

# MULTIPLE SCLEROSIS: Q&A

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## Multiple Sclerosis: Q&A

### 1. What is multiple sclerosis?

Multiple sclerosis (MS) is a central nervous system disorder that is, it affects the brain and spinal cord and spares the nerves and muscles that leave the spinal cord. MS is an inflammatory disorder in which infection-fighting white blood cells enter the nervous system and cause injury. It is a demyelinating disorder because the myelin sheath that protects nerves is stripped off during inflammation. When this happens, the nerves cannot conduct electricity as well as they should, causing various symptoms. Symptoms may be the type that come and go over time (relapsing-remitting MS) or progress over time (progressive MS). MS can happen to just about anyone and is long-term.

### 2. How is MS diagnosed?

Multiple sclerosis is often difficult to diagnose because there is no single test or finding on an exam that makes the diagnosis and because the disorder varies from person to person. In most cases, there is a history of neurological symptoms that come and go over years. The neurological exam may show changes that suggest problems with the spinal cord or brain. The magnetic resonance imaging (MRI) may show areas of abnormality that suggest MS, though the MRI in and of itself does not make the diagnosis. Spinal fluid testing may show that the immune system is active in and around the brain and spinal cord, supporting the diagnosis. Evoked potentials may assist in diagnosis. All of these need to be put together by the physician to determine if MS is the actual diagnosis. Even when all the tests are done, some people cannot be diagnosed for years after the beginning of symptoms.

### 3. What are some early symptoms of MS?

MS varies from person to person so there is no 'standard' set of symptoms for MS. However, we know those common symptoms of MS include:

- Numbness or tingling in various parts of the body

- Walking difficulties
- Weakness of one or more body part
- Fatigue
- Visual blurring, and occasionally, double vision
- Dizziness
- Lhermitte's phenomenon, a symptom in which people feel electrical tingling or shocks down their back, arms, or legs when they bend their neck forwards
- Urinary symptoms, such as hesitancy when trying to urinate, or a feeling of urgency (when you have to go, you have to go)

There is no way to predict which symptoms one person might develop.

#### **4. What is demyelination?**

In MS, patients develop various areas in the brain and spinal cord where the myelin is stripped off of the nerves. These areas are called plaques or sometimes lesions. When the myelin is off, the electrical conduction of these nerves is altered. It is like getting a fuzzy signal on a television set. This event may affect any aspect of central nervous system functioning, causing symptoms. The symptoms may vary over time depending on how extensive the demyelination is and on factors such as fatigue and heat.

#### **5. What do we know about multiple sclerosis?**

There has been widespread research about MS over the past 50 years. We do not know the cause of MS, but do know that it is an inflammatory disorder of the central nervous system that occurs in people with a tendency to such a problem. We know that it is more common further north and south of the equator, though we are still unsure why this is. Females tend to get MS about three times as often as males, a rate similar to other immune diseases. MS is more common in populations from Europe, North Africa, West Africa, Horn of Africa, Central Asia and South Asia, but can occur in other populations. It is not contagious, nor is it infectious.

#### **6. Did I do anything to bring on the MS or make it worse?**

As far as we know there are no activities that specifically cause MS or make it worse. People with MS may not tolerate heat as well as they used to and may need to avoid particularly hot or humid situations. There is evidence that having infections makes having an exacerbation of MS more likely. There does not appear to be a link to trauma. However, emotional stress has been linked to a worsening of MS symptoms. Having MS is not the fault of people who have it; it can happen to anyone.

#### **7. Is there anything new that we know about MS?**

Multiple sclerosis is being studied actively in many research institutions around the world, and new knowledge is being added constantly. For example, we now know that even with early MS, the nerve fibers themselves (the axons) are affected more than we knew before. We know from

MRI studies that new lesions (abnormal areas in the brain or spinal cord) occur about 5 to 10 times as often as people with MS have new symptoms; that is, much of the disease occurs 'under the radar scope'. We know that myelin repair occurs in the central nervous system all the time. Some groups feel there are different types of immune or pathological processes going on that we call MS, and perhaps MS may be many different disorders that we have lumped together.

