

## WHAT DO I DO NOW?

This is a sample chapter from **You, Me and Myasthenia Gravis**, a complete guide to Myasthenia Gravis for patients and physicians. The book is now in its third edition and covers vital topics such as:

- \* The Immune System and MG
- \* The Symptoms of MG
- \* How Is MG Diagnosed?
- \* How Is Myasthenia Gravis Treated?
- \* The Autoimmune forms of Myasthenia
- \* The Congenital Myasthenias
- \* Myasthenia in Children
- \* Issues of Daily Life
- \* Psychological Issues and MG
- \* Patient's Experiences
- \* and more

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**9****WHAT DO I DO NOW?**

The newly diagnosed myasthenic may react with relief, shock, grief, despair, or any combination of emotions. It takes time to adjust to a chronic illness. Long cherished plans and dreams may have to be abandoned, some temporarily, others forever. For a time it may seem that the dominant focus in one's life is MG, but as adjustment comes balance can be achieved. The fact that one has MG is eventually assimilated and the necessary adaptations are made.

As the patient becomes aware of his own personal pattern, and learns to work within it, life is not so constricted. Physical limitations can usually be worked around or planned around, though many MG patients have to live with some amount of physical disability.

**GRIEF FOR "OLD" SELF**

When myasthenic symptoms develop rapidly the contrast between before and after is sharp. The diagnosis may be devastating, like the sudden and unexpected death of a loved one. For a patient whose strength has gradually declined the diagnosis (at last!) may initially come as a relief, but when the sense of relief fades there is still a sense of loss.

The newly diagnosed patient may feel as if they are riding an emotional roller coaster. This is to be expected. The formerly reliable self has assumed a new and unpredictable aspect. There may be a change in roles when a wage-earner or homemaker becomes partially or totally dependent. Treatments and medications may cause pain or discomfort. It would be stressful for a healthy person to deal with. It is even more difficult to cope when in the grip of illness.

Patients often go through a grieving period similar to that associated with other kinds of loss. And, as with any loss, grief must be worked through before adjustment can be achieved.

Some patients will not allow themselves to grieve or will not acknowledge their grief. But grieving is a process, a kind of journey, which ends in adjustment. Grief follows a recognized pattern which has five stages.

### **STAGE 1: DENIAL**

An emotional numbness descends after any significant trauma. For a time the person may not feel anything at all, may deny that anything is wrong, or deny that what has happened has affected them deeply. This denial may be emotional, verbal or physical, as in the patient who refuses to slow down and rest, but continues to push from one crisis to another.

### **STAGE 2: ANGER**

“Why *me* ?” a patient may ask. “I’ve never been sick a day in my life!” Anger is sometimes directed at the doctor, the hospital, the medical establishment, family, friends, God, the family dog or any other nearby person or object. It’s helpful to realize that this anger has its roots in frustration, disappointment, fear and emotional pain. Even when we are angry it’s appropriate and necessary to let those around us know that they are not the source of our anger. Anger is something we must take personal responsibility for, and work through.

It’s been taught for years that we shouldn’t hold anger in, that it’s better to “let it all out”. But new evidence has proven that just the opposite is true. By following patients with implantable cardiac defibrillators (ICDs) cardiac researchers have learned that expressing anger is a potent trigger for heart attacks, unstable heart rhythms and strokes. Studies now show that angry outbursts put cardiac patients at risk for life-threatening events.

Since cardiac disease is the nation’s number one killer most of us are potential cardiac patients. Living with unresolved anger is like living in a cage with a tiger. If you have anger issues and can’t handle them on your own find an experienced counselor who can guide you.

### **STAGE 3: BARGAINING**

Bargaining generally doesn’t last long, and may merge into the first and second stages. The futility of trying to bargain one’s way out of MG is quickly apparent to most people and is soon abandoned.

**STAGE 4: DEPRESSION**

Depression may arrive when we fully realize that this illness may cause long-term changes in our lives. We mourn the loss of our healthy self, and ambitions, dreams and opportunities we may have long held dear.

Depression can range from transient sadness to the total deep freeze of dysfunction. The depressed person may literally cry over spilled milk. Depression of a minor nature may not interfere with day-to-day function, but it may make life seem dull, worthless and miserable. Serious or major depression may include a number of symptoms which signal that professional help may be needed.

