Chapter 8
Psychosocial Issues and Relationships

Getting a Good Start:
Hints for the Newly Diagnosed

Being diagnosed with MS can be very surprising. Those who are diagnosed are usually very healthy people who have not faced other chronic illnesses during their lifetime. If the diagnosis comes after the symptoms have been lingering for a long time, there may be a sense of relief of finally getting an explanation. Unlike in the past, current technology and specificity of brain imaging today often results in an early and quick diagnosis of MS. Sometimes, after only one episode and a few days of symptoms, the diagnosis of multiple sclerosis is made. It isn't unusual for the recently diagnosed person or their supporters to think that there must be a mistake and a simpler or more short-term answer is really at the heart of the symptoms. No matter what the circumstances, becoming accustomed to living life with MS and adjusting to the diagnosis takes some time and, for most people, some effort. This chapter is designed to provide a few ideas for people who are newly diagnosed and those who care for them to get a good start on dealing with the diagnosis.

There is a common experience that many newly diagnosed people describe. They say that when they tell acquaintances of their diagnosis, the acquaintances are quick to tell stories about other people they have known with MS. The details of the unknown MS persons’ struggles or accomplishments are relayed, often with an expectation that the newly diagnosed person will go through the same experience, i.e., “my cousin has MS and he just ran the Boston Marathon” or “my mother has MS and she is really struggling”. Those scenarios seem to make the tellers think they are more attuned to the newly diagnosed person, yet we hear that the listener may feel a sense of distance and confusion. It is often said that MS is different for everyone who has it and members of the general public have usually only met one or two people with MS. Their experiences color their assumptions about MS and their response to the person who reveals having just been diagnosed.
Also accompanying these stories may be a set of suggestions about what treatments, therapies, or other recommendations the newly diagnosed person should use to make the MS better. Rather than relieving the person with MS, these recommendations and advice can be confusing, as the person may not have heard the same recommendations from their health care providers and may have been given very different advice. Thus, it may be helpful to tell people you know whether or not you are ready to hear stories about the experiences of other people with MS.

Newly diagnosed people describe another difficulty in relation to the people in their lives. If they have recently recovered from an exacerbation, they may be told “you look GREAT”, often accompanied by the assumption that they must feel as good as they look. The problem of dealing with the world when your symptoms are mostly invisible is a significant one. Sensory symptoms such as pain, numbness, tingling, and fatigue are not obvious to anyone except the person having them, and it can be strange to have someone say that you are back to normal when your hand is still a little numb. We also tend to base our decisions about a person’s ability on their appearance and making the distinction between looking good and feeling good to another person can feel daunting. It isn’t practical to wear a sign on your head that informs the world that you are still adjusting to your MS and symptoms, but it may help to remind people in your life that it isn’t out of your mind, even if it’s out of their sight.

The shock that accompanies the words “you have multiple sclerosis” may make it impossible to listen to any additional advice or information from the doctor. Someone who is newly diagnosed, therefore, may end up asking a lot of questions about the disease after the visit is over. At some point in the process, newly diagnosed people should know the answers to at least the following questions:

- What is multiple sclerosis?
- What is an exacerbation (attack) of multiple sclerosis?
- What treatments are available to manage the disease, exacerbations, and symptoms?
- Are there any situations that should be avoided?
Are there any health habits to begin now?

In addition to your MS health care provider, there are many resources available to answer these questions. There are many good books available (see Recommended Reading List), as well as community professionals and reputable internet sites, which can be very helpful in finding answers to these questions.

After an MS diagnosis, it is common to experience many unique emotions. People often report feeling irritable, tearful, anxious, or distracted. They may describe themselves as depressed as a result of the diagnosis and unable to tolerate the idea of an uncertain future. These experiences are very normal. After any surprising, traumatic event, we are expected to take some time to adjust and come to grips with our feelings. Well-meaning friends and family members will sometimes encourage newly diagnosed people to "put mind over matter", to "be strong", to "not think about the MS", or to "get over" their fears. Health care professionals observe that it may take several weeks or months to begin to adjust to the diagnosis, and it is not unusual to see people whose grieving process takes years. It helps to be able to resume normal activities – most people also say that it helps to talk about the feelings, fears, and confusion that go along with MS. A common and normal response is to over-analyze sensations that your body normally experiences. Over time, a person relearns their body and these normal sensations return to the background and cease to cause concern.

