



## Frequently Asked Questions

*For persons with multiple sclerosis*

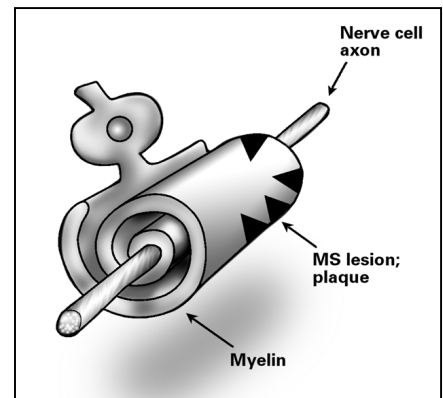
You may have many questions about the nature of multiple sclerosis (MS) and how it may affect you or your loved one. This list of frequently asked questions has been compiled to help you understand MS. Staff at the Western Multiple Sclerosis Center at UWMC are also great resources for other questions about MS that you may have.

### What is multiple sclerosis?

Multiple sclerosis (MS) is a disease affecting the brain, spinal cord, and optic nerves. The disease causes multiple areas of damage affecting these areas. Sclerosis is a medical term meaning hardening. Thus, the disease multiple sclerosis is named for these multiple areas of hardening or firmness scattered through the brain, spinal cord, and optic nerve.

The areas of damage are called plaques or lesions. These are usually located in the white matter of the brain and spinal cord. The nervous system has gray matter and white matter. The gray matter consists of areas having mostly the cell bodies of nerve cells. White matter consists mostly of the axons or nerve cells with their covering of myelin.

Axons are the long processes of nerve cells that conduct the nerve signal from one place to another. The myelin surrounds the axon and is made by another type of cell called an oligodendrocyte. The axon is like an electric wire and the myelin is like the insulation around the wire. The myelin spirals around the axon. If the end of a cut nerve is viewed, the myelin looks like a cinnamon roll wrapped around the axon in the center.



Axon

***MS has many symptoms and no two patients experience identical symptoms and disease courses.***

The plaques in MS consist primarily of areas of damage to the myelin. The axons are not entirely spared, but fare much better than the myelin. The symptoms of MS are due to the areas of damage to myelin, though many symptoms may also be due to axon damage.

Symptoms of MS often occur in attacks. Attacks are the same as exacerbations or flares. During an attack, symptoms develop over a few hours or days. This is associated with an attack on the myelin by the immune system. The attack subsides and healing then occurs. During healing, the damaged myelin repairs, though it may not return to normal. This forms the plaque of MS. Through a series of multiple attacks, multiple areas of plaques develop.

### **What are the symptoms of MS?**

MS may affect almost any part of the brain, spinal cord or optic nerves so it can lead to a great variety of symptoms. Most patients do not get all of the possible symptoms. No two patients have the same symptoms or disease course. Common symptoms include: fatigue, decreased vision, double vision, muscle weakness and/or stiffness, leg jumps, loss of coordination, numbness, tingling or buzzing sensations, pain, bladder problems, bowel problems, sensitivity to heat, memory loss, and emotional problems such as depression.

### **What are the different types of MS?**

There are several types of MS. Classifying MS is done primarily for research purposes to assure that patients entering research studies have similar forms of MS and for determining medicine to be prescribed. Prognosis differs between these forms of MS. However, prognosis for each form of MS is not very useful in predicting what the future holds for an individual patient with the disease. Rather, the speed at which disability develops, the symptoms that occur

and the number of attacks are much more useful in predicting future disability.

**Relapsing/remitting MS** is the most common form. In these patients, attacks occur. During attacks, symptoms develop over a few hours or days. Symptoms may then remain stable or may improve until the next attack occurs. In other words, patients decline because of a series of attacks. Despite the name, symptoms do not need to remit fully in this form of MS.

**Primary progressive MS** does not have attacks. Instead, patients slowly worsen. There may be periods of stability or periods of more rapid worsening, but attacks are absent.

**Secondary progressive MS** consists of a mixture of relapsing/remitting and primary progressive MS. Patients may have attacks, but they also have slow worsening of their disease between attacks. This most commonly starts out as relapsing/remitting disease and evolves into a slow loss of baseline occurring a few years later.