1. Change in sleeping patterns – sleeping far too little or too much.
2. Mood alterations which go on too long in relation to the cause.
3. Listlessness, lack of interest in things that formerly gave pleasure.
4. Inability to concentrate.
5. Eating too much or too little.
6. Inappropriate feelings of guilt.
7. Suicidal thoughts.
8. Feeling of worthlessness.
9. Loss of interest in sex or inability to have sex.
10. Lack of energy which increases over time. This can be misconstrued as “weakness” and lead to an increase in doses of Prednisone®, which can worsen the situation.

If a person has more than one or two symptoms of depression for a period of more than two weeks it is time to seek help. Prednisone® can cause mood changes, including irritability, insomnia, mania<sup>54</sup> and depression, and if these side effects appear they need to be addressed.

Should a person threaten or talk about suicide, or appear to be contemplating suicide, medical help should be sought immediately. The family physician may be able to give appropriate advice and guidance, but studies suggest that family physicians often overlook depression in patients. If the family physician is hesitant seek help from a mental health agency or professional.

Mild depression forces us to stretch our limits and it can be a useful prod. It may make us look for alternate solutions simply because it is such an uncomfortable and miserable state of mind. Severe depression on the other hand may cause such apathy that the

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54 Mania: A state of extreme overactivity and high mood.

patient cannot marshal the force of will required to shake it. If depression is taking too long to resolve it may take professional help to affect the change from negative to positive, but it can be done, sometimes more quickly than thought possible. If medication proves necessary the new antidepressant medications are excellent and have far fewer side effects than older medications did.

### **STAGE 5: INTEGRATION**

When we have taken stock, evaluated what is left, and have determined to do the best we can with what we have, we have adjusted. Old dreams may be replaced by new ones, but these can be as much of a challenge and ultimately just as satisfying. Options may have narrowed, but while reevaluating our lives we may discover opportunities we never dreamed of before.

Every patient goes through a period of adjustment. The time it takes to adjust will vary according to the individual. Some people are resilient and bounce back quickly from the stresses of life. For others it is more of a struggle.

Joining a support group composed of other patients may help the newly diagnosed myasthenic understand and come to grips with the disease. Even if you aren't a joiner by nature it's comforting to see others coping successfully with MG. These groups also give one the opportunity to compare attitudes and coping methods, because while every individual must develop their own, it helps to see what works best for someone else.

Basically there are two ways to cope; positively or negatively. Positive methods of coping reduce anxiety, bring peace of mind and restore the patient's inner equilibrium. Negative methods cause or reinforce anxiety, isolate the patient emotionally and induce stress.

### **COPING STRATEGIES**

#### **SOME POSITIVE METHODS OF COPING INCLUDE:**

##### **1. SEEKING INFORMATION**

It's human nature to fear the unknown. Most patients want to know as much as possible about the disease. It's also helpful and of great emotional support to know how other patients manage. Information and peer support can be found through MG chapters, and through MG forums and chat rooms on the internet.

**2. SPIRITUAL CONSOLATION**

Gaining strength from one's spiritual values, prayer, faith communities, meditation and a belief in a benevolent Higher Power or greater purpose.

**3. POSITIVE THINKING**

Remaining optimistic, and refusing to give in to the blues. Changing one's thoughts when they become sad or fearful.

**4. TALKING IT OUT**

Verbalizing concerns, fears, anger with family, friends and other patients, seeking professional help when needed.

**5. RECOGNIZING LIMITS**

Seeking to maintain a realistic level of independence while accepting the fact that some dependence on others may be necessary.

**6. MAINTAINING A STRONG SOCIAL NETWORK**

Close ties with family, friends and a strong support network are vital to both emotional and physical health. Helping others who may have just been diagnosed or are having problems adjusting is also a healthy coping mechanism.

**7. PHYSICAL ADAPTATION**

Maximize physical capabilities by analyzing the daily routine, and adapting it to conserve energy. Learning to rest when needed, rather than push beyond your capacity.

