MEETING THE CHALLENGE

Understanding and managing multiple sclerosis
Being diagnosed with multiple sclerosis (MS) can be overwhelming. While it may bring some comfort to have a diagnosis for your symptoms, you may also be left with many questions.

This booklet will help you understand your condition and how to manage it, and also provide you with information and resources to help you live well with MS. And if you have any questions that aren’t answered here, there’s space to write them on the back of this booklet, so you can ask your doctor or nurse at your next visit.
What is MS?

MS is thought to be an autoimmune disease of the central nervous system, which includes your brain and spinal cord. The central nervous system sends communications throughout your body along nerves, similar to an electrical impulse being sent through an electrical cable. The nerves, as well as the brain and spinal cord, have a protective covering called myelin. Myelin is necessary for the transmission of nerve signals through the nerve fibres.

In MS, your body’s immune system attacks myelin causing inflammation and often damaging the myelin. When this happens, the usual flow of the signal through the nerve is interrupted, similar to what happens with a frayed electrical wire. If damage to myelin is slight, nerve impulses travel with minor interruptions; however, if damage is heavy and if scar tissue replaces the myelin, nerve impulses may be completely disrupted, and the nerve fibres themselves can be damaged.

How did I get MS?

The cause of MS is not yet known. Current evidence suggests that lifestyle, environmental, genetic, and biological factors all play a role in who gets MS.

Here are some interesting facts on who gets MS:

- Usually diagnosed between the ages of 15 to 40
- MS affects more than 1 in every 500 Canadians
- MS is three times as likely to occur in women as in men
What is clinically isolated syndrome (CIS)?

The first time you experience symptoms that are suggestive of MS, such as blurring or loss of vision or a spreading numbness or tingling in a limb, it’s referred to as “CIS.” After experiencing CIS, your doctor will want to try and determine if you have MS. Unfortunately, there is no one test that can be used to diagnose MS. The diagnosis of MS is one made only once other potential causes for symptoms have been ruled out. Some of the tests your doctor may do are explained later in this booklet.

What are some common symptoms of MS?

MS is unpredictable and has many symptoms, and not everyone will have the same symptoms. You may experience different symptoms throughout the course of your MS.

Here are a few symptoms that are common in MS:

• Balance, vertigo, and dizziness problems
• Bladder or bowel dysfunction
• Short-term or other memory problems
• Depression
• Fatigue
• Difficulty walking
• Blurred or loss of vision
• Pain
• Weakness, spasms or tremors
• Numbness or tingling
• Sexual dysfunction
• Sensitivity to heat

If I have kids, will they inherit my MS?

MS is not directly inherited.

When a parent has MS

• the risk of the child and siblings developing MS is small:
  • between 3-5% if one parent has MS
  • about 30% if both parents have MS

Having MS will not directly affect pregnancy, labour or giving birth. Several studies have shown that most women with MS are just as likely to have healthy pregnancies and babies as any other woman.

IF YOU ARE PREGNANT OR PLANNING TO BECOME PREGNANT, TALK TO YOUR HEALTHCARE TEAM.
RRMS is characterized by clearly defined (but unpredictable) relapses (also known as attacks, exacerbations or flare-ups) during which new symptoms appear or existing ones get worse. In the period between relapses, these symptoms go away completely, or nearly completely (remit). It may be a few weeks, months or even years before you experience another relapse. RRMS is the most commonly diagnosed type—approximately 85% of people are initially diagnosed with RRMS. The information in this booklet focuses on RRMS, as it is the most prevalent.

In SPMS, relapses become less distinct, and MS begins to progress steadily.

About 10% of people diagnosed with MS have PPMS. This type is characterized by a slow accumulation of disability, without defined relapses. While it may have periods of stability, there are no periods where the disease is in remission.

Only about 5% of people with MS are diagnosed with PRMS. People with this form of MS experience relapses with or without recovery and their MS steadily gets worse from the beginning.
What happens in RRMS over time?

Although there are statistics that show what happens to the general population of people with MS, the bottom line is that every person with MS is different. While there is no way to know for sure what will happen with each individual’s MS, there are things you can do to affect your prognosis.

What factors can affect my prognosis?

Your doctor may use the term “prognosis” to refer to the anticipated course of your disease. Some of the factors that can affect your prognosis are listed here. This isn’t a complete list, so talk to your doctor if you have any questions about factors that affect your prognosis.