**Progressive relapsing MS** begins as primary progressive disease and then later develops attacks. It resembles secondary progressive disease.

**Benign MS** refers to a very mild form of relapsing/remitting MS that has no disability. This term is not commonly used because there is no consensus on the meaning of the term.

**Chronic progressive MS** is an out-of-date term that is no longer accurate. It has been replaced by primary progressive and secondary progressive MS.

## **What causes MS?**

The cause of MS is not known. It is clear that the immune system is directly involved in the damage that occurs to the myelin. What causes the immune system to be activated is not known.

***Exactly what causes MS remains unknown. Researchers know the immune system plays a key role in the progression of this disease.***

- Some believe a person could be exposed to a virus earlier in life. The proteins of this virus could resemble the proteins of myelin. An immune attack on the virus could cross react with myelin. Even though the virus is gone, the immune attack on the myelin could persist.
- Some believe that the immune system is at fault and is attacking the myelin in the absence of an outside stimulus.
- Alternatively, some believe that a virus may be the target of the immune attack. This could be a virus that persists in the brain or central nervous system and periodically flares or that is periodically encountered, leading to attacks of MS.

### **What role does the immune system play?**

The immune system plays a key role in MS. It appears to be directly involved in the damage that occurs to myelin. Lymphocytes, a type of white blood cell, play a role in controlling the immune response that develops in MS. Lymphocytes invade the brain and/or central nervous system during acute attacks. The balance between different types of lymphocytes determines the activity of the immune reaction in the brain and/or central nervous system. Along with microglial cells, lymphocytes are responsible for the damage that occurs to the myelin. What causes the immune system to be active in this disease is not known.

### **What is my prognosis?**

The prognosis for MS is extremely variable. It is impossible to predict what the future course will be in an individual patient. The disease may improve, stay the same or worsen over the course of time.

## **Will I need assistance with walking?**

In one study, patients were checked 20 years after the onset of the disease. About 20% of people had lost the use of their legs to the point that they required a wheelchair. Another 40% needed canes or other assistance to walk. About 25% had lesser amounts of disability and 15% had little disability. Death due to MS is rare, with only about 5% dying 30 years after disease onset and 12% dying 40 years after disease onset. These prognostic numbers were obtained before the use of disease-modifying medications. Prognosis with disease-modifying medications is probably better.

Some factors which suggest a better than average prognosis are: early age of onset, female, optic neuritis as the presenting symptom, sensory symptoms as the presenting symptom, acute onset of symptoms, excellent recovery after attacks, long periods of time between attacks, and little disability after five years. Some factors which suggest a less than average prognosis are: later age of onset, progressive course from the onset, male, frequent attacks, poor recovery from attacks, and involvement of coordination or motor functions. Even using these factors, determining a prognosis in an individual patient is not very accurate.

## **Will my children get MS?**

As many as 20% of MS patients have another close relative with MS. If a parent has MS, the risk of a son getting MS is 1% and the risk of a daughter getting MS is 5%. Siblings of an MS patient have a 4% risk. If one identical twin has MS there is a 30% chance of the other twin having MS. MS is more likely to occur in persons with a Northern European genetic background. However, it can occur in any racial group.

## **Why is MS so common in the Northwest?**

Multiple sclerosis is more common in northern areas including the northern part of the United States, Canada, and

Northern Europe. Rates are also high in southern Australia, New Zealand and southern parts of Africa. The Pacific Northwest is included in this high-risk area. This risk is determined by what geographic area a person lives in before the age of 15. The cause of this geographic link to MS is unknown. A number of factors have been eliminated as explanations for the distribution of MS including climate, soil, water, sunshine, industrialization, genetics, diet and access to medical care. Viruses or some other environmental factors are still considered possible explanations.

### **Why is MS more common in women?**

Women get MS two to three times as often as men. This may be due to differences in hormones, exposure to environmental triggers or differences in the immune system. The immune system in women is different than in men because of changes associated with hormones and pregnancy. Women have other autoimmune diseases more often than men, such as lupus and rheumatoid arthritis. Which of these factors is the cause of MS or other autoimmune diseases is unknown.

