Plaintalk: A Booklet about MS for Families

MANAGING MAJOR CHANGES

National Multiple Sclerosis Society

Chris (front cover), diagnosed in 1993.

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Introduction

Multiple sclerosis affects not only the person with the illness, but also family members and friends. **Plaintalk** explores some of the challenges families face and describes ways in which some families have handled them. Many chapters of the National Multiple Sclerosis Society offer support programs where family members can share their concerns and find encouragement. We designed this pamphlet to resemble a meeting of a family support group. You will hear husbands, wives, partners; and children and parents of people with MS speaking frankly about the stresses and strains — and opportunities — of living with someone who has MS.

The questions and comments that follow are typical of those voiced by families about MS, but just as the experience of MS itself varies from person to person, so too do the concerns of families. The responses are based upon professional advice, published material and expert opinion, and do not constitute therapeutic recommendations.

The National Multiple Sclerosis Society recommends that families discuss their own particular questions or concerns about MS with their personal physicians or other qualified professionals.

What is MS?

MS is thought to be an autoimmune disease that primarily affects the brain and spinal cord (central nervous system). It is usually diagnosed between the ages of 20 and 50, and is 2–3 times more common in women than in men. In MS, the cells and chemicals of the immune system that normally protect the body against illness attack the covering of the nerves (myelin sheath), causing inflammation and damage (demyelination).

Like insulation on electrical wires, healthy myelin insures rapid transmission of nerve impulses. When myelin is damaged, messages from the brain that control other parts of the body, and messages to the brain that interpret sensations, are not transmitted effectively. Body movement may be slow or uncoordinated and body sensations may be altered. Damage to the myelin sheath can occur at any time and affect any part of the brain or spinal cord. The location of the damaged myelin in the brain or spinal cord determines the type of symptoms a person with MS has. An episode of inflammation with demyelination is called a relapse, exacerbation, attack, or flare-up.

While healing and partial or complete resolution of symptoms (remission) may occur after a relapse, the residual scars (plaques) may permanently interfere with motor and sensory function, particularly if there is damage to the underlying nerve fiber. The disease is called multiple sclerosis because there are multiple areas of scarring (sclerosis).

Each person with MS has a unique set of symptoms depending on where in the central nervous system the demyelination and nerve fiber damage occur. Common symptoms include fatigue, weakness of arms and legs, numbness, incoordination, loss of balance, visual problems, alteration of bladder or bowel control, depression and emotional changes, cognitive problems, and difficulty speaking and/or swallowing. MS is not contagious or fatal, but a small number of people have a severe type of MS that may shorten life expectancy.

Diagnosis

The diagnosis of MS can be difficult to establish in some cases. There is no laboratory test that proves someone does or does not have MS. Tests such as magnetic resonance imaging (MRI), evoked potentials, and analysis of cerebrospinal fluid can only help to confirm the diagnosis or rule out other diseases. A neurologist or other physician will make the diagnosis when there are definite signs of MS in multiple parts of the central nervous system.

The basic "rule" for diagnosing MS, after excluding other diseases that can cause similar neurologic symptoms, is that the doctor must be able to find evidence of at least two separate areas of demyelination (lesions) in the central nervous system that occurred at different points in time — in other words, two distinct relapses. Because some people have had only a single relapse, or mild symptoms that come and go, it is not uncommon to have long periods of uncertainty before the diagnosis is made. MS experts recommend that people begin treatment (see below) as soon as possible after the diagnosis.

What causes MS?

Even though the exact cause of MS is not yet known, we do know that the destruction of myelin is caused by an abnormal (autoimmune) response of the person's immune system. As a result of this autoimmune process, cells that normally protect against illness react against the body's own tissues. A virus or other agent to which someone is exposed in childhood might trigger this abnormal immune response later on in life.

MS is not directly inherited. However, there appears to be some genetic susceptibility to MS, as evidenced by an increased risk in close relatives, especially identical twins.

What happens to people with MS?

