



What You Need to Know About Multiple Sclerosis

For people living with MS

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Introduction

You have recently been diagnosed with Multiple Sclerosis (MS). You may be confused and concerned about what this diagnosis means for you and your family. You may know someone who has been diagnosed with MS. Depending on your past experience, you may have a positive or negative outlook at this time.

The following information has been compiled with you in mind. It is also for your family and friends when you choose to share it with them.

The information is presented in two parts:

Part One will give a brief overview of what you need to know now.

Part Two will give more detail and suggestions for further reading.

Although there is presently no cure for MS, rest assured, it is not life-threatening. It has taken many years of research to gain our current understanding of this disease. Research continues to add to our knowledge.

So let's begin to help you get an understanding of life following a diagnosis of MS.



Although MS is not a curable disease, rest assured, it is not life threatening.



Part One

What is Multiple Sclerosis?



What is Multiple Sclerosis (MS)?

Multiple Sclerosis (MS) is a disease affecting the brain and spinal cord (the central nervous system).

Multiple = many
Sclerosis = scars or plaques

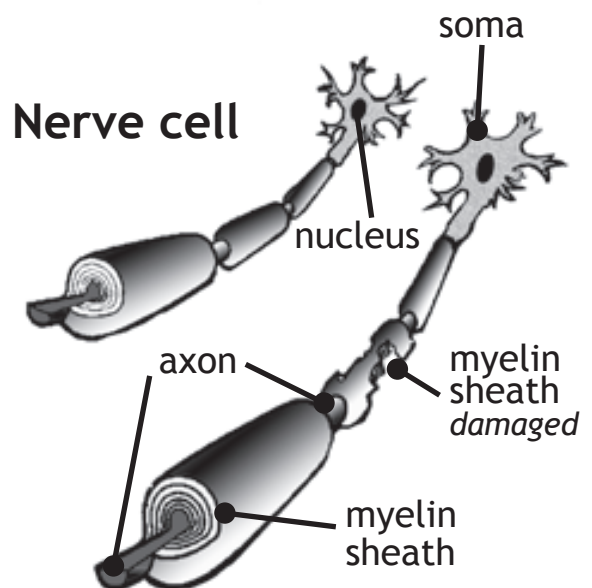
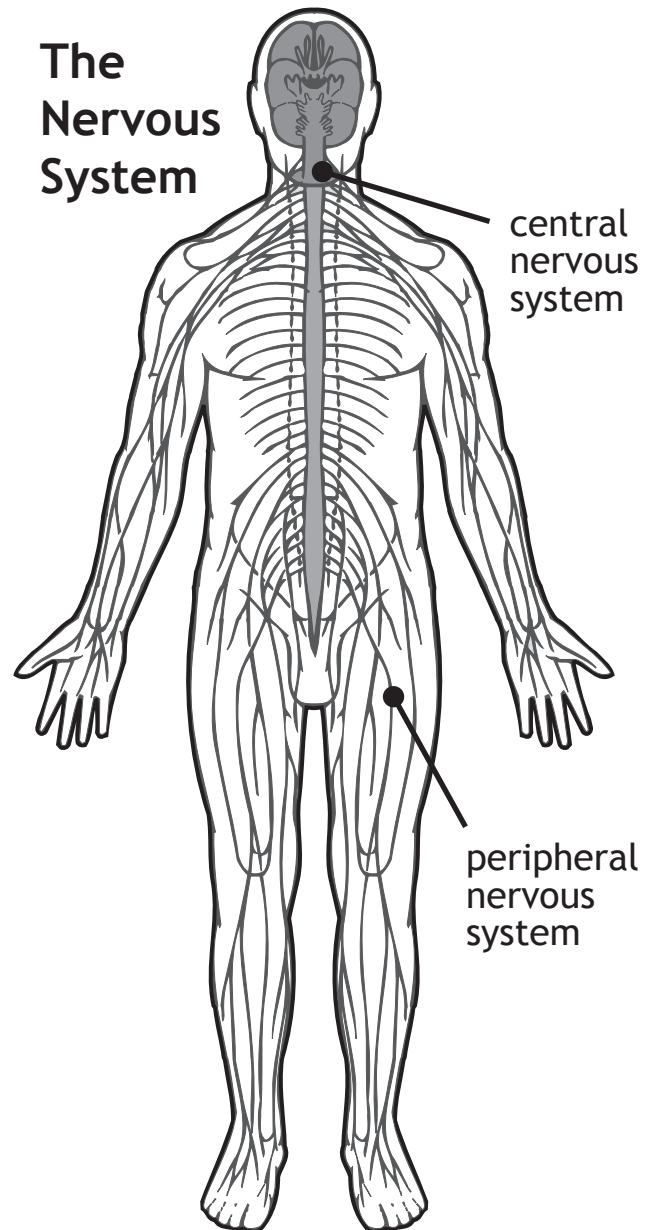
When you have MS, the covering protecting the nerves in the brain and spinal cord is affected. This cover, called the **myelin sheath**, protects the nerves and acts as insulation around the conducting part of the nerve which is called the **axon**, much like insulation covering an electrical wire.

In MS, this myelin sheath is damaged, affecting the nerves' ability to convey messages from the brain and spinal cord to other parts of the body. This damage sometimes results in physical problems; for instance, your hands may become clumsy or your legs may feel weak.

This can happen early in the disease process.

You should know that early treatment using **disease modifying therapies** (DMTs, see page 37) may delay this damage from occurring.

The Nervous System

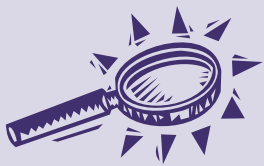


In MS the myelin sheath is damaged, disrupting the nerves' ability to conduct messages from the brain and spinal cord to other parts of the body.

What causes Multiple Sclerosis (MS)?

The usual age of the onset of first symptoms is between the ages of 15 and 40. However there may be earlier or later onsets. Three times as many women as men have MS.

There are several theories as to the cause of MS. One possibility is environmental, such as contact with a common virus during childhood which may have affected your immune system, causing it to start “acting up” when you are older.



There is no evidence that MS is

a directly inherited disease.

However, certain people have a genetic susceptibility to MS.

You should also know that MS is NOT a mental illness and it is NOT contagious.

What happens to people who have MS?

Multiple Sclerosis follows different patterns (courses). Comparisons should not be made between two people with MS. Even members of the same family may not follow the same pattern. It is difficult to predict with certainty what pattern you will follow when you are diagnosed.

The patterns of MS can be classified into the following types:

1. Relapsing Remitting (RR-MS):

Relapses or attacks occur followed by a period of remission and followed by more relapses. In the period of remission there may be few or no symptoms.

We believe that 75-80 % of people start with RR-MS.¹

2. Secondary Progressive (SP-MS):

In the majority of people with RR-MS, relapses become less frequent or disappear completely later in the disease. There tends to be a build-up of disability in place of relapses as time passes. This type follows the initial relapsing course and is called secondary-progressive because it occurs second.

The usual age of onset of the first symptoms is between 15 and 40.

3. Primary Progressive (PP-MS): **4. Progressive Relapsing (PR-MS):**

This form starts out with neurological problems that gradually appear and progress slowly without attacks.

This form begins as primary progressive. Over time however, relapses occur along with gradual progression.

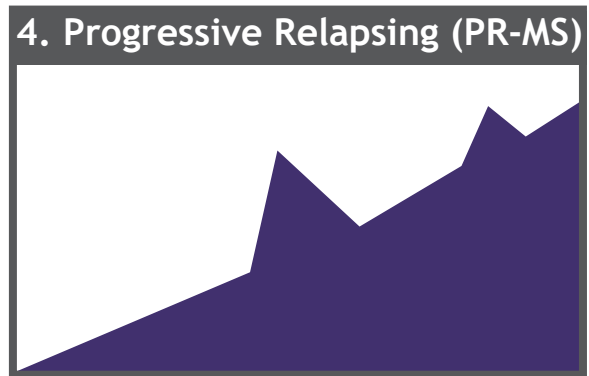
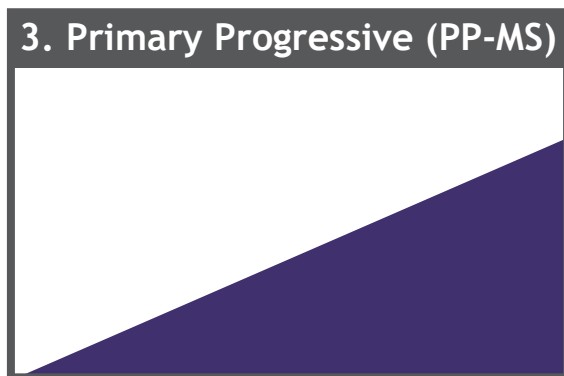
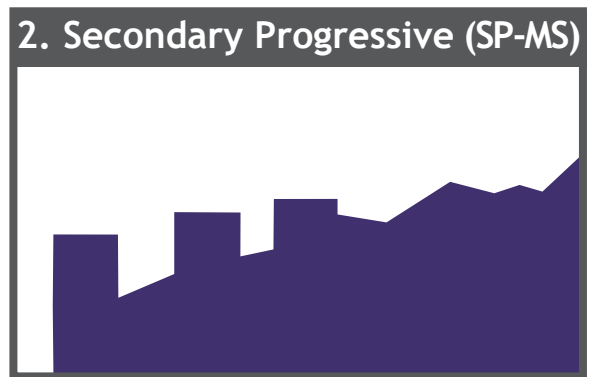
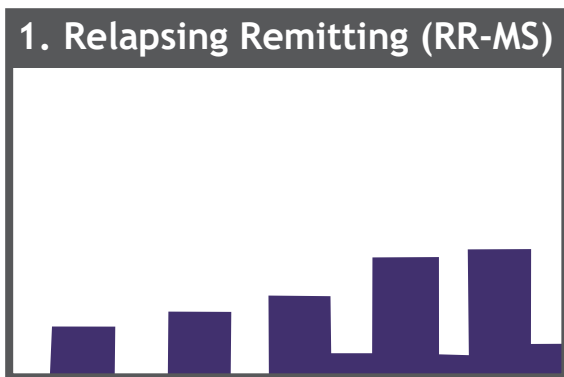
5. Benign:

A small number of people have very few neurological signs for up to 20-25 years after onset. Benign symptoms usually affect the senses of touch and sight.

