, religious advisor, etc., if you haven't already. Therapy can provide a safe space to vent. Adding a counselor to your support team may benefit your emotional health.¹⁷

“ Always check in on your partner or loved ones and try to do something each day to help them feel cherished. ”

Kathleen, mental health expert who lives with MG



A consideration for **supporters and loved ones** of people living with MG

PRACTICE GOOD SELF-CARE, SLEEP WELL AND GET EXERCISE

Caring for your loved one is important, but so is caring for yourself. Supporters of those living with MG should be sure to get enough sleep and exercise. A good night's sleep can be restorative and may help people function better with less anxiety, while exercise may also help to reduce stress and anxiety.¹⁸

BE KIND TO OTHERS



Do something nice for someone each day. Consider smiling at a stranger or talking with someone who you haven't connected with before. It may help you feel better and improve your mood.

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