

# Multiple Sclerosis: A Newly Diagnosed Guide



## Multiple Sclerosis: A Newly Diagnosed Guide

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## **CONTENTS**

#### 02 INTRODUCTION TO MS

- **03** Types of MS
- **03** MS relapses
- **04** Diagnosing MS

#### 05 TREATMENTS

- **05** Disease-modifying therapies (DMTs)
- **05** Relapse management
- **05** Symptom management

#### 06 SYMPTOMS

- 06 Fatigue
- 06 Pain
- **06** Bladder dysfunction
- **07** Bowel dysfunction
- **07** Cognitive change
- **07** Mood changes
- 08 Paresthesia
- **08** Other symptoms
- **08** Vision problems
- **08** Uhthoff's Phenomena (heat intolerance)
- **08** Sexual dysfunction
- 08 Vertigo
- 08 Speech
- 08 Tremor

#### 09 WELLNESS AND MS

- **09** MS healthcare team
- **09** Physical activity
- **09** Physiotherapy (PT)
- **09** Occupational therapy (OT)
- **10** Assistive devices and equipment
- 10 Diet and nutrition
- 10 Vitamin D
- **10** Complementary and alternative medicine

#### 11 LIVING WITH MS

- 11 Employment and education
- 11 Family and social supports
- **12** Mental health supports

#### 13 RESEARCH

- 13 Immunologic
- 13 Environmental
- **13** Infectious agent
- 14 Genetic
- **15** Current MS research

#### 16 SUPPORT & SERVICES

- **16** MS Society of Canada
- **16** MS Knowledge Network

## INTRODUCTION TO MS

Multiple sclerosis (MS) is the most common disease of the central nervous system affecting young adults in Canada. About 60 per cent of adults diagnosed with MS are between the ages of 20 and 49 years old and it is three times more likely to occur in women than in men. There are approximately 90,000¹ Canadians living with the disease.

The cause of MS is still unknown, but we do know that the myelin sheath - the covering around the nerve fibres in the central nervous system (CNS) – is affected. Myelin is necessary for the transmission of nerve impulses through nerve fibres. If damage to myelin is minimal, nerve impulses travel with minor interruptions; however, if damage is significant and if scar tissue replaces the myelin, nerve impulses may be completely disrupted, and the nerve fibres themselves can be damaged. The name "multiple sclerosis" is derived from this process multiple (many) since it occurs in a number of places within the nervous system and sclerosis (scars), which means the hardened patches of scar tissue that form over the damaged myelin.

MS varies considerably from person to person, and in the severity and course of the disease. At the time of diagnosis, a neurologist is unable to predict how an individual may be affected long-term.

There are a variety of treatment options for people living with MS that can manage the disease, from medications to wellness strategies such as physical activity and eating a balanced diet.

Symptoms of MS are unpredictable and vary greatly from person to person. Many symptoms are invisible to everyone but the person living with the disease. MS can cause symptoms such as fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder and bowel problems, cognitive impairment, and mood changes. While many different symptoms can be experienced in MS, it is highly unlikely that individuals would experience all the symptoms listed above. Symptoms will depend on the area within the central nervous system that has been damaged due to an inflammatory attack or progressive degeneration of nerve fibers called neurodegeneration.

Research shows that people with MS can expect to live 95 per cent of their normal life expectancy<sup>2</sup>. Depression, anxiety, high blood pressure, high cholesterol, and chronic lung disease have been identified as the most common conditions that exist alongside MS (also called comorbidities). Research suggests that treating comorbidities may help people to better cope with the symptoms of MS and the side effects of treatments, as well as improve overall quality of life. In addition, getting annual medical check-ups and seeking medical attention for new or persistent health issues is important to a person's overall health and can help identify, and potentially prevent, certain comorbidities from developing.

<sup>&</sup>lt;sup>1</sup> The Multiple Sclerosis International Federation, Atlas of MS, 3rd Edition (September 2020).

