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MYASTHENIA GRAVIS
FOUNDATION OF AMERICA

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, 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.

355 Lexington Avenue, 15th Floor
New York, NY 10017-6603
800-541-5454 (Helpline)
212-297-2158 fax
MGFA@Myasthenia.org

www.Myasthenia.org

Approved by the MGFA Medical/Scientific
and Nurses Advisory Boards

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CHILDREN AND ADOLESCENTS

Caring for Children and Supporting Adolescents with myasthenia gravis

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www.Myasthenia.org

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 should be considered in the overall context of your own child's health and daily life. Your child's neurologist will be a great source of information and help. The Myasthenia Gravis Foundation of America (MGFA) can also provide information and support.

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, transportation to school, allowing additional time between classes, providing a second set of books to be kept at home to prevent heavy backpacks, changing the number of repetitions of math problems, allowing computer access for classroom work or testing, changing nutrition/lunch times, and providing OT/PT/Speech Therapy as necessary. All, or none, of these modifications may be appropriate, depending on your child's individual needs.

Daily Schedule

1. **Regular Sleep**: Everyone's health improves with regular and adequate sleep. However, this is especially important for those 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 after-school activities 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 ways that a child's daily school schedule can be altered in response to medical needs. For more information on this, please visit our website at myasthenia.org.

Medications

1. **Dosing and Timing are Important**: The medicine schedule that works best for your child depends on their size, type of myasthenia, stage of disease and other health considerations. Once the schedule that works best for your child is identified, it is important that they receive 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 maintained on a daily basis.
2. **Refills/Emergency Supply**: It is important to know when the current supply of medicines will run out and to have a plan for refilling medications. The amount of medication given to families at once depends on health insurance, which will approve a one-

month or three-month supply. In general, it is not recommended that you keep more than a three-month supply as it could expire or decrease in potency if not properly stored. Do not 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 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 myasthenia gravis. Therefore, DO NOT give your child a new medication without discussing it with the pharmacist and/or your child's doctor first. While there are some lists of medications to avoid in myasthenia, the list does not take into account your children's condition or health issues. For example, some medicines on the list can be used under a doctor's supervision as needed and there are other medicines not on the list that should be avoided completely. Always ASK before starting a new medication.

Need to Know

Parents have the right to protect the privacy of their children, including who knows about a 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**: All people will receive emergency medical care under life-threatening circumstances. However, when the situation is less severe, adults providing supervision to your child need may need to contact a parent or legal guardian to get authorization for medical treatment, or to have written, notarized permission from you to 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 or facility that will provide the emergency care until you can be reached is most efficient.
3. **Meet Emergency Medical Service (EMS) Teams**: Myasthenia gravis is a relatively uncommon disorder. 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. 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 first responders and others are familiar with myasthenia gravis. Emergency management brochures and alert cards are available at myasthenia.org or by contacting us.

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