You may be told you have benign symptoms. A diagnosis of “benign MS” can only be made after you have the disease for a number of years.

PP-MS and PR-MS make up only about 5–20% of all people with MS.

The Patterns or Types of MS



MS involves different parts of the nervous system for each individual and may never involve all parts of the brain or spinal cord.

What are the Possible Effects of MS?

As mentioned in a previous section MS is a disease of the brain and spinal cord (central nervous system). The brain is divided into three main parts, the **cerebrum**, the **brain stem**, and the **cerebellum**.

It is important to remember that your course of MS is unpredictable. It involves different parts of the nervous system for each individual and may never involve all parts of the brain or spinal cord.

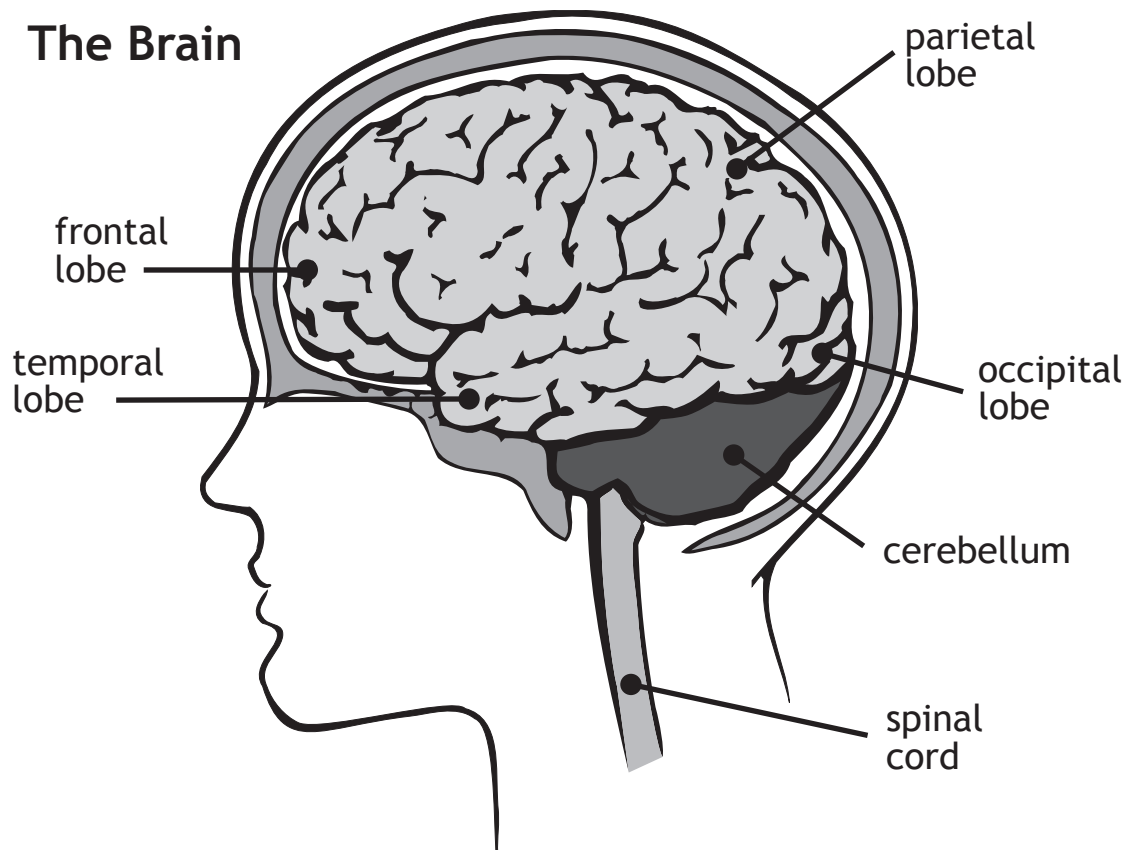
1. The Cerebrum

The cerebrum is divided into areas called lobes:

The frontal lobe: controls speech, mood, thought and planning for the future and language. **Plaques** caused by MS in this area may result in mood changes, inability to concentrate, and some difficulty in moving body parts.

The parietal lobe: controls body movement and interprets messages from the rest of the body. MS symptoms originating from this lobe may be numbness, weakness, and difficulties with eye and hand coordination.

The Brain



MS is uncertain, unpredictable, and different in every individual.

The Occipital lobe: vision problems occur when MS involves this part of the brain.

The Temporal lobe: controls memory and emotions. MS symptoms arising from this lobe can include short and/or long term memory loss.



Remember MS affects different parts of the brain and spinal cord in each individual.

2. The Brain Stem:

The brain stem controls many basic body functions. MS symptoms originating in this area can include difficulty with swallowing, speech, or eye movements, and problems with balance.

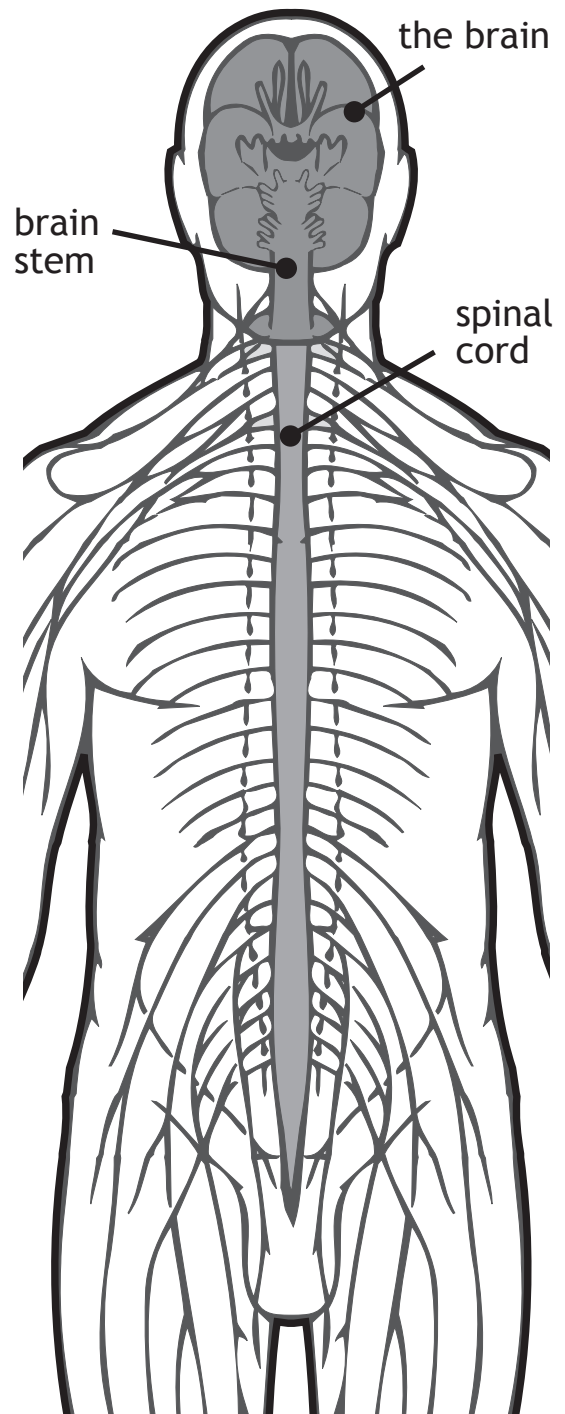
3. The Cerebellum:

The cerebellum controls coordination of all movement. Symptoms of MS can include poor balance, clumsiness of arms and legs, poor speech control, and tremors.

Multiple Sclerosis does not completely block all functions from these areas in the brain. Disruptions, or “slowing”, can occur in nerve impulses from these areas to other areas of the body.

The Spinal Cord:

The spinal cord contains cables (axons) that control motor and sensory functions in the arms and legs. Nerves that control bladder, bowel and sexual function are also located in the spinal cord. Symptoms arising from spinal cord damage include numbness and weakness in legs and arms, bladder and bowel control problems as well as sexual dysfunction.



The first step in diagnosis is a visit to your family doctor who will recognize the symptoms as being suspicious of MS.

How is Multiple Sclerosis diagnosed?

The first step in diagnosing MS involves a visit to your family doctor who will recognize the symptoms as being suspicious of MS. A referral to a neurologist will follow, where you will have a detailed history and physical exam. The neurologist may be able to make a definite diagnosis or even rule out MS in just one office visit. However tests and examinations may follow to confirm the diagnosis. It is important to tell the physician your past history relevant to the symptoms you are experiencing. You may want to bring this in a written form so it can become a part of your permanent medical record.

