

# Coping with Multiple Sclerosis -- Strategies for you and your family

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Most people are not prepared to deal with the changes in routine and lifestyle that MS may require. Coping with MS can feel overwhelming at times – giving up goals and plans, redefining roles and family structure, changing communication patterns, and dealing with emotional, physical and financial stress. All this can be very hard, even for the most capable of persons and the most stable of relationships.

## Feeling in Control

Trying these first steps in coping may be helpful:

- Acknowledge that you are dealing with a major issue. Do not minimize your situation.
- Clarify the problems that bother you most. Defining a problem is the first step to solving it.
- Ask for help from family and friends if you cannot do as much now as you used to. Trying to do too much can cause frustration, or aggravate fatigue and reduce your overall effectiveness.
- Use emotional support. Find someone with whom you can talk openly and share your feelings.
- Clearly identify your strengths, know what you can do and seek treatment for problem areas.

If you, your family, and/or significant others feel it would be helpful to see a therapist for some emotional support and guidance, please let your health provider know. Your provider can arrange a consult with a

rehabilitation psychologist familiar with MS and its effects and challenges. He or she can also refer you to a physical therapist, occupational therapist, speech therapist or a neuropsychologist to help, as needed.

## **Yoga**

classes, gentle stretching, pacing yourself, building pleasant breaks into your day, can all greatly expand your sense of well being and productivity.

## **Managing Information**

These strategies can help you feel better informed and more in control of your treatment process:

- Use a notebook. Many people find it useful to have one place in which to write and collect information about their treatment. Bring your notebook with you to the clinic. Write down names of staff, information about your disease, your medications, your treatments and notes from talks with staff.
- Ask your doctor to write down the type of MS you have, and then do your own research. Your nurse, doctor, psychologist or the MS Society can provide you with bibliographies and resources.
- Write down questions for your health care providers before you see them and take notes during your meeting. It usually helps to have someone with you during your visits to help remember all that is said. You can bring a tape recorder and make a tape of your meeting to play at home.
- Keep a calendar. This helps you to keep track of visits to see your health care providers, have procedures, tests, etc. Patients use their calendars to look back and see when they had their last MRI, doctor visit, etc. A calendar can be especially helpful for tracking billing charges.
- Reading books and pamphlets may help you become more familiar with medical terminology, so that it is easier to understand what your health care provider is telling you. You can also ask your doctor to suggest articles about your illness and treatment. This manual also has many helpful references.

## **Dealing with Anxiety and Stress**

Many patients have found that using relaxation techniques, meditation and/or imagery for stress management helps them feel better and gives them more energy to cope. Many audiotapes are available; a good one is *Letting Go of Stress* by Dr. Emmett Miller, available through many bookstores and the hospital gift shop. Your psychologist may also have some helpful suggestions.

### **Using Support Groups and Classes**

Support groups can be a good source of emotional support and information about MS and treatments. You may find it comforting to be with others who really understand what the

diagnosis of MS can mean in a way that family and friends sometimes cannot. You may wish to contact the MS Society, to see what kinds of support groups are currently active in your area.

If you are formally involved with outpatient neuro-rehabilitation treatment at UWMC, you may also be a good candidate for the eight-week Cognitive Group or Group Psychotherapy offered in the Department of Rehabilitation Medicine many times throughout the year.

## Taking Care of Yourself

- **Take good care of yourself.** This is the time to put you first. Your health has to be your first priority. Let go of other responsibilities that you do not want or need. This is the time to learn to say "no." This is also a good time to focus on exercise and good nutrition. Your energy may be limited. Maintaining an exercise routine (even if you must alter it a little bit) may help reduce fatigue and increase your sense of well being. Because good nutrition is key to maintaining your health, a visit to the nutritionist may be a good idea.
- **Continue with some sort of recreation.** Finding activities that are fun, that you enjoy and make you laugh may be a challenge when you feel sick, but distraction and humor are good medicine. Some patients find being with or watching small children or animals brings them pleasure or a good laugh.
- **Make time for your inner life.** If you have not been part of a spiritual community, this may be the time to look for a group that meets your needs. Many people find inspiration in reading or in nature that provides them with peace of mind and spiritual fulfillment. Whatever you choose, this part of your life is important.
- **If you have lost opportunities because of your illness, set new goals.** Some patients find they cannot work, but they can do something fun and worthwhile on a volunteer basis. Many patients find they are able to work part-time or on a modified basis. Some patients use their creativity, learn a new skill or spend more time with family and friends. Limits on activity caused by MS can present a challenge, but overcoming them can give great satisfaction.
- **It is also important to have an outlet where you can "blow off steam,"** and vent about frustrations without unduly upsetting your family. A support group, keeping a journal, individual counseling, talking with a pastor or new friend who also has MS might all be helpful.

## For Family and Friends

It is hard to see someone you care about in physical or emotional pain, or with changes in memory or in other aspects of thinking and behavior. Sometimes it can seem as difficult to be the support person as it is to be the patient. Both roles are challenging. Here are some tips for caregivers:

- Educate yourself about MS and its treatment. Ask your nurse, doctor or therapist for information. The MS Society also has excellent information, conferences, talks, etc.

- If you are not sure how to help your loved one, come up with suggestions of things you would like to do (for example, cook dinner once a week, provide rides to doctor visits, babysit so a patient can nap, read to a patient, etc.).
- Keep communication open. Do not hide information or your feelings unless the patient asks you to do so. It is easier to cope with the known, even when it is upsetting, than the unknown. Do not stop talking because you do not know what to say or are afraid of saying the wrong thing. Acknowledge your fears and feelings and ask the patient how you can best support them. Often what they want most is a caring listener.
- The MS Society can provide many helpful handouts.
- Take care of yourself as well as the patient.
- Remember that for the person with MS or the family member, there is no "right way" to cope.

