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Understanding multiple sclerosis

Multiple sclerosis (MS) is a chronic condition that affects the central nervous system (CNS). The brain and spinal cord make up the central nervous system (Figure 1). Sclerosis refers to the unusual hardening of tissue in the body. In MS, tissues that surround and protect the nerves of the CNS become damaged, leaving multiple areas of scar tissue. MS is thought to be an autoimmune disease. Normally, the body’s immune system battles bacteria and viruses to prevent sickness. In a person with MS, the body’s immune system mistakenly attacks the CNS.

How MS affects nerves

To understand MS, it helps to understand the nervous system. Think of the spinal cord as a bundle of wires tucked inside a canal in the backbone. These wires are really nerves that send messages, like electrical impulses, back and forth between the brain and the rest of the body.

Similar to the rubbery coating on a piece of wire, a special wrapping, called myelin, covers the CNS nerves, as shown in Figure 2. Myelin keeps the messages traveling within nerves and prevents them from slowing down or getting lost along the way.

Sometimes, the body seems to forget that myelin is good. Normally, the immune system defends the body against infection. But in MS, the immune system mistakenly senses that the body’s myelin is foreign and attacks it, destroying parts of it. This action is called demyelination. The body can heal some demyelination naturally. But sometimes the body can’t keep up with the damage and plaques or sclerotic areas are formed. Plaques, also known as lesions, may slow down or even stop messages from moving along the nerves. Multiple areas of sclerotic plaques cause the symptoms of MS. Figure 3 shows a demyelinated area of a nerve cell.

Figure 1: Central nervous system

Figure 2: Normal nerve
Figure 3: Nerve with demyelination

Nerves at work

Raising your hand seems simple—your brain sends a message down your spinal cord and out to your arm, telling your hand to move. When someone with MS wants to raise a hand, plaques can interfere with this process. Sometimes, the message jumps from nerve to nerve. This is called “cross-talk,” and leads to uncontrolled, spastic or jerky movements. Other times, the signal is stopped completely. People who experience this damage may not be able to move a particular body part, no matter how hard they try. When plaques form on the optic nerve, vision disturbances occur. They may include blurry, double or lost vision.

Who gets MS?

MS affects approximately 400,000 people in the United States, most often those between the ages of 20 and 45. Women are affected twice as often as men.

The cause of MS is unknown. Studies suggest that genetic factors make certain people more susceptible than others, but there is no evidence that MS is directly inherited. Geography may play a role because MS more often affects those living in areas that are farther away from the equator. It may be that many factors influence whether a person develops MS.

Diagnosing MS

In addition to a review of medical history, several tests and procedures are used to diagnose MS, including the following:

- Nervous system function tests. Your reflexes, balance, coordination and vision may have been checked for problems caused by MS.
- Magnetic resonance imaging (MRI). MRI offers an accurate way of viewing the brain and spinal cord without breaking the skin. MRI can also help track the progression of MS.
- Lumbar puncture (spinal tap). You may have had a small sample of spinal fluid removed and tested for levels of specific immune system components that may be present in MS.
- Evoked potential tests. You might have undergone tests that measured how quickly messages moved from your spinal cord to other parts of your body. In these tests, electrodes were placed on your head while you looked at a blinking light, listened to clicking noises or tones through headphones, or felt electrical pulses on your wrist or knee.

The first neurological incident for some people may resemble MS, yet there are not enough signs or symptoms to indicate a definite diagnosis of MS. When this happens, it is referred to as Clinically Isolated Syndrome (CIS). A patient with CIS is monitored by a neurologist to find out if this is an early stage of MS. Some people with CIS may go on to be diagnosed with MS, and some may have MS ruled out or be diagnosed with another condition. Many patients with CIS are prescribed MS medications because ongoing clinical studies show that early treatment with these medications may prevent further damage and delay further symptoms leading to a definite diagnosis of MS.
Types of MS

There are four types of MS, as shown in Table 1. Each can be mild, moderate or severe. Patterns of relapse and remission, or times when symptoms appear to fade, vary in different types of MS.

Table 1: Types of MS

<table>
<thead>
<tr>
<th>Type</th>
<th>Who is affected and how the disease progresses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relapsing-remitting MS</td>
<td>• This accounts for 85% of all MS diagnoses.</td>
</tr>
<tr>
<td></td>
<td>• Relapses are followed by remissions. People may recover completely or partially from relapses.</td>
</tr>
<tr>
<td></td>
<td>• Most people with this form of MS eventually develop secondary-progressive MS.</td>
</tr>
<tr>
<td>Secondary-progressive MS</td>
<td>• Most people with relapsing-remitting MS eventually develop this form of the condition.</td>
</tr>
<tr>
<td></td>
<td>• Irreversible disability accumulates gradually.</td>
</tr>
<tr>
<td></td>
<td>• Relapses or remissions are not clearly separated.</td>
</tr>
<tr>
<td>Primary-progressive MS</td>
<td>• This accounts for 10% of all MS diagnoses.</td>
</tr>
<tr>
<td></td>
<td>• Symptoms gradually intensify over time without clear relapses or remissions.</td>
</tr>
<tr>
<td></td>
<td>• Condition usually worsens continuously.</td>
</tr>
<tr>
<td>Progressive-relapsing MS</td>
<td>• This accounts for about 5% of all MS diagnoses.</td>
</tr>
<tr>
<td></td>
<td>• Relapses are often serious and usually have limited recovery.</td>
</tr>
<tr>
<td></td>
<td>• MS continues to progress during periods between relapses.</td>
</tr>
</tbody>
</table>

Relapses, or times when new symptoms last at least 24 hours and are separated from other new symptoms by at least 30 days, commonly occur in three of the four types of MS.
Having a better understanding of how MS affects your body will help you understand how to manage the condition, its relapses, and its symptoms.