What happens to people with MS depends on how often episodes of demyelination occur and the extent and location of damage in the brain and spinal cord. The most common form of MS is relapsing-remitting MS. In this type, people have clearly defined relapses (also called attacks or exacerbations) when they experience new symptoms or a dramatic worsening of existing symptoms, which is followed by recovery or remission when symptoms go away partially or completely. Eighty-five percent of people with MS begin with relapsing-remitting MS. About half of all untreated people who begin with relapsing-remitting MS develop secondary-progressive MS within 10 years or so. They may continue to have relapses and partial recovery, but their symptoms and disabilities generally worsen over time. Approximately 10% of people have primary-progressive MS, a disease course that is steadily progressive from the start, without any remissions. And 5% of people have a progressive-relapsing course, which is progressive from the beginning with occasional relapses along the way.

All these forms of MS may stabilize or become worse at any time. We believe that two out of three people with MS remain ambulatory over their lifetimes, but many need a cane or other assistive device for walking, and some will choose to use a scooter or wheelchair to conserve energy.

Are there any treatments for MS?

Yes. Today, there are federally-approved medications that "modify" the course of MS. These drugs reduce the number and severity of relapses, limit MS activity in the brain (as seen on MRI scans), and may slow the progression of disability. Many other medications are in various stages of clinical trials or are under review by the U.S. Food and Drug Administration (FDA). Please check **nationalMSsociety.org** for updates about current FDA-approved disease-modifying therapies and those in development.

Traditionally, corticosteroids have been used to shorten relapses.

There are also effective treatments and medications that offer relief for specific symptoms such as muscle spasms, pain, incontinence, and fatigue. Healthy living is also key to managing MS. Exercise that is geared to a person's abilities and limitations is known to be beneficial. A balanced low fat, high fiber diet promotes general health and well-being. And managing stress is also important for good health and coping with the challenges of MS.

Early days and diagnosis

"MS is so hard to diagnose! My wife had strange symptoms that none of the many doctors we saw could explain. The more symptoms she had, the more she thought she was going crazy."

When MS begins in a dramatic way such as loss of vision or paralysis, it is clear something is seriously wrong. More often, however, early symptoms are mild and transient. Neurological examinations and laboratory tests may be normal. The diagnosis of MS may not be made for some time. This discrepancy between what other people see and what the person with MS experiences can be confusing. Family, friends, and physicians may wonder whether the symptoms are exaggerated or if the person is depressed. Some people feel relief when a diagnosis is finally established, especially if they feared a far worse outcome.

"When we finally learned the diagnosis, we felt guilty because we had been so fed up with dad's complaints."

Guilt is a common feeling among family members after diagnosis. It is natural to interpret someone's complaints as psychological if you cannot see anything wrong physically. Family members should not be hard on themselves. How could they have known what was wrong when specialists found it so difficult to figure out?

"Our initial reaction on hearing our son's diagnosis was anger."

Many people feel angry when they learn the diagnosis. It seems unfair — and it is. Sometimes anger is directed against the doctor who made the diagnosis or against others in the family. Family members may be quarrelsome, irritable, and full of blame. It takes time to realize that it is the disease they are angry at, not one another, and to recognize they have a common problem to tackle.

"I felt nothing at all. I was numb, in shock."

Some people protect themselves from emotional pain by feeling nothing. Denial of feeling is a normal reaction that is common during the first weeks and months after diagnosis. Denial affects both the person with MS and family members. It may be expressed in not learning about MS or in minimizing its impact. Each person moves beyond denial at his or her own pace and, in time, is able to face the reality of the situation. Denial presents a problem when it prevents a person from obtaining appropriate medical care, making necessary life adjustments or has a negative impact on interpersonal relationships.

Living with MS

"My husband denies his disability by refusing to use a cane even though he falls frequently. This is very frustrating for us."

