



Self-Advocacy: You Can be Your Best Advocate

Because self-advocacy is highly individualized, the actions that you take will depend on your circumstances. What IS SELF-ADVOCACY? Speaking up on your own behalf to express your needs, desires, interests, and rights in order to have them fulfilled is a form of self-advocacy. Although self-advocacy is individualized, certain core elements are necessary for empowerment.

- **Knowledge:** Learn as much as you can about MG. Use resources such as the following websites; MGA of Kansas & Missouri (www.mgakc.org), the Myasthenia Gravis Foundation of America (www.myasthenia.org) and National Institutes of Health (<http://www.ninds.nih.gov>), your neurologist, and books on autoimmune diseases.
- **Understanding:** Know your MG. For example, how does it affect you physically and emotionally? Has it altered your relationships with family, friends, teachers, and co-workers? When do your symptoms occur or become more apparent?
- **Acceptance:** Recognize that, while your MG symptoms may lessen from time to time, MG has become part of your life and that you can't control it, but you can control how you deal with it and take care of yourself.
- **Records:** Keep written records including up-to-date lists of all your medications, dosages and when you take them. If you notice changes such as increased weakness, difficulty swallowing, or fever, write down the details. In preparation for your neurologist appointment, ask yourself, how am I? Record whether anything related to your MG or general health has changed since your last visit, e.g. improvement or worsening of blurred vision or fatigue levels, bladder infection, and nausea after starting a new medication.

- **Communication:** Talk to whoever is involved in your care or cares about you. This is particularly important during doctor visits. The point of the office visit to your physician is communication. Don't let your needs go unmet. Doctors can't read minds. You must talk to them. Tell them what's going on, and then, with you, they will execute a plan."

Why should I advocate for myself? This question can be answered by answering another question: "Who knows me better than I know myself?" Does anyone else really know how my MG feels, when my energy level has plummeted, what my concerns are, or what my medication regimen is and how it affects me? Probably not. Providing these details verbally or in writing is self-advocacy that will enhance your medical care and help family and friends to better understand MG.

How Should I Advocate For Myself? Self-advocacy occurs in many forms and is a fundamental part of taking care of ourselves and our MG. It can be preparation for a doctor's appointment as noted above, or developing a plan with our neurologist for how to respond if an emergency such as an MG crisis should occur. Self-advocacy also can be asking our prescriber or pharmacist whether a newly prescribed antibiotic or cardiac medication will affect our MG. It might be the filing of an appeal to an insurance company when it denies a claim. We also self-advocate when we prepare an advance directive or living will to express our desires when we cannot speak for ourselves. Self-advocacy can help you in an emergency. By carrying medical alert indicators such as bracelets, medallions or wallet cards that show MG as the diagnosis facilitates access to your information. Taking a log or notes with you that you've written about your condition also is helpful. These indicators and notes provide key information to first responders and hospital emergency personnel to help them provide timely and appropriate treatment. The MGFA Medical Alert Card is available for this purpose at www.myasthenia.org. Self-advocacy continues in the emergency room. You know what's normal for you. Many ER docs don't know neuromuscular diseases well and may minimize symptoms that are actually quite significant. If something isn't right and your gut tells you so, advocate until someone pays attention to you.

This article was reprinted from the Myasthenia Gravis Foundation of America's Spring 2012 Foundation Focus newsletter.