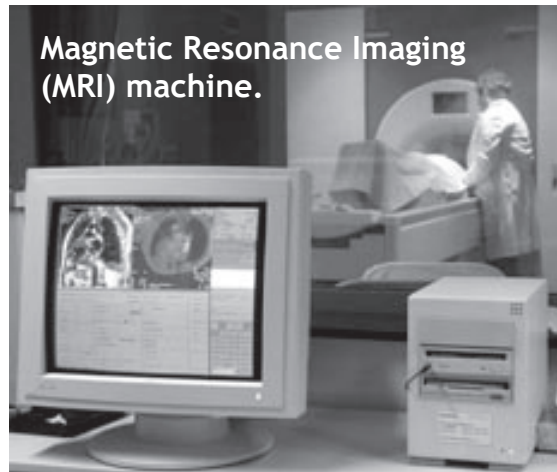
The diagnostic tests ordered will depend upon the findings in the physical exam. These are descriptions of some of the tests:

Magnetic Resonance Imaging (MRI)

Magnetic Resonance Imaging (MRI) will probably be one of your first tests. There may be a long wait to have this test performed; the waiting time depends on how busy the MRI is in your area. Waiting can be frustrating for you, but it's not dangerous. If there is a possibility of other serious problems, your neurologist can order an urgent MRI.

MRI technology has been available only in the last two decades. Having an MRI is not painful although it may be uncomfortable if you feel anxious in small spaces.

The procedure usually takes about 30 minutes and consists of lying on a table inside a tunnel shaped machine. You will hear a loud noise during this exam but earplugs can be worn to cut down on the noise.

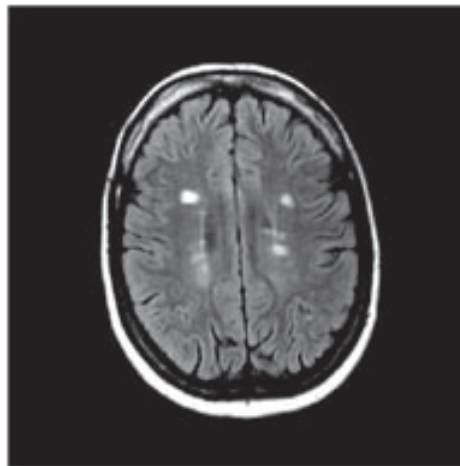
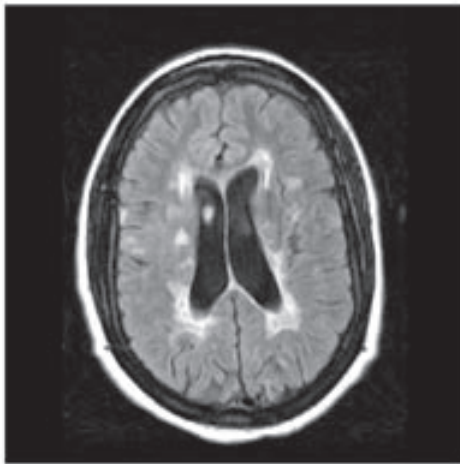
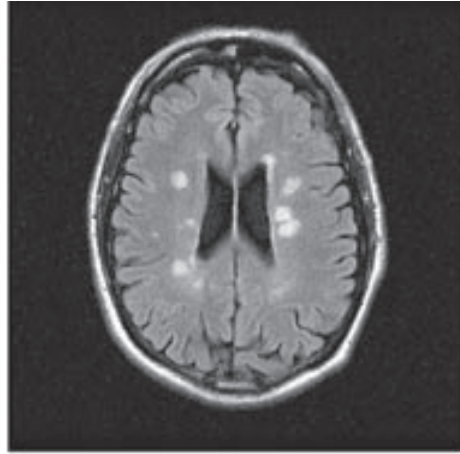


A computer is attached to the MRI and it produces a very detailed picture of your nervous system. In MS the areas of damage to the nervous system “show up” on the computer as “white spots” that are easily seen by a trained specialist.

It must be remembered that the diagnosis of MS cannot be made on the basis of an MRI alone. A normal MRI does not rule out a diagnosis of MS, especially early in the disease. Your history and clinical exam are extremely important parts of this diagnosis.

It must be remembered that the diagnosis of MS cannot be made on the basis of an MRI alone.

One characteristic of MS is a slowing of the nerve impulses where demyelination has taken place.



Output from a Magnetic Resonance Imaging (MRI) machine showing varying degrees of scarring that show up as "white spots" in patients with MS.

Evoked Potential Studies (EPs)

One characteristic of MS is a slowing of the nerve impulses where demyelination has taken place. This is true even when healing has occurred.



Electromyography (EMG) used for EPs

Evoked Potential Studies (EPs) are tests to measure the conduction to nerves and can detect areas of damage. These tests are usually done if the diagnosis is in doubt after the MRI.

Evoked Potential Studies involve the visual system (seeing), the sensory system (feelings in body parts), and less frequently, the auditory system (hearing). Evoked Potential Studies are painless, safe, and can even be done during pregnancy.

Lumbar Puncture (LP)

Lumbar puncture or spinal tap is performed to obtain cerebrospinal fluid (CSF) which surrounds the brain and spinal cord. A test can be performed on the proteins in this

fluid. In nine out of 10 tests on persons with MS, this test will show abnormalities suggestive of MS. This is not a routine test and usually is performed if and when MRI and EP tests are not conclusive.

This test should take about 15 minutes. The doctor will numb the area by injecting an anesthetic into the skin. A fine needle is then inserted into a space in the lower back to withdraw a small amount of fluid.

This test can be uncomfortable and some people may experience a headache after the test. This is normal and should not last long.

Blood Tests

There are no blood tests that will diagnose MS. If your doctor orders blood tests, it will be to rule out other diseases that look like MS.

Perhaps, after all of these tests, you still don't get a firm diagnosis. Your doctor may suggest a "wait and watch" period. This may be a difficult time but, it is better to wait and see, than to be labeled with the diagnosis of a chronic disease in error. The diagnosis of a chronic illness, such as MS, can influence the rest of your life.

What is an attack of Multiple Sclerosis?

You have just been told you have multiple sclerosis. Your physician has explained the disease. You were told you might have attacks. So what is an attack (**relapse** or **exacerbation**)?

The myelin sheath covering the nerves will periodically become inflamed leading to a breakdown of the myelin and axon. The myelin can be damaged without you experiencing any new symptoms, but, on occasion, you will feel what is called an **attack** or **exacerbation** of your symptoms. This will not always happen in the same nerves. For example, your attack may affect your eyes at one time and your hands the next time.

If you have been investigated for MS, the fact is, you have just had your first recognized attack. When your neurologist asked about your past medical history, they were looking for attacks that happened in the past that were not recognized or investigated as MS.

Attacks can be mild or severe. An attack, by definition, involves a recurrence of an old symptom or the appearance of a new symptom that lasts for at least 24-48 hours in the absence of fever.

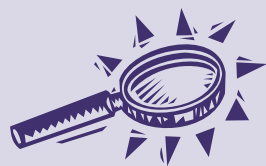
There are no blood tests that will diagnose MS. If your doctor orders blood tests it will be to rule out other diseases that look like MS.

The following example will give you an idea of how an attack may evolve.

Sally awoke Monday morning feeling physically well. She soon realized she was having difficulty feeling the floor with her foot. Throughout the day this “funny feeling” progressed to her knee. The next morning it was to her hip. It did not get any worse, after three to four days it began to improve.

This was a minor attack that did not require any special treatment. On the other hand, if it had continued to worsen to the point where she began falling, an appointment should have been made with her physician to determine if treatment was required.

Attacks can be treated with rest or medication. Medication may shorten the attack. This is a major benefit if the symptoms are severe.



Long-term studies have shown that treating attacks with medication, as opposed to rest, may not change the eventual course of the disease.

What are the symptoms of MS and how can I manage them?

Symptoms of MS vary and are, for the most part, associated with the area of the nervous system where damage has occurred.

Let's go over the most common symptoms of MS and discuss how they can be managed.

Fatigue

Fatigue is the most common symptom and is experienced by a high percentage of people diagnosed with MS. One study reported that two-thirds of people rate it as one of their worst symptoms.²

Though everyone experiences fatigue at some time or other, the fatigue experienced by persons with MS is different. It is often described as an invisible symptom and can lead to an overwhelming sense of physical or mental tiredness interfering with day-to-day activities.

It is important not to blame MS for every symptom you have or to confuse MS fatigue with that caused by other physical conditions such as anemia.

The causes of MS fatigue can be classified as primary and secondary.

It is important not to blame MS for every symptom you have or to confuse MS fatigue with that caused by other physical conditions.

Primary fatigue is most likely related to the disease process and interference in the conduction of nerves. Conduction in damaged nerves takes more energy than conduction in normal nerves.

Secondary fatigue is caused by other factors related to the disease such as urinary frequency that results in interrupted sleep.

Treating fatigue should only take place when the underlying cause has been determined.

A sleep diary can be of assistance in determining the cause of your fatigue. For example, if you have just started a new medication and one of its side effects is insomnia.

There are also some practical tips for conserving energy such as organizing your daily activities and workplace so that you are working systematically, which takes less energy. An occupational therapist can be of great assistance in giving tips to help you conserve energy.

There are also medications that can help the fatigue. Your physician will decide which medication you should use.

Sensory Disturbance

Sensory disturbance is also a common symptom in MS. This is usually more of an annoyance than a disabling feature. It will present as a symptom at some time during the disease process in the majority of people affected by MS. In many instances, it is the first symptom noticed.