## 8. Do any other diseases look like MS?

When neurologists evaluate MS they are also considering other diagnoses. While MS is the most likely cause of typical white matter changes and symptoms in an otherwise healthy young person, there are some other diseases that we consider and occasionally diagnose. These include a vitamin B12 deficiency that can cause an MS-like illness, and rarely, lupus, which may have symptoms that suggest MS. The MRI is very useful in ruling out many other disorders that could be confused with MS, and the blood tests and spinal fluid may also be helpful in diagnosing other diseases.

## 9. What does magnetic resonance imaging show in MS?

Magnetic resonance imaging has become the single most useful test for the diagnosis of MS; MRI is sensitive to brain changes which are seen in MS. Classically, the MRI shows lesions in the white matter deep in the brain near the fluid spaces of the brain (the ventricles). The test may also show changes in the cortex or near the cortex. MRI can also show changes in the brainstem and in the spinal cord.

There may be a loss of brain or spinal cord volume, a change which is called atrophy. Neurologists will occasionally use gadolinium, a heavy metal dye, to look at the brain more carefully. In a lesion that is active (a new plaque), this dye will leak out into the brain and show abnormalities. It is not clear how useful repeated MRIs are for following MS. However, many neurologists will repeat an MRI about a year after starting treatment for MS, or when there are unexplained changes in the patient's course that make it important to take another look. In MS, the MRI may not make the diagnosis, as sometimes the changes are not specific for MS. Other times the appearance may be characteristic of MS.

## 10. What are evoked potentials, and what are they used for?

Evoked potentials are tests where different sets of nerves are stimulated, and the activity of the brain, spinal cord, or nerves is measured electrically. Visual evoked potentials are done by flashing a checkerboard image in front of the patient and recording the brain's response at the back of the head. Auditory evoked responses are stimulated with a clicking noise in the ears, recording the brain's response. Somatosensory evoked responses are recorded after stimulation of the nerves usually in the arms or legs and are a measure of the nerve activity coming up the nerves and into the spinal cord. In MS, these tests may be normal but may show changes such as slower electricity conduction along the nerve pathways. In MS, visual evoked potentials are the most useful as they may show evidence of injury to the optic nerve not suspected clinically.

## 11. What is the lumbar puncture (spinal tap) for?

The lumbar puncture helps to show signs of inflammation and immune system activity in and around the brain and spinal cord. The test is really the only direct measure of immune activity that we can use clinically. In people with MS, there may be an increase in white blood cells and antibody formation in the spinal fluid. There may be 'oligoclonal' bands, which are a measure of immune activity found in MS but also in other

immune disorders. Spinal fluid helps to diagnose other diseases such as Lyme disease and lymphomas of the nervous system. Not everyone needs a lumbar puncture, but it can be very useful.

## 12. Are there different types of MS?

MS varies from patient to patient so that each individual has their own set of symptoms, problems, and their own course. There are people who have MS so mildly that they never even know that they have it. Of course, there are also others that have it severely. It is really a spectrum that ranges from mild to severe. An international panel of experts developed a classification of MS in 1999 that most neurologists use today:

- **Relapsing-remitting:** Patients have attacks of symptoms/signs, with or without recovery, but between attacks have no interval worsening.
- **Secondary progressive:** This is often after a few years of relapsing-remitting MS. The pattern changes from a relapsing pattern to progressive in between attacks, usually with fewer attacks.
- **Primary progressive:** This involves a gradual onset from the beginning and no attacks.
- **Progressive relapsing:** This is a rare form, and begins with a progressive course, while later developing attacks.
- **Fulminant:** This is a rare form, and is very severe, rapidly progressive MS.

## 13. Is there such a thing as benign MS?

The term, “benign MS,” is not part of the international classification. It is used when people have had MS for many years without developing a significant measurable disability. Recent studies have shown that it cannot be predicted early in the disease and so the term can only really be used retrospectively after people have done very well with MS for many years.

