

Myasthenia Gravis & Teens

What You Need to Know

- MG is a Autoimmune Disease that affects the transmission of nerve signals to your muscles
- No one knows how you get it. Nothing you did made it happen.
- It is not fatal, but chronic which means you will always have it.
- Some days you will feel tired, and others you may feel fine
- Some people go into remission for long periods of time. Remission means you don't have symptoms (but you still have MG).
- MG is managed with medication or treatments.

How Can MG Change My Life

- Arms and legs may tire easier. Activities like walking, climbing stairs, dancing, or running may be altered.
- At times you may need to eat softer food or eat slower because you may have difficulty chewing or swallowing.
- Your strength and stamina may change daily, so you may need to plan some activities to avoid tiring yourself out. You will usually feel stronger in the morning after a goodnight's rest.
- Feelings of sadness or anger are normal for anyone who learns they have a chronic disease. If it makes you feel overly anxious or depressed let your nurse or doctor know.

Will I Look or Act Differently

- It depends on what muscle groups are affected.
- If you are experiencing overall weakness, you may not feel very energetic. At times you may not be able to participate in Phys-Ed. class.
- At times you may have droopy eyelids, or you may have double vision. During these times you should not drive.
- If your facial muscles are affected, you may have a lop-sided smile or possibly look mad or sad.
- If your neck muscles are affected, you may have trouble holding your head up. Teachers may think you are sleepy or not paying attention. Textbooks may be too heavy to carry. Accommodations may have to be made for school.
- Symptoms may change from day to day.

Will I Need Medication

- Most likely. There are medications that work on symptoms, like Tylenol® works on a headache, and there are medications that work on the blood cells of the immune system.
- Learn about these medications – ask how they work, the possible side effects, when you should take them, what to do if you miss a dose.
- Ask for printed material regarding your medications
- Report any side effects to your doctor or nurse.
- **Always keep a list of medications in your wallet or purse**
- At school make sure your teachers know how important it is you take your medication on time.
- If you are traveling, keep your medicine in your pocket or purse. If your luggage gets lost, you will not be without your medicine. If flying, your doctor can provide you with prescription asking that you can carry your medication with you.
- Medication can help manage your symptoms, but they are not a cure.

What Should I Do When I Don't Feel Well?

- **STOP** what you are doing and **REST**. You will find that after a rest period, you will feel stronger.
- If you are out with friends and start not feeling well, ask them to either take you home or call your parents.
- Check to see if you are due for your medicine
- **ALWAYS** carry a card with your doctor's name and phone number as well as a current list of your medications. You should wear a medical alert bracelet to make medical personnel aware of your MG in the event you cannot tell them.
- If you are experiencing trouble breathing, get help right away. This could be an emergency situation.
 1. Call your parents, relative, neighbor or the doctor's office to inform them of your situation.
 2. It is a good idea to keep your cell phone handy for emergency use.
 3. If you need to go to the hospital make sure you take a current list of your medications.

General Good Health Practices

- Get enough sleep. Sleep recharges your batteries! Typically with MG mornings are a good time after a good night's rest.
- Eat a balanced diet. Carrying extra weight around can make you tired.
- Wash your hands several times a day, carry antibacterial gel with you. We get most of the germs that cause flu, colds and infection from our hands.
- Schedule time in your schedule for leisure activities!
- Plan your day, incorporate rest periods between activities.
- **DON'T** push yourself to exhaustion. Exhausted muscles take much longer to recover their strength.
- Stay away from sick people. Any illness can worsen your MG symptoms.
- Learn stress control techniques. Stress can also make symptoms worse.
- Avoid extreme hot or cold. Hot showers or tub baths can drain you of energy.

Why Do I Feel So Scared, Angry or Sad?

- People with a chronic condition (Which MG is) can:
 1. Sometimes become angry or depressed.
 2. Feel upset about what's happening to their bodies.
 3. Be frustrated that others don't understand what they are going through.
- Remember – Your feelings are not good or bad, right or wrong.....they just are.
- It is important you recognize and express your feelings about having MG.

Things you can do to help yourself feel better

- Talk to someone you trust. Let it out. Write in a journal, or create a poem or song about how you are feeling. Don't keep it in; this will only make things worse.
- Take care of your body by controlling the amount of caffeine and sugar you take in. Don't drink alcohol.
- Make sure you are getting adequate sleep every night.
- Keep the lines of communication open with family and friends. Let them know how you are feeling.
- Take some time every day to think and re-energize.
- Try to have FUN time with family and friends.
- Don't be afraid to ask for help. Don't be afraid to ask questions. Don't give up until you find the answers you need.
- If you start feeling really depressed ask your parents, school counselor, or doctor for the name of someone you can talk to.