**Slowing the progression of MS**

Some MS medications can help slow the progression of the condition. These medications, called disease-modifying therapies (DMTs), are meant to be taken over a long period of time. DMTs can help protect you from the long-term effects of relapsing forms of MS. Taking DMTs, even when you feel well, will give you the best chance of managing your condition. More information about DMTs is provided in the booklet *Understanding your multiple sclerosis medications*.

**Managing MS relapses**

During a relapse, increased demyelination causes swelling in certain areas of the CNS. Relapses can last from several days to many weeks or even months. Relapses can be triggered by emotional and physical stress such as fever, illness and childbirth.

Primary-progressive MS is the only type not characterized by clear relapses. In the relapsing-remitting, secondary-progressive and progressive-relapsing forms of MS, recovery after relapses can be gradual and is not always complete.

Doctors often prescribe a short course of corticosteroids such as prednisone or methylprednisolone when a relapse occurs. Corticosteroids can shorten relapses and are believed to help recovery by reducing the swelling of damaged areas of the CNS. For more information, see the booklet *Understanding your multiple sclerosis medications*.

**Pseudoexacerbations**

A pseudoexacerbation is a temporary worsening of MS symptoms that looks and feels like a regular MS relapse. The difference is that a true relapse is an actual worsening of the condition and can be prolonged, from several days to several weeks. A pseudoexacerbation is temporary—usually about 24 hours—and doesn’t cause any damage.

Most pseudoexacerbations are triggered by heat, or anything that raises body temperature. Common triggers include:

- Environments that are hot or humid
- Exercise
- Fever
- Hot baths and hot tubs
- Infections
- Menstrual or hormonal changes
- Sun exposure

Symptoms usually subside when the body cools down. Call your doctor if symptoms last longer than 24 hours.

**Coping with MS symptoms**

MS is an unpredictable condition. Symptoms depend on where myelin plaques have formed. Some symptoms may come and go over time, while others may be longer lasting. The range of symptoms that can occur in MS is described in Table 2, followed by tips on minimizing the discomfort of some symptoms. Symptoms can vary from person to person, and not everyone experiences every symptom of MS.
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description</th>
</tr>
</thead>
</table>
| Fatigue                         | This is the most common symptom. Fatigue can cause:  
|                                 | • Difficulty concentrating  
|                                 | • Forgetfulness  
|                                 | • Mood swings |
| Depression                      | This is the second most common symptom. Depression can be a side effect of interferon medication or a direct result of the condition. |
| Vision changes                  | Vision problems are usually caused by optic neuritis, or inflammation of the optic nerve. Problems can include:  
|                                 | • Blurry or double vision  
|                                 | • Difficulty focusing  
|                                 | • Eye pain  
|                                 | • Rapid, involuntary back-and-forth or up-and-down movement of the eyes |
| Thinking or learning (cognitive) problems | About half of those with MS experience cognitive problems. Most experience mild impairment. Common problems include:  
|                                 | • Difficulty performing everyday tasks  
|                                 | • Forgetfulness and short-term memory loss  
|                                 | • General confusion and impaired judgment |
| Mobility (movement) problems    | Movement problems are often caused by weakness, spasticity, or painful cramping of muscles. Common problems include difficulty with:  
|                                 | • Balance  
|                                 | • Hearing  
|                                 | • Speaking  
|                                 | • Swallowing  
|                                 | • Walking |
| Sexual dysfunction              | Sexual dysfunction can be caused by demyelination of CNS areas that directly affect sexual feelings and responses. Problems include:  
|                                 | • Decreased libido, or sex drive, in men and women  
|                                 | • Erectile dysfunction in men  
|                                 | • Vaginal dryness in women |
Table 2: Symptoms of MS (continued)

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder and bowel problems</td>
<td>Bladder problems include:</td>
</tr>
<tr>
<td></td>
<td>• Frequency, or having to urinate more than normal</td>
</tr>
<tr>
<td></td>
<td>• Incontinence, or the inability to control urination, usually described as “dribbling” or “leaking”</td>
</tr>
<tr>
<td></td>
<td>• Nocturia, or waking several times a night to urinate</td>
</tr>
<tr>
<td></td>
<td>• Sensation of incomplete emptying, or feeling as if urine remains in the bladder</td>
</tr>
<tr>
<td></td>
<td>• Urgency, or having to urinate without the ability to wait</td>
</tr>
<tr>
<td></td>
<td>• Urinary hesitancy, or the inability to start a urine stream</td>
</tr>
<tr>
<td></td>
<td>• Weak urine stream</td>
</tr>
<tr>
<td></td>
<td>These problems might also result in urinary tract infections. Bowel problems include:</td>
</tr>
<tr>
<td></td>
<td>• Bowel incontinence, or the inability to control release of stool</td>
</tr>
<tr>
<td></td>
<td>• Constipation</td>
</tr>
<tr>
<td>Pain and other sensory problems</td>
<td>Pain might include:</td>
</tr>
<tr>
<td></td>
<td>• Facial pain</td>
</tr>
<tr>
<td></td>
<td>• Muscle pain due to spasms</td>
</tr>
<tr>
<td></td>
<td>• A “pin-pricking” sensation on the skin called paresthesia</td>
</tr>
<tr>
<td></td>
<td>• Weakness, numbness, tingling, or a burning feeling in the arms or legs</td>
</tr>
</tbody>
</table>

**Fatigue**

One of the most challenging symptoms of MS is fatigue—a lack of physical or mental energy that can interfere with daily activities. Fatigue can be experienced at any stage of MS, and it doesn’t necessarily depend on age, gender, disability level or type of MS.