<sup>&</sup>lt;sup>2</sup> Marrie RA, Elliott L, Marriott J, et al. Effect of comorbidity on mortality in multiple sclerosis. Neurology. 2015;85(3):240-247.doi:10.1212/WNL.00000000001718.

### INTRODUCTION TO MS

## Types of MS

Clinically isolated syndrome (CIS) refers to a single episode of neurological symptoms suggestive of MS. Not all people will develop MS. Individuals with CIS and brain lesions similar to MS are considered highrisk to later develop MS; around 80 per cent will have an additional neurological event over the following years. A neurologist can make an earlier diagnosis of MS in someone with CIS, based on their brain and spinal cord imaging (magnetic resonance imagine or MRI) features and, the presence of oligoclonal bands, a protein that is detected in the spinal fluid that indicates inflammation in the CNS. Some people have radiologically isolated syndrome (RIS), which refers to demyelination as seen on MRI highly suggestive of MS but without any symptoms of the disease. Around one-third of people with RIS will be diagnosed with MS within five years<sup>3</sup>.

The majority of people who develop MS are initially diagnosed with **relapsing-remitting MS (RRMS)**, characterized by clearly defined attacks (relapses) followed by complete or partial recovery (remissions); in Canada about 90 per cent of all people living with MS are diagnosed with RRMS. Over time, most people with RRMS will transition to a phase of the disease called secondary progressive MS (SPMS). This phase of the disease has fewer relapses with variable disability progression.

About 10 per cent of people, will be diagnosed with primary progressive MS (PPMS). Individuals diagnosed with this type of MS are typically older than people diagnosed with RRMS and will experience

a continuous worsening of symptoms from the beginning usually without clear relapses or remissions. Some people living with early PPMS will experience occasional relapses with steadily worsening disease from the beginning (active PPMS).

### MS relapses

Relapses are defined as the appearance of new or significantly worsening of old symptoms lasting at least 24-48 hours in the absence of external factors such as illness, infections, stress, heat, or fatigue. During these times, symptoms may suddenly become worse, or new ones may appear. In between relapses, there are periods called remissions where the disease does not appear to progress. Sometimes there are years between relapses. Others may find that the way they feel changes from day to day. A fluctuation in presence and severity of old or pre-existing symptoms is not unusual.

Some people may sometimes experience pseudo-relapses (or pseudo-exacerbations). A pseudo-exacerbation is a temporary worsening of MS symptoms that have occurred before. This may result from a trigger such as a rise in body temperature (e.g., infection, fatigue, physical activity). A pseudo-exacerbation is not related to new inflammation or disease activity within the CNS and does not require treatment. Symptoms will subside as the body temperature regulates.

<sup>&</sup>lt;sup>3</sup> Yamout B, Al Khawajah M. Radiologically isolated syndrome and multiple sclerosis. Mult Scler Relat Disord. 2017 Oct;17:234-237. doi: 10.1016/j.msard.2017.08.016. Epub 2017 Aug 31. PMID: 29055465.

### INTRODUCTION TO MS

## **Diagnosing MS**

There is no one definitive diagnostic test for MS. The symptoms a person may have experienced over the months or years may easily have resembled other conditions, and a neurologist must rule out other diseases and conditions before making a definite diagnosis of MS. To diagnose MS, a neurologist will first take a detailed medical history and complete a neurological examination. The neurologist will test reflexes and sensations, look at eye movements, and watch a person's gait and coordination. Additional tests may be ordered to rule out other diseases and/or confirm a diagnosis of MS. Tests may include the following:

Magnetic resonance imaging (MRI) is a medical imaging technique commonly used to visualize the internal function and structure of the body. In MS, the MRI can provide pictures of the areas of damage (lesions) in the CNS. MRI can detect areas of damage that may not be seen by other types of imaging. Your neurologist may order an MRI of your brain and your spinal cord.

**Lumbar puncture** or spinal tap involves inserting a small needle at the base of the spine, just above the tailbone, to draw a small amount of the cerebrospinal fluid (CSF) to test for the presence of particular proteins (antibodies), called oligoclonal bands, which are known to be present with inflammation in the CNS.