**AMONG NEGATIVE METHODS OF COPING ARE:**

**1. DENIAL**

Denial can take several forms, denying the diagnosis, non-compliance with treatment, or pushing the body too hard. There is a difference between saying, "I'm not going to let this get me down!", and "I'm not going to give in to this disease an inch!" It's healthy to do as much (or sometimes a little more) as one can. It's not healthy to consistently demand more of the body than it has to give.

**2. BLAMING**

Bitterness or anger towards oneself or someone else is not healthy. Sometimes people feel they have become ill because they

were bad, or that their worth as human beings is diminished by their illness. If we look around we see that illness is part of the human condition and we are not the only one dealing with it. Moreover, anger, bitterness or guilt interfere with the process of adjustment and may weaken our ability to heal.

### **3. FOCUSING ON ILLNESS**

Allowing the illness to take over and control the entire life, letting it become the main focus of the thoughts, feelings and conversation or the only factor considered in decisions.

### **4. WITHDRAWAL**

Isolating oneself socially, giving up friends, interests and activities unnecessarily.

### **5. DEPRESSION**

Sinking into apathy, sleeping too much or too little, engaging in obsessive behaviors, giving up on life.

### **NO ONE COPE WELL ALL THE TIME**

It's unrealistic to expect a person with a chronic illness to always be upbeat and optimistic, but when a person is having difficulty coping a lot of the time it is useful to look at the attitudes that characterize those who cope well and poorly.

### **GENERALLY SPEAKING PEOPLE WHO COPE WELL:**

1. Are realistically optimistic about being able to cope with or solve their problems and generally maintain a high level of morale.
2. Are practical, ready to tackle immediate problems, rather than postponing action or wishing and waiting for some magical future solution.
3. Formulate a backup plan in case the current approach fails.
4. Project the consequences of their actions, reasoning from cause to effect.
5. Listen to suggestions, but retain the right to make their own decisions.
6. Tend to be emotionally stable, avoiding emotional extremes that might impair their judgment.
7. Are able to ask for help when they need it.

**PEOPLE WHO COPE POORLY:**

1. Tend to have unrealistically high expectations for themselves and find it difficult to compromise or ask for help.
2. Tend to be intolerant; see only in black and white.
3. Tend to deny and rationalize to an excessive degree, rather than face the problem at hand.
4. Find it hard to see and weigh alternatives, and postpone making decisions until a crisis, which may worsen the situation.

These people are not necessarily ineffective in dealing with everyday life, but their inflexibility and lack of confidence hampers their ability to cope in difficult times.

**WHAT'S GOING RIGHT?**

When we are under extreme stress there's a tendency to feel that everything is wrong when there are areas of life that are stable, Recognizing and drawing strength from these sources is an excellent coping mechanism.

**COPING FROM THE INSIDE OUT:**

One way to cope with stress is to turn down our reaction to it. One way to do that is through meditation. Meditation has been practiced in cultures all over the world for thousands of years. It's now being used with increasing frequency by western physicians and health care organizations to treat a diverse range of medical conditions.

The purpose of meditation is to calm the mind and restore a sense of quiet. When the mind is quiet the body can restore the delicate chemical, hormonal and electrical balance that promotes health. When a person is under stress the blood pressure rises, the heart rate and respiration quicken. The immune system becomes less able to deal with invasion and more prone to self-destruction. Blood moves from the skin, hands and feet into the large muscles and vital organs.

When you're stressed your ability to think on your feet tends to vanish because the tiny capillaries in your brain clench down. Thus the blood supply to your brain, with the oxygen and nourishment it carries, is diminished during periods of stress while blood is channeled to the large muscles and heart. In many people stress is a chronic state and a significant contributor to disease states.

There are many ways to reduce stress. Exercise and vigorous physical activity are often promoted as stress reduction techniques. Unfortunately vigorous exercise is not an option for most people with MG. Even gentle exercise regimes like yoga and tai chi can be too strenuous for some MG patients.

One proven way to reduce stress which all MG patients can practice, regardless of strength level, is meditation. Over the last 25 years a whole field of investigation has grown up around the practice of meditation. It is now known that the stress response in the brain is marked by low amplitude, high frequency beta wave patterns. Meditation induces just the opposite effect in the brain, and is characterized by a state with high amplitude, low frequency alpha and theta rhythms.

