



MYASTHENIA GRAVIS  
FOUNDATION OF AMERICA, INC.®

## Steering Your Child with MG to School Success



### A Parent's Guide

## *Table of Contents*

<b>Introduction</b> .....	3
<b>School</b> .....	4
Achieving Your Child’s Potential.....	4
Creating a Productive Relationship with School Staff.....	4
Open Communication .....	4
Sharing Health Information.....	5
Legal Support .....	5
The Laws.....	5
<b>Working with Your Child’s Teachers and Other School Staff</b> .....	6
Engage Your Child’s Team .....	6
Tips & Ideas .....	7
Practical Suggestions.....	7
Conversation Starters.....	7
Reach Out to Other School Staff .....	7
<b>Aids &amp; Services</b> .....	8
Classroom Accommodations.....	8
Overcoming MG Challenges.....	8
Schoolwork.....	8
Excessive Absences.....	9
Peers.....	9
<b>The Laws</b> .....	10
IDEA—Individuals with Disabilities Act .....	10
Prep for your IEP Meeting .....	11
Research & Records.....	11
Mental preparation .....	11
At the IEP Meeting .....	12
After the IEP Meeting.....	12
Section 504.....	12
The Office of Civil Rights.....	13
ADA.....	13
Extracurricular and recreational activities .....	14
<b>Further Resources</b> .....	14
MGFA Resources .....	14
Other organizations’ Resources .....	15
Government Resources.....	15

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# Introduction

As a parent, you will always be your child's number one advocate. You will set the tone for how your child adjusts to the challenges of MG, as well as to your child's school environment. School officials are well intended but most of them have no knowledge of MG and how it can affect a child's schooling.

Living with a chronic illness can be a challenge for any parent and child. Using the information in this guide will help you navigate MG and the challenges your child may face in school. You will find things to do that can help your child succeed. For instance, you'll read a variety of ways to work with the school to create the best environment for your child.

Encourage your child's independence. As he grows allow your child to make more decisions himself. At the same time, continue to support your child with the professionals in her life.

- Recall, MG is a rare disease. Even health care professionals may benefit from being better informed.
- The adults in your child's life will appreciate your sharing this information with them.

*Remember*, MG is a "snowflake disease." Each child will have different signs of MG's effects. Help the other adults in your child's life to know MG, and to know how MG affects your child.

The Myasthenia Gravis Foundation of America (MGFA) is here to help you. MGFA provides resource materials for you and your child's health care team. MGFA can also link you to other parents who have managed successfully. Check out the MGFA Facebook<sup>1</sup> page where parents have shared helpful tips and have offered supportive words. Go to [www.facebook.com](http://www.facebook.com) and search for Myasthenia Gravis Foundation of America, Inc. Or search Facebook for *MG Parents* a sharing and support group that grew out of the MGFA Annual Conference.

When you talk with the professionals, and other adults, in your child's life, it is important that you:

- Are informed, and factual.
- Develop relationships with the professionals in your child's life.
- Ask for their guidance and partnership.
- Seek and support what your child needs to be successful and happy.
- Be persistent, yet balanced.



**Legal Support.** There are federal and state laws to help a child with a disability. These laws help a child participate equally in school. Some children with MG might need only minor changes or help while others might not need any. By maintaining an open and positive relationship with your child’s school you are likely to avoid the need to seek legal action. And, while it is wise to know about the laws that apply to children with disabilities in public schools working cooperatively with your child’s school and teachers is always the best approach. These laws require schools to make changes that help a child with a disability participate in school. A child will fall under the protection of these laws if the child has a medically documented illness. The illness must fit into an authorized class. Or, it must be an illness that markedly affects the child’s ability to perform one or more “activities of daily living.”

**The Laws:** The two main laws affording accommodations for children in schools are:

1. The Individuals with Disabilities Education Act (IDEA) and,
2. Section 504 (Section 504) of the federal Rehabilitation Act.

