## **Supporting Someone with MG**

If someone you love has been diagnosed with MG, you want to be as helpful and supportive as possible. Research has shown us that family and friends play a very important role in helping a loved one deal with a chronic illness. When a person is diagnosed with MG, many things may change. A new diagnosis can be scary. And, everyone needs reassurance that the important things will stay the same. People diagnosed with a serious illness can feel helpless at first, and your support can truly make a difference.

Here are three crucial steps in providing meaningful support:

- 1. **Learn all you can about MG**: The MGFA website has a wealth of information to help you better understand MG. Make sure to use reliable, credible sources for information.
- 2. **Communicate**: Every relationship is different, so it's important to discuss ways that you can be the most helpful in your particular relationship as a spouse, parent, sibling, friend or someone else close to someone with MG.
- 3. **Take care of yourself**: Learn how to ask for and accept help when you need it. If you're overwhelmed, it makes it more difficult to care for your loved one with MG.

It's also important to learn how to support your loved one. People differ in the ways they feel supported. For instance, some like to have practical help, some like to spend time with others, and some like to partner on tasks that may be difficult. Everyone needs to know they're still loved as much as ever. You can also attend local support group meetings together. Learn more about MG support groups in your area.

Caregivers are welcome at our support groups. As a matter of fact, most support groups that we have consist of both patients and caregivers. In our larger support groups, patients and caregivers often will split into two groups as each group has their own unique set of issues that they may need to discuss with their peers. You can also take advantage of the MG Friend network to connect with another Caregiver.

## Come Up with a Care Plan Together

Availability is very important. Life continues to make demands of us and sometimes MG makes it very difficult or even impossible to meet those demands. That creates stress, which can trigger or worsen MG symptoms. Knowing that someone is available to help with those demands can make all the difference.

- Check in with your loved one. They may not want to seek you out for help but will respond to a specific offer of help.
- Use phrases that you both feel comfortable with. If you are not sure what to say, you will learn with time what approaches work for your particular relationship. It may be to the point, funny or compassionate. Or it may be just doing what you know needs to be done:
  - o "I'm here now. What can I do?" is simple and direct.
  - o "Hope I'm not being a pest, but you haven't told me how I do the laundry."
  - o "You look like you're having a hard day. I'm going to drive you to..." Or, "I'd like to drive you to..."
- Check that you are truly being helpful. After you have attempted to help, ask a question or two to see how the other person is feeling.
- **Communicate often.** Needs change, availability (including yours) changes, and it's important to have regular check-ins to determine if the current plan is still the best plan.

Remember that it can be quite difficult to ask for help and that it feels good to help someone. Keeping this in mind, you can work out tasks and other things that need to be done. Perhaps a person with MG cannot do a physically demanding task, but is able to take on a chore that is less physically demanding. Having a shared sense of purpose in approaching what needs to be done is the best way to make everyone feel needed, competent and valued.

Just spending time with your loved one is a precious gift. It's very important to spend time on things you both enjoy – these can be simple pleasures or special outings. Family visits, volunteering, entertainment and being in nature can all make for great memories. Be sure to savor the good times!

Listening to your loved one is, perhaps, one of the most important ways you can support them. Everyone can learn this crucial skill by keeping a few things in mind:

- Listening means being silent when another speaks, not making assumptions, and letting them finish their thoughts before responding (SILENT and LISTEN use the same letters).
- Reflecting back what you think you heard and allowing the other person to affirm or correct you is also very important.
- It is human nature to want to help but our solution may not work for someone else. Try to collaborate in problem solving rather than make the first suggestion.
- Again, check in on a regular basis to ensure that the current plan is meeting everyone's needs.

Recognize that everyone in the relationship needs to monitor their energy – physical, emotional and psychological. This applies both to those with the diagnosis of MG and their caregivers. Learn to care for yourself as well as your loved ones. Be sure to get enough sleep and to include pleasant activities in your daily routine.

## **Self-Care for the Caregiver**

Learn to ask for and accept help for yourself. This can be quite difficult for some people.

People differ in how much help they need. MG is a "snowflake" disease, which means that everyone's experience with MG is different in terms of symptoms, challenges and daily living. It can also be said that caregivers are "snowflakes" as needs can vary greatly!

- Ask for specific help this makes it easier on everyone. "I need a few groceries and can't get out now. When you go to the store, could you pick up some eggs and bread, please? Thank you so much!"
- Accept help when others offer. It may be almost automatic to say, "No thanks, we're fine," only to realize that you have far too much to do. Remember, it makes others feel good to be helpful. However, you will learn that not everyone will help in a meaningful way. Recognize this early on, so that you are not spending emotional energy on someone who is not reliable or helpful.
- Create a back-up plan for days when you're not able to provide the help needed. There may be times when you feel that you cannot provide the support your family member needs. Professional, volunteer and community services can be a wonderful resource during these times. To learn more about MG support groups in your area, use the Support Group tool.
- See Other Resources here.

Learn all you can about MG and stay up-to-date. There is always new information out there that can help. Stay connected to others, whether it be a local support group, a community resource or with other family and friends. Keep in mind that empathy and concern are vital to someone with a chronic illness—this is about them and your support can make all the difference. Often forgotten, but equally important, is to remember to take care of yourself—emotionally, physically and mentally.