Harvard University professor Herbert Benson, MD began studying meditation over 30 years ago. He soon proved that meditation can be practiced independently of any religion. The benefits of meditation are available to anyone who is willing to invest 20 minutes of daily practice. It is the practice, and not the religious intent, that brings about what Dr. Benson called the *relaxation response*. Dr. Benson has documented the uniquely altered quality of the meditative state; it's not like sleeping and not like being fully awake. Deep meditation is characterized by distinct changes in metabolism, heart rate, respiration, blood pressure and brain chemistry.

"There is significant data that meditation can enhance healing," says Saki Santorelli, director of the Center for Mindfulness in Medicine, Health Care and Society, University of Massachusetts.

So far, none of the hundreds of studies on meditation have looked specifically at MG. However, stress is associated with exacerbations in many kinds of autoimmune diseases, and many studies have shown meditation can significantly lower stress, chronic pain and anxiety.

Picture a small stream in a forest which a deer has muddied while wading across. Within a few minutes the mud, leaf litter, and debris which was stirred up by the deer has either settled, or has been swept away, leaving the stream clear. Now think of your mind as that stream. While sitting in meditation you allow your troubled thoughts, feelings and daily stress to settle or flow away, leaving your mind clear.

Meditation involves using any number of awareness techniques to quiet the mind and relax the body. Concentration practices and mindfulness meditation are perhaps the best known. These techniques focus on the silent repetition of a word, phrase, sound, or your own

breathing. When attention wanders, it is gently brought back to the focus of concentration.

Meditation allows you to respond rather than simply react to situations in your daily life. Meditation can also be used to get you through unpleasant or lengthy procedures. The ability to meditate can be invaluable at such times.

Meditation is simple to learn, but not easy to practice. It takes discipline to remain still and focused, physically and mentally, for the 20 minutes of daily practice required. But this repetition and stillness are at the core of meditation and the source of its many benefits.

### **HOW TO MEDITATE:**

Choose a quiet spot where you will not be interrupted. If you have a timer, set it for 10 - 15 minutes.

1. Sit quietly in a comfortable position. This can be in a firm but comfortable chair, or even lying down if you are unable to sit up. But the spine should be straight. Those who need to use a chair should sit upright with their feet touching the ground with the palms of the hands resting on the thighs.
2. The eyes should not be closed but the gaze should be focused downward to rest a couple of feet in front of the nose. The gaze is soft. The object is to reduce sensory input as much as possible.
3. Take several long, deep breaths. Breathe using the diaphragm, the lower belly should fill and expand, not the chest. The breath should be relaxed, natural and quiet.
4. Relax your muscles.
5. Breathe in slowly and naturally, and begin counting silently (or aloud if you prefer). As you inhale count *one*, and as you exhale count *two*, as you inhale the next time count *three* and as you exhale count *four*. Continue counting in this manner, focusing entirely on the breath and the count until you reach 10. Then begin again, counting to 10 as you inhale and exhale. If other thoughts intrude stop counting and begin again at *one*.
6. Assume a passive attitude. Don't worry about how well you're doing. When other thoughts intrude, simply acknowledge them, and gently return to your meditation.
7. Continue for your predetermined time.
8. Sit quietly for a minute or so, allowing other thoughts to return. Focus yourself and sit for another minute before rising.

Practice this technique twice daily. Expect it to take three or four weeks before you begin to be able to keep your mind still while you count, and before you'll begin to notice significant benefits. There are many meditation techniques. You may prefer a different technique. There are many books, tapes, CDs and videos available for purchase in bookstores. Just make sure that you are buying one which is consistent with your belief system, if that is important to you. There are also meditation teachers in most towns, so if you want a personal teacher or more information, seek out local resources through community colleges or health organizations.

### **LIFE ON A ROLLER COASTER**

It's important to cultivate a positive self-image. Even though there may be changes in a person's capabilities to perform certain tasks, it's important to remember, "I *have* a body, but I am *not* my body." Your body may find itself strong or weak, it may be well-rested or bone-tired, but that has nothing to do with your real *self*. Your body is an instrument of experience and action, but it is only an instrument. You must treat it well, cherish it, and seek to keep it in the best of health, but never mistake it for your real self: You *have* a body, but *you* are *not* your body.