## **Stress Control**

Stress control is an important part of managing your illness.

- Managing stress well can help you manage your MS well.
- Knowing your symptoms of stress will help you choose good stress control methods for you.
- Practicing stress control methods can lead to a greater chance of well being.

## **About Stress**

Stress is the effect of any intense or prolonged situation on our bodies and minds. Some people like to use the word pressure. Life is filled with stress and pressure. The things that have come up in our lives have an effect on the way our bodies react and on the way we think and feel. We tend to think of stress as bad, but when the pressure is on, in certain situations, you can turn stress around and make it work for you.

Stress affects bodies in different ways. It can cause symptoms such as headaches, upset stomachs, and sleeplessness. It can make some minor illnesses happen more often and last longer. It can contribute to the development of some serious chronic diseases such as heart disease, high blood pressure and stomach ulcers. It can bring flare ups in these chronic diseases and in others that have been under control such as asthma and diabetes. It can make symptoms worse in just about any illness from flu to cancer.

And, stress that is not managed or controlled can lead us to take on habits that are very dangerous to health, such as smoking, excessive drinking, and poor eating patterns. And while stress does not cause MS attacks, it can make you feel poorly and decrease your overall performance. This may lead MS patients who are under stress to feel worse even though there is no worsening of their disease.

Yet stress at moderate levels can actually motivate us to do something new, to grow, to learn and to make changes for the better. We may expand our horizons, reevaluate our goals and priorities, and create a more thoughtful life.

In summary, stress becomes harmful when there is no way to manage it, to make it work for you. Sometimes our own personality makes it harder to manage stress. At other times the situation creating the stress cannot be managed – or at least not right away or without help from others. Harmful stress is part of our lives. It is unrealistic to expect it can be totally eliminated. Accepting that harmful stress is part of all our worlds does not mean that you should live in fear about how it affects your MS. None of us manage stress perfectly in any given moment or even over time. It is the gradual evolution of improved coping to maximize quality of life that is our goal.

## **Symptoms of Stress**

Each person responds differently to stress. Some common symptoms not already mentioned are dry mouth, heart beating faster, sweating, and heavier breathing, as well as increased irritability. Some of the harmful responses to stress include:

- Hoping stress will go away.
- Ignoring your feelings.
- Trying to do it all yourself.
- Thinking only about bad things.
- Blaming yourself.
- Expecting yourself to be perfect.
- Expecting to be able to change everything.
- Treating your body badly by smoking, drinking too much alcohol, eating too much or too little.
- Being crabby or short-tempered with family and friends.

Stress that is not controlled or managed can cause very uncomfortable feelings such as anger, frustration, depression, helplessness, fear and guilt.

## **Causes of Stress**

Some of the causes of stress such as everyday pressures and personality traits have been discussed. Other causes include relationship problems, unexpected events, traffic, work, school, chronic illness, and even death.

## **Ways to Manage Stress**

There are many ways to manage stress. The ways that work for you may not work as well for someone else and vice versa. For starters, it will help to be aware of your stress reactions, cope with the causes of stress inside yourself, manage your time well and work together with others for a change. Here are some techniques to learn to relax your mind and body when you feel stressed.

- Deep breathing
- Meditation
- Positive statements

- Time management
- Visualization
- Quick stress busters

Learning to control stress takes time and practice. Skipping steps in this process makes it hard to achieve success. You may be doing a great job of relaxing your mind and body, but these practices won't yield the same health benefits if you don't get in touch with your stress reactions, causes of stress inside yourself, manage your time well, etc. Ask someone on your care team for help or a referral if stress is getting in your way.

Tips for Talking with Family and Friends:

- Be as open and honest as you can be from day one.
- Try to show an understanding of the feelings your family or friends may be having about your MS. This will help them, and ultimately help you.
- You may want to have a family meeting to share your feelings about having MS and invite those you love to do the same.
- Finds ways to embrace your family, in all aspects of having MS. This allows you to be supportive of each other.
- Accept offers of help from others.
- Be clear about what you do and what you do not want others to do for you. Keep in mind that your needs may change.
- Another way to help foster a supportive family-and-friends network is to remain positive and motivated, while reaching out in a clear and organized manner.

## What About Children

Many patients have questions about what to tell their children about their MS, its effects and its treatment. Parents often feel torn between wanting to inform their children and wanting to protect them. There is no right approach. Every situation will vary depending on the nature of family relationships, ages of children, role of sick parent, etc. Here are some general suggestions drawn from experience with patients and families and from research on children:

- It is best to be honest with children and talk to them about your MS, as they will be affected.
- If you don't talk with your children, they may harbor fears that may be worse than the reality. They may overhear information about your illness or hear it from someone else. Children can feel insecure if they sense something is happening and they are not being told.
- Children need reassurance that they are not responsible for the illness in any way and that their needs for care and comfort will continue to be met. With this reassurance, you will find that they are amazingly resilient and they can cope with almost any event if they feel informed and included.
- The National Multiple Sclerosis Society has helpful resources listed on its Web site: [www.nationalmssociety.org/library.asp](http://www.nationalmssociety.org/library.asp).

**Questions?**

Call 206-598-3344

Your questions are important. Call your doctor or health-care provider if you have questions or concerns. UWMC Clinic staffs are also available to help at any time.

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