Patients and families need to realize that learning about MS is a process that will take time. It is impossible to learn everything quickly, which can lead to information overload. It is important to ask the questions that occur to you and to be gentle with yourself and your supporters as you explore this new world.

Coping, Self-Esteem, and Identity

MS is an inherently vacillating illness and how people cope with it differs from person to person and from one stage of the illness to the next. Because there is such huge variation in what coping is, it is almost easier to talk about what coping is not. Coping well does not mean there is no problem, distress,
or difficulty. It does not mean you have made the MS go away. Rather, it is a gradual integration of the MS into your life, and a gradual adjustment of your life, so that the disruptions that MS frequently create are managed as gracefully as possible.

When patients say they are having difficulty coping with their MS, they may feel overwhelmed by all the ways their lives have become altered and unfamiliar. They may voice surprise and frustration that "things still aren't back to normal". They have unrealistic expectations about coping with MS that may come from past experiences managing acute illnesses- those that go away. These unrealistic expectations or "myths about coping" include such notions as "if you are coping successfully, you have the MS under control, you are free from distress, and you have accepted your MS".

MS is a chronic disease that has an unknown and unpredictable course, and often has a dramatic and traumatic onset. It is, therefore, not only understandable and logical that people will, from time to time, feel overwhelmed and unable to cope. Coping really means, "to struggle, with some degree of success." Feelings of distress in the struggle to integrate MS are normal and realistic. To evaluate whether you really aren't coping well involves looking at both the size of the struggle and the degree of success. If everything is a battle and you aren't winning any of them, and it's been going on for a while and you are feeling exhausted, then you probably aren't coping as well as you might. You probably would benefit from further exploration of your coping strategies.

Chronic illnesses require both short-term and long-term management strategies. Short-term coping involves basic crisis management strategies. They are those changes we make to our routines to manage emergency situations. For example, canceling plans, restricting activities, shifting responsibilities from one person to another, or simply letting the non-essentials slide, are the types of modifications a family might make to manage the crisis of an MS exacerbation.

Long-term coping strategies are not emergency measures. They involve modifications in how we think about our priorities, values, and goals. Making a career change from a highly
stressful, very demanding job to one that offers less stress and different rewards is a type of long-term strategy.

Because we are most familiar with illnesses that go away, people tend to use crisis coping when initially dealing with MS. Crisis management strategies are good for the short run, like those small spare tires that you install when you have a flat. They "fix" the problem but are not designed for long term, regular use.

When people deal with a chronic illness such as MS, they can rely too heavily on crisis management strategies. People get stuck in crisis mode, waiting for things "to return to normal." When you deal with a chronic illness, it is sometimes hard to comprehend that "normal has changed." Coping with MS requires both crisis and long-term strategies. The difficulty is knowing when to shift from one to the other.

There are things that can make coping more successful, and learning to integrate these techniques will likely facilitate coping. Before talking about them, however, it should be stressed that with MS, COPING IS A CHRONIC ACTIVITY. Every time there is a significant change in how you feel or function, you will likely have to readjust how you are coping. The biggest myth about coping is that you only have to do it once. The good news is that the more you do it, the better you get at it.

Good and accurate information can help you cope. The more you know and understand about your MS, the more control you have over the choices you make. You cannot control the MS, but you can make choices about how you manage it. You can also limit the amount and type of information about MS that you allow into your life. Sometimes it can be helpful to censor what you read if it is too overwhelming. Being well informed about resources in the community can also give a sense of control, help facilitate problem solving, and decrease isolation.