Common symptoms are numbness and/or tingling in arms, legs, and trunk. Some describe it as a feeling of a tight band around their midsection or limbs. Although this is usually referred to as a **benign symptom**, there are occasions when it will interfere with day-to-day activities. If the feet and legs are very numb, balance can be affected and falling can occur. You may also have numbness in the face. Treatment is usually not prescribed for numbness that does not present a problem with activities.

Numbness that does not interfere with your day-to-day activities will soon become a symptom that you can work with in your life. For example, the feeling in your fingers may be decreased, making fastening small buttons a problem, so you may switch to larger buttons or sweaters without buttons.

There can also be painful sensations (**dysesthesias**). These

There are also medications that can help the fatigue. Your physician will decide which medication you should use.

sensations are quite uncomfortable. The feeling can be likened to the feeling that one's hands feel after being asleep and waking up. If these painful symptoms persist you may need treatment.

Problems with mobility

Problems with mobility may be the result of **weakness, spasticity, or imbalance.**

All of these symptoms can be disabling if severe. They may come with an attack or develop over time.

Weakness and spasticity are very common in people (usually men) who develop the disease after 40 years of age. This may progress slowly without acute attacks.

Weakness is caused by damage to nerves that control muscle movement. Sometimes you may think your leg is weak because it feels heavy. This is likely because the muscles are spastic.

Spasticity occurs when nerve impulses to muscles are disrupted, interfering with the normal contraction and relaxation of muscle groups. The results of this disruption may mean that many groups of muscles contract at the same time. Spasticity that interferes with walking may require treatment.

Imbalance can be a major disabling symptom. We need balance to perform most of the functions in our daily lives. We need balance to sit, stand, and lie down. It is important to determine the cause of imbalance. Treatment of balance problems depends on the cause.

A proper exercise regime, established by a knowledgeable professional, and some medications will assist with mobility problems. Mobility problems are a major reason for disability in people with MS.

Bladder and bowel problems

Bladder problems may occur even if there are minimal MS symptoms elsewhere in the body.

Bladder problems are divided into three types depending upon which nerve pathways are involved.

1) **Failure to store**, resulting in frequent trips to the bathroom. You know where the bathroom is in every shopping center in town. This can be a nuisance; you may even wet yourself if you do not find the bathroom in a hurry. When you "gotta go, you gotta go." Frequency may also cause sleep disturbance and fatigue due to frequent trips to the bathroom

The symptoms of weakness and spasticity are very common in people who develop the disease after 40 years of age.

at night. Your physician may tell you that you have a small bladder.

2) **Failure to empty** means you do not empty your bladder completely. Trips to the bathroom always leave a little left behind. You may have trouble starting (hesitancy) or may not be able to begin the emptying process at all (retention). Emptying your bladder may still leave you with the feeling you have to “go”. There is a tendency when you have retention to have frequent infections in your bladder. Bladder infections can make you feel unwell.

3) **Lack of coordination** may also be a problem. Coordination between the contractions of the bladder wall and relaxation of the **urethral sphincter** causes both failure to store and failure to empty.

Treatment differs with the three types of bladder symptoms so a physician should perform tests to properly diagnose the type of problem you are experiencing.

If you are going to the bathroom too often, the natural response may be to force yourself to drink less. This is not a solution to the problem because the body requires fluids to maintain normal function.

Reducing fluids, therefore, can be harmful. If you are waking up at night to go to the bathroom too often, try drinking less, but only after your evening meal.

Bowel problems are less common, constipation being the most frequently experienced problem. This may be due to damaged nerves controlling the impulse to the bowel, a decreased fluid intake for bladder problems and a lack of proper exercise. Constipation can be managed with diet, bowel training and medication (if necessary).

Diarrhea and incontinence are less common bowel problems.

Problems with your cognition

Cognition may be defined as memory, planning, foresight and judgment.

Problems with cognition were unrecognized in people with MS and, in fact, were denied for many decades. We now know they are prevalent in 50-55 per cent of people with MS at some time during the disease process.¹

Cognition problems, in some instances, can interfere with work and social activities. They can also be affected by fatigue, stress, and heat.

Bladder problems may occur even if there are only minimal MS symptoms elsewhere in the body.

The ability to learn new material, remember schedules and concentrate on a subject for long periods of time may all be altered with MS. Judgment may also be affected, which sometimes results in poor decision making.

These problems with cognition are caused by the short-circuiting of nerves in the brain, particularly the frontal and temporal lobes, and are independent of any physical disability.

Depression and some of the medication used to treat other MS symptoms may cause cognition problems. Specialized tests (**neuropsychological**) are needed to make a definite diagnosis of cognitive problems.

You can compensate for cognition problems by making lists, using a calendar or daytimer and organizing your home and office to eliminate misplacing everyday articles.

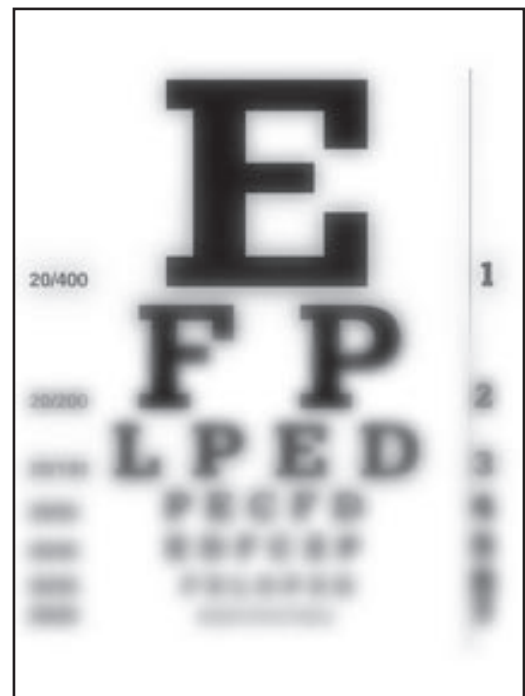
The most important thing is to recognize and accept the problem.

Help is available to assist you in adjusting to this symptom. An **occupational therapist** can be of great assistance in helping develop a plan to deal with cognition problems.

Visual problems

1) **Optic Neuritis (ON)**, or inflammation of the nerve of the eye, can cause blurred vision (which may be accompanied by pain that worsens when your eyes move), loss of side vision, or blind spots. Totally losing the vision in one eye is possible.

Your physician may order treatment with steroids and treatment is usually started very quickly after a diagnosis of optic neuritis. Optic neuritis is a common first symptom of MS. It is also possible to have optic neuritis and not have MS.



2) **Double vision** may also be a symptom. Separately, the vision in each eye is normal so the double vision disappears when

It must be remembered that cognition problems can also be the result of depression and medications used to treat other MS symptoms.

you cover one eye. The problem arises when the eye muscles don't work together to focus.

Sometimes the eyes themselves "jiggle," causing whatever the person is looking at to move. This can be very annoying if it becomes extreme.

It must be cautioned that not all visual problems are related to MS.

Visual problems that are fleeting are usually not caused by MS and may be caused by migraine headaches. Excessive heat can cause an old visual symptom to reappear for short periods or until the body cools.

Additional symptoms

Sexual function problems can occur, especially if the bowel and bladder are involved. It is overlooked in many instances, as it is sometimes a very sensitive issue, and is not seen as creating a "big" problem to anyone except the person experiencing the problem.

It can occur in males and females, with a higher percentage happening in males. It must also be taken into consideration that this problem may be caused by the mental stress of the diagnosis.

Sexual dysfunction in MS may be classed as:

- 1) **Primary:** due to the direct effect of MS, i.e., altered sensation and erectile dysfunction.
- 2) **Secondary:** due to indirect effects of MS or medication used to treat MS symptoms, i.e. spasticity, depression or medication used to treat depression.
- 3) **Tertiary:** caused by social issues, i.e., feeling different about your body.

Sexual difficulties should be addressed with the health professional responsible for your care. Counseling and/or medication can assist with this problem.

Depression:

Changes caused by adjustment to a chronic illness can cause feelings of sadness. Grief for a quality of life that no longer exists is a common reaction. Sadness, that lingers for long periods of time, causing social withdrawal, is a problem needing attention by a physician.

Speech & Swallowing Difficulties:

Usually these only occur in later and more progressive forms of MS. If these problems occur assessment by a speech pathologist can help determine appropriate treatment.

Sexual difficulties should be addressed with the health professional responsible for your care.

Pain:

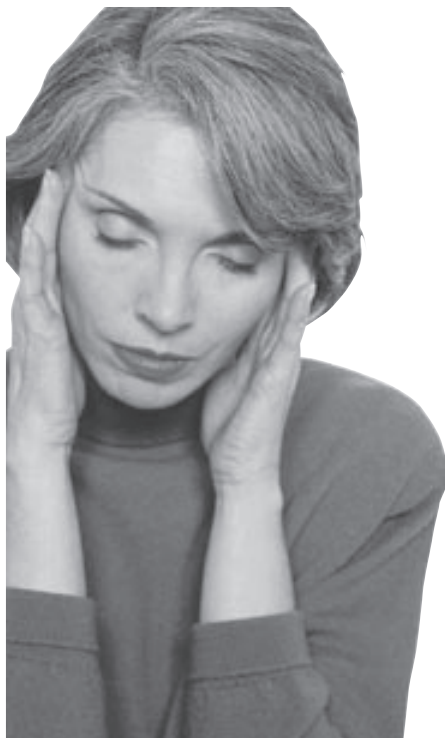
Until recently MS was thought to be a painless disease. Pain can affect 20-50 per cent of people with MS.³

Pain can be acute (short term) or chronic (long term).