**Evoked potentials** (EP) may be ordered by your neurologist to measure how quickly nerve impulses travel along the nerve fibres in various parts of the CNS.

A diagnosis of MS may bring on many different feelings. Some people may feel shock, anger, anxiety, sadness, or a combination of any of these emotions. Some people also experience relief to have a diagnosis to explain the symptoms that had been occurring. After receiving a diagnosis of MS, individuals are encouraged to maintain open and ongoing discussions with their MS healthcare team.

## **TREATMENTS**

There are several therapeutic options for MS. Disease-modifying therapies (DMTs) are medications that modify or influence the underlying disease course.

DMTs do not treat symptoms of MS but target the inflammation which causes damage to the CNS. There are also medications to treat relapses and diverse medications which help relieve the various symptoms that can be experienced in MS. There are many other strategies that can be used to maintain overall wellness and improve quality of life, such as physical activity, physiotherapy, rehabilitation, and following an overall healthy lifestyle with a balanced diet.

# Disease-modifying therapies (DMTs)

DMTs are designed to reduce the frequency and severity of relapses, reduce the accumulation of lesions (damaged or active disease areas) within the brain and spinal cord, and slow the accumulation of disability. The best course of action is to control the inflammation and prevent irreversible tissue damage early on. Current treatments available target the inflammatory process of MS; they have not been shown to be effective for most people diagnosed with progressive disease without inflammatory activity.

Individual lifestyle, disease course, known side effects, and the potential risks and benefits of the different therapies will be part of the discussion with a neurologist and MS healthcare team. Each person's body or disease can respond to medications in different ways.

Assistance with treatment cost varies among provincial, territorial, and federal drug plans and private insurance companies. Reimbursement criteria will also vary between drug plans.

### Relapse management

Relapses (also called attacks, exacerbations, or flare-ups) may be treated with steroid-type drugs such as prednisone or intravenous methylprednisolone to reduce the severity of an individual relapse and hasten recovery from it, particularly in the earlier stages of the disease. The steroids (also called corticosteroids) work by reducing the inflammation that occurs in the CNS during an MS relapse. Corticosteroids carry potential side effects and long-term use should be avoided.

## Symptom management

There are many strategies to manage symptoms in all types of MS. Medications as well as, or in combination with other strategies such as physiotherapy, rehabilitation, occupational therapy, and wellness approaches (improved sleep habits, quitting smoking, eating a balanced diet, and keeping physically active) can help to manage most symptoms.

## **SYMPTOMS**

## **Fatigue**

Fatigue is one of the most frequent symptoms of MS, affecting approximately 90 per cent of people living with the disease. Fatigue can be a primary symptom, resulting from damage that occurs to the CNS, or as a secondary symptom caused by other conditions or factors related to the disease such as urinary dysfunction, pain, spasticity, and sleep problems.

Poor diet, lack of physical activity, dehydration and certain medications can also contribute to fatigue. Fatigue may be managed in different ways depending on the individual and their lifestyle, including occupational therapy, regular physical activity, mobility aids, and medications.

#### **Pain**

People with MS may experience some pain over the course of the disease. Pain resulting from MS is classified into two categories: neurogenic (nerve pain) and musculoskeletal pain. Neurogenic pain is directly correlated to demyelinating lesions in the CNS, while musculoskeletal pain is a consequence of MS-related imbalances in the bones, muscles, tendons, and ligaments that make up the musculoskeletal system.

Dysesthesias are the most common types of neurogenic pain in MS involving burning, prickling, band-like, or tingling sensations. Allodynia is pain that results from a stimulus that does not normally provoke pain, such as changes in temperature or physical stimuli such as clothing touching the skin. Some healthcare providers recommend substituting a different type of sensation for the pain, such as pressure, warmth, cold or massage.

Pain due to spasticity (stiffness) can be aided by stretching exercises or, if caused by a gait issue, an assistive device may help. If the pain cannot be managed effectively using these techniques, medications may be necessary. Stiffness can be treated by antispasticity drugs and sometimes tranquilizers and drugs for epilepsy (which stabilize nerves) are used. Reactions to medications will vary so individuals may need to try different treatments before achieving satisfactory results. Some people may also experience spasms in the legs (if spasticity is severe), which can cause periodic cramping while sitting or lying down.

