

Caring for Children and Supporting Adolescents with Myasthenia Gravis

Every child's story and course with an illness like myasthenia gravis is different. The general issues outlined below are helpful suggestions but need to be considered in the overall context of your own child's health and everyday life. Your child's doctor will be a great potential source of information and help. The Myasthenia Gravis Foundation of America can also provide information and support.

Daily Schedule

- 1. Regular Sleep:** Everyone's health improves with regular and enough sleep. However, this is very important for individuals with myasthenia gravis.
- 2. Scheduled Rest:** Planning for quiet rest periods throughout a busy day or week is very helpful for individuals with myasthenia gravis. For example, not scheduling a birthday party on the same day as other after school activities like soccer practice or karate lessons is very helpful.
- 3. School Issues:** Informal discussions with the school, a Modification Plan under Section 504 of the 1973 Rehabilitation Act or an Individualized Education Plan under Federal Law 108-446 are different ways that a child's daily school schedule can be changed in response to medical needs. Many things can be done, as needed, to support the education of children with myasthenia gravis. These include: altering PE requirements (modified PE or temporary or long term exclusion), late starts, use of elevators between floors,

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This is an example of why it would be useful to contact the local EMS system and arrange for a scheduled meeting to make certain that the first responders and others are familiar with myasthenia gravis. Written materials can be obtained from the Myasthenia Gravis Foundation of America to provide needed background and a suggested outline of emergency response.

This information might seem overwhelming at first. However, it is important to recognize that with good ongoing health care and monitoring, the majority of children with myasthenia gravis have very normal and active lives.

The MGFA mission is to facilitate the timely diagnosis and optimal care of individuals affected by myasthenia gravis and closely related disorders and to improve their lives through programs of patient services, public information, medical research, professional education, advocacy and patient care.

This publication is intended to provide the reader with general information to be used solely for educational purposes. As such, it does not address individual patient needs, and should not be used as a basis for decision making concerning diagnosis, care, or treatment of any condition. Instead, such decisions should be based upon the advice of a physician or health care professional who is directly familiar with the patient. The information contained in this publication reflects the views of the authors, but not necessarily those of the Myasthenia Gravis Foundation of America (MGFA). Any reference to a particular product, source, or use does not constitute an endorsement. MGFA, its agents, employees, Directors, Chapters, its Medical/Scientific Advisory Board, and its Nurses Advisory Board or their members make no warranty concerning the information contained in this publication. They specifically disclaim any warranty of merchantability, fitness for any particular purpose, or reliability regarding the information contained herein, and assume no responsibility for any damage or liability resulting from the use of such information.

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transportation to school, allowing additional time between classes, providing a second set of books to be kept at home to prevent heavy backpacks that cannot be carried from affecting schoolwork, changing the number of repetitions of math problems, allowing computer access for classroom work or testing, changing nutrition/lunch times, providing OT/PT/Speech therapy as necessary to allow children to benefit from their education. All or none of these modifications may be appropriate for an individual child with myasthenia gravis.

Medications

- 1. Dose and Timing are important:** Each child's best schedule of medicine for myasthenia depends on their size, their own type and stage of disease and other aspects of their health. However, it is important that once that **BEST** schedule is identified, that the children receive their medication with the right **dose** at the right **time**. If there are issues relating to after school care, parent's work schedule and so forth, it is important to discuss these with your child's doctor so you can develop a schedule for giving medication that can be kept up on a daily basis.
- 2. Refills/emergency supply:** It is important to know when current supply of medicines will run out and to plan for refilling medications for your child's myasthenia. The amount of medication given to families at one time depends on the insurance companies who decide whether they will provide one month or up to three months at a time. In general, it isn't good to try to keep more than three months at a time as the medicine could become outdated. Don't use medicine after the expiration date on the label. You should discuss the issue of emergency medication supply with your child's doctor: i.e. what phone number to

call if the medication is lost or stolen either at home or while travelling. Including a supply of medication in emergency or evacuation plans for threatening weather systems (floods, hurricanes) is important.

- 3. New medicines (prescription or over-the-counter):** Some medicines (including herbal medicines and ones available at drug stores without prescription) can affect the transmission of the signal between nerve and muscle. This could worsen a child's control over myasthenia gravis. Therefore, **DO NOT** give your child a new medication without discussing it with the pharmacist and/or your child's doctor. While there are some lists of medications to avoid in myasthenia, the list alone cannot be depended on as there are medicines on the list that can be used under a doctor's supervision, when needed, and other medicines that are not on the list that should be avoided. Always ASK before starting a new medication.

Supervision

Need to Know: Parents have the right to protect the privacy of their children, including who knows about the child's medical problem. However, as children grow, parents include other adults (family members, teachers, neighbors, group leaders and coaches) in a larger group of responsible adults who supervise their children during the day. Since myasthenia gravis can be unpredictable, it is important that parents create an environment where all responsible adults know that changes in strength or function in a child with myasthenia gravis are paid attention to. If a child develops double vision and complains of "blurry vision", an adult who doesn't know about the myasthenia may think the child has dust in their eye. An adult might think that a child who suddenly has garbled speech and drooling is "trying to be funny". If the supervising adults are aware of the problem and have a plan about who should be contacted, the change in function can be handled safely, quickly and with as much privacy as possible.

Accessing Emergency Care

- 1. School Emergency Plan:** Schools assign responsibility to someone (generally a nurse) to identify children with various health problems (including asthma, serious allergies, immune suppression as well as myasthenia gravis) and to develop emergency action plans. Participation of parents and a child's doctor allows the school to know what specifically they might expect in terms of symptoms (although they understand that unexpected problems might also occur) and to know what the recommended action should be on their part. While paperwork is always a hassle, this opportunity to make suggestions and requests for action on the part of the school is a very valuable opportunity to protect your child's health.
- 2. Authorization to Treat for Coaches, Group Leaders, Family/Friends who provide Supervision:** All people will receive emergency medical care under life-threatening circumstances. However, when the situation is less severe, adults providing supervision to your child needs to be able to either contact a parent or legal guardian immediately and at all moments to get authorization for medical treatment or to have written, notarized permission from you to provide that consent on your behalf. Since it is generally not possible to guarantee that phone lines might not break down or mobile phone transmission might not fail, it is important to think about this issue and consider providing authorization to selected adults. Sometimes having that authorization at the emergency room/institution that will provide the emergency care until you can be reached is most efficient.
- 3. Meet/Greet EMS teams:** Myasthenia gravis is a relatively uncommon disorder. Therefore, in large cities, the emergency medical system will be familiar with this disorder. However, in small communities, particularly ones that depend on volunteer EMS teams, the initial responders may not be familiar with myasthenia and the possible, urgent health issues that can arise. In that setting, some myasthenic patients have felt that their care was delayed while an extended history or interview was attempted while their shortness of breath or weakness made it difficult to respond.