Examples of acute pain are Trigeminal neuralgia (a stabbing pain in your face) and **L'Hermitte's sign** (pain shooting down arms or legs when you flex your neck) and **Dysesthesia** (a burning, aching, tingling discomfort that most often occurs in your limbs).

Examples of chronic pain are **Dysesthesia** that lasts longer than usual, muscle spasms, cramps, and back pain.

Treatment for pain will be discussed later in this booklet.



What about medications for MS?

During the last decade, medications that successfully alter the course of MS have become available.

Before this, only the symptoms of MS were treated and the course of the disease was not altered.

Medications that alter the course of MS are called **Disease Modifying Therapies (DMTs)**, or **Immunomodulatory Drugs (IMDs)**.

There are five approved therapies in Canada: three Beta-interferons, Glatiramer Acetate, and Tysabri. These medications have been proven in clinical trials to decrease the number of attacks, decrease the severity of attacks and, to some extent, decrease the progression of MS.

These medications are given either by injection or infusion and are very expensive. In most instances, either the government or an insurance plan will help pay for the cost of these medications.

Good education about these medications is a must so that the best results are attained.

There is still not a cure for MS, nor is there anything that will completely stop its progression.

Until recently MS was thought to be a painless disease. Pain can affect 20-50% of people with MS.

Where do I go from here?

Taking control after the diagnosis.

You have been diagnosed with Multiple Sclerosis. Your life has changed.

You are the same person you were yesterday but you may feel different about yourself.

You may have to make minor adjustments to your lifestyle.

There is no magic cure, but overall general good health is still as important today as it was yesterday.

Here are some things you can do that have proven to be helpful in the lives of others with MS:

Diet:

There is no specific diet for the treatment of MS. Though many fad diets have been promoted through the years, none have been scientifically proven to be effective.

The best approach is to eat a nutritionally sound diet (Canada's Food Guide). It's important not to become overweight.

Exercise:

Stay physically fit. Heat can cause MS symptoms to surface for a short time so exercise sensibly and within your capabilities. Swimming is an excellent exercise as it enables you

to remain cool while you exercise. Exercise will also help control weight problems.

Live a sensible lifestyle:

Remember, fatigue may be your worst symptom. Plan your life's activities in a way to allow time for relaxation and rest. This will likely be the first and biggest adjustment to your life.

Employment:

You are not required to tell your employer about your diagnosis. You may want to tell if you require some adjustments to your work schedule, **but REMEMBER, this is your decision to make.**

It's better to alter your work schedule than to quit your job. The majority of people with MS who continue to work feel that their life is "normal".

Education:

Educate yourself and those around you about the disease. When you are ready, there are numerous references, resources, and web sites for you to explore. It is important to do this in moderation. You need to judge when you are ready to increase your knowledge.

When to tell? What to tell?

Everyone who is newly diagnosed has this question. The answer is quite simple. Tell your family when you are comfortable enough to

There is no magic cure, but overall general good health is still as important today as it was yesterday.

talk about how you feel about this intrusion in your life. Tell them what you know and give them the information sources you have so they can continue to explore. **REMEMBER**, this is a diagnosis that will affect your family as well as yourself so they need to know the answers to their questions.

Medication:

Medication can be used to help control the disease and the symptoms. The decision to start any medications is yours after you educate yourself and consult with your health professional.

Participating in MS Research: it's your choice.

We don't have a cure for MS or a medication to stop the disease from progressing. Research continues in these areas. Much time and money is being spent in an effort to find these answers.

You may be approached to take part in a clinical trial on a new medication or research to further answer questions as to the cause of the disease.

It is your right to say NO to any research. Saying no will not affect the care you are given by your health professional. You need an understanding of what you are getting into before you even consider participating in a research project.

Research projects may be as simple as a questionnaire or they may be clinical trials using unproven medication; trials comparing the effectiveness of proven medication against other proven medications, or trials comparing a proven medication against an unproven medication. This can all be very confusing.

Clinical trials using unproven medications are generally **placebo** controlled. You may be given the medication being tested or you get a placebo (sugar pill). Clinical trials are very important to finding a more effective medication for MS.



Important points to know if you participate in a clinical trial:

- You are helping in the search for new therapies or medications.
- You will be getting follow-up care by those conducting the research.
- You can choose to withdraw from the study at any time.

The decision to start any medications is yours, after you educate yourself and consult with your health professional.



Part Two

The Pathology of Multiple Sclerosis



What is the exact cause of MS?

The exact cause of MS continues to remain a mystery!

Most experts agree that there are both **genetic and environmental factors** involved. The risk of MS is higher when another family member has the disease. In identical twins (who share the same genes), where one twin is known to have MS, the risk of MS in the other twin is only 30 per cent. This proves that genetic or hereditary factors cannot entirely explain the disease. It is likely that environmental factors (likely a virus in childhood, but there are other possibilities) are involved. These factors change the immune system, which, years or decades later, acts up, causing the disease.

The body's immune system is very complex and has the responsibility of protecting the body against foreign elements like bacteria and viruses. The principle cells of the immune system are the **T lymphocytes, B lymphocytes, and macrophages**. These cells in the immune system are programmed to recognize foreign tissue (like bacteria) and they fight to destroy it. At the same time, these cells recognize our tissue as "our own" or "safe" and leave it alone.

Mistakes can occur in the immune system when it fails to recognize its own tissue and starts attacking it. For example, in **rheumatoid arthritis**, the attack is on the joints, whereas in MS the attack is on the myelin, axons and **neurons (nerve cells)** in the brain and spinal cord. Such diseases are referred to as **autoimmune diseases**. Multiple Sclerosis is probably an autoimmune disease.

The exact process of how this "mistake in the immune system" causes MS is not yet known but new research points to the following possible steps:

- 1) **T cells** in the blood get activated.
- 2) Activated **T cells** cross the **blood brain barrier**, a barrier that normally prevents unwanted cells and substances from getting into the brain.
- 3) **T cells**, with the assistance of **macrophages**, attack the myelin, axons and possibly even neurons.
- 4) **T cells** produce cytokines, which at this point increase their fighting activity. A full attack occurs resulting in inflammation and scars forming.

Fortunately, not all myelin is involved and only selective areas are "targets" in each attack.

The immune system in the body is very complex and has the responsibility of protecting against foreign elements like bacteria and viruses.

Recovery takes place but it may or may not be complete. In an incomplete recovery, some damage or scarring remains. At this stage, the person may have very few or no symptoms because the surrounding brain compensates and adapts. However, over the years, with repeated attacks, progression in the disease occurs.

With MS, the immune system is not weakened but functions in an irregular fashion.

Treatments are not directed at strengthening the immune system, but rather in changing its action.

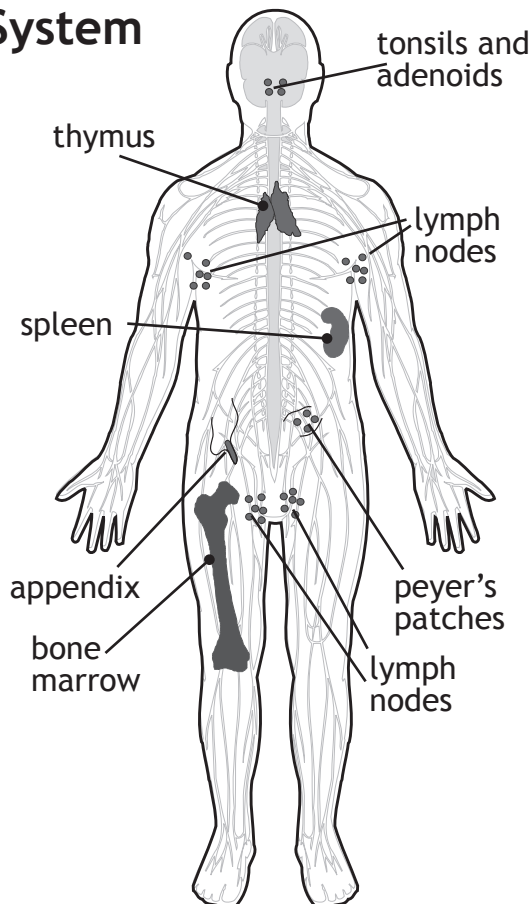
The first question you should ask yourself when you have symptoms of an MS attack is:

Is there a Reason for the Change in my Symptoms?

Do you have an infection? The most common are bladder and respiratory infections.

There has to be an absence of fever in order to have a genuine MS attack. Otherwise, the symptoms may be the result of fever. A rise in body temperature resulting in the reappearance of old symptoms is referred to as a “pseudo” attack or a false relapse.

The Immune System



What are the treatments for a MS attack?

The treatment of attacks varies depending on the individual and the preferences of his/her physician. More importantly, the choice of treatment depends on the severity of the relapse.

Mild relapses may be treated simply with rest, while more severe relapses are appropriately treated with medication and rest.

Rest:

This means sitting with a good book, feet up, in a relaxed frame of mind. Some people think they are resting,

A genuine MS attack has to be in the absence of fever. Otherwise the symptoms may be the result of fever.

when, in actual fact they are fretting all the while on “shoulds,” such as: “*I should be cleaning the living room, I should be mowing the lawn.*” This is not a time for “shoulds.” It is a time of caring for yourself.

Medication:

The medication of choice, for many years, has been **steroids**. These are not the performance enhancing or anabolic steroids taken by athletes. Steroids prescribed for MS attacks are cortiosteroids, which are similar to those produced in everyone’s body. **Prednisone** and **Decadron** are taken by mouth in pill form.