+ POSITIVE FACTORS
- Female
- Low rate of relapses per year
- Complete recovery from the first MS attack
- Long interval between first and second relapses
- Symptoms are predominantly sensory (e.g., numbness)
- Low disability at 2 to 5 years from onset
- Younger age of onset
- Involvement of only one central nervous system location at the time of onset
- Low number of lesions on MRI

- NEGATIVE FACTORS
- Male
- High rate of relapses per year
- Incomplete recovery from CIS/first MS attack
- Short interval between first and second relapses
- Symptoms are predominantly motor (e.g., tics)
- High disability at 2 to 5 years from onset
- Older age of onset
- Involvement of more than one central nervous system location at the time of onset
- High number of lesions on MRI

What other factors might affect my prognosis?

While the factors listed are out of your control, the good news is that there are things you can do that may improve your prognosis. Having a healthy lifestyle is important for everyone, and science suggests that your lifestyle can impact your MS. Recent evidence suggests that lifestyle changes like exercising, getting enough sleep, eating low-salt diet, and ensuring that your level of vitamin D is adequate may make a difference in the course of MS.

And if you smoke, quitting could be one of the most important things you do for your MS. Evidence from scientific studies has suggested that smoking may be a risk factor for transforming RRMS into SPMS. In another study, researchers reported finding links between smoking and brain tissue damage observed on brain scans of people with MS.
As mentioned, the way your MS “behaves” in the early stages can have a major impact on the course of the disease over the long term. Studies have found that people with fewer relapses, as well as those who experience a complete recovery from their relapses, have a lower risk of disease progression.

Science has shown that there is a therapeutic “window of opportunity” to optimize long-term MS outcomes: in people with a diagnosis of RRMS, starting treatment early in the disease course is associated with better long-term outcomes than delaying treatment. Evidence from clinical trials has shown that delaying treatment, even for 1 to 2 years, may lead to an irreversible increase in disability. For this reason, your doctor may recommend that therapies used for RRMS should be given as early as possible—when the “window of opportunity” to change the course of MS appears to be at its widest.

How is MS treated?

There is no cure for MS, but there are many medications in Canada that can help you manage the condition. There are several different categories of treatments for MS.

Disease-modifying therapies

These medications generally target the inflammation caused by the immune system to help reduce relapses and slow disease progression. They are capable of modifying or influencing the underlying disease course.

Relapse management therapies

During a relapse, you will likely be given a steroid specifically to help to decrease the severity and duration of the relapse. Steroids work to actively suppress the inflammation.

Symptom management therapies

You may also be prescribed medication to help manage the symptoms of your MS such as fatigue, pain or depression.

Complementary alternative medicine

This category includes anything that falls outside of “conventional” medicine, such as acupuncture, natural medicine, and massage.

Rehabilitation and physical therapy

Your MS treatment may include physical therapy to help you maintain or improve your physical condition.

Why should MS be treated at its earliest stages?

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People who begin treatment after their first attack have been found to have fewer brain lesions and fewer relapses over time. Preventing relapses is an important goal of treatment because it’s been shown that every relapse carries the risk of irreversible worsening in your Expanded Disability Status Scale (EDSS) score, and the number of relapses in the first 2 years is predictive of long-term disability.

Also, studies indicate that half of those with RRMS will need some kind of help walking within 15 years of their diagnosis—if they remain untreated.

### Setting personal goals

The goals you set for yourself will depend on your lifestyle, your MS, and what you want to achieve with your treatment. Take some time to think about what you want for yourself, and talk about possible solutions with your healthcare professional.

“I’d like to swim for twenty minutes, three times a week.”

“I want to keep working part-time.”

“I want to be relapse-free at my next appointment.”

“I want to quit smoking.”

“I’d like to play with my grandchildren.”
In the past, the goal of MS therapy was only to prevent relapses. Now we know that there’s more to the condition than just relapses. Disability, damage to the brain (scarring or lesions), aspects such as cognition, fatigue, and depression also play an important role in the quality of life of patients with MS.

According to Canadian MS guidelines, cognitive assessment should be included as a component of how doctors assess treatment and MS progression. Learning more about cognitive impairment in MS and how to measure it may one day help with optimizing treatment.

Some evidence has supported changes in brain volume as a predictor of MS progression, but more work needs to be done to understand the biological processes behind it.

