

Plaintalk: A Booklet about MS for Families



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Introduction

Multiple sclerosis (MS) affects not only the individuals with the illness, but also their family members and friends. **Plaintalk** explores some of the challenges families face and describes ways in which some families have handled them. The National Multiple Sclerosis Society offers support programs where family members can share their concerns and find encouragement. This booklet was designed to resemble a meeting of a family support group. You will hear husbands, wives, partners, children, siblings 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. However, just as the experience of MS varies from person to person, so too do the concerns of family members. The responses are based upon professional advice, published material and expert opinion, and do not constitute therapeutic recommendations.

We recommend that families discuss their own particular questions and concerns among themselves, with friends and extended family, and in MS support groups in-person or on the web. If more help is needed, please talk to your MS care provider, family physician or a mental health professional.

What is MS?

MS is thought to be an immune-mediated 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 two to three times more common in women than in men. In MS, the immune system that normally protects the body against illness attacks the covering of the nerves (myelin sheath), causing inflammation and damage (demyelination). Exposure to a virus or other agent in childhood may also be involved, but what triggers this abnormal immune response later in life remains unknown.

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 properly. Body movements 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. An episode of inflammation with new or worsening of old symptoms 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 areas of demyelination (lesions, plaques or scarring) 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).

The location of the damaged myelin determines the types of symptoms a person with MS has. Common symptoms include fatigue, weakness of arms and legs, numbness, incoordination, loss of balance, visual problems, impaired bladder and/or bowel function, depression and other emotional changes, cognitive problems, and difficulty speaking and/or swallowing. MS is not contagious. Although not directly inherited, there is some genetic susceptibility to MS, as evidenced by an increased risk in close relatives, especially identical twins. MS does not shorten life expectancy except for a small number of people with a very severe form of the illness.

Diagnosis

The diagnosis of MS can sometimes be difficult to establish. 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 which is made on the basis of history and physical examination. The basic “rule” for diagnosing MS, after excluding other diseases that can cause similar neurologic symptoms, is that there must be evidence of at least two areas of demyelination in the brain or spinal cord that developed at different points in time — in other words, at least two distinct relapses. Because some people may have 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.

What happens to people with MS?

What happens to people with MS depends on how often episodes of demyelination occur, the extent to which they resolve and the amount and location of permanent damage in the brain and spinal cord. MS starts as a relapsing-remitting illness for about 85 percent of people followed by recovery or remission when symptoms go away partially or completely. Without treatment, half of the 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 percent of people have primary progressive MS, a disease course in which there is steady worsening from the start, without any remissions. Five percent 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 worsen at any time. Approximately two out of three people with MS remain able to walk over their lifetime, although many may need to use a cane or walker, and some will choose to use a scooter or wheelchair to conserve energy.

Are there any treatments for MS?

Yes. Today, there are many U.S. Food and Drug Administration (FDA)-approved medications that “modify” the course of MS, called disease-modifying therapies (DMTs). These medications limit MS activity in the brain (as seen on MRI scans), reduce the number and severity

of relapses and may slow the progression of disability. MS experts recommend that people begin treatment as soon as possible after the diagnosis. Many other medications are in various stages of clinical trials or are under review by the FDA. Please check nationalMSSociety.org for updates about current FDA-approved disease-modifying therapies and those in development, and discuss them with your doctor.

Corticosteroids are often used to shorten relapses, and there are effective medications and non-pharmacologic treatments that offer relief for specific symptoms such as muscle spasms, pain, incontinence and fatigue. Healthy living, including a healthy diet and exercise geared to a person’s abilities, is important. MS presents many challenges, but they can be met successfully with a positive attitude, determination to live a full and meaningful life, and the support of family and friends.

Early days and diagnosis

“MS is so hard to diagnose! My wife had 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 with loss of vision or paralysis, it is clear something is seriously wrong. More often, however, early symptoms are mild and transient, perhaps some numbness and tingling or unsteadiness when walking. Neurological examinations and laboratory tests may be normal. This discrepancy between what the person with MS experiences and what other people see may be confusing. Family, friends and physicians

may wonder whether the symptoms are exaggerated or if the person is depressed. The person with MS may feel frustrated and unsupported. The diagnosis may not be made for some time, and some people feel relief when it is finally established, especially if they feared they had a life-threatening disease.

“...and when we finally learned the diagnosis, we felt guilty because we had become tired of hearing about her symptoms.”

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?

“We were mad when we heard our son’s diagnosis.”

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 over time becomes able to face the reality of the situation. Denial presents a problem, however, when it prevents people from obtaining appropriate medical care or making necessary life adjustments and when it has a negative impact on interpersonal relationships.

Living with MS

“My husband refuses to use a cane even though he falls a lot. This is very frustrating for us.”

Sometimes denial does not easily give way to an acceptance of reality. While some people with MS (or their family members) know that the 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 reality while maintaining an optimistic outlook and moving forward to make the best of an unfortunate situation.