While some people with MS (or their family members) clearly know that MS exists, they act as if it doesn't. Refusing to believe that something is true is different from having hope. Hope involves adapting to the reality while maintaining an optimistic outlook, and taking reasonable steps to make the best of an unfortunate situation.

It is important to allow an individual time to make difficult transitions. If denial persists people may need to call on family advisors, clergy, spiritual advisors, or mental health professionals.

"What we find hardest to deal with is the constant unpredictability."

People with MS don't know from day to day, or even hour to hour, whether they will feel well or not. Symptoms of MS typically fluctuate. Will the person with MS be able to join in the family's activities? Will special help be needed? Will some hoped-for event have to be canceled? This unpredictability is frustrating. It can lead to misunderstanding and conflict: Is the person really so unwell? Should he or she be pushed or left alone?

Unpredictability makes it hard to plan for the future. Should the family buy that new house, or does it have too many stairs? Will there still be two incomes to meet the mortgage payments? Should the person with MS change jobs or stop working?

Uncertainty may be easier to live with if it is expected. There may be less disappointment when a plan falls through if an alternate plan has been made — just in case.

"I get very angry at how things have changed, but I feel guilty about my feelings."

These are two of the most common feelings in families dealing with MS. It is natural to feel angry about the changes and the demands the illness places on a family (a drop in income, new responsibilities, changes in traditional roles). These are practical and emotional burdens that everyone has a right to be angry about.

"My wife is so self-centered and angry these days that it is hard to live with her."

Some people with MS become so focused on getting through each day that they pay less attention to other people. Their own feelings and body functions become the objects of their emotional investment. They may become angry and critical of those caring for them. They may believe that their situation would improve with a different doctor, another treatment approach, a better therapist, or a more supportive family. Angry criticism or lack of interest in others easily provokes hurt or anger among family members.

Recognizing that these feelings are not uncommon in people with MS and that they usually pass with growing adjustment to the disease may help families remain tolerant. Communication about feelings is critical among family members.

"Most of the time I don't mind helping at home, but sometimes I can't stand it. One day I lost my temper and told my mom that I really hated having to do so much extra work. Then I felt bad that I had yelled at her."

Tension builds when family members fear that the expression of strong emotion will make MS worse. Holding feelings back, however, may lead to angry outbursts or to avoiding the person with MS. Family members may blame the person with MS for everyone's distress. In the end, tension, anger, and loneliness are far more damaging than the open airing of feelings. Talking frankly, at a calm moment, helps every member of the family understand the strains each person feels.

"Last night when I transferred my wife from her wheelchair to the bed, I was kind of rough. This morning when I saw the bruise on her leg, I wondered whether I intended to hurt her. We had been arguing, and I was mad. I'm exhausted from taking care of her and the kids. I feel frightened."

When people are very angry and frustrated, they may have the impulse to lash out verbally or physically. Most of the time, people can control such impulses. But when caregivers feel overwhelmed, or are worn out, stressed, or sick, even the most thoughtful can lose control. Sometimes a caregiver is emotionally hurtful or physically rough; sometimes a caregiver is actually assaultive.

People with MS who must depend on others are very vulnerable. Some have been victims of neglect, physical attack, and sexual abuse. People with MS may also be overwhelmed and become verbally or physically abusive to others.

Family members who are troubled by their own behaviors should seek professional help. All communities have mechanisms for reporting abuse and obtaining help, and both caregivers and people with MS should not hesitate to report their concerns. Inability to care appropriately for a person with MS does not mean that the caregiver is "bad." It means that there are serious problems that need to be corrected. Calling the National MS Society can be a good first step — or talking to physician, nurse, or clergy. Many communities have domestic violence hotlines or adult protective services available.

"My husband is so frustrated and angry about MS that he frequently takes it out on me. Even though I understand where it's coming from, it's hard to take."