Not all pain is associated with MS, so it is important for individuals to discuss any pain with their healthcare provider to establish a proper diagnosis.

## **Bladder dysfunction**

Bladder dysfunction occurs in approximately 80 per cent of people with MS. There are a wide range of treatment options for bladder dysfunction, and typically lifestyle adjustments are the first line of treatment. In addition to changes in lifestyle, there are medications, rehabilitation approaches and in some cases, surgery. The most common urinary problem involves an overactivity of the bladder's detrusor muscle which interferes with the storage of urine, emptying the bladder or a combination of both. This can cause symptoms such as urgency (sudden need to void), frequency, and incontinence (inability to control the time and place of urination). Individuals with MS may be at increased risk of urinary tract infections (UTI), often due to residual (leftover) urine in the bladder.

### **SYMPTOMS**

Symptoms of a UTI may include frequent urination, burning with urination, strong odour, and discolouration of the urine. Sometimes urinary tract infections present with signs of increased pain or spasticity, rather than the usual signs. Any changes in urinary function should be discussed with a healthcare provider. There are a variety of ways to manage this symptom effectively.

## **Bowel dysfunction**

The most common bowel issue reported among people with MS is constipation. Other bowel problems that may affect people with MS include urgency, impaction, and loose stool or involuntary bowel movements. While it is not necessary for good health to have a bowel movement every day, if irregularity is a problem, there are several steps an individual can follow. Timing of bowel movement, adequate fluid intake, balanced diet that includes fibre, and physical activity are some treatment strategies that can help to promote good bowel health. Temporary measures such as medications, suppositories, laxatives, or enemas may be recommended by a health care provider if the problem persists. Diarrhea occurs much less commonly than constipation in people with MS. People are encouraged to talk to their MS healthcare team for help in managing bowel symptoms. It is important to rule out causes of bowel changes which are not due to MS.

## **Cognitive change**

Cognition refers to brain functions including attention, memory, information processing, planning, organization, problem solving, visual and spatial perception, and language use.

Typically, cognitive change is mild however a small percentage of people with MS may develop cognitive change that interferes with their day-to-day functioning. Cognitive change may be caused by damage to myelin and the nerve cells. However, some cognitive symptoms can also be indirectly affected by depression, anxiety, stress, fatigue, or medication side-effect. Like other symptoms, cognitive symptoms vary from person to person, and can come and go. There are several ways to manage this symptom, including cognitive rehabilitation, medication adjustment, and self-help options (Smartphone apps, note-taking). Individuals with cognitive change are encouraged to speak with their health care providers about a cognitive assessment and treatment options.

## **Mood changes**

Most people will feel a range of emotions following their diagnosis, such as sadness, fear, anxiety, frustration, anger, and/or uncertainty. While mood changes can be a reaction to the circumstance, the disease process itself can also cause changes in mood, such as depression. Depression is more common in MS than in the general population or in other chronic conditions and more than half of all people with MS will experience a major depressive episode at some point over the course of the disease. Depression can occur early or late in the disease, regardless of a person's other symptoms or level of disability. Healthcare providers may suggest a combination of talk therapy (mental health therapist, counselor) and antidepressant medication as a treatment strategy for depression. Wellness approaches such as physical activity and meditation have also been shown to be helpful in managing mood changes.

### **SYMPTOMS**

#### **Paresthesia**

Paresthesia's are abnormal skin sensations that occur spontaneously and may present as burning, aching, numbing, prickling, or "pins and needles". Numbness of the face, body, or extremities (arms and legs) is a common symptom and is often the first symptom experienced by those eventually diagnosed with MS. L'Hermittes sign is a typical and unique MS symptom. In this phenomenon, an uncomfortable, "electrical" sensation runs through the back and into the limbs when the head is bent forward. Discuss management of paresthesia's with your MS healthcare team.