## 14. What is an attack?

An MS attack is also known as a ‘relapse’, an ‘exacerbation,’ or a ‘bout’ of MS. All of these terms mean the same thing—usually a worsening of MS symptoms or new MS symptoms lasting more than 48 hours and not due to infection or fever. An attack may be mild or severe; it may or may not correlate with MRI changes, though neurologists do not usually perform MRI imaging as part of an attack evaluation. Many patients have a daily variation of their symptoms; this is not an attack. Similarly, some patients may develop transient symptoms lasting only seconds such as twitching in an arm or a leg. This is also not an attack. Attacks are one marker of disease activity.

## 15. What is the prognosis for MS?

Most people think that MS is a rapidly disabling disorder. This is not true for most people with MS. A recent study of people with MS in the Olmstead county area near the Mayo clinic showed that most people did well even without treatment. An older study showed that after 25 years without treatment most people were still able to walk. However, only a small percentage of people followed for years do not show some measurable signs of MS on examination.

## 16. Will the medications for MS make me feel better?

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There are now six FDA-approved medications to control the course of MS; four are for relapsing patients with active disease and two are for people with more severe MS or for those failing standard therapy. In general, the medications do not 'make you feel better,' but do reduce MS activity. People treated for MS are less likely to develop new attacks, have fewer new MRI changes, and tend not to progress as much as those on no treatment. So, while the medications may not make people feel better in the present, they do help prevent people from feeling worse in the future.

## 17. What is spasticity?

Spasticity is an increased muscle tension and tightness that may interfere with useful movements. It is often present when people have had MS for a few years, and tends to be happening more often in the legs than in the rest of the body. Phasic spasms are rapid movements of limbs that occur suddenly, such as sudden flexing of a leg. Tonic spasms are a tightening of limbs in place. Spasticity may be painful and may interfere with walking, transferring, and sitting; in general, this is when spasticity is treated. While patients with spasticity may be weak, the two are not the same, and strength may be preserved in someone with spasticity.

## 18. Do people with MS get pain?

In the past, physicians thought that MS did not cause pain. However, recent studies have shown that up to one-third of people with MS will have pain related to their MS at some time during the course of their disease. This pain comes in a variety of forms, including trigeminal neuralgia, a syndrome involving sharp, stabbing pain in the side of the face or the jaw. It may come and go for days, weeks, or even longer. Medication may help with this. Some people develop back or neck pain, similar to the pain that many other people get. Some patients may get burning or tingling pain in the legs, arms, or body which may stay or come and go. Pain is part of MS and should be treated appropriately.

## 19. Do people with MS get bladder problems?

Some people with MS will have problems with bladder function due to injury to the nerves that tell the bladder and the sphincters what to do and to the nerves that help the bladder sense when it is full. The most common symptom of bladder problems in MS is urgency, a feeling that "when you have to go, you have to go." Sometimes people find that it is hard to start going, for the urine to flow. Some people cannot tell when they have to go or may have accidents (incontinence).

Many of these symptoms can be treated either with medication or with approaches such as self-catheterization, which allows the bladder to be emptied whenever it needs to be. People with MS and bladder problems are at a higher risk of urinary tract infections. Bladder problems in MS may range from being a nuisance to being a major problem that needs to be addressed.

## 20. Is fatigue part of MS?

Fatigue, a sensation of being tired all the time, is very common in MS. Most patients with MS feel tired more than they used to, despite getting sleep at night. While fatigue in MS can be due to a lack of sleep or poor sleep, it is often just one of the symptoms of MS. It may be due to

activation of the immune system, like fighting off an infection. It may be due to having to work harder to re-route information in the brain because of the MS. In any case, it can be treated. Taking naps helps with afternoon fatigue. Regular exercise actually improves fatigue symptoms. Avoiding very heavy meals may help. Making sure that night-time sleep is good is also useful. There are medications that have been shown to be helpful in MS-related fatigue.

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