A number of other problems can lead to fatigue:

- Breathing problems
- Heart problems
- Leg weakness and mobility problems
- Sleep disturbances
- Thyroid disease
- Urinary tract infections (UTIs)

Your doctor can help identify conditions that may be triggering fatigue for you. If no treatable cause can be identified, you may have primary MS-related fatigue, one of the most common symptoms of MS.

MS-related fatigue is experienced as a feeling of being drained and incapable of performing everyday tasks. MS-related fatigue is different from fatigue experienced by people who do not have MS in that it:

- Happens suddenly
- Occurs on a daily basis
- Worsens as the day progresses
- Is more severe than normal fatigue
- Tends to be worsened by heat or humidity
- Is more likely to interfere with daily responsibilities
- May occur early in the morning, even after a good night’s sleep
If fatigue is new or has become worse during the previous six weeks, it is considered acute fatigue. This can be an early warning sign that other MS symptoms are about to become worse. Fatigue that lasts for more than six weeks, more than half of the days, during some part of the day is known as chronic persistent fatigue.

**Tips for managing MS-related fatigue**

- Simplify tasks and save energy. Ask your doctor for a referral to an occupational therapist who can show you how to simplify tasks at work and home so you can use your physical energy more efficiently.
- Keep cool. Fatigue caused by being overheated usually eases as your temperature returns to normal. Drape a cool, wet towel around your neck if you’re exercising or feeling warm. Stay in air-conditioned areas when the weather is hot.
- Get moving. Physical activity helps strengthen muscles and may make you feel more energetic. Meet with a physical therapist who can design a program tailored to your specific needs. Always talk to your doctor before starting an exercise program.
- Get plenty of rest. Try to find times to rest or nap throughout the day and focus on getting a good night’s sleep. If MS-related bowel or bladder symptoms are interrupting your sleep, talk with your doctor about ways to deal with these problems.
- Ask your doctor about medication for MS-related fatigue. See the booklet *Understanding your multiple sclerosis medications* for more information.

**Vision changes**

Vision problems are common in MS. Optic neuritis, the most frequent problem, is caused by demyelination of and swelling around the optic nerve. Optic neuritis may cause blurred or double vision and eye pain with movement. It may make it harder to see objects clearly and may affect how you see colors. It can also cause loss of peripheral vision, which allows you to see things that are not directly in your line of sight. Optic neuritis can develop suddenly or gradually over a period of several days. Complete recovery may take weeks to months. Treatment often includes corticosteroids such as prednisone. See the booklet *Understanding your multiple sclerosis medications* for more information. If your symptoms are mild or are improving on their own, your doctor may choose not to treat your optic neuritis.
When demyelination occurs in the brain stem (the place where the brain and spinal cord meet) or near the nerves that control the eye muscles, it can cause other visual disturbances, including uncontrolled eye movements and double vision. Double vision can also occur when weakened eye muscles are not able to help the eyes focus at the same time. It can worsen with fatigue or overuse during activities such as reading or performing computer work. The condition usually improves with rest and goes away without treatment.

If you are experiencing vision disturbances, tell your doctor. While most MS-related vision problems go away on their own, others require immediate attention to prevent permanent vision loss.

**Depression**

Depression is a medical condition that affects mood, thoughts, and feelings, as well as relationships with others. Feeling sad or down at times is normal, but feelings of sadness that don't go away can be a sign of depression. The changes that happen in the body due to MS, as well as some of the medications used to treat MS, can lead to depression. Experiencing depression does not mean that you are weak. Many people with MS experience depression. If you think you may be depressed, talk with your doctor. Symptoms of depression may include some or all of the following:

- Feeling sad, empty or anxious most of the time
- Losing interest or pleasure in activities that you previously enjoyed
- Being tired or lacking energy
- Feeling restless or irritable
- Eating too much or too little
- Having difficulty concentrating or making decisions
- Feeling worthless, helpless or guilty
- Sleeping too much or too little
- Thinking about death or suicide

If you have thoughts of suicide, you should call 911 or your local emergency services number immediately. If you don't want to do that, contact a doctor, mental health professional or therapist, crisis center or hotline.

The most common forms of treatment for depression are counseling, also called psychotherapy, and antidepressant medications. Counseling involves talking with a mental health professional about your thoughts and feelings. Antidepressant medications can also help improve your mood by helping to correct imbalances in brain chemicals.

