

Understanding Primary Progressive Multiple Sclerosis

A BRIEF GUIDE TO PPMS

What is Multiple Sclerosis?

Multiple sclerosis or MS is an immune mediated disease. This means that the immune system, which is normally responsible for attacking germs when an infection occurs, begins to misfire and starts attacking the brain and spinal cord.

MS causes your own immune system to attack the outer coating of nerves in the brain and spinal cord. This outer coating is called the myelin sheath. It helps to send messages along the nerves in your brain and spinal cord. When this damage occurs, it disrupts the ability of the nervous system to communicate with the rest of the body.

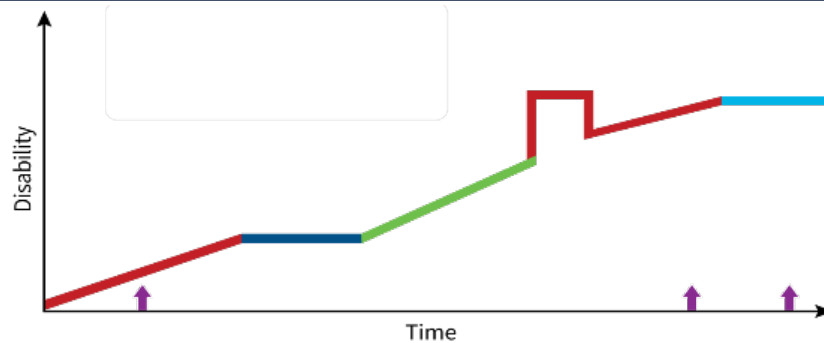
What type of MS do I have?

You have been diagnosed with **Primary Progressive Multiple Sclerosis.**

In progressive MS, disability slowly and continuously increases.

Primary Progressive MS (PPMS)

- Neurologic symptoms gradually worsen over time. Sometimes people experience periods of time where their symptoms stay stable. These can last for months or even years.
- Sudden worsening of symptoms (or relapses) can occur but these are uncommon.
- Usually begins around age 40 or older
- Rate of PPMS is the same for women and men



- Active (relapse or new MRI activity) with progression
- Active (relapse or MRI activity) without progression
- Active without progression
- Not active with progression
- Not active without progression (stable)
- ↑ New MRI activity

People with **Primary Progressive MS** may experience a variety of symptoms. There are a number of symptoms which are clearly related to MS and there are others that are not. To learn more about MS symptoms visit <https://mssociety.ca>.

Common MS-related symptoms

- Numbness, tingling
- Walking, Balance, and Coordination Problems
- Bladder, Bowel and Sexual symptoms
- Blurry or double vision
- Loss of vision with pain behind the eye
- Dizziness and Vertigo
- Cognitive Decline
- Stiffness/pain in muscles (spasticity)
- Fatigue
- Depression (more common among individuals with MS)

Symptoms NOT related to MS

- Headache
- Vision disturbances, such as seeing lights or spots (auras), with or without headache
- Fever
- Cough
- Breathing problems
- Nausea or vomiting
- Worsening of MS symptoms that occurs at the same time that you are sick with any kind of infection

Are there treatments available for Primary Progressive MS?

There are medications that are available to treat primary progressive MS. These medicines help to slow the progression of MS symptoms. They will not reduce your MS symptoms. While they can slow progression they do not completely stop it.

These medicines are called Disease modifying drugs (DMDs). DMDs are prescribed to people with primary progressive MS if they have evidence of active inflammation and if they are not limited in the distance that they can walk. Active inflammation means that the person has experienced a worsening of MS symptoms over the past year and has evidence of new disease activity on the MRI scan. These are the situations where we have found that these medications work.

Your neurologist and MS nurse will help you to make an informed decision on if taking a DMD is right for you.

DMDs do not make you feel better or reduce your symptoms. In fact, in the first few weeks on medication, you may have side effects, but these are generally easy to manage. Your MS nurse will teach you ways to effectively manage these side effects.

How will I know if my treatment is working?

When you first start on a DMD (for the first 3-6 months), we are most concerned about helping you to manage medication side effects and ongoing MS symptoms.

It will take between 3 and 6 months for a DMD to reach full effectiveness. The goal of treatment with a DMD is slowing down progression of your MS symptoms. It will be difficult to know whether or not your DMD is working as even with treatment your MS may continue to progress.

At clinic visits, your neurologist will be assessing the effectiveness of your treatment by asking you about your current symptoms and any changes or new symptoms that you may have developed since your last visit. We will also see how well you are tolerating your treatment. Periodically you will have an MRI scan.

Your MS nurse is available by phone to discuss any questions you may have and to provide you with suggestions on how best to manage medication side effects and ongoing MS symptoms.

What is a Relapse?

Generally speaking, people with progressive MS do not have relapses. It is possible, but unlikely, that you will experience a relapse at some point. Contact the MS Clinic if you think that you are having new or suddenly worsening MS symptoms.

A relapse is any new or worsening neurological symptom that lasts for at least 24 hours or more in the absence of other causes such as illness, fever, medication side effects or stress.