## Other symptoms

**Vision problems:** Temporary loss of vision, double vision, and jerky eye movements may present in MS. These symptoms often resolve spontaneously though depending on the severity of the symptom, treatment with corticosteroids may be necessary.

#### Uhthoff's Phenomena (heat intolerance):

Many people with MS experience sensitivity to increased body temperature. Demyelinated fibers in the CNS can be very sensitive to even small elevations of core body temperature resulting in conduction delays or conduction block. This sensitivity can be brought out by sunbathing, exercise, hot baths, emotion, fatigue, fever, or any other factor associated with an increase in body core temperature. This may trigger a pseudo-relapse, a temporary worsening of MS symptoms that have occurred before. This is not related to new inflammation and does not require treatment. Symptoms will subside as the body temperature regulates.

Sexual dysfunction: MS can affect sexual feelings and functions both directly and indirectly. The CNS makes sexual arousal possible as the brain, sexual organs, and other parts of the body send messages to each other along nerves within the spinal cord. Other sexual problems may occur due to medication side effects or other MS-related symptoms such as fatigue, mood changes, spasticity, bladder or bowel problems, sensory changes, cognitive impairments, and pain. Treatment typically involves several strategies including medications, physiotherapy, and individual or couples counseling. While it may be an uncomfortable topic to discuss, it is important that individuals discuss any sexual problems with their healthcare team.

**Vertigo:** Some people experience dizziness or vertigo (spinning sensation). Treatment options may include medications or physiotherapy. Assistive devices such as a walker may reduce the risk of falls related to vertigo.

**Speech:** MS can sometimes cause changes in normal speech patterns. Speech and language therapists can be helpful for individuals with speech disorders (called dysarthria). In more severe cases, assistive devices are available.

**Tremor:** Involuntary movements of the body, head and limbs (tremor) may be experienced in some individuals and can interfere with daily activities. Medications, physiotherapy, and occupational therapy may be helpful in managing tremor.

## **WELLNESS AND MS**

#### MS healthcare team

Most individuals will visit their MS healthcare team ranging from every six months to one year unless there is an emergent care need that requires a neurology consultation. Individuals who are taking MS medications may be required to have periodic blood work and other treatment monitoring tests. Typically, an annual appointment with the prescribing neurologist will also be arranged for treatment renewals and to assess any changes that may have occurred within the disease course. Annual appointments with family doctors or nurse practitioners should continue as usual for routine check-ups and screenings.

## **Physical activity**

Research has provided evidence that exercise is beneficial for people living with MS and is an important aspect of the overall management of the disease. Exercise offers many benefits including improving overall health, aerobic and strength exercise reduce fatigue and improve bladder and bowel function, strength, balance, mobility, and mood. Stretching exercises reduce stiffness and increase mobility. The Canadian Society for Exercise Physiology (CSEP) released the Canadian Physical Activity Guidelines for Adults with MS to provide the minimum frequency, intensity, duration, and type of physical activity necessary for improved fitness. For more information on the Guidelines visit the website at mssociety.ca/physicalactivity.

## **Physiotherapy (PT)**

A physiotherapist will evaluate a person's movement and functioning, including strength, mobility, balance, posture, fatigue, and pain management. For some individuals, physiotherapy will play a fundamental role in managing MS throughout the disease course. It may be especially helpful during and after relapses to try and recover pre-relapse function, and during periods of progression. Physiotherapy can help individuals adapt to increased changes in function.

While there is limited evidence in MS, many people also find chiropractic care helpful in managing musculoskeletal pain, especially lower back pain. As with other healthcare and wellness practitioners, identifying a chiropractor familiar with MS is ideal.

## Occupational therapy (OT)

The goal of OT is to enhance independence, productivity, and safety in all activities related to personal care, employment, and leisure activities. Occupational therapists provide training in energy conservation techniques and the use of adaptive tools and devices to simplify tasks at home and in the workplace. They can recommend modifications to the home and workplace to ensure accessibility and convenience.