### **Should I eat special foods if I have MS?**

Low fat diets have been proposed for MS, but they have not been shown to be effective. We agree with the National MS Society and recommend eating a well-balanced diet.

### **Does stress or trauma affect MS?**

It was once believed that stress or trauma could worsen MS, but recent studies have shown that they do not cause MS and do not cause MS attacks. However, stress may make us feel poorly and decrease our overall performance. This may lead MS patients who are under stress to feel worse even though there is no worsening of their disease. MS patients under stress have the same chance of having an attack as if there were no stress.

## **Will surgery affect MS?**

For MS patients, the chance of experiencing an attack following trauma (such as surgery) is the same as if there were no trauma. Though it is probably not wise to seek out stress, the normal stresses of life, job and family may be endured without being overly concerned about their effect on MS.

## **Does heat affect MS?**

Many, but not all, people with MS are sensitive to heat. Increases in body temperature make it more difficult for signals to be transmitted along denuded (demyelinated) axons. This may cause nerve signals to fail, leading to increased symptoms. In general, patients' usual symptoms may increase. In addition, new symptoms that have not been experienced before may also develop. Upon cooling back to a normal temperature, the symptoms return to baseline. People who are sensitive to heat usually know how to avoid situations that increase their temperatures such as fevers, hot weather, hot baths, exercise, etc. If these situations do not increase symptoms, they do not need to be avoided.

## **Does exercise affect MS?**

It was once believed that high levels of exercise might worsen MS. This is not the current belief. Instead, there is evidence that regular exercise actually improves function. Stretching exercises are key for maintaining flexibility and reducing spasticity. Strengthening and aerobic exercises are also useful. In general, it is best to find an exercise that you enjoy doing. There is no one exercise program that is right for everyone. Physical therapists may be useful in crafting an exercise program that fits your needs. It is important to remain cool during exercise with air conditioning, iced drinks, wet rags, cold water, etc.

## **Can I get pregnant or breastfeed with MS?**

In most cases, MS does not affect a woman's ability to get pregnant, carry a pregnancy, or deliver a baby. Also, most disabilities resulting from MS do not affect pregnancy. In a few cases with severe weakness of the legs and lower trunk muscles, the ability to deliver a baby may be affected. Even in these cases, Cesarean section can usually circumvent the problem. Breastfeeding is not affected by MS. MS may affect a man's ability to have erections or ejaculations. In many cases, sperm may be obtained and used for impregnation.

## **Should I have children if I have MS?**

The greatest issue facing family members with MS who are planning to have children is whether they are physically able to take care of children. Fatigue and cognitive issues (memory) are the greatest limitations, although weakness, lack of coordination, or other disabilities may also interfere with childcare. The uncertainties of having a disease with unpredictable attacks and a variable prognosis must also be considered.

## **Should I stop my medications if I want to become pregnant?**

During pregnancy, steroids may be used for MS attacks. It is recommended that Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Copaxone<sup>®</sup>, and Rebif<sup>®</sup> be discontinued while attempting to get pregnant and while pregnant. The risk of these drugs to the baby is likely very small but there are little data in humans. These medications are usually restarted within a few days of delivery. It is unknown if they are safe to use during breastfeeding. Other medicines should be minimized or eliminated during pregnancy. Novantrone<sup>®</sup> must be stopped prior to attempting pregnancy.



During pregnancy, most women with MS have fewer attacks. However, during the three to six months after delivery, there is an increased risk of attacks. With nine months of fewer attacks during pregnancy and three to six months of increased attacks after delivery, most women “break even.”

## **Do children get MS?**

The peak age for the onset of MS is 20 to 40, with a mean age of 28. However, people may get MS outside of this age range. Even children may get the disease. The disease behaves the same in children as it does in adults.

## **Is MS contagious?**

No.

## **Do infections make MS worse?**

Many patients have a worsening of their MS symptoms during an infection. Common infections include bladder, upper respiratory (colds, sinus infection, pneumonia, flu), and GI tract (diarrhea, stomach flu). This worsening may be due to being generally sick from the infection, or it may be due to the increased symptoms that result from an increase in body temperature due to fever. It is very important to treat fevers quickly because of this. Pseudo-exacerbation is the name for mild worsening of MS symptoms linked with infections or fevers. Pseudo-exacerbations are usually not treated with steroids.

