



ONWARD

CARING FOR YOURSELF AS YOU CARE FOR YOUR LOVED ONE



Disclaimer: This content does not intend to provide medical advice and does not replace HCP support. Talk to your doctor if you are worried about your emotional well-being and for medical guidance with anything suggested in this document. This document is intended as advice only.

THIS BROCHURE AIMS TO
SUPPORT YOU AS A
CAREGIVER BY EXPLORING
THE FOLLOWING TOPICS:



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1. THE IMPORTANCE OF
CAREGIVING

Caregiving can be a fulfilling experience that can bring individuals closer together, even when challenges arise. As a caregiver for a loved one with generalized myasthenia gravis (gMG), your role is important. Your acts can provide great value to the life of your loved one.

You may be a parent, a friend, or a significant other, assisting and supporting a loved one needing extra levels of care. Caring for someone with a rare disease like gMG can be more demanding. You may be challenged by your loved one's unpredictable, unique, and changing symptoms. At the end of a long day, you may also find yourself cooking, cleaning, or searching for hard-to-find information about gMG.

39% of patients bring a
caregiver to their gMG
appointments.

2. THE IMPORTANCE OF
SELF-CARE

There may be moments when you feel overwhelmed by the responsibilities of caregiving. You are not alone: Feeling the physical and emotional effects of caring for another person is normal.

There are things you can do to recharge so that you stay strong for your loved one when facing complex care situations or increased stress and strain.

Learn to identify the effects that caregiving may have on your physical health or emotional well-being. If you begin to feel the pressures of caregiving, explore outlets of support such as your healthcare provider or therapists.

3. MANAGING STRESS AND
BURNOUT

Did you know your well-being can be compromised by placing your loved one's needs before your own? There may be occasions when you don't have enough time for yourself, and that can negatively impact aspects of your family life. The signs of caregiver burnout are similar to those of stress and depression. These changes are normal. Pay attention to them so you can take the action needed to get through them and continue to take care of your loved one and yourself.

Signs of burnout include:

- Emotional and physical exhaustion
- Loss of interest in activities previously enjoyed
- Changes in appetite and/or weight or sleep patterns
- Irritability, frustration, or anger toward others
- Withdrawal from friends and family
- Feeling hopeless and helpless
- Getting sick more often

If you think you may be experiencing signs of caregiver burnout, there are resources available to help. Continue reading for self-care recommendations and reach out for professional support when needed.



Studies show that more than 60% of caregivers experience symptoms of burnout. Don't feel guilty if you are experiencing any of these symptoms. Caregiver burnout is common.



Don't forget to take the time to care
for yourself

As a caregiver, it's important to maintain your own health and well-being. Be aware of these signs and know that there are things you can do to help yourself. You may join a support group, find a respite care program, or work with your doctors to stay healthy—physically, and emotionally.

Most importantly, know that burnout and compassion fatigue are completely normal, and you are not alone.

4. SELF-CARE STRATEGIES

While you may be focused on your loved one's well-being, it's incredibly important to maintain your own health and peace of mind as well. This will enable you to continue to provide the best possible care.

To get you started thinking about how you can do this, here are some strategies for managing your feelings and thoughts:

Emotional Self-Care Strategies

Mindfulness Exercises

A type of meditation where you focus on being very aware of what you’re sensing and feeling right now, without judging or interpreting those feelings. This practice includes breathing techniques, guided imagery, and other activities that help relax your body and mind, reducing stress.

Journaling

Write down your thoughts and feelings to process your emotions.

Seeking Emotional Support

Reach out to friends, family, or support groups for emotional support.

Physical Self-Care Strategies

Time Management

Develop a daily or weekly schedule to organize your tasks and activities efficiently. This helps you prioritize your responsibilities, stay on track, and make the most of your time.

Setting Boundaries

Define clear limits on your time and energy to ensure you have dedicated moments for yourself. This helps prevent burnout and maintains a healthy balance between work and personal life.

Engaging in Hobbies

Pursue personal interests or hobbies to maintain a sense of normalcy and joy.

Caregiver Activity Checklist

Think of some activities you’d like to incorporate into your schedule. You may already have some activities in mind, or you can use the list below for ideas.

- ☐ Carve out time for a yoga session, meditation, relaxation, or a walk.
- ☐ Make a weekly meal plan with healthy food and things you love.
- ☐ Reserve time for your favorite TV show.
- ☐ Allow yourself to get a good night’s sleep.
- ☐ Set limits for what you can do.
- ☐ Make time for an activity that you find meaningful and enjoyable.
- ☐ Be sure to ask family members and friends for help with household chores.
- ☐ Make an effort to keep the lines of communication open among your loved one, your family and friends, and the healthcare team.
- ☐ Ask for help when you need it. People are usually happy to lend a hand.
- ☐ Share your feelings with family members or other caregivers or join a support group.
- ☐ Don’t forget to give yourself credit: The care you give makes a difference.

Add some ideas of your own:

5. MAKING IT HAPPEN – SELF-CARE IN ACTION

Finding Moments for Self-Care

While it may feel overwhelming to think about working self-care into your busy schedule, there are steps you can take to get started. Here are some methods to introduce self-care into your daily activities in small but meaningful ways:



Plan for Healthy Eating

- Consider weekly meal planning. Meal planning provides opportunities to save time. Pick your recipes for the week, organize your shopping list, and consolidate preparation activities.
- Have healthy snacks on hand.
- Consider using a meal planning or delivery service to lighten your load.
- Everyone needs a break. It’s OK if you need to grab take-out or a prepared meal to save time when you’re busy.