When emotions run high, the caregiver may be the target of angry and frustrating outbursts or even abusive behavior by the person with MS. This behavior may take the form of hurtful insults (e.g., "You don't care about me" or "You only care about yourself.") and berating language (e.g., "You don't know what you're doing.") or even physical lashing out (e.g., using the wheelchair or cane as a weapon). When a family finds that these types of behaviors are becoming more common, it is time to seek professional help. Recognizing when anyone in the family, whether the person with MS or someone else, has lost control and crossed the line of respectful, appropriate, and safe behavior is an important first step in solving these problems. Seeking professional help is an essential next step.

"At some point I stopped being angry all the time and became very sad."

Anger may mask feelings of sadness. Losses from MS may lead to feelings of grief (waves of painful emotion, tears that seem to come from nowhere and seem endless). People may have trouble sleeping or lose interest in food or activities. Some people don't want to be alone; others seek solitude. These feelings may arise when the diagnosis is first made, or may come years later.

When grieving is allowed to follow its natural course, there usually comes a time when the losses are accepted and energy is renewed. When grief is stifled, the grieving person remains stuck in anger and bitterness, unable to move forward.

"When I look at my wife I feel so helpless. Sometimes I think I just can't stand it any longer."

Helplessness is painful. It can make people feel powerless, frightened and angry. Instead, some people imagine that they can stop the MS or could have, if only... but that makes them feel guilty. Others try to help too much, but may do so in the wrong ways, at the wrong times. The truth is that there are real limits to how much anyone can do. Facing that fact is the first step in helping the person with MS and the family come to terms with the illness.

"I can give up a great deal for my husband, but after a while I get annoyed."

When people help so much that they have no time for themselves, they are not really helping as much as they think they are. Even the strongest people sometimes feel burdened and angry. They may take out their frustration on those they want to help or feel so guilty and depressed that they have nothing left to give. While it may be difficult, family members need to find time for their own activities. Some communities offer respite services to give families — and people with MS — much needed breaks.

Sharing information and strategies for coping in a support group can also help. The understanding and advice of people "in the same boat" can make a big difference. Some people also find that learning stress management techniques helps them cope more effectively.

"We never go out or have friends over anymore."

When families are overwhelmed with the care of a chronically ill person, and with adjusting to new roles and responsibilities, they may feel they have no time or energy left to socialize. Some think that their friends don't understand what they are going through or won't want to be burdened by their problems. Others worry that friends won't enjoy their company because they are so depressed or preoccupied. But avoiding friends or rejecting their offers to help may push them away. While socializing may be more difficult than before, it is an important source of emotional well-being. If going out is too taxing, many families adjust by inviting friends over more frequently (e.g., for a pot luck meal or house party).

Being around others can help restore a feeling of normality. Families often come to realize that their friends have not pulled away, as they may have thought, but that they themselves have been withdrawing from their friends. Indeed, friends generally welcome learning how the person with MS and the family are really feeling. They appreciate clear and specific information about how and when they can help.

"We seem to have more trouble coping now than when my husband was first diagnosed five years ago."

It is not uncommon for stresses and painful feelings to emerge a number of years after the diagnosis. Many people with MS have few symptoms at first. They can get around, work and participate fully in family and social activities. Only later, if the disease progresses and places limitations on their daily functioning, do people recognize how MS has changed their lives.

"I find it difficult to deal with my husband's loss of sexual function."

MS can affect sexual functioning in both men and women. As in any other chronic illness, sexual desire may lessen. In addition, MS plaques in the spinal cord can interrupt the pathways for sensation and arousal in both sexes and for erection in men. Sexual dysfunction, like other MS symptoms, may come and go, and this unpredictability makes people anxious about intimacy. Anxiety itself can interfere with sexual functioning.

These problems should not be ignored. Sexual problems can make it difficult for a couple to be loving and intimate with each other. Talking openly about sex and working together to find other ways to give and receive pleasure allows many couples to have satisfying sexual relationships.

"Are there ways to treat the sexual problems caused by MS?"

There are several options. Non-medical sexual aids are widely available and may be useful in enhancing pleasure for both men and women.