About one in ten MS attacks are preceded by a viral infection. The symptoms of a true attack are usually more severe than those of a pseudo-exacerbation and they do not improve with treatment of the fever or infection. Most MS attacks are not preceded by a recognized viral infection and most viral infections do not lead to MS attacks.

## **Can people with MS get vaccinations?**

Once there was concern that vaccinations might increase the activity of the immune system leading to MS attacks. This does not seem to be the case. Studies have not found any increase in MS attacks following flu and hepatitis vaccines. Since most other vaccines are given in childhood, and MS affects mostly adults, there have not been sufficient studies of other vaccines to find out if they are a problem for people with MS. However, it is known that the flu, pneumonia and other infections may cause MS attacks from time to time. The risk of attacks from the infection is believed to be higher than the risk from the vaccine. It is therefore recommended that people with MS get vaccinated for diseases to which they may be exposed.

## **Does MS cause mental illness?**

Depression is common with MS. People with chronic diseases or disabilities often become depressed over their medical situation. In addition, the stresses that MS places on work, finances, and family also contribute to depression. It is also likely that damage to the brain plays a direct role in the depression that may be seen with MS. Discuss depression with your health care provider because it can be treated. Sometimes treating contributing factors such as work or financial stresses may help. Counseling to improve family understanding, coping strategies, or further understanding may be of great help. Medications may be needed in some cases.

Other mental illnesses (such as bipolar disease, schizophrenia, attention deficit disorder, etc.) are not increased in patients with MS. The frequency of these diseases in MS patients and the general population is the same.

## **Does MS affect thinking or memory?**

Many patients notice that MS affects their thinking or memory. They may be forgetful, especially for recent memory items. They may not be able to solve problems quickly, retrieve information quickly or deal with multiple tasks at one time. Intelligence quotient (IQ) is often normal because IQ testing does not require much rapid information processing or recent memory. Most people with MS either do not have these problems, or have these problems to a mild degree. Sometimes patients may have thinking or memory difficulties that are more disabling.

Neuropsychological testing can be done to identify the type and severity of thinking/memory loss. Speech therapists are trained to help people compensate for these symptoms.

## **What is the EDSS?**

The EDSS is the Extended Disability Status Scale. It was developed by Dr. John Kurtzke and is also called the Kurtzke scale. It is the most common measure of disability in MS. It is used in research studies as a measure of physical impairment. It ranges from 0 to 10 with higher numbers representing greater disability.

## **Can I continue to work with MS?**

Many people with MS continue their working careers. However, weakness, fatigue, memory loss, other symptoms or frequent attacks may make it difficult to remain in the work force. Employers are required by law to make reasonable adjustments to the work environment for disabled employees. Vocational rehabilitation counselors can help employees request job modifications needed to compensate for disability, job retraining or job placement. Check with your health care provider about your employment rights or the American Disabilities Act guidelines before making changes in your employment situation.

## **Questions?**

Call 206-598-3344

Your questions are important. Call your doctor or health care provider if you have questions or concerns. UWMC Clinic staff are available to help during regular business hours.

**Western Multiple  
Sclerosis Center at  
UWMC  
206-598-3344**

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## **What do I need to do when I go on vacation?**

Travel is not restricted by your diagnosis of MS or any medication you may be taking. It is important to travel with your medicines in their original, pharmacy-labeled container. If flying, we recommend you carry your medications in your carry-on luggage. Pharmacies are willing to provide smaller containers upon request. If you are using an injectable medicine, be aware of the correct disposal of syringes in the region you are traveling to and for overseas travel, ask if you can bring the used syringes home.

Travel with an insulated container and if refrigeration is not available, keep your medicine on ice. Review the refrigeration needs for your medicine. If you need to rent equipment, contact a local rental vendor for a recommendation in the city where you will be traveling. Before you leave on your trip, locate a facility that you can go to for treatment and urgent care if necessary.

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