Experience and familiarity also facilitate coping. When a problem is new to you and you don't know how to solve it, it can create anxiety and a feeling of incompetence. Patience and practice are the keys. It takes time to become familiar with MS.
in general and with "your" MS in particular. It is not unusual for it to take five years to come to terms with the diagnosis of MS. It is a confusing and difficult process. Give yourself time.

A strong support system facilitates coping. Isolation can keep you from getting both the emotional and the "nuts and bolts" assistance that make difficult situations more bearable. Maintaining connections with friends, family, and meaningful activities are important. Becoming involved in MS specific activities like educational programs or support groups can also be helpful.

Denial makes coping with MS more difficult. If you cannot acknowledge the MS as a reality in your life, it will be difficult to make necessary changes. It is certainly expected that you may spend some time feeling that "I really don't want to have this disease and if I ignore it, it will go away." This mindset becomes problematic when the denial is so strong or long lasting that it prevents you from getting the things you need. Therapy, spiritual counseling, and an evaluation for depression are just some of the interventions that may be helpful if continued denial is a problem.

Fatigue does make coping more difficult. Learning how to manage fatigue is critical, especially learning and implementing energy conservation techniques. Using social supports and physical aids is often helpful, especially when coupled with a reevaluation of priorities in your life.

Finally, flexibility facilitates successful coping. Being able to change plans and directions and have an alternative route in mind can decrease frustration and increase success when obstacles are encountered, much as you would have alternate routes in mind in the event of a traffic jam.

**Working with MS**

Our society is very oriented to work. We ask what people do, at even the most social occasions, but really mean to inquire where and what they do for wages. During the period immediately after diagnosis, some people with MS report that
they become very concerned about their work and the demands of their job. They may fear that they will not be able to continue to work if the MS progresses. People worry that if there are frequent exacerbations, they will need to use a lot of sick leave and their jobs won’t be able to accommodate their needs. Health insurance, which is most often tied to our work, becomes very important when expensive medications and treatments are needed. Many people elect not to disclose their diagnosis to their employer and choose to remain very selective about who is to be told. For those individuals, the dual concerns of having a diagnosis with few answers and maintaining work responsibilities without giving any indication of their current status can be challenging.

Being diagnosed with MS doesn’t automatically mean a person can’t work. It also doesn’t automatically qualify you to receive Social Security Disability (SSDI or SSI), although every year some people with MS apply for those programs and are able to receive them. Each person is unique and must take into account their symptoms and exacerbation rates, job duties, and financial needs. Many people with MS work up until normal retirement age and after. But, for some people, it isn’t always possible to continue to work at pre-diagnosis productivity levels. Some of the reasons people cite for having trouble at work include, fatigue, depression, cognitive problems, vision disruptions, and physical limitations. The Americans with Disabilities Act (ADA) was enacted in 1992 to provide people with disabilities, including those with MS, equitable treatment in the workplace. There are some very specific limitations to the ADA, and it is important to know your rights, as well as where you are at risk. There are many good resources to educate you about the ADA. A good place to start is with the National ADA Homepage at www.usdoj.gov/crt/ada/adahom1.htm or by calling the toll-free ADA information line at 800-514-0301 (voice) 800-514-0383 (TDD).

If you are having trouble at work, consider the following steps:

Your MS health care provider can help you define what reasonable job duties you can fulfill. This may include information about physical labor such as heavy lifting or construction, hours per day you should be able to work, and
any other restrictions related to your MS. These may be temporary restrictions during the recovery from an exacerbation or more permanent restrictions related to your day-to-day functioning.

Often, making minor changes in your workplace can be very helpful. These may include moving your desk so that you are closer to the parking lot or restroom, altering work hours to take advantage of your highest energy levels, improving your lighting or air circulation with lamps and fans, or finding ways to vary your activities during the day.

You may need to request reasonable accommodations from your employer. A vocational counselor, occupational therapist, or other MS specialist may be able to help you determine what reasonable accommodations you need to do your job. Contact the ADA resources above for more information to explore what you need.

Consider retraining in another job or field if MS seems destined to interfere with your work. Local colleges and universities and many online resources as well as your state office of Vocational Rehabilitation should be able to help you decide on your next career.