If you begin taking antidepressants, it can take several months before you start experiencing the full benefits. However, you may notice side effects sooner. Side effects of antidepressants may include headache, nausea, diarrhea, constipation, and lack of sex drive or libido. Be sure to talk with your doctor if your depression does not improve. Your medication dose may need to be adjusted, or you might need to try a different antidepressant.
In addition to medication, there are steps you can take now to improve your mood:
- Maintain regular sleeping patterns to prevent fatigue. Discuss any sleeping problems with your doctor.
- Reduce stress. Try stress management techniques such as yoga or meditation.
- Keep a journal. Write about your feelings, positive and negative.
- Exercise regularly. Choose activities that you enjoy.
- Talk about how you feel. Family, friends and MS support groups can all be sources of help. You can find local support groups through the National Multiple Sclerosis Society at www.nmss.org.

**Cognitive changes**

You might forget a conversation just minutes after it occurs. Or you might begin misplacing your car keys. Then, you might begin to forget simple instructions. When these problems happen repeatedly, they may be caused by plaque formation in sensitive areas of the brain. Cognitive problems may include:
- Memory or recall problems. These are the most commonly reported cognitive symptoms. Memory loss usually happens with recently learned information, such as a friend’s new phone number or address, rather than information from the distant past.
- Difficulty with problem-solving or abstract reasoning. These problems are less common than memory or recall problems.
  - Examples include difficulty thinking through and carrying out a plan and judging situations or reactions.
  - Often, family members or co-workers notice these problems first.
- Change in visual-spatial abilities such as difficulty driving or navigating directions.
- Verbal fluency problems, often experienced as having a word on “the tip of the tongue” as opposed to speech problems, which may affect the speed or pronunciation of words.

If you are experiencing problems such as these, talk with your doctor about having a professional evaluation. Also, here are some steps you can take to help yourself:
- Substitute organization for memory.
  - Use a loose-leaf binder to organize information you might need but may forget, including appointments, to-do lists, phone numbers and driving directions.
Consider purchasing a computer-based personal digital device to help keep yourself organized.

- Take extra time when learning a new task. Studies have shown that with extra practice, people with MS can improve the ability to recall information.
- Put frequently used items such as car keys in the same place every time.
- Plan ahead. Schedule your most challenging mental tasks for the time of day when you’re likely to be at your sharpest.

**Staying mobile with MS**

Mobility is the ability to move when you want to move. It is affected by balance and coordination. These two things depend on your ears, eyes, brain, perception and position sense—all of which can be affected by MS. Common mobility problems are shown in Table 3.

**Walking**

Over time, MS may make it harder to walk. Balance and weakness can affect walking, which is also known as gait. Many gait problems can be helped by exercise, medication, physical therapy, or an assistive device such as a cane or walker. It’s estimated that about half of people with relapsing-remitting MS will need assistance with walking at some point.

Some people think assistive devices represent weakness or “surrendering” to a condition. But, in fact, the opposite is true. Assistive devices provide independence and safety. A cane can allow you to walk confidently without danger of falling, or a motorized scooter can help preserve your energy while allowing you to be out in the world. Talk to your doctor about whether you might benefit from an assistive device. A good source of information about assistive devices is ABLEDATA, a federally funded information clearinghouse on assistive devices and technologies. More information is available at www.abledata.com.
Tremor
Uncontrolled muscle shaking, or tremor, can also make walking difficult. Tremors are caused by damaged areas along the nerves that coordinate movement. They can occur in various parts of the body and can be associated with speech and swallowing difficulties. Tremors can occur when a person tries to move or when the muscles are at rest.

Treatment for tremor may include a combination of medication and weights or other devices to stabilize a body part. Talk with your doctor about your options. Ask for a referral to an occupational therapist for advice about assistive devices.

Spasticity
Muscle spasticity is a feeling of stiffness or tightness that can interfere with mobility. Spasticity may be mild or severe, causing painful, uncontrollable muscle contractions, usually in the legs. It may also cause feelings of pain or tightness in and around joints, and lead to low back pain. Spasticity can be aggravated by sudden movements or position changes, temperature and humidity extremes, infections or even tight-fitting clothing. Treatment for spasticity usually blends medication, exercise and changes in daily activities. Talk with your doctor about getting a referral to occupational and physical therapists who can help you manage spasticity.
### Table 3: Common mobility problems in MS

<table>
<thead>
<tr>
<th>Symptom</th>
<th>How symptom is experienced</th>
<th>What you can do</th>
<th>How your healthcare team can help</th>
</tr>
</thead>
</table>
| **Balance issues** | • Unsteady, swaying gait  
• “Heavy” feeling in legs or feet that cause one or both feet to drag when walking                                                                 | • Make minor changes to body positioning.  
• Exercise.  
• Use assistive devices.                                                                 | • Diagnostic tests can identify the cause.  
• Physical therapy can help improve balance. |
| **Weakness**   | • Loss of strength or function in the arms or legs                                                                                                          | Light weight training                                                            | Meet with a physical therapist to discuss assistive devices.  
• Talk to your doctor if your weakness is severe or lasts longer than 24 to 48 hours. A sudden increase in weakness may be due to infection, fever or medication side effects. |
| **Tremor**     | • Shaky, uncontrolled movement of a body part  
• May occur when trying to move or when muscles are at rest  
• May occur in arms, legs, trunk, head or eyes                                                                 | Weights or supportive braces may help stabilize affected parts of the body.       | Some medications may ease tremor. |
| **Spasticity** | • Felt as an uncontrollable tightening or stiffening of a muscle  
• May be triggered by coughing, sneezing, or a full bladder  
• Can affect grooming, bathing, walking and sexual activity  
• Can affect mood, self-image and motivation                                                                 | • Smooth-motion exercise, such as swimming, biking or walking, can relax spastic muscles.  
• Prevent factors that may aggravate spasticity, such as skin irritation, ingrown toenails, constipation or UTIs. | Talk to your doctor about medications that may help to ease spasticity. |
Speech and swallowing

When MS affects brain control of the tongue, vocal cords, or diaphragm (the large muscle in the chest that is important in breathing), everyday tasks like talking and swallowing can become difficult. As many as 40 percent of people with MS may have speech or swallowing problems at some point. Because many of the organs used for speech also affect swallowing, the two problems often occur together.