For men who cannot get or maintain an erection, there are oral medications such as Viagra® (sildenafil), Cialis® (tadalafil) and Levitra® (vardenafil). Injectable medications include papaverine and alprostadil. Surgical implantation of a mechanical device (called a penile prosthesis) may help some men. A urologist can discuss these medical options with you and help you determine the best approach.

For women, vaginal lubrication may be enhanced by using over-the-counter, water-soluble lubricants.

Other MS problems such as spasticity; bowel and bladder problems; fatigue and weakness; as well as depression and anxiety, often interfere with sexual activity. Many of these problems can be treated successfully with medications, rehabilitation, counseling, and life-style changes.

Although many people are uncomfortable at first, speaking to a doctor about such concerns is vital. Counseling with a mental health professional or certified sex therapist may also help couples identify barriers to a satisfying sexual relationship and develop strategies to overcome them.

"We both want to have a child, but I'm afraid pregnancy will make my wife's MS worse."

Research suggests that pregnancy has no negative effect on the overall course of MS, although there is a greater chance of a relapse in the period immediately following pregnancy. Although women with MS are more likely to deliver by Cesarean section and may give birth to babies with a slightly lower birth weight than women without MS, most neurologists do not discourage a couple from having a child. A woman who is taking a disease-modifying medication will be advised to stop before getting pregnant; this should be fully discussed with her healthcare providers.

The parents-to-be also need to consider how they will care for the child should the parent with MS become disabled. These difficulties should not be exaggerated or minimized, but approached realistically. Talking to people with MS who are raising children can be very helpful.

"I'm not the one with MS, but I've been quite depressed. All we talk about are doctors and medicines. There is no fun anymore, just arguments and misunderstandings."

It is important to remember that MS affects everyone in the family, and that all family members are entitled to their feelings. Family members have also lost a great deal. They may feel discouraged and depressed, unappreciated and resentful. Sometimes they feel guilty about seeking help for themselves, believing they should be tougher, or that they don't deserve the special attention of a counselor or a support group.

"We no longer share the interests and lifestyle that brought us together. Sometimes I think we'd both be better off if we divorced."

The strains MS places on a relationship cannot be underestimated. Much of what a couple had planned and worked for may now be impossible. Both partners feel cheated. Some couples adopt goals that are more feasible, and although disappointment remains, they work together to achieve these alternative aspirations.

Some partners find themselves unable to give up their wishes or change their expectations, and they may ultimately pursue a separation or divorce. Of course, this is difficult for everyone, but it need not be devastating. With the help of family, friends and professionals, couples can work out separation agreements that take into account the emotional, financial and physical needs of both people.

"As parents, we feel torn between wanting to do everything we can for our daughter and knowing she has to learn to take care of herself."

It is hard for parents of children and young adults with MS not to be overprotective. It is terribly painful to see one's child become disabled and to face the fact that his or her life will not be what the parents had hoped. Parents inevitably worry about who will care for their son or daughter when they are gone.

But if parents, out of love and concern, do more than is absolutely required, they will prevent their child from developing the abilities and confidence needed for independent living. Sometimes it is more helpful to be less helpful!

"Our son was so angry about his MS that we asked him to see a psychotherapist for help."

Seeking professional help does not mean that the family has failed. In fact, it is best to seek counseling before a crisis develops or distress becomes overwhelming. Many people find it easier to talk to someone outside the family. Professional psychotherapists (psychiatrists, psychologists, or psychiatric social workers and nurses), teachers, and clergy who have had experience with chronic illness and disability, are all valuable resources.

Children and MS

"Our biggest problem has always been 'What do we tell our children?'"

Even very young children notice slight physical changes in a parent. They readily pick up on their parents' emotional distress. If parents avoid talking about MS, a child may think it is too terrible to talk about. Children may not express their worries openly, so they should be encouraged to share what they are thinking. This gives parents an opportunity to clear up their misconceptions and offer reassurance. The Society's "Keep S'myelin" newsletter for children can help you to discuss MS in an age appropriate way with your child.