To find summaries of the two laws and a general comparison, please go to page 10. For a more detailed, side-by-side comparison, please refer to the Muscular Dystrophy Association’s website at [http://www.mda.org/Tips\\_for\\_Success/School\\_Advocacy](http://www.mda.org/Tips_for_Success/School_Advocacy).

	<b>Yet it is wise to at least be knowledgeable about the laws that apply to children with disabilities in public schools.</b>
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## Working with Your Child's Teachers & Other School Staff

**Your Child's Team.** Ideally, aim to engage your child's teachers and other school staff as allies. By treating these adults in your child's life as team members you'll help your child receive the best educational experience possible, while also engaging them in your child's development and care.

### Tips & Ideas

- Each new school year, or whenever your child has a new teacher or school environment, request a meeting with the teacher as early as possible.
- Remember to talk with your child before you meet with teachers. It's very important to get an understanding from your child's perspective. What is she having problems with? What does she like about school? What does she think could make things better? And, remember to meet with your child after you've spoken with the teacher too. Explain what you learned, what changes will be made, and so on.
- Prepare notes and questions; put them in order of importance.
- In the meeting, make the teacher aware of your child's MG, but also make them aware of your child's strengths as a student and as a person.
- Listen to the teacher's perspective and knowledge. She may have taught other youngsters with health and disability issues.
- Be prepared to explain MG and the issues it raises, for instance, taking medication in a timely manner or loss of strength.
- Share information about MG, for instance, MGFA has brochures such as
  - Autoimmune Myasthenia Gravis and
  - Caring for Children and Supporting Adolescents with Myasthenia GravisYou can order paper copies or go to the MGFA website to download them at <http://myasthenia.org/LivingwithMG/InformationalMaterials.aspx>
- Explain how MG typically affects your child and how it might affect your child's time at school. Make sure the teacher understands that the physical manifestations of MG, such as trouble with keeping the eyes opened; inability to smile; weakness in the limbs and other signs of myasthenia gravis, are not "being funny" but symptoms of MG.
- Ask what you can do. Make it clear you are a partner and willing to help.
- Share coping strategies that have worked for you and your child.
- Ask for extra time to complete school projects or adjustments in homework assignments such as fewer problems to solve while still covering the lesson content.
- Discuss how certain accommodations may make a significant difference for your child's ability to function, for instance, a desk seat that allows feet to rest on the floor; not having to stand in line; using a computer/laptop instead of writing; or more time to take tests, help with heavy school doors, reduced need to walk or climb steps<sup>2</sup>.

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<sup>2</sup> Adapted from [www.myasthenickids.org](http://www.myasthenickids.org)

- Assure the teacher that you are willing to help—you are an integral part of your child’s team.
- Set the stage for further communication.

Take these steps in speaking with other school staff such as the School Nurse, Principle, PE Coach and others who may be a part of your child’s schooling.

Remember building a collaborative relationship with these adults will make a major difference for your child’s schooling. There’s an investment of time but that investment will reward you in terms of your child’s health and wellbeing as well as her school success.

**Practical suggestions:**

- Find out how the teacher likes to be reached, share emails & phone numbers.
- Respect the teacher’s time.
- Look for something positive – share a compliment.
- Never talk negatively about a teacher in front of your child.
- Participate in school events.
- Share the positives – let others know that your child’s teacher does a good job.