Life can sometimes be difficult for myasthenics and their families. When a family member is blind, an amputee or is disabled in a predictable way, the family knows what to expect from day-to-day. The family knows what their disabled family member can and can't do, knows what help they need, and what they can manage on their own. Unfortunately the nature of MG symptoms means that abilities vary from day to day. It's often difficult to know what help is needed. Maintaining the balance between dependence and independence is much harder than in cases where disability is consistent.

Unless they are severe, MG symptoms may not even be noticeable to the outsider. The patient may not be strong enough to stand or perform the simplest task and yet may look quite normal. Perhaps, because of the invisible nature of the disease, families tend to forget how limited the strength of the myasthenic can be. Patients (especially mothers) are frequently expected to function well beyond their physical capabilities. Many push themselves beyond their limits. Patients themselves must learn to do what is possible independently, and ask for help when it is needed.

Though the household routine may need adaptation, every attempt should be made to maintain a sense of normal family life. The

patient should be as independent as possible but they should have the necessary support in place for times when they are unable to handle daily tasks.

### **YOU LOOK WONDERFUL!**

It is sometimes disheartening for the myasthenic to hear, “But you look so well!” No one wants to look sick, but somehow it's hard not to feel defensive when it's subtly implied that you couldn't possibly be as sick as you let on. Because myasthenics do tend to look better than they feel, it's easy for others to assume that they are capable of more than they are. It takes courage, determination and creativity to lead as active and joyous a life as is possible under the circumstances. When energy is in limited supply it's wise to spend it carefully on those things that bring you and the ones you love the most happiness.

Most myasthenics can lead normal (though adapted) lifestyles. It may take time to get the disease under control, but many MG patients experience good recovery and some eventually have no symptoms at all.

It's helpful to remember that most myasthenics stabilize eventually and that many others share or have shared your battle – and have won! Attention should be focused on the positives which remain, and not on what has been put on hold or lost. The person with MG may not be able to take their children skating but can listen when they need to talk, which is more than lots of physically active people ever do. It's not what you can't do that makes you the person you are, it's what you do with what you have.

### **SOME WORDS FOR THE FAMILY**

Having a family member with a chronic illness puts an enormous strain on family relationships. Everyone must adjust and learn to cope. Tasks not only must be reassigned and the household routine upset or interrupted, but additional time and energy may often be devoted to caring for the patient.

This may be only an inconvenience if the illness is of short duration, but when the illness is chronic the adjustments may cause serious problems. It is not unusual for marriages to break down under the additional stress of chronic illness, especially when the partner who falls ill is the woman. We have high expectations of ourselves, our partners and of marriage itself. When illness intervenes and it

becomes impossible to even approach (let alone fulfill) these expectations, relationships may literally come apart.

While it may not be true for all MG patients, families often expect more of a myasthenic patient than they are able to give. Because MG is not highly visible and strength levels vary so much, it is easy to forget how disabling the illness can be. It is hard for the unaffected person to fully realize the enormous amount of effort and self-discipline it requires for the myasthenic to perform even simple daily tasks. The loss of the sense of accomplishment, and the lack of control over the illness itself, cause distress enough to most patients. Unfortunately, families often add to the psychological trauma by resenting the changes imposed by the illness.

Roles and relationships may change as the family goes through the grieving process and adapts to the reality of the situation. It is important to maintain realistic expectations, ones which allow the patient both support and independence. Some families find this a difficult process and may need to seek outside counseling. It is unrealistic to expect total patience, total self-sacrifice and unconditional acceptance of anyone. There will be good days and bad, times when the household runs smoothly and times of total chaos.

A great deal of satisfaction can be derived from working together to overcome obstacles. Difficult circumstances can bring families closer together. Unfortunately, many of us have not been taught to persevere in the face of adversity. Past generations were brought up to expect a great deal of hard work and very few comforts. They didn't anticipate easy lives. This very attitude helped them through times of hardship and crisis. Considering that life itself is full of challenges, it seems that this philosophy could be as useful to us today as it was to our ancestors.

The expression of mutual support and a determination to see the crisis through can go a long way toward cementing relationships. Family counseling can be a big help in adjusting to the changes that chronic illness brings to a home. It is very helpful if the entire family understands MG and works to minimize its impact together.