

FREQUENTLY ASKED QUESTIONS

1. What is multiple sclerosis?

Multiple sclerosis (MS) is an unpredictable, at times disabling disease of the central nervous system - the brain and spinal cord. The disease attacks the protective myelin covering of the central nervous system, causing inflammation and often destroying the myelin in patches. The severity of MS, progression and specific symptoms cannot be predicted at the time of diagnosis.

2. What causes MS?

We do not know as yet what causes MS. Most researchers believe that MS is an autoimmune disease. For reasons that are still unclear, the body's immune system malfunctions and starts attacking the myelin which protects the central nervous system. There is some evidence that MS may be triggered by a common virus, and that certain people are more susceptible to developing MS because of genetic factors. There is no evidence, however, that MS is a directly inherited disease. A number of genes are probably involved in whatever makes some people more susceptible to MS.

3. Is MS contagious?

No, MS is not contagious, nor is it directly inherited although research studies now underway are suggesting that genetic factors make certain people more susceptible to developing MS.

4. Who gets multiple sclerosis?

Multiple sclerosis most often strikes young adults - women and men between the ages of 15 to 40 who are in their career and family building years. The average age of diagnosis is 30, but cases of MS have been diagnosed in childhood, and people in their fifties have been diagnosed as well. Women develop MS almost three times as often as men.

5. Is multiple sclerosis fatal?

MS is not a fatal disease for the vast majority of people with MS. Most people who have MS can be expected to live a normal or near normal life span, thanks to improvements in the treatment of symptoms and in other therapies for people with MS.

6. Why do MS symptoms develop?

MS attacks the protective covering - myelin - of the brain and spinal cord, causing inflammation and often damaging the myelin in patches. When this happens, the natural flow of nerve impulses along nerve fibres is interrupted or distorted. The result may be the wide variety of MS symptoms, depending upon what part or parts of the central nervous system is affected. The damaged parts of myelin are often called "lesions" or "plaques".

7. What are some common MS symptoms?

While MS symptoms are unpredictable and vary greatly from person to person, they may include those listed below. Remember, not all people with MS will experience all symptoms and often the symptoms will improve during periods of remission.

- **Visual disturbances** - These may include blurring of vision, double vision (diplopia), optic neuritis (inflammation of the optic nerve), involuntary rapid eye movement and very rarely, total loss of sight.
- **Extreme fatigue** - This is a debilitating kind of fatigue that comes on suddenly or is out of proportion to the activity. It is one of the most common and troubling MS symptoms.
- **Balance and coordination problems** - These may include loss of balance, tremor, unstable walking (ataxia), dizziness (vertigo), clumsiness of a limb and lack of coordination.
- **Stiffness of muscles (spasticity)** - Altered muscle tone can produce spasticity or muscle stiffness, which can affect mobility. Sometimes the muscles go into spasm which can be painful.

- **Weakness** - The muscles of the legs can feel weak, which in turn affects walking.
- **Altered sensation** - These may include tingling, numbness (paraesthesia) or a burning feeling in one particular area of the body. Facial pain may occur because of trigeminal neuralgia (also known as tic douloureux), which involves a malfunction of one of the major facial nerves.
- **Sensitivity to heat** - Many people with MS find they become sensitive to heat and their symptoms worsen while in a hot environment.
- **Speech and swallowing problems** - These may include slowing of speech, slurring of words, changes in rhythm of speech and difficulty in swallowing (dysphagia).
- **Bladder and bowel problems** - Bladder problems may include the need to urinate frequently or urgently, incomplete emptying of the bladder or emptying at inappropriate times. Bowel problems may include constipation and, infrequently, loss of bowel control.
- **Sexuality and intimacy** - These can include from time to time impotence, diminished arousal and loss of sensation.
- **Short-term memory and cognitive problems** -
These may include problems with short-term memory, concentration, judgment or reasoning

8. How do doctors diagnose MS?

Early MS may consist of vague symptoms which come and go. Many of the signs and symptoms might be attributed to other medical conditions so it may be some time, and a number of examinations later before the doctors says, "I think you have multiple sclerosis."

Ordinarily, the physician - most often a neurologist -- requires evidence that at least two separate areas of the central nervous system are involved over two different times. MS is still diagnosed clinically since there is no one test that is specific to it. However, there are a number of helpful tests and procedures including:

Medical history

The physician will ask you to recall symptoms that happened in the past.

Neurological examination

The physician tests for abnormalities in nerve pathways. Some of the most common neurological signs involve changes in eye movements, limb coordination, weakness, balance, sensation, speech and reflexes.

Testing of visual and auditory evoked potentials

When damage to myelin occurs, the passage of nerve signals along the nerve fibres may be slowed. Evoked potential tests measure the time it takes for the brain to receive and send signals. Small electrodes are placed on the heads to measure brain waves in response to visual and auditory (hearing) stimuli. If there is demyelination, the tests will pick up delays in nerve signals. These tests are not invasive or painful.