A goal of “no disease activity”

Science has shown that achieving a state where there is “no evidence of disease activity” can have a positive effect on long-term disability. Talk to your doctor about setting treatment goals and how they will be measured.
How can the doctor tell if my MS is progressing?

Your doctor will track the progress of your MS by looking at the number of relapses you have, assessing your EDSS (disability) score, and by using a type of brain scan called magnetic resonance imaging (MRI).

**EDSS (disability) scoring system**

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>0.0</td>
<td>No signs or symptoms</td>
</tr>
<tr>
<td>1.0</td>
<td>Some symptoms, no disability</td>
</tr>
<tr>
<td>2.0</td>
<td>Minimal disability</td>
</tr>
<tr>
<td>3.0</td>
<td>Moderate disability</td>
</tr>
<tr>
<td>4.0</td>
<td>Relatively severe disability</td>
</tr>
<tr>
<td>5.0</td>
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<td>Restricted to wheelchair</td>
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<tr>
<td>8.0</td>
<td>Restricted to bed or chair</td>
</tr>
<tr>
<td>9.0</td>
<td>Confinement to bed</td>
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</table>

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What exactly is a relapse?
A relapse, sometimes called a flare-up, attack or exacerbation, is a period where you are experiencing clear symptoms of MS, in the absence of fever or infection. You can’t predict when a relapse will happen or how long it will last. A relapse can last from a few days to several months.

It can be difficult to know what is and what isn’t a relapse. Over time, you will get to know your MS, but it’s not uncommon to experience some “MS-like” symptoms even during remission—for example, fatigue. New symptoms can be shocking or distressing, but not every symptom will be a sign of a relapse.

If you’re not sure whether or not you’re having a relapse, it’s best to consult your healthcare professional right away. If your doctor thinks that a relapse may have occurred, he or she may order certain tests, such as an MRI, to check for any signs of MS activity in your brain or nervous system.

What is an MRI, and why do I need one on a regular basis?
An MRI provides your doctor with a picture of your brain. In the picture, your doctor can see areas of damage (lesions) caused by MS and also any changes in brain volume.

MRI is typically used in diagnosis of MS but can also be used as regular monitoring to help stage patients with MS and measure disease progression. Because it is such a powerful diagnostic and monitoring tool in MS, MRIs are often used by neurologists.

IT’S IMPORTANT TO GET REGULAR MRIs BECAUSE LESIONS CAN OCCUR EVEN IN THE ABSENCE OF OTHER RRMS SYMPTOMS.
MRIs serve the following purposes:

**To Help:**
Determine prognosis or the risk of a second MS attack in people with CIS

**To Evaluate:**
Individuals who may have experienced an MS relapse in order to determine the extent of damage to the brain or spine

**To Assess:**
Whether a patient is responding to an MS drug; MRI is done before and regularly during treatment

**To Detect:**
Possible side effects from certain MS drugs, and to look for signs of infection and unexpected disease activity

**For Routine:**
Monitoring of patients with MS (the frequency depending upon each patient’s clinical situation)

What other tests will be done regularly?
Your doctor may also do tests to check for specific symptoms of MS such as:

- The 9-hole peg test for coordination and control of your upper extremities
- A timed 25-foot walk test
- Tests to monitor your memory and problem-solving abilities
Apart from medications, what can I do?

Wellness and MS are both a life-long journey. As discussed earlier in this brochure, quitting smoking can have a positive effect on your MS. But there’s more you can do to help manage day to day. Here are a few tips that can help address some common symptoms of MS. You can talk to your healthcare team for more recommendations.
Several studies have shown that low sun exposure and/or low levels of vitamin D in the blood are associated with higher rates of relapses and disability progression in people with RRMS. Make sure you’re getting enough vitamin D.

Muscle spasms can contribute to fatigue as well as making it more difficult to walk, move, and stand.

As mentioned earlier, smoking has been shown to have a negative effect on MS. Quitting isn’t easy, but it’s worth it.

Although there isn’t any strong evidence showing that diet can affect your MS, eating a well-balanced diet is important for everyone. MS can make tasks like grocery shopping and preparing meals more challenging.

In addition to helping you stay mobile and manage some MS symptoms, exercise can help you control your weight and improve your overall health.

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Memory problems, such as difficulties with short-term memory, are common in MS. But, you can develop strategies to help.

