Ethnocultural elements

**MS is a worldwide community.** While MS has been known in the past to affect primarily people of Caucasian ancestry, people from a wider range of ethnic backgrounds are now being diagnosed worldwide. For example, MS is now found throughout several Islamic countries, such as Pakistan, Jordan, Saudi Arabia, and Iran. It is being studied now in Asia and Africa, and in Brazil and Mexico, it is found in many more women than men. The ratio of women to men with MS in the U.S., Canada, and Europe is 2 to 1, whereas the ratio is 4 to 1 in Central and South American populations.  

Financial elements

**Now is the time** to make new life-planning goals and form a workable plan so that you can achieve these goals. While very few people with MS become incapacitated and require long-term care, it’s still important to take steps immediately to plan your financial security for the future. Financial planning is not just for the wealthy. In fact, the fewer resources you have, the more important it is that you plan wisely.

Seek professional advice. Some people who can help include:

- A financial planner who understands disability planning for people of all ages
- An insurance expert who understands how to obtain insurance after diagnosis, including disability coverage
- An attorney who specializes in disability law, employment rights, and insurance coverage
- A vocational rehabilitation counselor, who can meet with your employer to discuss how your work environment can be adapted to accommodate cognitive and physical changes that may be involved

For more information, there are good books on financial matters for people with MS. You’ll find more information in the last section, Hot MS Topics and Resources.

Know Your Rights

In 1990, The Americans with Disabilities Act (ADA) was passed. It is the first comprehensive legislation in the world to prohibit discrimination on the basis of disability.

The ADA considers MS a disability and covers almost everyone with MS. Even people with MS who have never had any disabling symptoms can be protected.

On January 1, 2009, the ADA Amendments Act of 2008 was put into effect, clarifying the definition of disability to further prevent discrimination against people whose major life activities may be impaired by a physical disability.
essential elements
The Basics of Managing Your MS
The Basics of Managing Your MS
Taking the path to wellness

Day-to-day management of multiple sclerosis (MS) or any other chronic condition involves more than just doctor visits and taking medication. It involves “whole-person management,” affecting several aspects of daily life. As you read further in the Essential Elements series, you’ll benefit from the experience and advice of others who’ve already been there, and with some help, you can begin to piece together a path to wellness with MS.

Experts say there are essential areas to cover as you start to learn about MS. These elements are: emotional, physical, social, and financial. As your knowledge about MS grows, you’ll want to learn more. The Hot Topics and Resources section at the end of this publication can direct you to helpful resources and increase your MS expertise.

Emotional elements
MS can change the way people feel about themselves. MS is a complex and unpredictable condition that will take some time to process both for you and those who know and care about you. Most people go through many emotional changes once they find out they have MS. There are several normal reactions that people with MS can experience:

Uncertainty, anxiety, and fear. People with MS are called upon to adjust to a lifetime of uncertainty about the future. When they first hear their diagnosis, they are sometimes relieved to have an explanation for their mysterious symptoms. Moving ahead, questions such as, “Is my MS getting worse with this new symptom?” or “What is a relapse and what did I do to cause it?” can increase anxiety. Clear lines of communication with your healthcare team can promptly address these concerns. Speaking to others with MS or joining support groups can also help.

Depression or “the blues.” It is easy to understand when a diagnosis of MS brings on depression, but it is also important to know why it is occurring. Feeling blue may be a result of the condition itself or it can be an expected reaction to the diagnosis of a lifelong illness. Family and friends can certainly help, but professional counseling services can help even more. Psychotherapy and/or antidepressants are often successful and can prevent an even deeper depression that is harder to treat.

There is a widespread, caring MS community of healthcare professionals and people like you who are there to help you. Make MS a part of your life, but do not let it take over your life.

June Halper, MSCN, ANP, FAAN Director, Consortium of Multiple Sclerosis Centers (CMSC)
Adaptation, adjustment, and acceptance.
After feeling a bit relieved that there's a name for your symptoms, you also may feel shock and disbelief. “Why is this happening to me?” “I cannot believe it.” “I will never learn to live with this.” In time, you will learn to adapt to MS as part of your life. This is an important step, because without accepting the diagnosis, learning how to live a full life with MS may be short-circuited. Adapting to MS is an ongoing and challenging process that requires patience, understanding, and good communication with your loved ones, friends, colleagues, and your MS healthcare team.

Challenges to self-image and identity.
MS is a very personal diagnosis both internally and externally. It may make you feel different although you may not look different. It may interfere with your ability to do things you once took for granted. In contrast, some say being diagnosed with MS can be a blessing in disguise; they can rediscover themselves in their families, work, and special interests. MS can help you refocus on what is meaningful and important to you and help you put aside trivial issues and concerns.

Grief: A healing, restorative process.
Reacting to loss is common in people with MS upon diagnosis. For many, expectations of how life was going to unfold suddenly change. The grieving process is important to work through, and it is a healthy and normal part of letting go of the past and moving on to a new and personally meaningful future.