"I know I will start to cry if I tell my daughter what's wrong with my wife."

It is not harmful for a child to see a parent's genuine feelings. While it is inappropriate to burden children with adult problems, honest expression of sadness, frustration, or anger makes it clear that such emotions are normal and acceptable. This may also help a child be more willing to talk about his or her own feelings.

"Our son began to do poorly in school shortly after my wife returned home from the hospital after an exacerbation."

Children's fears often appear as changes in behavior, withdrawal from family and friends, poor schoolwork, or aggression. If the home atmosphere is one in which thoughts and feelings are shared and questions are answered honestly, children are more likely to turn to their parents with their worries. This is an ongoing process; children's concerns will change as they grow and as the MS itself changes. Communicating family challenges to school officials may promote understanding.

"I know my daughter is having a hard time, but it upsets me to see how embarrassed she is about her father."

Many older children and teenagers seem embarrassed by their parents whether they have MS or not. Children may worry that their friends think less of them because of their parent's disability. Embarrassment may also be an indirect way of expressing fear, sadness, and anger.

Parents can help by encouraging their children to express their underlying feelings. Eventually most children will see qualities in their parents that make them proud.

"Our son says he cannot go away to college because he needs to be around home to help."

Children who have a parent with MS grow up with first-hand knowledge of illness and disability. Many become unusually aware of the feelings and needs of others. But, paradoxically, this valuable quality makes some children feel selfish if they pursue their own goals. They may need to be encouraged to balance their desire to be helpful with their equally important need to have lives of their own. Some children who try too hard to help or are too "good" may harbor the fear that they did something to cause the MS or that they could do something to stop it. They may need help to overcome this.

Memory, behavior changes, mood swings, and depression

"My husband is no longer working, so he is home by himself for most of the day while I work. He has difficulty with household tasks, and I worry about his safety because he often seems forgetful and distracted."

To varying degrees, as a result of the disease process, about half of all people with MS have some trouble with cognitive functions. Short-term memory problems are the most common. People may forget recent events, but remember things they have known for many years. Other cognitive functions such as the ability to organize, plan, and problem-solve; focus, maintain, and shift attention as necessary; and analyze spatial relationships and directions can also be affected by MS. These problems may contribute to a person's ability to carry out everyday tasks and may impact safety. If you are concerned that your spouse might be experiencing any of these symptoms, you may want to ask your doctor about a neuropsychological evaluation. Greater personal awareness of the problems and tips for compensating for these problems may improve safety and independence.

"My wife has had a few 'fender-benders' in the past couple of months. She'd hate to give up her driver's license, but I'm worried about her getting into a more serious accident."

Driving can be affected by many MS-related symptoms including vision changes, problems with weakness or coordination, and cognitive problems. An occupational or physical therapist can assist people with MS to assess driving skills and determine whether adaptations may work. A full driving assessment will include mobility, visual, and cognitive components. Adaptations such as hand controls for braking and acceleration, steering knobs to help people who have the use of only one arm, and other vehicle modifications can make driving easier and safer for many people. However, if it is determined that a person can no longer drive safely, it may be helpful to have this difficult conversation with the help of the doctor or therapist.

"A frustrating thing about MS is that the symptoms are not always apparent to others. I think a lot of our friends wonder why we change or cancel plans with them — they just don't 'get it' because my husband looks so healthy."

MS may be characterized by many symptoms that are "invisible" to others, for example, extreme fatigue, numbness or other sensory symptoms, or the need to stay close to a bathroom. Because these symptoms may not be immediately apparent to others, friends and family may assume that you are exaggerating or making excuses to stay away from social and family activities.

Fatigue is one of the most common symptoms of MS and can significantly interfere with a person's ability to function even in a person who otherwise has minimal visible limitations.

Bladder and bowel problems may cause people with MS to be fearful of leaving the house or not being close to a bathroom at all times. The fear of an embarrassing accident often leads to social isolation.