If it appears that you are not able to continue to work at what the government calls the “substantial gainful activity” level, you may want to look into applying for disability retirement. Some people have short-term or long-term disability insurance through their current employer (many of us have it and don’t even know it). You may also be able to qualify for Social Security Disability (SSDI) or Supplemental Security Income (SSI) through the Federal Government. Social Security has a very good website at http://www.ssa.gov. You can also contact them by phone at 1-800-772-1213. To find out about private disability insurance that may be offered through your employer, check with your human resources department.

No matter what you decide to do with work, plan to stay as active and involved as you can. There are hundreds of organizations that need volunteers and would be happy to work within your schedule and abilities. Churches, libraries, cultural
and arts facilities, nonprofit organizations, and hospitals are all good places to look for meaningful volunteer work. Staying active may entail honing your skills at an important hobby or making yourself available to others who are struggling with their MS. Your talents should not be wasted!

**Maintaining Relationships**

Relationships with friends, family and partners can change when you have MS because anything that alters you, even in very subtle ways, can alter how you interact with other people. How much impact MS has depends on many factors.

Because the course of MS is individual and unpredictable, different symptoms and stages of the illness can cause unique difficulties. If MS has caused significant disability, it creates different problems than when the disabilities are minimal, invisible, or episodic. Remember, however, that the amount of difficulty MS creates for people and relationships is not necessarily correlated to the degree of disability. Mild and moderate problems can also present significant challenges.

MS has varied effects on families at each stage of family development. Families grow and change and have different needs at different times. An interplay between family needs and MS-imposed limitations will determine how a family may alter.

The people in your life have unique strengths and struggles, so MS can affect each one differently. People close to you may be troubled by other issues than you or by similar issues, but at different times. People with MS frequently experience feelings of vulnerability, loss of control, and uncertainty. Their partners can experience these feelings too. Partners can also feel helpless and inadequate because they do not know how to be helpful. They may mourn the loss of companionship because activities that have always been done together have changed. They may experience a loss of freedom because of increased responsibilities. Partners often have difficulty recognizing they have needs too.
Children also experience losses when a parent has MS. They often feel a loss of parental attention because MS makes so many demands on their parents. Parents may be less playful because they are more tired and worried. Children may have more worries about safety—both for their parents and themselves. Parents are sometimes reluctant to talk about what is happening. This results in children experiencing insecurity and instability when they don’t know what is going on.

Friendships, including the friendship we feel for partners, spouses, and family, may be altered in subtle and not so subtle ways. Relationships may suffer from a lack of attention because there are so many other, seemingly more important demands. Emotional distance may develop when it feels like people simply do not understand or do not appear interested in how you feel. Common interest may change and roles may shift as people take on or give up responsibilities. People with MS sometimes become less involved in activities that they previously enjoyed either because the MS makes it physically more difficult, or because of feeling withdrawn and disinterested. This may result in a decrease of frequency of interaction with others and isolation.

Communication is critical when you are dealing with a constant stress. If you were having fire alarms twice a week at work, you would certainly insist on a reliable and effective public address system. So it is with MS. Communication skills become critical when dealing with MS because other people do not necessarily know what is going on with you and won’t know until you tell them. Talking about MS and the stresses it creates is difficult for many people. The issues that make MS hard to manage also make it hard to talk about. It is an elusive, unpredictable illness. It is the "it depends" disease. It is difficult to explain that today you are fine, but tomorrow you might not be able to go to the party, but "it all depends."

There is no simple recipe for good communication. It takes time and patience. It also requires that you have some clarity about how you feel what you need, and what is still unclear for you. If you cannot talk about your MS, it will be difficult for others to do so. Emotional distress and confusion are
predictable in the wake of MS. However, prolonged inability or unwillingness to talk about the issues can hamper effective coping. In such cases, a referral for counseling, an evaluation of depression, or a consultation with your spiritual advisor are types of interventions that are often recommended and can be helpful.