Relapses are unpredictable and may occur months or years apart.

Relapses can be:

- Mild – noticeable but not significantly interfering with your daily activities
- Moderate – you may have to change your daily routine until the symptoms resolve but you are still able to attend work and/or do most of your daily activities
- Severe - may require staying home from work and/or prevent you from doing most of your daily activities

Relapses may come on over a period of days to weeks and last for several months. During this time you may notice that the symptom is gradually improving. Some symptoms persist or do not completely resolve even after 6 months.

How are Relapses Treated?

Relapses can be treated with corticosteroids (commonly called steroids). Steroids can be given in pill or intravenous forms. Steroids help to lessen the relapse symptoms and help to speed up your recovery. Not all relapses are treated with steroids. If you think you are having a relapse, contact your MS nurse to review your symptoms and discuss what if any treatment is required.

Who is on my Health Care Team?

Your MS team consists of a neurologist, nurse practitioner, and nurses who have specialized training in treating MS. Your MS team will provide you with information about MS and your treatment options. We will assist you in getting started on an MS treatment and monitor your response to treatment and help you manage your MS symptoms.

Your health care team may also include physiatrists (rehabilitation physicians), physiotherapists, occupational therapists, psychologists, psychiatrists, and urologists. Specialists can help you to find ways to manage your MS symptoms.

What Else Should I Do?

Take Vitamin D	We recommend that persons with MS take Vitamin D 2000-4000 IU per day . It can be taken in one single dose at whatever time is convenient for you. Adequate intake has been shown to reduce the risk of MS and may help to lessen the severity of your MS.
Exercise Regularly	Exercising regularly can help lessen MS symptoms and improve overall health. Even 15 minutes of activity 3 times per week is beneficial.
Eat Healthy	There is no one special diet for MS. We recommend following Canada's Food Guide https://food-guide.canada.ca/en/ . Ensure that you are drinking at least 1.5 liters of water per day.
Quit Smoking	Recent research shows that people with MS who continue to smoke are at risk of more disease activity and more progression of their disease than people who are non-smokers. For more information and support: https://tobaccofree.novascotia.ca/ or talk to your family doctor or pharmacist.
Conserve Energy	Fatigue is one of the main symptoms most people experience with MS. Prioritizing your daily activities allows you to conserve energy for the things you want or need to do. It is also important to get enough sleep to allow your body to rest when you're feeling fatigued. Visit https://mssociety.ca for more information.
Mental Health Self Care	People with MS are at greater risk of developing depression and anxiety. It is important to look after your mental health and seek out the help you need. For mental health support call 211 or 1-855-922-1122 or visit https://mha.nshealth.ca/en .

	If you have a mental health emergency, call the Nova Scotia Mental Health Crisis line at 1-888-429-8167. It is available 24 hours a day.
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See Your Primary Care Provider Regularly	<p>It is important to see your primary care provider (family doctor/nurse practitioner) on a regular basis (at least once per year). Your primary care provider will address any health concerns that are not related to your MS such as yearly wellness examinations, immunizations, and prescription renewals for medications. By seeing you regularly, they will get to know you and also have a greater understanding of how MS is affecting you so that they can work with us to help you take control of your disease.</p> <p>Your family doctor should be your first contact for both MS-related and non-MS-related symptoms. Your doctor is able to prescribe medications to treat your MS symptoms.</p>
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Tracking your symptoms	Some people find it helpful to keep track of their MS symptoms and other health concerns. This can be helpful information for your health care team to have. If you choose to keep track of your MS symptoms, you do not need to write down how you feel every day. What is often most helpful is making note of significant changes. For example, if a new symptom starts or your ongoing symptoms get worse (especially if it lasts for more than a day), if you develop an infection of any kind, or if you make any changes to your medications.
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Complementary Therapies	Some people find some complementary therapies are helpful in managing specific MS symptoms. These therapies should not replace your disease modifying drug. If you are thinking about adding a complementary therapy to your MS treatment plan, discuss it with your primary care provider or neurologist.
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Routine Eye and Dental Care	It is recommended that you have an eye examination every 24 months. You may need
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to see the optometrist more often depending on your eye health.

Once a year you should see a dentist for a regular dental cleaning and checkup.

Where can I get more information?

There are many helpful resources available including the following websites:

Multiple Sclerosis Society of Canada:

- For questions about MS, MS Navigators are a great resource. To reach a **Navigator call 1-844-859-6789** or email msnavigators@mssociety.ca.
- To learn more about MS visit <https://mssociety.ca>.

MSology:

- Canadian-based online information service. <https://msology.ca/>

Books about MS

- Dr Paul O'Connor, Multiple Sclerosis: The Facts You Need to Know, Fifth Edition. <https://mssociety.ca/managing-ms/newly-diagnosed>

MS Clinic Contact Information

If you have questions about your MS you can contact your MS Clinic Nurse. Together you, your MS Clinic Nurse and your Neurologist can help you to find the answers you need.

MS Clinic Telephone Number: 902-473-5734

MS Clinic Fax Number: 902-425-1512