

## Stress & MG

*The following document was prepared by Judith Schiffbauer, MSW, former social worker for MGA of Western Pennsylvania.*

Most myasthenia gravis patients learn very quickly that emotional stress and excitement affects their MG. Stress causes many physical changes in one's body and uses up energy. The end result of tense muscles caused by stress can be similar to the effect of vigorous exercise – it may exacerbate your symptoms of weakness. Much of the literature cautions people with myasthenia to limit their stress and avoid conflicts, but you might well ask, "How?" when life is by nature stressful and full of conflict. Indeed, stress and conflict can be positive forces such as the challenges that bring about personal growth or the "good" stress that you feel when you're happily excited. Without stress and conflict, life would be boring. The answer perhaps should lie not in eliminating stress in your life, but in learning better coping skills to deal with it.

While the sources of individual stress can be varied and personal, some common sources of stress in the person with MG can be:

- MG symptoms and the accompanying frustration and anger when your body can't do what you want to do when you want to do it.
- Anxiety from continual worry that new symptoms may appear; anticipation of day to day fluctuations in strength, or a fear of crises. Anticipation of medication side effects such as diarrhea or potential long term side effects of steroids can also cause anxiety.
- Dissatisfaction with personal appearance. Drooping eye lid(s), weight gain (fluid retention), weak facial muscles (causing an inability to smile), and slurred speech can cause loss of confidence, lowered self esteem, and avoidance of social contacts.
- Significant changes in lifestyle, such as having to quit your job, going back to school, giving up caring for the home, yard, and children. These are the things that are part of your identity. When you lose them, you may feel depressed and cheated at times.
- Interpersonal relationships may be strained as you (and your family) try to cope with the limitations of MG and changes in your lifestyle. The person with MG may believe their status and family role has become less important and even feel like a burden on the family.
- The range of emotions you may feel from time to time (a few herein mentioned were frustration, anger, guilt, depression, fear and anxiety) may be difficult to handle. Emotions which run rampant or mood swings can cause family members to "walk on eggshells" around the person diagnosed with myasthenia gravis.
- Feeling stigmatized by MG or believing that one is somehow different from others. This can lead to withdrawal from social activities and a sense of remoteness from family, friends and co-workers.
- Lack of understanding about MG, when family members and friends find it difficult to understand why weakness can vary daily or even hourly (especially when you look well), it can leave them feeling cheated and resentful. When MG is a mystery to you, it can leave you fearful of the unknown.

Here are a few constructive steps one can take to minimize stress:

1. First, realize that it's okay sometimes to feel frustrated, scared, angry, and depressed. All of us do. Accepting your illness doesn't mean you have to like it. It only means that you realize your body has some limitations, and denying it won't make it go away, so you might as well work at having the best life you possibly can. In other words, concentrate on all that you can do, all that you have, and all that you are (which certainly is a lot!) rather than concentrating on what you cannot do.
2. Avoid self-pity. It builds stress, zaps your energy, and doesn't help you. As Abraham Lincoln once said, "Most people are about as happy as they make their minds up to be".
3. Take charge of your life. You control our own behavior and attitudes, and can work on developing more positive behavior.
4. If you've always been an overachiever and you are still pushing yourself too hard, learn to slow down. You may be able to do almost everything you used to do if you balance your day with periods of activity sprinkled with little periods of rest.
5. If you have always been an underachiever and an inactive person, resist using MG as an excuse for doing even less. When you use your diagnosis as an excuse too often when you don't need to, you run the risk of reducing your credibility with your family. Because the weakness is often invisible to others, they find MG hard to understand anyway. Try to remain active and involved with your social groups, finding activities which are within your limitations.
6. Know yourself. MG affects everyone differently. While some people are severely weak and fatigue rapidly, other MG patients are working full time, jogging and playing racquetball. It is important for you to learn what your own capabilities and physical limitations are. Venture trying new activities. Pace yourself; know when to slow down or when you've had enough. Get enough rest and sleep.
7. If family members don't understand MG, try to involve them in your treatment, encourage them to ask your doctor questions, take them to MG meetings so they can learn more about this muscle weakness disorder. The same applies to your friends. Many MG patients conceal the fact that they have a problem from others, and that's okay. It's not always appropriate to broadcast it, particularly when it could jeopardize a job. But if you want to explain it to some of your close friends, it may help reduce your stress. Remember: "A friend is someone who knows you well . . . and likes you anyway!"
8. If you don't understand MG very well, don't be afraid to ask questions about anything and everything that concerns you. Between appointments with your doctor, make a list of your questions and symptoms that you want to mention. This can help prevent the stress of "Why didn't I remember to ask about . . .?" Many anxieties and fears about MG are unfounded, and learning more about myasthenia gravis can put your worries at ease.
9. Learn how to express your emotions constructively with your family members and close friends. Communicating your thoughts can aid mutual understanding and support, and bring you closer together at a time when you need it most.

10. Consider others more and yourself a little less. Love more. Love can be as healing as potent medication.
11. Laugh more; it relieves stress. Learn to laugh at yourself, so you don't take yourself too seriously.
12. Avoid loneliness. Seek out compatible friends. Take the initiative; join clubs or take a stimulating class. Participate in MG activities where the support from other people with myasthenia can erase that feeling of being alone with this disorder.
13. Take time each day to make the most of your personal appearance. Good grooming habits, pretty makeup, an attractive and easy hairstyle, and flattering clothing which conceals or distracts the eye from weight gain all go a long way. For diet tips which can help minimize fluid retention, ask your nurse or dietician. If your health permits, get regular exercise. Exercise helps work off stress. Start out slow with an early evening walk or a game of croquet on the lawn. It's pleasant time spent with family, too.
14. Develop hobbies and interests such as reading, needlepoint, exotic cooking, or painting. Immersing yourself in a hobby helps dissipate tension.
15. Look into stress management classes or go to your library for books or tapes on relaxation techniques. A few techniques include meditation, yoga, or visualizing restful scenes.
16. Seek professional counseling when your self-concerns or family problems threaten to overwhelm you. All of us need extra help at difficult periods in our lives. These behavioral tips are not magic, but with practice, they can help you to reduce stress and become happier. So make the effort – it will be well worth it.