Other symptoms such as sensory problems, cognitive difficulties, and depression also may not be obvious to others but can have a significant impact on work, home and social activities.

Help family and friends better understand the impact of these symptoms by providing them with information. (The Society's website has many brochures and fact sheets about these and other symptoms.) Hopefully, this will lead to greater sensitivity and understanding on their part. Also, consult with your physician and rehabilitation professionals who may be able to help you manage these symptoms more effectively with medications, rehabilitation and/or lifestyle strategies so that you can continue to participate in the activities you enjoy.

"Our father seems so different from how he used to be. It's as if his personality has changed."

Changes in the brain areas that control behavior and emotions may cause people to lose their tempers more easily; become more disorganized or less interested in what goes on around them; or be less concerned with social norms. Some people have trouble initiating activities, planning, or following through.

While many people with MS do not have mental or personality changes, it is important to recognize such problems if they develop and to seek professional advice. A neurologist may suggest a consultation with a neuro-psychologist, speech-language pathologist or occupational therapist who can test cognitive functioning and recommend strategies for both the patient and the family that will make limitations less troublesome.

"My husband seems to go through a lot of mood swings. One minute he seems happy and content and the next he's angry and depressed."

There are several causes for abrupt changes in mood, which is also called "emotional lability." Some people have MS lesions in the brain that result in mood swings. Others may be taking medications that contribute to mood swings such as high-dose steroids. Emotional lability may also stem from emotional distress in the face of the day-to-day challenges of MS. In some cases, mood swings may indicate an underlying mental illness called bipolar disorder.

Since the right diagnosis is important, mood swings should be discussed with a doctor. Depending on the cause, mood swings may respond to antidepressant medication, mood-stabilizing medication, changes in the dosage of steroid medication (or the use of lithium or depakote with it), psychotherapy, and family counseling.

"I don't understand how my wife can seem so cheerful day in and day out when she is so disabled."

While not very common, some people with MS show a surprising lack of concern about their illness and appear cheerful no matter what takes place. This is called euphoria and is caused by damage to parts of the brain that control the expression of emotion. Appearances may be deceptive, however, and the person with MS may actually feel sad and worried. This discrepancy can confuse family members and friends. It may help to discuss how to address this problem with a neurologist, a neuropsychologist, or a psychiatrist.

"My wife starts to cry for no apparent reason and says she can't stop herself. When I ask what she's sad about, she says she doesn't know."

Similar to the damage that causes euphoria, MS lesions can cause a condition called pseudobulbar affect, or uncontrolled laughing and/or weeping. People cry or laugh for very little or no reason and have difficulty stopping. They know that the crying or laughing is out of proportion to the situation, but cannot help themselves. This symptom occurs in other brain conditions such as stroke, and can usually be treated effectively with medication.

"We can't tell if my husband is depressed or losing his mental sharpness."

It is often difficult to distinguish cognitive and personality changes from depression, but it is important to do so because the treatments are entirely different. Almost everyone with MS is depressed at some time. For some, depression is mild and passes quickly. The support of family and friends helps the person through. But for others depression is much more serious. The distress lasts for a long time. It may affect sleeping and eating habits as well as family, work, and social relationships.

Depression can make people lose interest in things that used to bring pleasure and become fatigued, withdrawn, and irritable; it can affect concentration and memory. Depressed people may think life is not worth living and may contemplate suicide.

Some people try to hide these feelings out of shame. Clues to watch for include loss of interest in activities, withdrawal from people, and ongoing sadness or irritability. People who had depression before MS began or who have family members who have been depressed are particularly at risk. Depression can be treated effectively with a combination of psychotherapy and antidepressant medication. A psychiatrist can help clarify the extent to which depression or cognitive problems are causing symptoms and prescribe antidepressants if appropriate. Psychiatrists, psychologists, psychiatric nurses and social workers can provide therapy.

What does the future hold?