It is sometimes necessary, depending on the dosage of the medication prescribed and the dosage of each pill, to take a large number of pills at one time. **Hydrocortisone** and **Methylprednisolone** are given by needle into a vein in hospital or by a visiting nurse at home.

As you can see, there are many ways steroids can be prescribed, depending on you and your physician’s preference.

Currently, the most preferred choice is **Methylprednisolone** (solumedrol) given intravenously daily for three to five days. Sometimes this is followed by a series of pills taken in decreasing amounts over one or two weeks.

There may be side effects associated with steroid treatment:

Possible Side Effects are:

Short-term use:

- allergic reaction (rare)
- sleeplessness
- stomach upset (usually with pills)
- fluid retention
- increased appetite
- acne
- bone damage (rare)
- psychotic reaction (rare)

Long-term use:

- weight gain
- high blood pressure
- cataracts
- hardening of the arteries
- diabetes
- infections
- loss of bone mass

Side effects from short term use usually only last for a short time after the course of injections is completed.

There is no evidence that long-term use of steroids is a useful treatment in MS. You may hear stories from people who have had MS for a long while that they had a steroid “shot” in their buttocks to make their MS better.

Steroids do have a feel-good effect. Decades ago they were used for long-term treatment. It is generally accepted that there is no reason for long-term use of steroids in MS.

There is no evidence that long-term use of steroids is a useful treatment in MS.

I am always tired. What are the treatments for fatigue?

Fatigue in MS may not necessarily need medication as a treatment. Some simple lifestyle changes may help lessen this troublesome problem.

The first step, after identifying that you have fatigue, is to determine its type and cause.

Do you have chronic fatigue?

It limits your activities for more than six weeks, during part of the day on more than half the days.

Do you have acute fatigue?

It limits your activities and is new or worse during the last six weeks.

Acute fatigue will sometimes precede an MS attack.

Common Causes of Fatigue:

- Other medical conditions, i.e. anemia, thyroid abnormalities, or infections.
- Heat sensitivity, which can make most people feel tired. It is very common in people with MS. Use cooling techniques, such as cool drinks, and cold sweat bands, to help this fatigue.
- Medication. Your physician or pharmacist can tell you if

any of your medications will also aggravate fatigue. Your physician can adjust or change these medications.

- Sleep problems, which may be caused by a medication that aggravates insomnia. Some MS symptoms may cause sleep problems, such as frequent night trips to the bathroom or spasms. If you have trouble getting to sleep, try listening to restful music at bedtime rather than watching a movie thriller on TV.

- Stress and worry can drain your energy, so try to eliminate as much stress from your life as possible. It is not an easy task to become a non-worrier. Counseling may help you.

- Depression is common in persons with a chronic illness and can certainly lead to fatigue. **Constant depression over time needs the attention of a physician.** Counseling and/or antidepressant medication may be necessary.

Fatigue might be primary MS fatigue or it may be related to other symptoms. To make a diagnosis of primary MS fatigue, all other reasons must be ruled out or treated. If fatigue remains, then a trial of medication may be justified.

Fatigue in MS may not necessarily need medication as a treatment.

Tips to help Fatigue:

- Exercise to your potential without overdoing your efforts. A fit person feels better.
- Plan and organize. Don't waste energy.
- Ask for help from family and friends.
- Eat a healthy diet.
- Keep a diary of your activities.

Medications for fatigue:

• **Amantadine (Symmetrel)** helps about 50 per cent of people with MS-related fatigue. While side effects are infrequent, it may cause sleeping problems especially when it is taken late in the day. Hallucinations, nausea, and constipation are rare side effects. It may also cause the skin to become mottled in the legs but this is purely cosmetic and not a serious problem.

• **Modafinil (Alertec)** helps some people with fatigue, especially those who tend to have daytime sleepiness. Side effects of this medication are mild and include feeling jittery. This medication may decrease the effectiveness of oral contraceptives. Other side effects may include headaches, weakness, and nausea. If rash

occurs stop taking the medication and notify a doctor.

• **Methylphenidate (Ritalin)** is a powerful stimulant and should only be used with close supervision. It has the potential to be addictive. Side effects may include insomnia, decreased appetite, and hyperactivity. People who have heart problems or seizures should not take it.

Remember the Four P's:

- Planning
- Prioritizing
- Pacing
- Patience³



Additional Reading for Coping with Fatigue:

Coping with Fatigue

- Sharing Solutions in MS available from, www.sharedsolutions.ca

Managing MS-Related Fatigue; A Guide for Individuals with MS and Their Families

by Lauren B. Krupp MD

- available from the MS Society of Canada, www.mssociety.ca

Depression is common in persons with a chronic illness and can certainly lead to fatigue.

I am in pain. What are the treatments for MS-related pain?

Treatment of painful sensations (neuropathic pain)

Burning, pins and needles, or tingling are painful sensations called “neuropathic pain” that can be from damaged nerves.

Non-medication pain treatment:

While their effectiveness has not been proven in randomized clinical trials, these treatments may be effective in some individuals:

- Transcutaneous electrical nerve stimulation (TENS)
- Biofeedback
- Acupuncture
- Meditation



Medications for Pain:

- **Gabapentin (Neurontin)** is used quite commonly in chronic pain. Side effects may include drowsiness, dizziness, fatigue, unsteadiness, and nausea.
- **Carbamazepine (Tegretol)** may be effective in neuropathic pain of any type, especially trigeminal neuralgia, where it is the drug of choice. Side effects may include dry mouth and throat, constipation, impaired urination, decreased sense of taste, dizziness, drowsiness, lack of steadiness, loss of appetite, nausea, vomiting, indigestion, and diarrhea. If rash occurs stop taking the medication and notify a doctor.
- **Sativex**, a cannabis-based drug for the treatment of MS-related pain, became available for prescription in 2005. It is administered via a spray into the mouth. Sativex is particularly



Additional Reading for Pain in MS:

Pain and Multiple Sclerosis and Living for Today: Managing MS Pain (available from the MS Society of Canada.) www.mssociety.ca

Burning,
pins and
needles,
or tingling
are painful
sensations
called
“neuropathic
pain” that
can be from
damaged
nerves.

useful for neuropathic pain and spasticity. Canada is the first country to approve Sativex. It is only available from your doctor.

- **Amitriptyline (Elavil)** helps especially when there are accompanying sleep problems.

Side effects may include drowsiness, dizziness, insomnia, blurred vision, rash, and dry mouth.

I have trouble walking. What are the treatments for mobility problems?

Weakness, spasticity, and imbalance can lead to problems with mobility.

This is a major problem, as we depend on our mobility to function from day to day. Unfortunately, they are also difficult symptoms to treat.

Exercise for Mobility:

Exercising may help with weakness and mobility. It's true, "if you don't use it, you'll lose it". Just think of what happens to the muscles in an arm or leg when a person has to wear a cast for a long time.

Exercise must always be tailored to your needs. That is why exercise videos warn you to ask your doctor before attempting any new exercise program.

If weakness is due to poor electrical transmission to the muscle, then exercise will likely not have positive results. There are no effective medications available to improve this transmission problem but research is being conducted in this area.

Exercise may help with weakness and mobility.

What are the treatments for spasticity?

Spasticity is another big mobility problem and may be confused with weakness.

In MS, normal conduction to the muscles is altered which may make some muscles feel stiff all the time. This stiffness can sometimes work in your favor. For example, if your leg is weak, you may be able to use the stiff leg muscles for support when you walk.

Severe spasticity is a problem that can lead to poor balance and falling. It may also interfere with sleep and be a cause of fatigue.

Proper exercise, like stretching, can benefit spasticity, especially if done in a pool. Relaxation exercises are also beneficial.

Medications to treat spasticity:

- **Baclofen (Lioresal)** Most people have good results with this medication. Starting with a low dosage and increasing it slowly will obtain the best results. This should be monitored by your physician. Side effects may include transient drowsiness, daytime sedation, dizziness, weakness, and fatigue.

- **Tizanidine (Zanaflex)**

is a newer medication and it may be effective in decreasing stiffness and muscle spasms. It has less effect on strength than many other medications. This medication should also be taken at lower doses increasing the dosage slowly. Side effects may include dry mouth, sedation, weakness, and dizziness.



Additional Reading for Spasticity in MS:

Everybody Stretch: A Physical Activity Workbook for People with Various Levels of Multiple Sclerosis

- available from the MS Society of Canada. www.mssociety.ca

Exercise and MS

- available from the MS Society of Canada, Edmonton Chapter

Keeping your balance may also be as simple as using your eyes to see where your feet are placed.

Are there treatments for balance problems?

Balance problems (imbalance) are the third major cause of mobility problems.

There are no medications currently available for imbalance.

Exercising for imbalance:

Regular exercise improves strength and fitness and can help improve balance. As stated earlier, the program should be tailored to your needs, in consultation with your physician.

Keeping your balance can sometimes be as simple as using your eyes to see where your feet are placed.

It is important to consider aids as a form of treatment for mobility problems. Using a cane to assist with safe mobility is not a form of giving in to the disease, but rather being smart and taking control. Giving in to the disease would be to restrict your activities because you didn't want to use some type of aid. Your physician can refer you to a physiotherapist or occupational therapist to help determine if you need a device to assist you with mobility and to fit you appropriately.

What treatments are there for bladder and bowel problems?

It is especially important to determine the cause of bladder problems.

If you are having bladder or bowel problems it's helpful to keep a journal of your voiding experience before you visit your physician.

Write down how often you go to the bathroom, how much you drink, what you drink, and if you have accidents, and whether you void a little or a lot. This will help your physician in recommending treatment for the type of bladder problem you are having.