It is important to allow people time to make difficult transitions. If denial persists and interferes with self-care, mental health professionals can help.

“What we find hardest to deal with is the unpredictability and uncertainty.”

People with MS don’t know from day to day, or even hour to hour, whether they will feel well or not. Symptoms may come and go, worsen and improve, and cause both the

person with MS and family members to wonder: “Will she be able to join in the family’s activities?” “Will he need special help?” “Will we have to cancel this even we’ve been planning for so long?” This unpredictability is frustrating. It can lead to misunderstanding and conflict: “Is he really so unwell?” “Should we push or leave her alone?”

The future is uncertain. It is hard to plan. “Should we buy that new house, or does it have too many stairs?” “Will there still be two incomes to meet the mortgage payments?” “Should he change jobs or stop working?”

Unpredictability and uncertainty may be easier to live with if they are expected. There may be less disappointment when a plan falls through if an alternate plan has been made — just in case. And uncertainty is not so troubling when we recognize that nothing in life is certain.

“We were totally overwhelmed at first, but we have a lot of support from our family, friends and church. This certainly isn’t what we would have chosen, but amazingly, some good things have come from it.”

While there are harsh realities associated with MS, many people find that in coping with the disease, they uncover strengths they never knew they had and qualities they didn’t recognize in the people surrounding them. They may come to appreciate more fully the many good things they have in their lives. Families and friends often report that the experience of living with MS has drawn them closer. Facing a difficult challenge together can lead to a new intimacy in the family and a new perspective on what is really important in life.

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

Anger and guilt 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 whether it be a drop in income, new responsibilities, changes in traditional roles or something else. These are practical and emotional burdens that everyone has a right to be upset about. People can’t control when angry feelings surface, but we can all manage how we express those feelings. If family members are concerned about how angry feelings are being managed, mental health professionals can help.

“My wife is so concerned with herself 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. Others become so preoccupied with their own feelings and body functions that they cannot see how other members of the family are doing. Still others become angry and critical of those caring for them, believing that their situation would improve with a different doctor, another treatment approach, a better therapist or a more supportive family. Lack of interest and angry criticism 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, but they may need professional help to do so effectively and respectfully.

“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 expressing strong emotion will make MS itself worse — which it will not. Instead, holding feelings back may lead to angry outbursts or to avoiding the person with MS or to blaming him or her 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, and maintaining respect for everyone’s feelings and ideas, 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 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 carepartners feel overwhelmed, worn out or sick, even the most thoughtful person can lose control. Sometimes a carepartner is neglectful, verbally and emotionally hurtful, physically rough or frankly assaultive.

People with MS who must depend on others are very vulnerable to abuse or neglect. And, people with MS may also be overwhelmed and become verbally or physically abusive to others.

Of course, none of this is acceptable. Family members who are troubled by their own behaviors should seek professional help. All communities have adult protective service agencies for reporting abuse and obtaining help, and both carepartners and people with MS should not hesitate to call them to discuss their concerns. This is not “snitching” or “causing trouble” — it is an effective and timely way to get help. People with MS and family members may also talk to their healthcare providers who are required by law to do whatever is necessary to resolve the problem. Inability to care appropriately for a person with MS does not mean that the carepartner is “bad.” It means that there are serious problems that need to be corrected. Before problems escalate, it is important to talk to a physician, nurse, clergy, the National MS Society or a domestic violence hotline.

“My husband is so frustrated and angry about his 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 carepartner 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 a 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 which come in waves of painful emotion, and tears that seem to come from nowhere and feel 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 bereaved person remains stuck in anger and bitterness, unable to move forward.

“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 exhausted that they have

nothing left to give. Carepartners may become depressed and physically ill when they don't take care of themselves. While it may be difficult, family members need to find time to meet their own needs to be restored by rest and leisure 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.

“...and 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 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, perhaps for a pot luck meal or just to watch TV.

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. A social support network is a lifeline for many families.

“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 many people anxious about intimacy. Anxiety itself can interfere with sexual functioning.

Sexual problems should not be ignored: they 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 partners and help them 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 sexual 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. Most neurologists do not discourage a couple from having a child. A woman who is taking a disease-modifying medication may be advised to stop before getting pregnant; this should be fully discussed with her healthcare providers.

The FDA has significant concerns about the use of some DMTs during pregnancy, but recognizes that the use of others involve a balanced decision based on the severity of the disease.

The parents-to-be also need to consider how they will care for their 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 will have feelings about it. Family members have also lost a great deal. They may feel discouraged and depressed, unappreciated and resentful. Sometimes they feel guilty and ashamed in wanting help for themselves, believing they should be tougher or that they don’t deserve the special attention of a counselor or a support group. If they don’t receive the help they need, however, the person with MS and others in the family also suffer.

“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, teens 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 everyone 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 having trouble coping with his MS, so 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 begin 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 can help people adapt and cope in ways that substantially improve the quality of their lives.