**Conversation Starters:** Here are some great ways to help you start your conversations with your child’s teachers:

- I’m concerned about my child’s ...
- Help me understand ...
- Have you considered...
- I’ve noticed ...
- She has a hard time doing ..... when .....
- How can I help?
- Thank you for ...<sup>3</sup>

**Reach out to other School Staff.** Apply this guidance to working with other school staff, such as school nurse or PE teacher. Consider the special responsibilities of these adults and adjust your discussions with them accordingly. For instance:

- With the school nurse, share brochures *Emergency Management 1 & 2* as well as *Drugs to Avoid*, which can be found at <http://myasthenia.org/LivingwithMG/DrugstoAvoid.aspx?>
- With your child’s PE teacher/coach make sure he understands MG and that your child can exercise and play games but that he may need more frequent rest or he may need activities and exercises adapted to be less demanding.
- Speak with cafeteria monitors – often volunteers – in case there are swallowing difficulties. You can find more on the issue of swallowing in the MGFA’s brochure, *Effects of Myasthenia Gravis on Voice, Speech and Swallowing*, go to <http://myasthenia.org/LivingwithMG/InformationalMaterials.aspx> and choose from the General Information Pamphlets listing.

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<sup>3</sup> Adapted from [www.understood.org/en/school-learning/partnering-with-childs-school](http://www.understood.org/en/school-learning/partnering-with-childs-school)



## Aids & Services

These ideas for aids and services might assist with the educational needs of a student with MG.

### Classroom Accommodations

- Allow water or snacks in the classroom in order to take medication.
- Allow the ability to leave the classroom if having digestive issues due to medications.
- Schedule classes to minimize trips across campus and up/down stairs to conserve energy.
- A desk chair allowing the feet to rest on the floor.

### Overcoming MG challenges

#### *Concrete Challenges*

- Provide a school nurse or administrator to oversee a student's medication administration and monitor a medication's effects.
- Allow the use of an eye patch for double vision.
- Provide alternative locations for classroom, recess, or physical activities when the temperature is too hot or cold.
- Provide an elevator pass so that the student does not have to climb stairs.
- Allow wheeled backpacks for necessary books or equipment.

#### *Coping Challenges*

- Provide speech therapy with a goal of improving speech and swallowing challenges.
- Provide occupational therapy for learning ways to conserve energy.
- Meet with the school counselor to learn coping skills.

### Schoolwork

- Provide extra time for rest breaks during prolonged testing periods.
- Allow audio recording devices for note-taking.
- Reduce the number of homework problems without reducing the content of the homework goal.
- Provide a second set of textbooks to keep at home so the student doesn't have to ferry her books to and from school each day
- Create an absence make-up plan so that parents and teachers keep each other informed of
  - reasons for absences
  - expected length of absences
  - classwork and homework required to cover the absences
- Create a delivery system for notes, handouts, books, or project materials.
- Create a communication notebook or online account so that parents and teachers keep each other informed of the child's progress or challenges.

### **Excessive Absences**

School Attendance Mandates: During periods of worsening MG or immediately following diagnosis, your child may need to miss school due to surgery, IVIG (intravenous immunoglobulin infusions) or other treatments. In addition, clinic visits, extreme muscle weakness or fatigue may cause absences. In the situation of excessive absences, it is important to keep in mind that your child's school also has state and federal law requirements it must fulfill. The school might have a minimum number of days a child must be present in the classroom or a minimum amount of lessons learned.

If your child needs to be absent, the best approach is to talk openly with the school. Explain the reason why your child must be absent and when the doctor expects your child to return. Most importantly, ask how you can work with the school to make sure that your child is keeping up with the educational requirements he needs to move to the next grade. You will find that by keeping open communication with the school, in most instances, the school will work with you to find solutions to completing coursework and meeting classroom attendance requirements.

### **Peers**

You may find that the more challenging aspect of school is your child's relationships with other youngsters. It may be difficult for your child to adjust to his or her peers' reactions to myasthenia gravis symptoms or diagnosis. If this happens here are some ideas for handling the situation.

It might be helpful to meet with the parents of your child's friends (and classmates), or with parents and friends together, to talk about the experience with myasthenia. Although you and your child might know that MG is not painful and not a terminal illness such as cancer, their friends/classmates and their parents, may not know. It might be a good idea to meet in a familiar setting to answer questions that friends/classmates might have about whether the MG disease hurts, the effects of MG, and what they should do if their friend/classmate asks for help. Some students with MG have presented to their classmates or at a school assembly about what MG is, how it affects him or her, and how in all other aspects they are the same.



