

## **“How do I provide emotional support to a loved one who has MG?”**

Most myasthenics believe that the support of their family and friends is extremely important to their task of coping with this disease. Your willingness to be a part of your relative's support system is quite valuable toward his/her well-being.

Recognize that your relative has experienced a loss, i.e., a loss of muscle strength, perhaps also a loss of functioning at home, at work or at play, and a loss of a perception of themselves as having a “well body”. Therefore, allow them time for grieving their losses. The stages of denial, anger, bargaining, depression and acceptance are normal for people coming to terms with any type of major loss.

Let them know that you are there to listen when they want to talk. Offer your presence and your time. Don't feel that you must solve all of their problems or give advice. Sometimes a good listener who genuinely cares is all that is needed.

Empathize rather than pity. Empathy conveys your understanding of the other person's feelings, whereas pity conveys only your distress at your perception of their suffering. Pity is not welcomed by most myasthenics because they find it demoralizing. Your distress about their illness also compels them to help you feel better by offering your assurances that they will be all right.

Learn as much as you can about MG. Request literature from your local MG chapter. Attend MG meetings or support groups with them if such programs are provided in your area. With your relative's permission, you may want to accompany them to their doctor's appointment so that you may hear, learn and ask questions.

Myasthenics may need help with certain tasks, but find it difficult to ask for help. They are reluctant to bother people who they know are busy with their own responsibilities. Offer to perform specific tasks periodically, such as helping with child care, hair styling, shopping for groceries, clothing, or their Christmas gifts, wrapping their presents, driving them to a doctor's appointment or taking them out of the house for a social excursion.

Be prepared for the unpredictable ups and downs of MG. The myasthenic may have to cancel an eagerly awaited social outing due to unexpected weakness. Do not feel hurt or suspect that you are “singled out” for these cancellations. Many myasthenics hesitate to make advance plans, preferring instead, to do things when they feel strong enough.

Now for a few “don'ts.” Don't give simplistic advice like, “Maybe you should just take vitamins...exercise more...eat better...get more rest,” etc. Chances are they already have opinions about these things, and your statements reveal that you don't understand the disease. Don't minimize or dismiss their complaints with “if you wouldn't dwell on it, it wouldn't seem so bad.” No one can be expected to be stoic and brave at all times.

Myasthenics frequently hear the comment, “but you look so well!” While you may give this compliment intending to boost their moral, myasthenics often think that you are doubting that they are indeed ill. Although the myasthenic may look like the picture of health, be aware that the symptoms of muscle weakness and rapid fatigue are not always visible to your eyes.

Don't disappear from the scene because you don't know what to say or fear saying something that would make it worse. Most myasthenics welcome your questions about MG and appreciate the opportunity to talk to someone who cares to listen.

Don't withdraw from a loved one because you suspect an “emotional powder keg” will explode if you bring up a problem they are having. Rather, if you or they ignore a problem, it is bound to worsen or grow more awkward to handle. If talking about it brings tears, don't run away. Tears can be quite healing. A touch of the hand or a hug in silence can convey more comfort than any words or advice ever could.

While being a good listener is an important part of offering support to your relative, they also value a friend who can be honest with them. You can let your relative vent his/her anger, frustration or bitterness, then later at a better moment, offer your honest feedback. Try to recognize when your relative needs help beyond what you can offer and encourage him/her to seek professional counseling.