The most common speech problems include slurred speech, hoarseness, trouble speaking clearly, speaking slowly or a loss of voice volume. Swallowing problems can range from constant coughing or difficulty clearing the throat to difficulty swallowing thin liquids or rough foods. Talk with your doctor about getting a referral to a speech and language therapist.

To help prevent swallowing problems:

- Begin a meal with something cold and thick, such as a milkshake or fruit smoothie, to improve nerve function and help with swallowing.
- Blend or process your food to a texture that is easier to chew and swallow.
- Drink cold, iced drinks to stimulate your swallowing reflex.
- Eat four to six small meals throughout the day because it may be less tiring than eating three large meals.
- Eat slowly.
- Sit upright or lean forward slightly when eating or drinking to avoid choking.
- Swallow solid foods at least two times per mouthful, the first to pass the food down, the second time to catch any leftover pieces.
- Take small bites to reduce fatigue and the risk of choking.

Don’t wash down food with a liquid. Swallowing can be more difficult when you mix liquids and solids. Instead, add moisture, such as sauces, broth, water or milk, to solid foods.
Understanding multiple sclerosis (continued)

Staying safe
MS may cause cognitive, mobility, or vision problems that could affect your safety, particularly during an emergency. Because of this, it is important to plan how you might respond to an emergency.

To stay safe:
- Ask your police and fire departments for a safety inspection to identify safety concerns.
- Choose a visual reminder at the table where you eat that will remind you to turn off the stove or oven to prevent fire.
- Install electric door lock and intercom systems to make it easier for you to open doors for yourself and guests.
- Keep electrical cords and computer cables out of your walkways to prevent tripping and falling.
- Make sure you can get to and use the telephone, doors, window latches, and your mobility devices, especially when you are at your weakest.

MS and intimacy
MS can affect the ability to have and enjoy sex. Sexual arousal begins in the CNS, as the brain sends messages to the sexual organs through nerves running through the spinal cord. If the messages are disrupted because of demyelination, sexual response—including arousal and orgasm—can be affected.

Women may experience loss of libido, vaginal dryness, or difficulty reaching orgasm. Men may experience loss of libido, difficulty achieving or maintaining an erection, or difficulty reaching orgasm.

Other MS-related problems that can affect sexual activity include:
- Fatigue and weakness
- Spasticity that causes cramping or uncontrollable spasms in the legs
- Pain that interferes with pleasure
- Embarrassment caused by bowel or bladder incontinence

There are a variety of therapies to treat sexual dysfunction. Erectile dysfunction may be addressed through use of medications and sexual aids. Vaginal dryness can be relieved by using water-soluble personal lubricants that may be purchased without a prescription. Do not use petroleum-based lubricants, such as Vaseline®, because they could lead to a vaginal infection. See the booklet Understanding your multiple sclerosis medications for more information. In addition, counseling can help individuals and couples cope with the intimate physical and psychological issues that are part of living with a chronic condition.
**Bladder and bowel problems**

MS can affect many aspects of your private life, including bladder and bowel function. Problems may include storing and releasing urine, UTIs, constipation and stool incontinence.

**Problems with storing and releasing urine**

The storing and releasing of urine is a complex task regulated by the nervous system. In MS, damage to nerves that control urination can lead to a condition called neurogenic bladder. This can cause problems with storing and releasing urine. You may be tempted to decrease your fluid intake to relieve these symptoms, but this can cause urine to become concentrated, irritating the lining of the bladder, and making many bladder symptoms worse. Restricting fluids can also lead to constipation and dehydration.

If diagnostic tests show that you have a urine storage problem, your symptoms are likely caused by an overactive bladder wall muscle, the muscular part of the bladder that squeezes to discharge urine from the bladder. Your doctor may prescribe medication to help relax this muscle. Things you can do to help include the following:

- Drink eight full glasses of fluid each day. Water is best. This flushes bacteria, waste and mineral deposits out of your bladder. Don’t restrict fluids, unless advised to do so by your doctor.
- Avoid alcohol and caffeine. Both can irritate your bladder and make it hard to store urine.
- Avoid drinking too much liquid shortly before going to bed.
- Try visiting the bathroom every two to three hours, even if you don’t feel the need.

If diagnostic tests show that urine remains in your bladder after you urinate, your doctor may recommend intermittent self-catheterization (ISC), or the short-term use of a catheter, or tube, to remove urine from the body. This helps retrain your bladder. Some people find that bladder function returns to normal or near normal after several weeks or months. ISC can be discontinued at that time. For others, performing ISC remains a part of daily life. If ISC is not enough, your doctor may talk to you about using an indwelling or Foley® catheter, a flexible rubber tube that remains in the bladder to allow urine to pass out of your body and into a drainage bag.