## The Laws

### *IDEA – Individuals with Disabilities Education Act*

Your child may qualify for help in school under different laws. These include the Individuals with ***Disabilities Education Act***, Section 504 of the ***Rehabilitation Act*** and the ***Americans with Disabilities Act***. These laws are described below. Explore with the help of your child’s health care provider with of these laws are applicable to your child’s situation and needs. The following introduces key elements of these laws and provides some guidance on how to use the IDEA especially. You can find additional information about these laws through an internet search and some helpful resources are listed below.

***The IDEA*** is a federal law aimed at helping a child with a disability to thrive in a school setting that is the least restrictive. Your child’s school needs to comply with the IDEA requirements, if it receives federal funding. Most public elementary and high schools receive federal funding. The Office of Special Education and Rehabilitative Services (OSERS), within the U.S. Department of Education, oversees the IDEA.

In order to receive services under IDEA, a student must meet the criteria. She must have at least one of 13 disability categories. These include visual, hearing, or academic impairment. Schools are now required to assist with the functional goals of a child. Previously they had a limited obligation to assist only with academic goals. This update is significant for a child with MG. She might be keeping up academically, but having physical difficulties due to neuromuscular weakness.

The IDEA lists several disability categories. To be found eligible, a child must fit at least one of these categories:

- Autism
- Blindness – see visual impairment
- Deafness
- Deaf-blindness
- Developmental delay
- Emotional disturbance
- Hearing impairment
- Intellectual disability
- Multiple disabilities
- Orthopedic impairment
- Other health impairment
- Specific learning disability
- Speech or language impairment
- Traumatic brain injury
- Visual impairment, including blindness

An article *Evaluating Children for Disability* is available at <http://www.parentcenterhub.org/repository/evaluation/#idea>

You can also find another helpful article, *10 Basic Steps in Public Education* by going to: <http://www.parentcenterhub.org/repository/steps/>

**The Individualized Educational Plan (IEP):** The IDEA lays out a formal process with the goal of ensuring that a child's schooling meets her needs. This includes education in a regular classroom when possible. The formal planning process will result in a plan specific to your child. The Individualized Educational Plan (IEP) is developed by school personnel, along with the child with a disability, and her parent(s). It lists the goals and the services needed to reach the goals for the child, including specialized instruction.

This law is a federal mandate. However, each state has individual requirements. The difference among states is less for children who are eligible because of medical or health problems than for those who are eligible because of learning problems.

A parent can request an IEP evaluation for his child at any time. Federal law requires this initial evaluation to be completed within 90 days. A meeting is held with school personnel and the family to review results of that evaluation and to develop an IEP for the child if they are determined eligible.

Prior to that meeting, it is a good idea for parents to prepare. For instance, list one to three objectives that you find important for your child. As you work to identify these objectives, think about what your child needs in order to succeed in school. Review the following outline for tips and ideas on how to make the most of your IEP meeting.



- Seek the best solutions possible for your child. If you are told that the school district won't cover a service you believe to be necessary, ask to see the Individuals with Disabilities Education Act (IDEA) section that supports this.
- Summarize the meeting as you understand it. Repeat the main points you heard during the meeting to ensure that everyone understands these in the same way. Refer to your P.A.R.T. - prepare, ask, repeat, take action, preparation.
- Take the IEP drafted in the meeting home to re-read before signing it, especially if you have any remaining doubts or concerns.

#### **After the IEP Meeting**

- Write a letter or email summarizing the important decisions or questions that arose. Send it to the case manager. Keep your own copy.
- Review and sign the final version of the IEP by the deadline and keep a copy. Before you sign, compare it to your notes from the meeting.
- Send thank you notes to all those who attended the meeting. Be sincere and mention how they made a difference.
- Talk with your child about the IEP. Keep in mind his age and maturity. Speak in concrete terms. Focus on the positive, but also share the challenges. If your child participated in the meeting, get his/ perspective. Let your child know how you value her efforts and praise what he's done well.
- Organize your records, notes, the IEP, etc. so that you can easily find these documents in the future.