"My wife can no longer work and we need her income. I have taken a second job now, but who will make dinner and watch the kids? We don't have family nearby and cannot afford to hire help."

MS can put enormous financial burdens on a family. Not only may an important source of income be lost, but the costs of medical care, transportation, home health care, and child care can be overwhelming. Such problems require major decisions. Should the family move to less expensive housing? Should the partner without MS take a second job? Should the family deplete its resources to qualify for government assistance?

There are no easy solutions, but health and social service agencies, lawyers and financial planners, and chapters of the National MS Society are excellent sources of information. The Americans with Disabilities Act, passed in 1990, has had an encouraging impact in the areas of employment, public accommodation, and transportation. Find out how this Federal legislation protects you or offers additional options.

"My husband now needs a lot more help, but since we depend on my income, I can't stay home to care for him. Perhaps he would get better care and more attention in a nursing home."

Decisions regarding appropriate care for a severely disabled person may be very painful. Sometimes an institutional living arrangement is the only reasonable alternative. While most nursing homes are not designed for younger residents, some do make efforts to provide special programming for them.

Visiting and talking to the staff and residents of several facilities is essential. Finding a home near the family will make it easier to visit. Peer groups and professional counseling may help family members resolve the feelings of guilt, anger, and sadness that can accompany the transition to a new living arrangement.

"Every so often I wonder where all this will end."

It is normal to have some pessimistic thoughts. But when bleak fantasies are persistent or out of line with reality, they produce needless unhappiness. It is important to remember that most people do not have the most severe type of MS. While no one can predict the future, talking with a neurologist may help one form a realistic picture and maintain a balanced perspective. Sharing fears and worries also makes them easier to bear.

"When I talk to other people, it seems there are some problems we have in common and others that are unique to me."

Families coping with MS are alike in many ways. They go through the same reactions of anger, sadness, and guilt. Families at the same developmental stage share similar problems. Young couples just starting out wonder about having children or staying together at all. Couples with children face helping them adjust to a parent who does not always feel well and may become disabled. Older couples have to find new ways to enjoy their leisure years.

Each family has its own unique stresses and ways of coping. Some couples split up because they cannot resolve their problems. Some families stay in a state of chronic unhappiness, frustration, and loneliness.

But many others, on their own or with professional help, find a way to make up for what MS takes away. They are able to talk about painful feelings — anger, hurt, sadness — and to bring their grievances out into the open. They learn to identify their problems and tackle them with a sense of competency and hope. In these families, the well members are able to find ways to help without doing too much for the person with MS. They take time for themselves without feeling guilty.

Perhaps the most important feature of these families is that the members talk openly with one another and respect each other's feelings and wishes. They also recognize that many of life's problems have nothing at all to do with MS.

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Some of our popular pamphlets include:

- ADA and People with MS
- A Guide for Caregivers
- Intimacy and Sexuality in MS
- Taming Stress in Multiple Sclerosis
- Multiple Sclerosis and Your Emotions
- Urinary Dysfunction and MS
- MS and Pregnancy
- Pregnancy and MS — Kara's Story (Webcast at nationalMSsociety.org/MSLearnOnline)
- Keep S'myelin: Activity Book for Kids
- When a Parent Has MS: A Teenager's Guide
- Someone You Know Has MS (for children 5–12)
- Solving Cognitive Problems
- Financial Planning for a Life with MS
- Depression and Multiple Sclerosis

Notes:

Notes:

The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendations or prescriptions. For specific information and advice, consult your physician.

The Society publishes many other pamphlets and articles about various aspects of MS. Visit nationalMSsociety.org/brochures to download them, or call your chapter at 1-800-344-4867 to have copies mailed to you.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at nationalMSsociety.org or 1-800-344-4867 (1-800-FIGHT-MS).

MS STOPS PEOPLE FROM MOVING.

WE EXIST TO MAKE SURE IT DOESN'T.

JOIN THE MOVEMENT®

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For Information:
1 800 FIGHT MS (1 800 344 4867)

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