

Resources

MGFA:

- Visit the MGFA website to learn more about MG and to find other resources for parents of children with MG. Here are a few:
 - MGFA's Literature on MG, medications, emergencies and related issues.
<http://myasthenia.org/LivingwithMG/InformationalMaterials.aspx>
 - Patient Resources including patient and prescription assistance:
<http://www.myasthenia.org/LivingwithMG/PatientResources.aspx>
 - See Patient Stories at
<http://myasthenia.org/CommunitySupport/PatientStories.aspx>
 - Drugs to Avoid at <http://myasthenia.org/LivingwithMG/DrugstoAvoid.aspx>
 - See Patient Stories at
<http://myasthenia.org/CommunitySupport/PatientStories.aspx>
- You can also find webinars and podcasts on the MGFA website. Look for these resources:
 - Webinar, *The Role of Exercise in Taking Control of Your MG*, featuring MG exercise expert, Dr. Charlene Hafer-Macko, University of Maryland School of Medicine and Hospital, <http://myasthenia.org/LivingwithMG/MGFAWebinarSeries.aspx>
 - Podcast: *The Benefits of Exercise in the Care of Patients with Myasthenia Gravis* Drs. Richard Macko and Charlene Macko, University of Maryland School of Medicine and Hospital, <http://myasthenia.org/LivingwithMG/PodcastEducationalSeries2.aspx>
- MGFA can offer important resources to the physician open to learning more about MG. Visit <http://myasthenia.org/HealthProfessionals/EducationalMaterials.aspx> where you and your doctor can find the MGFA book, *Myasthenia Gravis: A Manual for the Health Care Provider* as a PDF. This manual is also available as an iBook -- [Myasthenia Gravis: A Manual](#)

for the Health Care Provider - #iBooks, <https://itun.es/ca/04G68.l>. It can only be viewed on an Apple device.

Other Sources

Get more information and ideas from other expert sources such as these:

Other Health Agencies and Parent Support Organizations

- Find helpful information at the United Kingdom’s Myasthenic Kids website and download this brochure: <http://myasthenickids.org/wp-content/uploads/2013/05/MGkids-Flyer-2012-final1.pdf>
- **MG Parents** Facebook page--to reach this group of parents of MG children go to Facebook and type in MG Parents in the “Find Friends” search box – if you are a parent ask to join the group.
- American Psychological Association www.apa.org/helpcenter/chronic-illness-child.aspx
- The American Academy of Pediatrics at HealthyChildren.org: <https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/Coping-With-Chronic-Illness.aspx>
- Many health organizations are likely to have guidance on coping with a child’s chronic illness. The University of Michigan’s site has a very helpful article with links to many other resources. Go to: <http://www.med.umich.edu/yourchild/topics/chronic.htm>
- Other sites with helpful resources include: www.kidshealth.org; Bandaides & Blackboards: <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/> a site for and from youngsters with chronic illness
- Women’s and Children’s Health Network/Parenting and Child Health: <http://www.cyh.com/healthTopics/HealthTopicDetails.aspx?p=114&np=304&id=2578>



- Pacer Center, www.pacer.org “Champions for Children with Disabilities” has a spectrum of helpful programs and information
 - BestSchools.com provides a list of grants, scholarships and education resources that are available to students with disabilities. They recently published their **2016 College Resources for Students with Disabilities**, find this comprehensive guide at <http://www.bestschools.com/disability-resources/>.
 - Livestrong.com article on physical therapy and MG: <http://www.livestrong.com/article/477048-physical-therapy-for-myasthenia-gravis/>
 - Video of *Myasthenia Gravis and Exercise* presentation by Physical Therapist, Brittany White, October 2014 seminar hosted by MGF of Illinois at Palos Community Hospital <https://www.youtube.com/watch?v=QC4uYYo171k>
 - Website, My Physical Therapy Coach presents this article: *Exercise and myasthenia gravis (MG)* at <http://www.my-physical-therapy-coach.com/exercise-and-myasthenia-gravis-mg.html>
- **Government Resources**
 - Go to the U.S. Department of Education IDEA website at <http://idea.ed.gov/> for a spectrum of related topics including the Individualized Education Program or IEP.
 - Check out the IDEA Partnership for help with improving educational outcomes for students with disabilities. Go to www.ideapartnership.org.
 - The U.S. Department of Education also maintains a site with frequently asked questions on Section 504 at <http://www2.ed.gov/about/offices/list/ocr/504faq.html>
 - To find out what programs and regulations your state may have in relation to IDEA and to education for children with disabilities search the internet with your state name and *Individuals with Disabilities Education Act*.