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’mylein” 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 her mother.”

It is not harmful for a child to see a parent’s genuine feelings. While it is inappropriate to burden children with adult problems, sadness as well as frustration and disappointment expressed about the MS — not the person with it — 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 while my wife was in hospital with an exacerbation.”

A child’s fear may manifest itself as a change 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 for help with their worries. This is an ongoing process; children’s concerns will change as they grow and as the MS itself changes. It is important to share with teachers and other important adults in the child’s life the challenges the family is facing.

“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. They worry that their friends will think less of them when their parent is “different” — and a parent with a visible disability or who uses a cane or wheelchair is indeed “different” from most other parents. This kind of 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 grow to see qualities in their parents (“different” or not) 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 firsthand knowledge of illness and disability. Many become unusually aware of the feelings and needs of others. Paradoxically, this valuable quality makes some children feel selfish if they pursue their own goals. They need encouragement to balance their desire to be helpful with their equally important need to live full lives of their own. 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 need help to overcome these painful feelings.

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. Patients and family members who are concerned about these or other cognitive symptoms should request a neuropsychological or cognitive evaluation. A neurologist may suggest a consultation with a neuropsychologist, 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. Greater personal awareness of the problems and use of compensatory strategies 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 — 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, fatigue, numbness or other sensory symptoms, trouble thinking clearly, and bladder or bowel problems that make the person want to stay close to a bathroom. Because these symptoms may not be immediately apparent to others, when a person with MS declines an invitation or misses work because of these problems, friends, family, employers and co-workers may assume that he or she is simply exaggerating or making excuses.

Information will help others better understand the impact of these symptoms. The Society’s website has many brochures and fact sheets about these and other symptoms. Hopefully, information will lead to greater sensitivity and understanding. It is also important, of course, to consult with doctors and rehabilitation professionals about managing these symptoms more effectively with medications, rehabilitation and/or lifestyle strategies.

“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, also called “emotional lability,” including MS lesions and high-dose corticosteroids. 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 such as bipolar disorder.

Since the right diagnosis is essential, mood swings should be discussed with a doctor. Depending on the cause, mood swings may respond to antidepressant medication, mood-stabilizing medication, changes to other medications, 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. Euphoria can be confusing and distressing to family members and friends, although not to the person with MS. It may help to discuss how to address this problem with a neurologist, a neuropsychologist, psychiatrist or other mental health professional.

“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 ‘nothing’.”

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 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 cause them to be 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 usually be treated effectively with a combination of psychotherapy and antidepressant medication. A psychiatrist can help distinguish depression

from cognitive problems and prescribe antidepressants if appropriate. Psychiatrists, psychologists, psychiatric nurses and social workers can provide psychotherapy.

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 healthcare 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 the National MS Society are excellent sources of information. The Americans with Disabilities Act (ADA), passed in 1990, has had an encouraging impact in the areas of employment, public accommodation and transportation. Find out how this Federal legislation protects families and offers additional options. (Refer to “Other Popular Resources” at the back of this booklet.)

“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 option. While most nursing homes are not designed for younger residents, some do make special efforts to meet their needs. Several homes around the U.S. have many residents with MS and provide exceptional programs 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 severest type of MS, and that disease-modifying therapies have improved the outlook for many people. New treatments are in the pipeline, offering even more reason to be hopeful. While no one can predict the future, talking with a neurologist may help families have a realistic understanding 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 also has its own unique stresses and ways of coping. Some couples split up and some stay in a state of chronic unhappiness, frustration, and loneliness.

But many couples and families, 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. Some may even feel that facing the challenges of MS together have strengthened their bond as a family. 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.

More Questions?

Not all questions can be answered in this publication alone. The National MS Society has brochures on many different topics. Visit [nationalMSSociety.org/brochures](https://www.nationalmssociety.org/brochures) or call 1-800-344-4867.

The Society's MS Navigators are highly skilled professionals who can help you address the challenges of MS with a personalized response to your unique needs. For answers to your questions and access to information about all of the options available to you, call 1-800-344-4867.

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The National Multiple Sclerosis Society ("Society") is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient's use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

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 healthcare professional and contacting the National MS Society at [nationalMSSociety.org](https://www.nationalmssociety.org) or 1-800-344-4867.

The Society publishes many other resources about various aspects of MS. Visit [nationalMSSociety.org/brochures](https://www.nationalmssociety.org/brochures) or call 1-800-344-4867.

Other popular resources include:

- A Guide for Caregivers
- ADA and People with MS
- Driving with MS
- Intimacy and Sexuality in MS
- MS and Your Emotions
- Urinary Dysfunction and MS
- MS and Pregnancy
- When Parent Has MS: A Teenager's Guide
- Someone You Know Has MS (for children 5 to 12)
- Managing Cognitive Problems

The National MS Society mobilizes people and resources so people affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, and provides programs and services designed to help people with MS and their families move their lives forward.



National
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nationalMSsociety.org

1-800-344-4867