You may also be required to have some of the following tests.

Post-Void Residual (PVR):

This is a simple test where you will be asked to drink two liters of water the day before the test. The day of the test you will be required to drink two eight-ounce glasses of water. After voiding, you will have a small catheter put in your bladder to measure the amount of urine remaining. (The catheter does not remain permanently in your bladder.) You should not have more than three or four ounces remaining in your bladder after voiding.

It is especially important to determine the cause of bladder problems.

Bladder ultrasound:

This post void residual can also be determined by bladder ultrasound performed in the outpatient clinic.

Urodynamic tests:

Urologists perform these tests and they also require the insertion of a catheter.

Cystoscopy:

A small instrument is inserted into the bladder to allow the physician to “look at the bladder walls” to see if the bladder is too small or too big.

- It may be necessary to perform self-catheterization on a regular basis if you are suffering from failure to empty. Self-catheterization is quite easy. A small tube (catheter) is inserted into the bladder by way of the urethra (the canal through which urine passes) and is removed when the bladder is empty. A professional will give you detailed instruction if this procedure becomes necessary.

Though they are not MS symptoms themselves, infections sometimes occur as secondary to bladder problems in MS. Often, you can have bladder problems due to MS and not have a bladder infection.

Bladder problems:

Non-medication treatment bladder problems:

- Caffeine, aspartame, alcohol, infection and constipation are some things that may aggravate bladder symptoms.
- Do not restrict fluids during the day, restrict fluids only in the evening.
- Retrain your bladder by trying to go a little longer between bathroom breaks. Increase the intervals by small amounts to eliminate accidents.
- If you work outside the home, try to have your workstation near a bathroom.

A severe bladder infection causes fever and a feeling of being very unwell.

Prevention is the best treatment.

Prevention consists of:

- Drinking eight glasses of water a day
- Limiting citrus drinks and adding cranberry juice to your diet.
- Trying to completely empty your bladder.

If you are having bladder or bowel problems it will be helpful to keep a journal.

- Making sure you always use proper procedures and techniques with intermittent or indwelling catheters.
- Ensuring you make an appointment immediately with your health professional if you suspect that you have a bladder infection

Medications to treat Bladder Problems:

The following medications lengthen the times between voiding and decrease urgency, allowing more time to reach the bathroom to avoid dribbling and wetting.

- **Flavoxate (Urispas)**
- **Oxybutinin (Ditropan)**
- **Propantheline (Pro-banthine)**
- **Tolterodine (Detrol).**

Of these medications the most commonly used are **Oxybutinin** and **Tolterodine**.

The most common side effect of all these medications is dry mouth and, in some instances, urinary retention. Each of these medications will have a list of possible side effects that will be included with your prescription when you have it filled at your

pharmacy. You should read this information before beginning the medication.

Medications for “failure to empty bladder problems” are less effective.

Bowel problems:

The most frequent bowel problem is constipation. It may also be secondary to fluid restriction (due to bladder symptoms), restricted exercise (due to mobility problems), and medications taken for other symptoms. Constipation can cause discomfort. Diarrhea and incontinence are less frequent.

Non-medication treatment for bowel problems:

- Drink adequate water.
- Add fiber to your diet. Fiber and fluid go hand in hand. Never add bran to your diet unless you continue to drink adequate amounts of fluid.
- Eat a well-balanced diet including plenty of fresh fruits and vegetables.
- Train your bowel. Set a specific time to sit and relax in the bathroom. Take a good book with you. A good time to do so is usually after a meal and a hot drink.
- Exercise within your capabilities and have a physiotherapist develop an individualized program for you.

Often, you can have bladder problems due to MS and not have bladder infections.

Medications to treat bowel problems:

- **Metamucil** or **Citrucel**
- bulk formers
- **Colace** or **Lactulose**
- stool softeners
- **Phillip’s Milk of Magnesia, Ex-lax** or **Senokot**
- oral stimulants
- **suppositories** or **mini enemas**
- rectal stimulants

It is not a good practice to take stimulants or stool softeners on a regular basis as you can become dependent on laxatives to have a bowel movement.



Additional Reading for Bladder and Bowel Problems:

Understanding Bowel Dysfunction
- available from the MS Society of Canada. www.mssociety.ca

Urinary Dysfunction and MS: A Guide for People with Multiple Sclerosis
- available from the MS Society of Canada. www.mssociety.ca

Preventing Bowel Problems in Multiple Sclerosis
Sharing Solutions in MS
- available from, www.sharedsolutions.ca

I seem to be getting more forgetful. What treatments are there for cognition problems?

At present there is no “magic pill” to improve your memory. There is some indication that the beta-interferons may decrease cognitive problems. Research trials using medication to improve MS memory dysfunction are underway.

Neuropsychologists, speech pathologists, or occupational therapists usually perform specialized testing. These tests can take up to a half day or more to complete and involve a series of questionnaires and game-like tests of your cognitive abilities.

You should not be afraid if your physician suggests you have these tests. Results of these tests will make it possible for you to adopt new strategies for improving your cognitive functioning.

Tricks to improve your memory:

- Make shopping and to-do lists.
- Use a calendar to remember appointments. Place weekly reminders in a place you and your family visit often, i.e., the fridge door.

If you are computer savvy, get an electronic handheld computer.

- Carry a small note pad and pencil to jot things down you need to tell people as they come to your mind. If you are computer savvy, get a handheld computer (PDA). You can use it to store a great deal of information and then transfer it to your desktop computer
- Use pill containers with special slots for each day's pills.
- Organize your personal space and home. Always put things back in the same place.
- Try to keep distractions to a minimum when carrying on a conversation.

Follow these tips and you will remember things and be better organized than a person without cognitive problems.



Additional Reading for Cognition Problems:

Solving Cognitive Problems
- available from the MS Society of Canada. www.mssociety.ca

What treatments are there for sexual dysfunction?

Are the problems new or were they present before the diagnosis and are now exaggerated and blamed on MS?

The general population has a high percentage of sexual dysfunction. According to a National Health and Social Life Survey, 43 per cent of men and 31 per cent of women report some form of sexual dysfunction.⁴

The reasons for dysfunction in MS can be divided into:

Primary, due to damage to areas or pathways in the nervous system that control sexual function. This damage is usually in the spinal cord resulting in altered sensation in the genital area. This may cause problems with erections in men and decreased lubrication and vaginal muscle tone in women. Treatment can be in the form of medication, lubricants, and Kegel exercises. Your healthcare professional can help you decide which is best for you. You need to let your doctor know the problem so you can get help.

Secondary, where symptoms of MS, such as fatigue, spasticity, pain, and depression can result in sexual dysfunction. Medications used to

Communication and professional counseling should always play a part in treating sexual dysfunction.

treat these symptoms may also have sexual dysfunction as a side effect. Your health care professional needs to know all the medications you are taking in order to help you. Some herbal remedies can contribute to sexual dysfunction. Never stop or start taking a medication without your physician's knowledge.

Tertiary, which are psychological or social issues that may contribute to your dysfunction. Anxiety over the diagnosis or feelings of “not liking yourself due to the diagnosis” may be among these issues.

In some instances, there may be a life change. For example, you may have suddenly had to go back to work or maybe you just lost your job. It is difficult to be amorous in the bedroom if you are quarreling in the kitchen. Communication and professional counseling should always play a part in treating sexual dysfunction.



Additional Reading for Sexual Problems:

MS and your Sex Life

- Sharing Solutions in MS available from, www.sharedsolutions.ca

Sexuality and Multiple Sclerosis

- available from the MS Society of Canada. www.mssociety.ca

What treatments are available for depression in MS?

Depression is common in MS and most likely affects half of all persons with MS at some point in the disease process.³

Depression may be due to actual changes in the brain, but it is most likely due to changes in the life of the person with MS.

The normal reaction to the diagnosis of a chronic illness is to feel sad about perceived changes in your life. When this sadness persists, it will make your life and those who care about you miserable. It is OK to have a “pity party” but, when the party lasts for months, it's time to seek help.

Help can come in the form of counseling or medication.

Remember, your significant other should ideally be involved in this counseling with you.

Medications to treat depression:

- **Antidepressants**, known as **Selective Serotonin Re-uptake Inhibitors (SSRIs)**, are the most common medication for depression at this time. They have fewer side effects than older medications. A physician should

Depression is common in MS and most likely affects half of all persons with MS at some point in the disease process.

monitor medication taken for depression very closely both for effectiveness and side effects.



Additional Reading for Depression in MS:

Living Well with MS: Mind Matters
- available from the MS Society of Canada. www.mssociety.ca

What do I need to know about disease modifying therapies (DMTs)?

The last decade has seen changes in the way we view the treatment of multiple sclerosis and medication can now change the course of the disease.

There are five approved therapies in Canada: three Beta-interferons, Glatiramer Acetate, and Tysabri

The world of MS treatment changed in 1993 when the results of the first successful trial in treating MS were published. The first medication was **beta-interferon 1b (Betaseron)**.

The results of the large-scale clinical trial over three years showed that MS attacks could be reduced by about 33 percent, attacks were milder, and MRI activity was markedly less in treated patients as opposed to the placebo group.

Since 1993 four more DMTs have been approved;

- **Avonex and Rebif (beta- interferon 1a)**
- **Copaxone (glatiramer acetate)**
- **Tysabri**

These medications have also been proven to reduce the number of attacks, make attacks milder and improve MRI results.

Beta-interferon 1a (Avonex and Rebif) and **1b (Betaseron)** act to block the migration of **T cells** across the **blood brain barrier** and inhibit to some extent the attack on the myelin and axons.