### **WELLNESS AND MS**

## **Assistive devices and equipment**

Assistive devices, such as mobility aids and other equipment can provide individuals with freedom, independence, and security. The use of assistive devices and equipment may be occasional or on a regular basis. An occupational therapist can help to identify what type of mobility aid will best meet an individual's lifestyle and personal preference. Mobility aids can take many forms and can be for the home, vehicle, workplace, and social and recreational activities.

#### **Diet and nutrition**

Most dietitians recommend a balanced diet that is high in vegetables and fruit, whole wheat grain products, lower fat dairy products, lean meats, poultry, and fish as suggested in Canada's Food Guide. Several special diets for MS have been reported however the MS Society does not endorse any particular diet for MS.

#### **Vitamin D**

Research suggests there is a connection between vitamin D and MS risk, and vitamin D as a potential disease modifier. As research continues to advance to identify and strengthen the link between vitamin D and MS, recommendations on vitamin D in MS were developed to help people living with MS make informed decisions about their health.

## Complementary and alternative medicine

Complementary and alternative medicine is a term used to describe approaches that come from a variety of traditions and practices, such as exercise, natural health products, herbs, homeopathic medicine, vitamins, acupuncture, massage, meditation, and spirituality. Many people use complementary and alternative medicine as part of their MS management in addition to enhancing their overall wellness. A practice is generally considered complementary if a person uses it in addition to taking other medications or therapies. It is considered alternative if a person uses this healthcare approach exclusively. Individuals are encouraged to maintain open and ongoing discussions with their MS healthcare team when exploring or using complementary and alternative medicine.

## LIVING WITH MS

## **Employment and education**

It is natural to wonder how MS might affect your ability to work or study. While it may not be possible to predict how MS might affect you, most people with MS lead the same lives they did before their diagnosis. Medications that help manage MS and its symptoms, in addition to certain technical aids are available to help many people remain in the workplace and at school. When MS affects someone's job or academic performance, they have a right to ask for accommodation. Accommodation refers to any change in the work (or academic) environment that gives an individual an equal opportunity to accomplish their job or education.

In the workplace, individuals are not legally required to disclose their diagnosis or discuss their medical condition with an employer. There are some occupations which may require a medical exam as a condition of employment. In this situation, disclosing the diagnosis may be necessary. The only questions an employer can legally ask an employee about a health condition relate to their ability to perform the essential duties of the job. Individuals who require workplace accommodation may also need to disclose their diagnosis. If, for whatever reason an individual must leave their workplace, temporarily or permanently, there are different income support programs and benefits available.

## Family and social supports

Talking to family members and friends about MS can be difficult for some people, and what, and with whom people choose to share their MS with is a very personal decision. Each person within a family or social network will have a different way of relating and coping with a diagnosis of MS. In addition to this booklet, the MS Society has many other resources related to living with MS that can help explain the disease and offer some tips to living well with a diagnosis of MS. Many people also find it helpful to speak with others who have been through similar experiences. The MS Society helps bring people affected by MS together, through various programs and services; support is available to individuals diagnosed with MS, their family members, caregivers, and other loved ones.

Talking to children about MS may require a different approach compared with speaking to adults about the disease. Some parents find it helpful to position the discussion in a way that reflects their child's personality, age, and maturity level. Whether it is a younger child or a teenager, keeping open communication and encouraging questions and sharing of feelings may lessen any concerns children may have and will help families adapt to life with MS. The MS Society has information geared to children and teenagers that may help with some of these discussions.

## LIVING WITH MS

## Mental health supports

In addition to managing mood changes with treatment options such as medications, talk therapy, or physical activity, developing a strong support network can also be beneficial following a diagnosis of MS. There are many resources and services available to people affected by MS. Talk to your healthcare team and reach out to an MS navigator about what support resources are available. Some examples of community resources include personal support workers, mental health services, dietitians, occupational therapists, physiotherapists, social organizations, income supports, and government services and programs.