The end result of the IEP planning process is a specific plan which outlines what services the school provides, who will provide the services, the frequency of those services, and the goal sought for the specific objective.

## **Section 504**

In contrast to the IDEA, *Section 504 of the Rehabilitation Act* has more general requirements and a less formal planning process and plan. What this means for a student with MG is that he might be able to get educational services under Section 504 even though he did not meet the requirements under IDEA. Because the individualized program of aids or services is developed in a less formal manner, it might also mean that the plan and provision of the services might occur more quickly if it is provided under Section 504 rather than IDEA.

A student is eligible for Section 504 if he has a physical or mental condition that substantially limits a "major life activity." Major life activities for a child in school include

- walking
- talking
- breathing
- caring for oneself
- learning

The disability must be substantially limiting to the extent that the student needs specialized services or accommodations in order to participate in school activities.

The goal of Section 504 of the Rehabilitation Act is similar to IDEA. Its goal is to ensure equal access to students with disabilities. The plan is less detailed and specific than the IDEA act. The plan does not have to be written. Parents are not required to participate in the planning process. Section 504 plans may include any of the services covered in the IEP, except for specialized instruction services. For more about Section 504, see these resources:

<http://www.greatschools.org/gk/articles/section-504-2/>;  
<http://www2.ed.gov/about/offices/list/ocr/504faq.html>.

## *The Office of Civil Rights*

The Office of Civil Rights (OCR) is a unit within the U.S. Department of Education. The OCR is charged with ensuring that a school district provides a "free appropriate public education" (FAPE). The FAPE is required for each qualified student with a disability, who is in the school district. This is the case no matter the nature of the student's disability. Under Section 504, FAPE involves the provision of regular education or special education. This includes related aids and services designed to meet the student's individual educational needs. And, it should do so as adequately as it addresses the needs of other students.

## *ADA*

The Americans with Disabilities Act (ADA), as well as similar state laws, prohibits discrimination against a person with an eligible illness and limitations. The ADA can help in an educational setting. For instance, it can help with providing access to public areas such as bleachers, or stand-alone classrooms. The IDEA and Section 504 are more geared toward educational goals.

### **Extracurricular and recreational activities**

Many of the protections of the ADA, and other federal civil rights laws, do not apply to "bona fide" private membership clubs. Such clubs are exempt from paying taxes under Section 501(c) of Title 26 of the US Code. Organizations such as the Boy Scouts and Girl Scouts of America are considered bona fide private membership clubs. But these organizations often have their own policies for ensuring that children with disabilities are included in the activities of the organization. As always, the best approach is to build a harmonious relationship with the activity organizer. Provide information about your child's medical condition that will keep your child safe and able to participate.

## Further Resources

For more information on these medications and therapeutics, see the MGFA's brochures on each at <http://myasthenia.org/LivingwithMG/InformationalMaterials.aspx>.

- MGFA can offer important resources to the physician open to learning more about MG. Visit [www.myasthenia.org/HealthProfessionals/EducationalMaterials](http://www.myasthenia.org/HealthProfessionals/EducationalMaterials) 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.I>. It can only be viewed on an Apple device.
- Visit the MGFA website to learn more about MG and to find other resources for parents of children with MG. Here are a few:
  - Your Child and Exercise -- <http://www.myasthenia.org/LinkClick.aspx?fileticket=-VVS9MCpDuQ%3d&tabid=339>
  - 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>
- **Other Non-Profit & Service Organizations & Websites:**

Get more information and ideas from other expert sources.

  - American Psychological Association [www.apa.org/helpcenter/chronic-illness-child.aspx](http://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](http://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](http://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/>.
- **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](http://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*.

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