Studies have shown that those who plan their meals in advance are more likely to have a better-quality diet.



Get Adequate Sleep

- Aim for 6–8 hours of sleep per day.
- Put your phone away. Studies have shown evidence of improved sleep for those who stop using their phones 80 minutes before bedtime.
- Set up your bedroom to be a calm, relaxing environment.
- Consider blackout curtains so you can grab a quick nap during the day.

Schedule Exercise

- Coordinate with a friend to attend an exercise class.
- Block off time in your day, like you would an appointment.
- Start where you can. Even a 20-minute walk can be physically and mentally refreshing.

Stay on Top of Your Personal Health

- Don’t minimize your physical needs or wellness.
- Listen to your body. Not sleeping well, lack of energy, and changes in weight are a few of the indicators that you may be burned out.
- Monitor your own nutrition and physical symptoms with the same care and attention you give to your loved one.
- Don’t push yourself to the point of exhaustion.
- Make and keep your medical wellness appointments.

6. WORKING AND CAREGIVING

Working can be rewarding. So can caregiving. But together, they can be a demanding combination.

But there are ways to manage your home, work, and life demands. Here are some ideas that can help you manage your caregiving role and your personal needs a bit more smoothly:



Familiarize yourself with workplace laws

You may be eligible to use the Family Medical Leave Act (FMLA) to take some time off work to handle your loved one’s care. Familiarize yourself with the law at [dol.gov](https://www.dol.gov).

Look into helpful services to help lighten your load

With everything you do, taking care of the everyday chores can tend to get overlooked. There are services that can assist in almost every aspect of your home life. From childcare, elder care, parenting resources, housekeeping, dog walking and pet care, to home improvement services such as contracting, plumbing, and yardwork. Don’t forget online shopping and ride-share services. There are numerous services you can take advantage of to make your life a bit less stressful and help lighten your load.

Stay focused

Make a list of your top 3 tasks to accomplish for the day. Consider if there are things on your daily calendar to regain some time in your day.

Read your employee handbook

Your company may have policies on caregivers, flexible work options, and family leave that apply to you. You may also have access to an employee assistance program, which can be a helpful resource.

Keep work separate

Try to take care of caregiving duties in your personal hours, rather than during work hours. Schedule calls and doctor’s appointments during your lunch hour and do your research on your loved one’s condition after you’ve gone home for the day.

Finding someone to talk to

You have a lot going on. And things like being stretched thin and anxiety about the future – yours and your loved one’s – could be on your mind. You may not want to burden anyone else with what you’re going through. But if you don’t talk about it, you may find it will burn you out. Find a friend or family member, even a neighbor you speak with often, and just let them know what you’re going through. They’ll be happy to listen, and you’ll feel much better for it. If you don’t have anyone you can share with, you could consider talking to a therapist.



7. LOOKING FOR SUPPORT

Caregiver support groups are a way to learn more about caregiving for various types of conditions. With these groups you can get—and give—emotional support and share experiences. Each type of group is structured differently. Some offer telephone conference meetings, while others take place online via chat, or email, and the local meetings occur in person. But all caregiver support groups are aimed at facilitating a connection between caregivers who can help each other along their journey.

1 in 5 people in America is a caregiver of a family member.

Here are a few resources for you to explore. If you need help finding them, reach out to your ONWARD Care Coordinator.

The following information is provided for educational and support purposes. UCB does not endorse any specific organization or the content on their respective websites. This is not a complete list. Be sure to look for local support groups that may be in your area.

The Caregiver Action Network

The Caregiver Action Network (CAN) is a nationwide non-profit organization aimed at helping to support all types of caregivers,

including family caregivers who are parents of children with disabilities, caregivers helping wounded veterans, as well as caregivers for people with dementia and other age-related debilitating disorders.

The National Alliance for Caregiving

The National Alliance for Caregiving is a non-profit coalition of national organizations who share a vision of a society that values, supports, and empowers family caregivers to thrive at home, work and life. Its mission is to build partnerships in research, advocacy, and innovation to make life better for family caregivers.

Today’s Caregiver

Today’s Caregiver is a leading provider of information, support, and guidance for family and professional caregivers. Founded in 1995, they produce Today’s Caregiver magazine, the first national magazine dedicated to caregivers, caregiving books, custom publications, the Fearless Caregiver conferences, and their website, [caregiver.com](https://www.caregiver.com).

For a more extensive list of support groups, please refer to our gMG Advocacy & Community Group brochure and discover more resources at [ucbONWARD.com](https://www.ucbONWARD.com).





REMEMBER TO TAKE CARE OF YOURSELF

To continue being the best caregiver you can be, you must be sure to make your health and well-being a priority. That starts with having the information, preparation, and support you need for your journey. This will allow you not only to provide better care but may also improve your own quality of life at the same time.

And while reaching out for support may seem difficult or even uncomfortable, it can create a much-needed lifeline. While your journey is unique, you can gain incredible insight from the experiences of others, and sharing your story may even help someone else.

DON'T FORGET – pick 3 self-care activities to try this week!



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US-RZ-2500459



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