## RESEARCH

Despite decades of research, the cause of MS is still unknown. The best current evidence suggests that biological, environmental, lifestyle, and genetic factors all contribute. Studies funded by the MS Society look at certain risk factors, such as gender, age, family history or lifestyle habits that may impact a person's susceptibility to MS.

### **Immunologic**

MS involves an autoimmune process an abnormal immune response directed against the CNS; the brain, spinal cord and optic nerve. The exact antigen, or target that the immune cells are sensitized to attack remains unknown. In recent years, researchers have been able to identify which immune cells are mounting the attack, some of the factors that cause them to attack, and some of the sites, or receptors, on the attacking cells that appear to be attracted to the myelin to begin the destructive process. The destruction of myelin – as well as damage to the nerve fibres themselves, cause the nerve impulses to be slowed or halted and produce the symptoms of MS.

#### **Environmental**

Certain surroundings and lifestyle choices can increase MS risk. Among the most studied environmental risk factors for MS are vitamin D levels, childhood obesity, and smoking. Vitamin D deficiency can influence MS risk early in life and obesity has been found to be critical in dictating MS risk during adolescence. The association between smoking and MS suggests that second-hand smoke exposure may be related to the risk of pediatric onset MS, while active smoking is later acting and highly apparent in adulthood. Migration patterns and epidemiologic studies - those that consider variations in geography, socioeconomics, genetics, and other factors have shown that people who are born in an area of the world with a high risk of MS and then move to an area with a lower risk before the age of 15, acquire the risk of their new home<sup>4</sup>. Such data suggest that exposure to some environmental trigger that occurs before puberty may predispose a person to develop MS later on.

## Infectious agent

Since initial exposure to numerous viruses, bacteria and other microbes occurs during childhood, and since viruses are well recognized as causes of demyelination and inflammation, it is possible that a virus or other infectious agent is the triggering factor in MS. More than a dozen viruses and bacteria, including measles, canine distemper, human herpesvirus 6, Epstein-Barr, and Chlamydia pneumonia have been or are being investigated to determine if they are involved in the development of MS.

<sup>&</sup>lt;sup>4</sup>O'Gorman C, Lucas R, Taylor B. Environmental risk factors for multiple sclerosis: a review with a focus on molecular mechanisms. Int J Mol Sci. 2012;13(9):11718-11752. doi:10.3390/ijms130911718

### RESEARCH

While no one virus has been identified as a definitive trigger, the virus for which the best evidence exists is Epstein-Barr Virus (EBV). EBV is the most common cause of infectious mononucleosis, an infection highly prevalent among adolescents. The risk of developing MS is 10 times greater in individuals infected with EBV during childhood, and 20 times greater in those who have developed mononucleosis.5 The other virus being investigated for its potential involvement in the development of MS is the human herpesviruses 6-A (HHV-6A). Infection with HHV-6A tends to result in viral latency, meaning the virus is in a state where it is not fully infectious. Studies have shown that people with MS have increased production of HHV-6A related proteins in their blood compared to people without MS. Researchers believe there is likely more than one virus implicated in the development of MS.

#### Genetic

While MS is not hereditary in a strict sense, having a first-degree relative such as a parent or sibling with MS increases an individual's risk of developing the disease above the risk for the general population. The general population has approximately a 0.25 per cent risk of developing MS. An immediate family member of someone with MS (e.g., a child or sibling) has a 3-5 per cent chance of developing MS. While statistically significant, this is still a relatively low risk. There are studies that show a higher prevalence of certain genes in populations with higher rates of MS.

Common genetic factors have also been found in some families where there is more than one person with MS. Some researchers theorize that MS develops because a person is born with a genetic predisposition to react to some environmental agent that, upon exposure, triggers an autoimmune response. Sophisticated new techniques for identifying genes may help answer questions about the role of genes in the development of MS.

#### **Current MS research**

MS is a complex disease, researchers are studying the immune system, myelin regrowth and repair, genetics, viruses, and epidemiology. Over the past 10 to 15 years, there has been a remarkable increase in scientific knowledge about MS. Every day, seven research papers are published on MS internationally – that's more than 2,000 a year.