Sometimes, it is hard to talk about MS with people close to you because people are protective of each other. For example, it may be difficult for you to talk openly about how you feel, for fear of upsetting those close to you. Others may try to problem solve when you simply need them to listen, or may not want to talk about the depth of their feelings for fear of distressing you. When couples are unable to talk about important issues, the problems worsen, they don't go away. When communication is difficult or becoming impossible, a marital therapist can often help identify the source of the problem and facilitate improved communication.

Children need reliable information that is geared to their age level. There are various educational materials available about MS for children. Reading these with your children can provide them with both information and reassurance. Again, keeping the line of communication open is important. Discussion about MS, like the discussions about where babies come from, are conversations you will have with your children more than once, the content changing as children mature.

It is true with all of humankind that when we are totally preoccupied with something, we assume the rest of the world is too. It can be very frustrating when the people around you do not seem to understand what is going on with you. Bear in mind that MS is not a common illness. Most of us didn't know much about it until we had to learn. Do not assume that people around you know anything about MS in general and your MS in particular. Because most people use the acute illness model to organize their thinking about disease, they probably do expect you to "get better" and may assume you are "over it" if your symptoms are not visible. Sometimes people say things that seem insensitive or hurtful, and it may seem that they don't care or believe you. This "insensitivity" is due more often to ignorance than lack of concern. Be willing to educate people
about the unpredictable nature of MS and the subtleties of many of its symptoms. People generally want to be helpful, but often don't know how. You can help them understand.

**Genetics, Reproduction, and Family Concerns**

People who have been diagnosed with MS often ask their health care providers questions about raising a family. They wonder whether it is safe to have children, whether their children will be at increased risk for an MS diagnosis, and whether they will be able to support their family if their disease progresses. This chapter will highlight our current understanding of the topics of genetics, pregnancy, delivery, breastfeeding, and child rearing for people with MS.

**The Genetics of MS**

Multiple sclerosis is not one of the strictly genetic diseases as we usually think of them. Diseases like Huntington’s, Sickle Cell Anemia, and Muscular Dystrophy are well-known genetic diseases. If a person carries the inherited gene that dictates the disease, it will be diagnosed in that person sometime during their life. Many important diseases of the modern era, such as heart disease, cancer, and diabetes, are now thought to have some inherited risk factors. The tendency to inherit a “genetic risk” means that you might be more likely to develop a particular disease if a blood relative also has it. Researchers have to distinguish between the genetic aspects of a disease that runs in a family and some of the other non-genetic aspects that make a group susceptible. If you tend to have the same exercise habits or dietary patterns as your family, your predisposing factors may not be inherited at all, but rather learned. The big question on many people’s minds, then, is whether MS is a primarily genetic disease or more an environmental disease.

A very large project has been going on at the University of California, San Francisco, Mt. Zion MS Center, along with Vanderbilt and Duke Universities. The MS Genetic Susceptibility Project has been analyzing genetic data from two kinds of families affected by MS, those with several members and those with only a single person diagnosed with MS. Most
patients with MS (80%) are in the second group. Usually he or she is the only person in their family with a diagnosis of MS as far back as anyone can remember. In the remaining twenty percent however, several generations or several members in a single generation have MS. The current evaluation of these different types of families provides us with the following estimation of risk of MS among people in the US:

- If no one in the family has MS: 1 in 1,000
- If the mother has MS and the child is a girl: 1 in 50
- If the father has MS and the child is a boy: 1 in 100
- If a sibling has MS: 1 in 20 – 50
- Risk for other fraternal twin if one has MS: (same as other siblings)
- Risk for other identical twin if one has MS: 1 in 3

What is known is that, even when first degree relatives are diagnosed with MS, there is no predictability about the type, severity, or symptoms that a person will have compared to his or her relative. (This even holds true for identical twins!)

Currently, we can’t test a person to determine whether or not MS is a risk, but research is continuing in this arena and it is hoped that families may someday be able to identify their risk of MS through genetic counseling. In the meantime, if a family member of a person with MS experiences neurological symptoms, medical treatment should be sought and the examining physician should hear about the MS as well as any other family ailments.