Re-emergence: Making MS just one part of life. Right now, MS may seem overwhelming. To help you feel more in control, start learning as much as you can about it. You can choose to attend educational programs or support groups, participate in online chats, or talk one-on-one with a healthcare professional. The key is to realize that you need to learn to make MS part of your life, part of your everyday routine, part of you. The ongoing message to you at this time is that you are not alone.

Physical elements
MS is an individual experience. Take an active role in your individual healthcare, because you are the only person who really knows how you feel and what you need. In this kit, you will find the Essential Elements Daily Journal where you should write down your feelings, concerns, coping strategies, worries, and appointments. Logging your symptoms as well as your accomplishments keeps MS in its place and will allow you to communicate them to your healthcare support team.
Pain. Pain is a complex problem that should not be ignored. MS-related pain is manageable. Reach out to your healthcare team with a careful description if you experience this symptom. Frequently, a combination of medication and physical activity can reduce or eliminate pain.

Muscle weakness, or inability to do things as usual. MS can cause weakness in your arms or legs due to the disease itself or a lack of activity and exercise. Lack of use over time can result in loss of muscle tone and weakness, known as deconditioning. Physical therapy and appropriate regular exercise can help. Yoga, swimming, t’ai chi, Pilates, and other exercise programs have shown to sustain muscle strength and improve endurance in people with MS.

Fatigue, or feeling tired, is one of the most common symptoms of MS. For fatigue, talk to a rehabilitation specialist (see the MS Support Teams section for more information). Set realistic daily goals for yourself, and do the things that are most meaningful and rewarding first. Many people with MS find wearing a device called a cooling vest very helpful in preventing fatigue.

Spasticity (stiffness). Spasticity is a feeling of stiffness and is one of the more common symptoms of MS. Spasticity can also affect the muscles that help you urinate, giving you the urge when you do not need to void. There are a number of ways to manage spasticity, including daily stretching, exercise, medication, proper seating when awake and positioning at night in bed, or a combination of these. See the MS Support Teams section on Rehabilitation Specialists for more information.

Cognitive impairment (memory problems, or “fuzzy thinking”). This refers to the ability to learn and remember information, organize, plan, and problem-solve. If you or your loved ones find these issues happening more frequently, talk with your healthcare team. An in-depth assessment might be required to determine how it can be helped. Some simple strategies to try in the meantime include: writing things down, using a calendar like the Essential Elements Daily Journal, or using an electronic calendar device.

Elimination problems (bladder and bowel problems). Let your healthcare team know if you are having any problems with elimination. Urinary problems are one of the most frequent causes of MS-related hospitalizations and can be avoided with proper assessment and treatment. Bowel dysfunction can also be managed with dietary modification, medications, and education.

**Characteristics of MS-Related Fatigue**

Occurs commonly

Is aggravated by heat and humidity

Is likely to interfere with daily responsibilities

Worsens with infections
What do I say? Some tips on breaking the news.

Consider whom you’re talking to. Tailor your language to their level of understanding.

Watch for cues on how they are responding to the news. Some people need time to process the news. Others will immediately react with acceptance and understanding.

Emphasize the basic facts about MS. Tell them that even though there is no cure for MS, new medicines make a “normal” life possible for longer than ever.

Most of all, be kind to yourself. There is no right, wrong, or perfect way to tell someone you have MS. You will find your way one person at a time.

Social elements

One major concern you may have is how MS will change the relationships in your life. These changes do not have to be negative; in fact, the diagnosis of MS may actually enrich your relationships and bring you closer to loved ones. First, recognize that MS affects everyone you know—whether you have it or care about someone who does. Next, decide whom you want to tell and what you want them to know.

Your family. Some of the most profound changes people with MS may experience are at home. The family goes through many emotional changes as they try to learn about the condition. Families experiencing MS often find themselves in uncharted territory. It is important that the family gives MS no more space in the household than it needs.

Your spouse/partner. Your husband, wife, or partner will usually know what you were going through as you took the tests that led to the diagnosis. Sometimes a partner is thoughtful and caring. Sometimes, however, a partner may find it difficult to accept the news. Try not to be too disappointed. This can be a natural reaction from someone who cares for you deeply. To help, have your partner come to your next appointment. There, he or she can talk to a professional who can answer questions informatively and relieve the anxiety that he or she is feeling.

Your friends. If you do decide to tell friends about your MS, keep in mind that how you tell them about your MS and how you are coping will set the tone for future conversations about your diagnosis. Give friends time to process the information. Most people will take their cue from you—be ready to let them know if you want to talk about it, if you are willing to answer questions, and if there is anything they can do for you.

Your employer. MS can have varying effects on a person’s ability to work. New symptoms might make you question whether you can continue working and, when symptoms subside, you might wonder why you were worried about work at all. The decision on whether or not to tell your employer could have an impact on your work. It may ensure more support or, in some cases, unfairly affect your career prospects. The decision is complex and needs to be researched thoroughly before you act.