• Include sources of vitamin D in your diet such as oily fish, fortified dairy products, egg yolks, and beef or pork liver.
• Ask your doctor about supplementing with vitamin D, especially in the winter.
• Stay in an air-conditioned environment during periods of extreme heat or humidity.
• Wear loose, lightweight, "breathable" clothing.
• Use cooling products, like neck-wraps or bandanas, when you’re exercising outdoors.
• Exercise in a cool pool.

• Many grocery delivery services are available, which can save you a trip to the store and carrying groceries.
• Gather your ingredients together before you start cooking.
• When preparing meals, sit whenever possible.
• Massage can help relax sore muscles and improve range of motion.
• Yoga and meditation can help with the fatigue that comes from muscle spasms.
• Talk to your physiatrist or physical therapist about devices and gadgets that can help make your life easier.

• If you haven’t exercised in a while, talk to your healthcare team before starting up again.
• Start slowly—don’t try to do too much the first time, and warm up with gradual stretching.
• Remember to stay cool by taking regular breaks, drinking cool drinks, and exercising in a well-ventilated area.
• Identify your triggers and come up with plans to handle or avoid them.
• You may feel silly, but practice positive self-talk in front of a mirror, such as “I don’t need a cigarette to have fun at a party.”
• Build a support network of friends and loved ones who can help, and let them know what they can do to help you quit, for example, “Can you text me first thing to distract me from having a morning cigarette?”

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Who’s on my team?

Through the course of your MS treatment, you’re likely to encounter many different doctors and specialists. These members of your healthcare team all have different roles in helping you manage your MS. In addition to the people listed below, you may see specialists to help you with specific symptoms of your MS such as a speech or language pathologist for help speaking or swallowing, or a urologist to help you with bladder dysfunction.

**Neurologist**
A neurologist is a doctor who specializes in diseases of the nervous system. Your neurologist will be involved in diagnosing, treating, and tracking your MS as well as helping you manage your symptoms.

**MS Nurse**
The main role of your nurse is to help educate you and your family about MS and support your efforts to initiate and maintain a comprehensive treatment regimen. The nurse also helps people coordinate the care they need to maintain their overall health and wellness.

**Pharmacist**
In addition to ensuring that your MS treatment won’t interact with any other medications you are taking, your pharmacist can help you understand your MS treatment, how to take it, and what to expect. Pharmacists may also provide services aimed at medication compliance, monitoring treatment adherence, and modern tools such as automated medication administration or refill reminders via e-mail or text message.

**Physiatrist**
A physiatrist is a doctor who specializes in physical rehabilitation. Treatment can involve various exercises, assistive devices to promote mobility and safety, and medications.

**Physician’s Assistant**
A physician’s assistant is a doctor who specializes in physical rehabilitation. Treatment can involve various exercises, assistive devices to promote mobility and safety, and medications.

**Physical therapist**
The goal of a physical therapist is to help you improve your mobility in everyday life. A physical therapist can help you improve strength, coordination, and balance.

**Occupational therapist**
An occupational therapist supports people’s efforts to remain productive, safe, and independent in their home and work environments using exercises, adaptive equipment, home work space modifications, and work simplification strategies.

**Social worker**
The social worker helps people with MS and their family members to connect to essential community resources related to employment, home modifications, disability applications, long-term care or any other services you might need.

**Psychologist**
The psychologist can play a key role in helping you learn about and adapt to MS. Psychologists can help people deal with their feelings of loss and anxiety, learn effective coping strategies, and think through major decisions. Psychologists also evaluate and treat mood changes that may occur, such as mood swings or depression.

**Neuropsychologist**
Neuropsychologists are doctors who specialize in the evaluation and treatment of cognitive changes, including problems with memory, attention and problem-solving. They evaluate cognition and teach compensatory strategies that can help optimize your ability to carry out activities at home and at work.

**How can I make the most of each appointment?**
- Always be honest and open about any new or changing symptoms.
- Attend all appointments you have with a member of your team.
- Make sure every member of the team has the whole picture of your health.
- Ask lots of questions if you aren’t sure if you understand something.
- Take notes, or bring a companion to your appointment to help take notes.
Having MS can feel isolating, but it’s important to remember that you’re NOT alone. Your family, friends, and healthcare team are all there to support you along your journey. Here are some other resources that offer information, support, and more.

**Multiple Sclerosis Society of Canada**
www.mssociety.ca
Provides information, support, educational events, and other resources for people with MS and their families.

**MS Connection**
www.msconnection.org
A US-based online support group for individuals with MS, their families, and friends.