Magnetic resonance imaging (MRI)

The MRI scanner takes very detailed pictures of the brain and spinal cord and shows existing areas of MS plaques (lesions). However, even an MRI scan isn't conclusive since other conditions can produce similar plaques. The MRI scans plus evidence from the neurological examination, the medical history and other tests often confirm the diagnosis of MS.

Lumbar puncture

In this test, cerebrospinal fluid (the fluid which flows around the brain and spinal cord) is tested for the presence of antibodies. The fluid is taken from the spinal cord by inserting a needle into the back and withdrawing a small amount of fluid. The procedure is uncomfortable, but not usually too painful.

9. Does a diagnosis of MS mean I will be disabled?

The diagnosis of MS is a shock and the first thing many people think of is being disabled. Fortunately, an MS diagnosis does not necessarily mean that you will become disabled. Although most people with MS do have to make adjustments in their lifestyles over time and may find they need to use a mobility aid, they can and do live productive and fulfilling lives.

10. How many people in Canada have MS?

An estimated 55,000- 75,000 Canadians have multiple sclerosis. Prevalence rates range from one MS case per 500 people to one in 1,000 across the country. Canada is a high risk area for the disease, which occurs more often in countries, like Canada, which are further away from the equator. Nearly three more people a day in Canada are diagnosed with MS.

11. Are there different types of MS?

The course of MS is unpredictable but over time, doctors are able to determine what "type" or "form" of MS you have. Some people are minimally affected by the disease (benign MS or relapsing-remitting MS without permanent disability) while others are affected more severely. Most people fit in between these two groups.

The main types of MS are:

- a) **relapsing-remitting MS** - characterized by clearly defined attacks (relapses) followed by partial or complete recovery (remissions); most common form (70% at the time of diagnosis).
- b) **primary-progressive MS** - relatively rare (10 to 15% at time of diagnosis), people with this type of MS have a nearly continuous worsening of MS from the beginning with no clear relapses or remissions.
- c) **secondary-progressive** - about half of people with relapsing-remitting MS start to worsen within 10 years of diagnosis, with the possibility of increasing levels of disability.
- d) **progressive-relapsing** - relatively rare, combines attacks with steady worsening and no remissions.
- e) **benign MS** - few attacks with long periods of remission and little disability after 15 years; about 20 - 25% of people who were diagnosed originally with relapsing-remitting MS have this type.
- f) **malignant MS** - rapidly progressive disability within five years of diagnosis; quite rare.

12. Does MS change over time?

Most people are diagnosed with the relapsing-remitting form of MS. Over time, some people in this category develop secondary-progressive MS, which does carry a risk of disability. Others may have mild attacks but do not worsen and are considered to have benign MS.

13. Are there treatments for MS?

Since 1995, four medications have been approved in Canada for the treatment of relapsing-remitting MS and one is now available for secondary-progressive MS. The treatments have been shown in clinical trials to actually modify the course of the disease. They decrease the frequency and severity of MS attacks, reduce the number of MS lesions in the brain and several have been shown to slow the progression of disability. Therapies that are available as well to help MS symptoms such as spasticity, bladder problems, pain and fatigue.

14. Is there hope for a cure?

Absolutely. Researchers are learning more about what causes MS everyday and zeroing in on ways to prevent it. Multiple Sclerosis Society of Canada funded researchers are targetting these areas:

- a) **Repairing or growing myelin** - Since the central problem in MS is the destruction of myelin, a crucial focus is to find a way to stop the damage and stimulate myelin regrowth. Almost 50 percent of MS Society funded research goes to myelin research.
- b) **Immune system** - The immune system attacks the body's myelin so it is vital to understand what triggers that attack and to find ways to block it. Twenty-eight percent of MS Society funded research is directed at immunology.
- c) **Virus research** - Some investigators think that a number of common viruses may trigger MS attacks. Work is underway to identify them.
- d) **Genetics** - Significant progress is being made in understanding how genes may contribute to the development of MS. The world's largest study of genetic susceptibility is taking place in Canada.
- e) **MRI studies** - Since the 1980s, magnetic resonance imaging (MRI) has been used to allow investigators to see into the living brain and to detect MS lesions. MRI allows for faster diagnosis of MS and, equally important, faster evaluation of potentially useful MS therapies. Canadian scientists are leaders in this field.
- f) **Health Research** - This new program funds research that seeks to find the overall determinants of health and that helps people with MS to better cope with the disease. Areas funded include: epidemiology, health economics and psycho-social and behavioral issues.

15. What other role does the MS Society of Canada play?

Besides funding MS research, the MS Society provides services for people who have MS, family members, caregivers and health care professionals. These services are delivered through the network of divisions and chapters across Canada. In Vancouver, the Lower Mainland Chapter has professional client services staff that can assist you through the major areas of information, funding and support.

Information includes MS Society publications, literature & videos and education. Support includes services such as individual advocacy, support counselling, consultation, support & self-help groups & recreation & social groups. Services offered through MS Society divisions and chapters vary depending upon existing provincial and community programs and financial resources available to Client Services. The MS Society does not duplicate any services available through other groups or community agencies.