**UTI**

Although anyone can develop a UTI, it is more common in people who are unable to fully empty their bladders. Urine that stays in the bladder over a prolonged period of time can breed bacteria, leading to infection. Symptoms of a UTI can include:

- Sudden urge to urinate
- Need to urinate more often than usual
- Burning sensation with urination
- Abdominal or lower back pain
- Fever
- Dark-colored, foul-smelling urine
- Increased spasticity

UTIs are usually treated with antibiotics. It is important to take all of your antibiotics even if your symptoms go away. Stopping your antibiotic earlier than prescribed can cause the symptoms to return because the infection was not successfully treated.

UTIs can cause a pseudoexacerbation, which stops after the infection has been treated. Your doctor may look for bladder symptoms or other evidence of infection when trying to determine if you are having a relapse or a pseudoexacerbation.
Other causes of bladder problems

Sometimes, bladder problems may be related to other MS symptoms, medication side effects, fatigue, constipation or even cognitive problems. Bladder problems can also be caused by conditions unrelated to MS, such as diabetes, arthritis, pregnancy, or (in men) an enlarged prostate. Some medications, especially diuretics, or “water pills,” which may be used to treat high blood pressure, may affect urinary function. It’s important to tell your doctor about all the medications you are taking, including over-the-counter products and supplements such as vitamins and herbs.

Constipation

Constipation is defined as having two or fewer bowel movements per week or having difficulty passing stool. Waste material normally moves through the intestine before being stored in the colon, where water is removed and reabsorbed. If bowel activity is slowed, more water is removed from the stool, making it hard to pass. The problem is worsened when a person drinks less fluid to prevent urinary frequency. To avoid constipation:

• Whether you’re thirsty or not, drink eight to 10 glasses of noncaffeinated fluids a day, such as water, fruit juice or sports drinks, unless your doctor advises to do otherwise.
• Eat a high-fiber diet, including fruits, vegetables, cereals and grains. Aim for 25 to 30 grams of fiber each day. If this is difficult, talk to your doctor about using a fiber supplement.
• Try to move your bowels at a regular time each day.
• Exercise regularly to stimulate your bowels.
• Ask your doctor about stool softeners, rectal lubricants or stimulants if fluid and fiber don’t improve your bowel function.

Stool incontinence

While the most common bowel complaint for people with MS is constipation, the most distressing is often stool incontinence, which occurs when solid waste passes out of the body without your control. This may be caused by constipation that results in stool overflow, decreased rectal sensation, rectal sphincter (the valve that releases stool out of the body) dysfunction, medications or diet. If you have problems with stool incontinence, there are things you can do to ease the problem:

• Eat a high-fiber diet, including fruits, vegetables, cereals and grains. Aim for 25 to 30 grams of fiber each day. If this is difficult, talk to your doctor about using a fiber supplement.
• Avoid alcohol, caffeine, spicy foods and fatty foods, which can irritate the bowels.
• Try to move your bowels at a regular time each day.
• Ask your doctor about medications that may help prevent stool incontinence. For more information, see Understanding your multiple sclerosis medications.
Pain and other sensory problems

You may feel an odd, prickling pain around your waist or a burning pain in your foot. Or you could have a dull ache in your shoulder or a spasm that tightens around your calf muscle. These are all forms of MS pain. The chronic pain of MS can steal sleep, drain energy, spoil mood and curb appetite.

Primary pain, also called neurogenic pain, is caused by demyelination anywhere in the CNS. Primary pain can occur spontaneously or as the result of physical contact, such as injury, touching or rubbing of a body part. Different types of primary pain are listed in Table 4.

Table 4: Primary pain in MS

<table>
<thead>
<tr>
<th>Location of pain</th>
<th>Sensation of pain</th>
<th>Other information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face</td>
<td>Sharp or stabbing</td>
<td>• Also known as trigeminal neuralgia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Occurs at any time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Often confused with dental pain</td>
</tr>
<tr>
<td>Head</td>
<td>Dull, sharp, squeezing or throbbing</td>
<td>• Caused by demyelination of spinal nerves near the head, neck or optic nerve</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Occurs at any time</td>
</tr>
<tr>
<td>Head, scalp, skin</td>
<td>Burning, itching or sensitivity</td>
<td>• Also known as alodynia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Caused by a stimulus, such as touch on the skin</td>
</tr>
<tr>
<td>Anywhere</td>
<td>Burning, aching or “pins and needles” sensation</td>
<td>• Also known as paresthesia</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Most common type of MS pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Triggered spontaneously</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Usually worse at end of the day</td>
</tr>
<tr>
<td>Midsection</td>
<td>A dull, hugging sensation around the stomach</td>
<td>• Also called the “MS hug”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Distracting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Persistent</td>
</tr>
</tbody>
</table>
Secondary pain can result from pressure sores, stiff joints, muscle contractions, urinary retention or infection. It usually improves when the underlying cause of the pain is treated. Different types of secondary pain are listed in Table 5.

**Managing pain**

Many medications are available to help manage MS pain. Information on pain medications is provided in the booklet *Understanding your multiple sclerosis medications.*

Alternative therapies might also help. Some approaches include hypnosis, yoga, meditation, acupuncture or biofeedback, a technique that uses monitoring equipment and techniques to help a person control the body’s involuntary responses, such as muscle tension. Stress management techniques, such as massage, relaxation and listening to music can also help.