In the 1990s, research yielded the first generation of treatments directly targeting MS. Today there are several therapies that have been shown to reduce relapses and slow the progression of disability. Currently, there are no therapies on the market that can repair damage to the nervous system or protect nerves from degeneration. There is growing interest in the area of remyelination, and therapies resulting from this work may have significant implications for the treatment of progressive MS.

<sup>&</sup>lt;sup>5</sup> Ascherio, A. and Munger, K.L. (2007), Environmental risk factors for multiple sclerosis. Part I: The role of infection. Ann Neurol., 61: 288-299. https://doi.org/10.1002/ana.21117

### RESEARCH

Research supported by the MS Society of Canada (both investigator-driven and targeted) is focused on several key priority areas, including cause and risk factors of MS, progression/progressive MS, myelin repair, diagnosis, cognition and mental health, and life modifying therapies. The MS Society supports projects at various points along the research spectrum – from laboratory research, clinical trials, and research on aspects of healthy living. Much of MS research is so-called "basic" research, with researchers trying to understand the complexity of the CNS, how it works, and why parts of it stop working. Findings from basic research provide an important foundation for many advancements in MS research.

Discoveries are now moving much faster from the laboratory to the person with MS. Potential treatments are tested in clinical trials to find out if the drug or therapy is s afe and effective – a complicated process in a disease like MS, which has spontaneous remissions. Currently, there are hundreds of different clinical trials for MS therapies taking place around the world. New and promising areas of MS research include the search for treatments that can block attacks on the myelin and nerve fibres (neuroprotection) and the repair of myelin and nerve function (neuro-regeneration).

The Multiple Sclerosis Society of Canada has been a strong supporter of MS research since it was founded in 1948. Funds go to carefully selected research projects at universities and hospitals across the country. Research is also a priority of other MS societies around the world. The Multiple Sclerosis Society of Canada is a member of the Multiple Sclerosis International Federation (MSIF). Comprised of more than 40 national societies, the MSIF coordinates and distributes information on MS research at the international level.

While MS research has advanced significantly, much is still unknown about the disease. This makes it susceptible to all sorts of speculation, theories, and false claims. Unfounded claims and unreliable information are common, especially in the age of social media. Individuals are encouraged to connect with an MS Navigator at the MS Society to discuss any research or information circulating on social media or news channels to assess the validity and credibility of the information.

## **SUPPORT & SERVICES**

## **MS Society of Canada**

The Multiple Sclerosis Society of Canada is a national voluntary organization, which supports research into multiple sclerosis, provides services to people with MS and their families, provides advocacy, engages in government relations activities, and raises funds to support MS Society activities.

#### The MS Society of Canada supports people:

- Living with a diagnosis of MS;
- Waiting for a diagnosis with respect to MS;
- Close to a person with MS, such as family and friends:
- Caregivers to a person with MS, who may also include family and friends.

The MS Society also provides information and support to health professionals, employers, institutions, and students. The MS Society offers a variety of programs and services to help people affected by multiple sclerosis effectively manage and cope with the disease. Please note that programs and services vary from province-to-province.

- Information and referral
- Support and self-help groups
- Recreation, social, and wellness programs
- Conferences, workshops, and education programs
- Quality of Life Funding for equipment
- Government relations and advocacy

## **MS Knowledge Network**

The MS Knowledge Network is the MS Society of Canada's hub of knowledge, lead by a team of MS Navigators, who provide trusted, consistent, quality MS information and support and connect people to community resources and MS Society programs. MS Navigators are available to assist anyone in Canada, from 8am to 8pm ET, Monday to Friday.

**Phone:** 1-844-859-6789

**Email:** msnavigators@mssociety.ca **Live Web Chat:** Available by visiting

www.mssociety.ca

Outside of the navigator service hours, or if you prefer finding information on your own, you can use our website to find reliable information & support 24/7.



#### **Our Mission**

To connect and empower the MS community to create positive change.

Disponible en français.

Multiple Sclerosis Society of Canada Toll-free in Canada: 1-800-268-7582

**Email:** info@mssociety.ca