Glatiramer Acetate is a combination of four amino acids and its make up closely resembles myelin. Somehow it tricks the immune system so that the T cells entering the brain start producing “good” cytokines, resulting in a lessened attack on the myelin.

Tysabri is a monoclonal antibody, also classified as a selective adhesion molecule inhibitor. The drug inhibits the movement of immune cells from the bloodstream into the brain, preventing further inflammation and damage. In general, it is indicated in patients who either cannot tolerate or are not doing well on one of the existing four disease modifying drugs (interferons

The last decade has seen changes in the way we view the treatment of multiple sclerosis.

or glatiramer acetate). In select cases, it can be given as first line therapy. As this is a new therapy, patients receiving Tysabri should enroll in a monitoring program designed to provide support to people with MS and the physician prescribing the drug.

The action of these agents is still not fully understood. Research in this area continues. These medications are all given by injection.

All the medications have some side effects that may last for the first few months after beginning treatment.

These are also long-term treatments. Education is necessary before commencing any of these medications.

You should be given information to read concerning the five medications. This will include:

- What results you should expect from taking the medication.
- What NOT to expect from these medications.
- What side effects you can expect from each medication.
- The follow up you will receive after beginning therapy.

You should also know that when given all the information the decision to start therapy is yours.

*You are the person
in control of the treatment
of your disease.*

After you make the decision to start treatment, you will be instructed by a trained nurse on how to inject yourself properly. You will be amazed at how easy this process can become. You will be given ongoing support in the days and weeks following this training.

If you prefer, you may choose to have someone close to you do the injection. However, the majority of people do not have a problem with self-injections.

Conclusion

The writers of this booklet sincerely hope that this information will help you in the coming months.

We encourage you to become a member of the MS Society so you will continue to receive updates on research and new therapies in MS. (See page 43.)

Support communities are available in most areas when you are ready to meet others with MS.

***Remember it is not
the end of the world,
but the beginning of the rest
of your life!***

*You should
also know
that when
given all the
information
the decision
to start
therapy is
yours.*

Glossary of Terms

Alleles: genes containing specific inheritable characteristics that occupy corresponding positions on paired chromosomes.

Asthenia: lack or loss of strength; weakness.

Antiemetic: a drug that reduces nausea.

Attack: see **relapse**.

Autoimmune disease: a disease in which the body's immune system mistakenly attacks the body's own tissues. MS is an autoimmune disease.

Axon: a projection from a nerve cell used to transmit information to other nerve cells.

B-cell: a kind of white blood cell that makes antibodies.

Bradycardia: a slow heartbeat characterized by a pulse rate below 60 beats per minute.

Brain stem: part of the central nervous system, linking the base of the brain to the spinal cord.

Brain stem auditory evoked potentials: a test in which the brain's electrical activity in response to auditory stimuli is recorded

by an electroencephalograph and analyzed by computer. Demyelination results in a slowing of this response time.

Catheter: a flexible tube inserted into the bladder to drain away excess urine.

Central nervous system: the brain, spinal cord, and optic (eye) nerves connected to the nerves of the peripheral nervous system which extend throughout the body.

Cerebellum: a part of the brain behind the brainstem, controlling balance and coordination.

CNS: See **Central nervous system**

Computerized Axial

Tomography (CT scan): an X-ray technique that assembles multiple images into an image of the brain or other area of the body.

CT scan: see **Computerized Axial Tomography**.

Corticosteroids: medications, usually given intravenously, to reduce inflammation during an MS attack.

Demyelination: destruction of the nerve cells' protective myelin.

Depression: feelings of sadness and helplessness that don't go away.

Diplopia: double vision.

Dysesthesia: abnormal sensations in the skin such as tingling, prickling, numbness or burning associated with pain.

Dysuria: painful or difficult urination, usually associated with infection in the urinary tract.

Electroencephalograph: a machine that records a patient's brain waves.

EEG: see **electroencephalograph**

Encephalitis: inflammation of the brain.

Evoked potentials tests: tests to see how quickly and completely specific nerve signals (visual, auditory, etc.) reach the brain. Signals are usually transmitted more slowly in someone with MS.

Exacerbation: see relapse.

Flare-up: see relapse.

Glatiramer acetate: a small protein fragment similar to a protein in myelin. Injections of glatiramer acetate seem to help stabilize MS, at least in the relapsing-remitting phase.

Frequency: the need to urinate more often than usual.

Immune system: a complex system that defends the body against viruses and other invaders. Sometimes the system malfunctions. See **Autoimmune disease**.

Immunoglobulin: a protein produced by cells that are overactive in MS. A high level of immunoglobulins in spinal fluid may indicate MS.

Incontinence: the inability to control the time and place of urination.

Interferons: immune-system proteins. Injections of some interferons seem to help stabilize MS, at least in the relapsing-remitting phase.

Kegel exercises: repetitive contractions of the muscles that are used to stop the urinary flow in order to increase muscle tone to help control incontinence.

Lesions: see **plaque**.

L'Hermitte's sign: an electric-shock sensation brought on by flexing the chin toward the chest.

Magnetic Resonance Imaging (MRI): a sensitive technique that

uses a magnetic field to create an image of the brain or spinal cord.

Major histocompatibility complex (MHC): a group of genes that code for the antigens that determine tissue and blood compatibility.

MRI: See **Magnetic Resonance Imaging.**

Myelin: soft, white, fatty protein protecting and insulating a nerve cell.

Myelin basic protein: Proteins associated with the myelin of the central nervous system that may be found in higher than normal concentrations in the cerebrospinal fluid of individuals with MS.

Myelitis: inflammation of the spinal cord.

Myelopathy: any pathological condition of the spinal cord.

Neurology: branch of medicine concerned with the nervous system.

Neurologist: a physician who specializes in disorders and diseases of the nervous system.

Neuron: nerve cell.

Nocturia: excessive urination during the night.

Nystagmus: an eye condition characterized by constant, involuntary, and cyclical movement of the eyeball.

Oligoclonal bands: a diagnostic sign indicating abnormal levels of certain antibodies in the cerebrospinal fluid. Oligoclonal bands are seen in approximately 90 per cent of people with MS, but they are not specific to MS.

Oligodendrocytes: cells in the central nervous system that are responsible for making and supporting myelin.

Optic neuritis: damage to the optic nerve causing blurred or double vision, blind spots, and pain.

Oscillopsia: a visual disorder in which the visual field appears to swing or oscillate.

Paresthesia: a sensation of burning, prickling, or tingling in the limbs that may be associated with neurological disease.

Peristalsis: a progressive, wave-like movement that occurs involuntarily in the bowels and assists in the elimination of feces.

Plaque: scarred area in the central nervous system, where the protective myelin of many axons is damaged or destroyed.

Primary Progressive MS (PP-MS): progressive MS that was not preceded by a relapsing-remitting phase of the disease.

Polymorphic: occurring in more than one form.

Post-void residual test (PVR): a test that involves passing a catheter into the bladder following urination in order to drain and measure any urine that is left in the bladder after urination. The PVR test is a simple but effective technique for diagnosing bladder dysfunction in MS.

Prognostic: indicating the prognosis (anticipated course) of a disease or medical condition.

Progressive MS: a stage in which the disease grows worse without remissions. Usually preceded by a lengthy Relapsing-Remitting phase.

Relapse: the appearance of a new neurological symptom, or significant worsening of old neurological symptoms, lasting more than 24 hours, and occurring without fever or acute illness.

Relapsing Remitting MS: a stage in which symptoms come and go. Sometimes followed by a progressive stage.

Remission: a period when symptoms temporarily diminish or disappear.

Sclerosis: hardening of tissue. In MS, the scar tissue that forms where myelin has been damaged. Also called plaque.

Secondary Progressive MS: progressive MS that begins after a Relapsing-Remitting phase of the disease.

Somatosensory evoked potentials: a test that measures the brain's electrical activity in response to repeated, mild electrical stimulation of different parts of the body. Demyelination results in a slowing of response time.

Somnolence: prolonged drowsiness or sleepiness.

Spasticity: muscle stiffness, often accompanied by painful cramps or spasms.

Spinal cord: bundle of nerves extending down (and protected by) the spine, connecting the brain to the nerves that extend throughout the body.

Steroids: see corticosteroids

Subcutaneous: just under the skin, as in subcutaneous injection with a needle.

Synapse: the microscopic space between nerve cells, across which electrochemical impulses are transmitted.

Tic douleureux: a condition characterized by severe facial pain. Chewing, eating, and drinking, can be painful.

T-cell: or **T-lymphocytes**, are manufactured in the bone marrow, but mature in the thymus. Helper **T-cells** help B-cells produce antibodies. Suppressor, or killer **T-cells**, suppress the production of antibodies by B-cells.

Tremor: shaking. In MS, usually in the limbs, but, occasionally in the head or neck.

Uvula: a fleshy structure hanging from the free edge of the soft palate above the root of the tongue composed of muscle, connective tissue, and mucous membrane.

Vertigo: a dizzying sensation of spinning; sometimes a symptom of MS.

Visual evoked potentials: a test in which the brain's electrical activity in response to visual stimuli (e.g., a flashing checkerboard) is recorded by an electroencephalograph and analyzed by a computer. Demyelination results in a slowing of response time.

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Donald W. Paty, George C. Ebers,
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F.A. Davis Company, 1998

The Canadian MS Clinic Nurses Network,
The Canadian Multiple Sclerosis Nursing Care Plan

Resources

**MS Society of Canada,
National Office**
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