It is important to stay active and keep a positive outlook. Research has shown that staying as active as possible helps keep your mood up and your pain level down. Keep in mind that changes in the severity, location, or type of pain do not necessarily mean your MS is worsening.

**Keeping track of pain**

You can help your doctor understand your pain better by keeping a journal and bringing it to your office visits. In the journal, describe your symptoms and their severity as clearly as possible because treatments vary for different pain types. In your journal, keep track of:

- Activities that triggered the pain, such as specific physical movements
- Pain ratings on a scale of 0 to 10 (with 0 meaning no pain, and 10 meaning the worst pain)
- Time of day your pain occurred, where you were, and who you were with when the pain started
- Description of your pain, such as “sharp,” “achy” or “stinging”
- What you did to try to relieve the pain, and how well it worked

**Sensory problems**

Many people with MS have damage to nerves that cause changes in feeling, called sensory disturbances. These can include numbness, tightness, or the tingling, burning, “pins and needles” feeling of paresthesia. Sometimes, these sensations can be uncomfortable and confused with the muscle tightness that accompanies spasticity. Even when they are not painful, sensory problems can change the way you move and affect your balance. For example, sensitivity on the bottoms of your feet may affect how you walk. Talk with your doctor about your symptoms and therapies or medications that might help.

<table>
<thead>
<tr>
<th>Location of pain</th>
<th>Sensation of pain</th>
<th>Other information</th>
</tr>
</thead>
</table>
| Anywhere         | Stiff, painful spasms | • Also known as spasticity  
|                  |                    | • Caused by strong muscle contractions  
|                  |                    | • Intensified by irritating problems, such as a full bladder  
| Lower back, radiates to hips and thighs | Dull, aching | • Also known as indirect, chronic pain  
|                  |                    | • Occurs at any time  
|                  |                    | • Poor posture in walking or sitting puts strain on weakened muscles of lower back  
|                  |                    | • Usually caused by poor physical fitness and muscle strength prior to diagnosis  

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Table 5: Secondary pain in MS
Living with MS

Lifestyle changes
Simple lifestyle changes can help you manage your condition and prevent your symptoms from getting worse.

• Take your medications as prescribed.
• Avoid hot showers or baths.
• Stay in air-conditioned areas in hot weather.
• Get enough rest.
• Get regular, moderate exercise (after consulting with your doctor).
• Eat a healthful diet that is low in saturated fat and rich in whole grains, fruits and vegetables.
• Avoid rapid changes in your weight.
• Explore stress management techniques such as massage.
• If you smoke, quit.
• Join a support group.

Healthy eating
Eating healthy foods and following a regular fitness program can help increase your energy, maintain a healthy weight and improve your general well-being. Avoid “special” diets that have been advertised as a treatment or cure for MS. There is no scientific evidence that they are effective. Because MS is not caused by a deficiency in nutrients, vitamins or minerals, there are no special dietary requirements for people who are living with MS.

Physical activity
Exercise can be challenging for some people with MS, but it can help increase your strength, improve your reflexes and balance, and ease spasticity. Be sure to talk with your doctor before starting an exercise program. To make exercise enjoyable, choose an activity that you like and one that is within your abilities. Some tips for success include the following:

• After a relapse, talk with your doctor before you resume exercising. Be patient. It may take several weeks for your strength to return.
• Choose activities like golfing, boating and gardening to increase strength and stamina.
• Choose gyms or clubs that have nonslip floors in locker rooms and around the pools. Lean against a wall, or use a chair for support during classes, if necessary.
• Exercise with others to help stay motivated and committed to your exercise program.
• Practice yoga to help loosen tight muscles and improve range of motion.
• Try tai chi or Pilates to improve or maintain strength, flexibility and balance.
• Try to stay cool. Drink plenty of fluids before, during and after your activity and consider wearing a cooling device. Exercising in a pool can help prevent overheating.
• Use weights to help increase strength.
Rest
Your body needs daily rest to heal and repair itself. While exercise will help strengthen your body, rest gives your body time to recharge. Rest is even more important when you are living with MS. These tips may help you meet your need for added rest:

- Pace yourself. Make sure all your tasks are worth your time and effort. Take your time. Try not to schedule too many activities in one day.
- Plan your activities. If you plan to shop, prepare a list in the order you’ll find the items in the store or mall to minimize your steps and decrease the amount of time you will be on your feet.
- Sleep. Always aim for seven to eight hours of sleep. If you often wake up in the middle of the night, talk to your doctor.
- Reduce stress. Try to schedule some time each day for relaxation and quiet activities, such as reading or watching television. A stress management program, relaxation training, or support group may also help.
- Don’t do too much. Set realistic expectations about what you can do each day. Overextending yourself will make fatigue worse.

Smoking cessation
In order to take charge of your ongoing MS management and healthy living, you need to be aware that clinical studies have shown that cigarette smoking contributes to a worsening of MS. People with MS who smoke are encouraged to quit. If you smoke, the following resources may help you stop:

- Talk with your doctor about any behavioral therapies and medications that may help you quit smoking. Your doctor’s practice or associated hospitals may offer community programs to help people quit smoking.
- Check your employer’s health benefit plan to see if a smoking cessation program is offered.
- The National Institutes of Health provides free resources to help people quit smoking. You can get further information and tools by going online to smokefree.gov or by calling 1-800-QUITNOW (1-800-784-8869).