**Pregnancy, Delivery, and Breast Feeding**

Men with MS are sometimes forgotten in the discussion of challenges associated with conceiving and bearing children. There is no current evidence that a father with MS enhances the risk of a complicated pregnancy for his wife, and men are usually not impaired in their ability to father children as a result of their MS. There are occasional issues for men with MS related to sexual function, which can be addressed by a urologist.
The reason so many women with MS ask about pregnancy and childbearing is the fact that both issues tend to come up in young adulthood. MS is most often diagnosed in a woman’s 20s, 30s, or 40s, therefore cutting across her potential childbearing years. Several studies of the effect of pregnancy on MS have been completed. The most recent and largest of these was done by the Pregnancy in Multiple Sclerosis Group (PRIMS Group), lead by Dr. Christian Confavreux. Dr. Confavreux’s group studied 254 women with MS prior to conception, during their pregnancies, and for a year after the pregnancies. Their results were published in the New England Journal of Medicine in 1998. They found that women had a lower rate of exacerbations during their pregnancies than in the year prior to becoming pregnant. The greatest decrease was seen in the third trimester, when there was an approximately 70% decrease in the relapse rate compared to the pre-pregnancy year. In the first three months after delivery, they found that women entered a period of increased exacerbation activity for approximately twelve months, with about a 70% increase in relapse rate in the first three months compared to the pre-pregnancy year. The participants’ MS sometimes worsened, but there was not an indication that the pregnancy made the MS more likely to progress. Finally, there was no increase in disability rates among women who received epidural anesthesia or those who breast-fed their infants.

Dr. Elsie Gulick, a researcher from Rutgers University, has been studying the difference between mothers who breastfeed and those who do not. Preliminary results of the study of 175 mothers enrolled indicate that those who breastfeed their infants have a lower postpartum exacerbation rate than those who do not. Whether there is a difference in levels of hormones in the blood of those who breast feed and those who do not, and whether women are more likely to breast feed if their MS is less active must still be evaluated, but it appears that breast feeding may provide some protection from disease activity to mothers after delivery.

Additionally, an analysis of women enrolled in the NARCOMS Patient Registry has looked at the impact of childbirth on the progression of disability in MS. This study found that women who gave birth after their diagnosis of MS had less disability
than women who had children before their MS symptoms began. This phenomenon is thought to be due to the age at which the women studied were diagnosed with MS, with later onset predicting a more progressive course, rather than being related to early or late childbirth.

The end result of this research and several additional studies is that pregnancy does not appear to change the nature of the disease or increase the risk of progression of the MS.

**Raising Children**

Ask any parent-- raising children is a challenging job and one that heightens the fears and doubts of even the most confident parent. It is difficult enough to care for an infant (or twins or triplets), without being further challenged with MS-related fatigue, strength, balance, mobility, or mood problems. It is not advised, therefore, for a woman with MS to take on the task of raising children alone, if at all possible. Some additional considerations may help new parents cope:

Don’t rule out using outside childcare occasionally, even if one parent stays home due to their MS. Use other family members, friends, and supporters to help!

Communication with your children is important. Children should learn about the MS in words that are appropriate to their age and education level. They may have questions along the way, even when MS has been in the background during their entire lives, and it is important that they are able to talk about their feelings and curiosity about the disease at every age level.

Children raised in families where one parent has a disability may have more chores than their peers. Research into the effects of MS indicates that the extra expectations placed upon children, if they are appropriate for their age, and not inhibiting to their education, are not damaging. In fact, a child who feels needed in the family may have a greater sense of self-esteem than one who never has any demands made upon him or her.

Kids report that it is the emotional symptoms that some parents experience with their MS (i.e., mood swings,
depression, and sudden bursts of anger) that are more frustrating for them than the physical symptoms or the extra chores that they are asked to perform. Family counseling may be helpful if there are communication barriers or frequent fights.

In conclusion, as with every major life decision, the choice to have children is not an easy one. Planning, communication between partners, and support are keys that may help ease the process of bringing up a family.