MS and pregnancy
Years ago, many women with MS were advised to avoid pregnancy because of the belief that it might make their MS worse. More recently, doctors have suggested that pregnancy appears to have a relatively protective effect in some women with MS, possibly due to the changes in immune system function that occur during pregnancy. Many expectant women experience fewer relapses, especially in their second and third trimesters. However, an estimated 20 percent to 40 percent of women experience a relapse during the first three to six months after childbirth. The effects of relapses that occur during this period are usually temporary. If you are contemplating pregnancy, talk with your doctor. You should avoid becoming pregnant while taking many types of MS medications, including DMTs, until you have spoken with your doctor. If you become pregnant while taking a DMT, stop taking the medication and contact your doctor immediately.
Complementary medicine refers to treatments used along with conventional medical care. Alternative medicine is used instead of conventional medical treatments. Unfortunately, many people who try alternative medicines believe that anything sold without a prescription is safe. While the U.S. government regulates prescription medications, there is no such regulation of food supplements and other forms of complementary and alternative medicine (CAM). Because of this, there is no way to ensure that products are safe, effective or accurately labeled.

Considering other therapies
If you are considering a complementary or alternative therapy, ask the following questions first:

• What does the treatment involve?
• How and why is it supposed to work?
• How effective is it?
• What are the risks?
• How much does it cost?

The answers to these questions can help you weigh the risks of a therapy against its benefits. Often, when something seems too good to be true, it is. If you do decide to pursue alternative therapy, the steps below can help to protect you from problems:

• Keep your doctor informed. Your doctor needs to know all therapies that you are using, so you may be alerted to possible side effects or medication interactions.
• Do not take any CAM on your own. If your doctor advises against it, do not take CAM.
• Do not abandon your conventional therapy. Consider using CAM in addition to, not in place of, your conventional therapy.
• Document your experience. If your doctor approves of CAM, keep a detailed log of what you are doing, taking, and any changes you are experiencing. If you notice any unusual side effects, contact your doctor, nurse, or one of our specialty pharmacists.
• Taking excessive amounts of many nutrients or supplements can be harmful and even sometimes life-threatening. Always speak with your doctor before taking any nutritional supplements.
To learn more

The more informed you are, the better you can manage your health. Our specialty pharmacy Care Team provides personalized, supportive and dependable care to help you achieve the best results from your prescribed therapy.

Sources

The following sources were used in the development of this booklet and the companion piece Understanding your multiple sclerosis medications.


Resources

ABLEDATA
www.abledata.com
800-227-0216
ABLEDATA provides objective information about assistive technology products and rehabilitation equipment available from domestic and international sources. Although ABLEDATA does not sell any products, the organization can help you locate the companies that do.

AllSup, Inc.
www.allsupinc.com
800-279-4357
AllSup assists individuals applying for Social Security disability benefits.

American Chronic Pain Association
www.theacpa.org
800-533-3231
ACPA offers support and education for those with chronic pain and their families.

Can Do Multiple Sclerosis™
www.mscando.org
800-367-3101
Can Do Multiple Sclerosis, formerly the Heuga Center for Multiple Sclerosis, is a national nonprofit organization that provides innovative lifestyle empowerment programs for people living with MS and their support partners.

Consortium of Multiple Sclerosis Centers (CMSC)
www.mscare.org
201-487-1050
Consortium of MS Centers mission is to be the preeminent professional organization for MS healthcare providers and researchers in North America, and a valued partner in the global MS community.

International Organization of Multiple Sclerosis Nurses (IOMSN)
www.iomsn.org
201-487-1050
IOMSN is an international organization that supports ongoing MS professional nurse education to best improve the lives of those with MS.

Multiple Sclerosis Association of America
www.msaa.com
800-532-7667
MSAA is a national nonprofit organization dedicated to enriching the quality of life for everyone affected by multiple sclerosis. It provides ongoing support and direct services to individuals with MS and the people close to them.
The Multiple Sclerosis Foundation provides a comprehensive approach to helping people with MS maintain their health and well-being. They offer programming and support to keep individuals self-sufficient and their homes safe, while their educational programs heighten public awareness and promote understanding about the disease.

**Multiple Sclerosis International Federation**

www.msif.org

This organization is an international body linking the activities of national MS societies around the world.

**National Family Caregivers Association**

www.nfcacares.org

800-896-3650

NFCA supports, empowers, and represents more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age.

**National Multiple Sclerosis Society**

www.nmss.org

800-344-4867

The National MS Society helps people address the challenges of living with MS through its home office and 50-state network of chapters. The organization funds MS research, provides services to people with MS, offers professional education, and supports advocacy efforts.

**National Rehabilitation Information Center**

www.naric.com

800-346-2742

NARIC provides interactive information to the disability and rehabilitation community through online publications, searchable databases, and timely reference and referral data.

**Smokefree.gov**

1-800-QUITNOW (1-800-784-8869)

Free government program providing support and tools to stop smoking.

**Trigeminal Neuralgia Association**

www.fpa-support.org

800-923-3608

This organization serves as an advocate for patients living with trigeminal neuralgia and related pain conditions by providing information, encouraging research, and offering support.