

# Living with Progressive MS



## LIVING WITH PROGRESSIVE MS

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## **COVER ARTWORK**

Bill Miller

*Opportunitus 4b*

*"Representing the potential of pursuing any or all opportunities that are continually available."*

Opportunitus 4b is part of a series of works by Edmonton artist Bill Miller, which he calls, 'Chairbrush Paintings.' Bill, who has had progressive MS for over 25 years, uses hands-free computer technology to create beautiful expressionist images from photographs of his wheelchair tracks in the snow.

For more information about Bill and his work, visit his site:

**<http://www.theartmiller.ab.ca/bluewind/>**

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## INTRODUCTION

If you're reading this publication, you may have been told that you have a progressive form of multiple sclerosis (MS). A diagnosis of progressive MS can stir up many different feelings. The uncertainty that surrounds MS can make people feel frightened, vulnerable, frustrated, and even angry. You may have many unanswered questions.

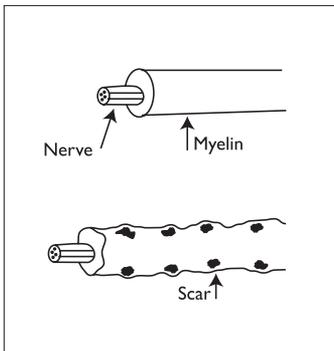
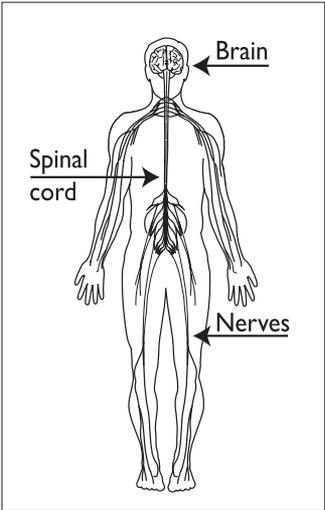
This publication is designed to offer you some information and practical suggestions. We will begin by explaining the basics of progressive MS. From there, we'll look at some simple, yet practical ways to improve your quality of life. We'll also focus on some of the major symptoms that individuals may experience and suggest how these symptoms may be managed. To further assist you, we've included a glossary of commonly used terms at the end of this publication. Each of the terms found in the glossary are underlined (as is the word symptoms above) throughout the text. This glossary will help you understand what these terms mean when talking about progressive MS.

This publication may not answer all of the questions you have, but we hope that it will put you on a path to finding some answers, locating helpful resources, and increasing your quality of life. Living with a chronic illness such as MS can be very difficult. Many people feel that they have 'lost' their former self and former life. While MS may affect many parts of your life, it does not need to define who you are and what you have to offer.

## UNDERSTANDING PROGRESSIVE MS

### What is going on in my body?

Your central nervous system (CNS) is comprised of your brain and spinal cord. The CNS communicates with the rest of your body by sending electrical messages along your nerves. Nerve fibres have a layer of protection around them called myelin which is crucial for transmitting these messages quickly. We do not yet understand why, but with MS, your immune system mistakenly attacks the myelin, leading to scarring or demyelination. As well as damage to the myelin, injury to the nerve itself may also occur. As a result,

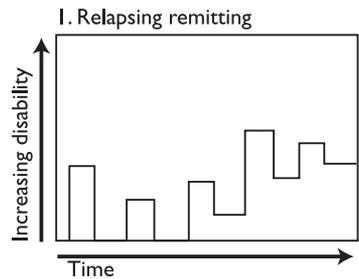


messages get sent through the body too slowly or not at all. For example, when your brain tells your arm to move, your arm may be very slow to respond or may not move at all. The scarring or lesions can occur throughout the CNS and their location will have some impact on the symptoms experienced.

## Different types of MS

There are four types of MS — relapsing remitting MS (RRMS), and secondary-progressive MS, primary-progressive MS and progressive-relapsing MS. Half of MS patients have RRMS and the other half have a form of progressive MS. The majority of people who develop MS are initially diagnosed with RRMS. Many of these people will eventually shift to a progressive form of the disease. Much research is still being done on the different types of MS. Let's take a closer look at the different types of MS: [Figures adapted from Coyle PK, et al. Figure 1.3. Demos 2001.]

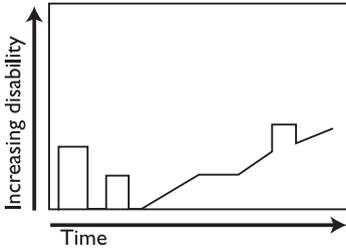
1. **Relapsing-remitting MS (RRMS)**. Eighty-five percent of people with MS are initially diagnosed with this form. People with RRMS have relapses (also called attacks, flare ups, or exacerbations) followed by full or significant recovery (also called remission). During remission the disease does not worsen.



Notice how the lines in Figure 1 resemble steps. This diagram illustrates initial attacks followed by full recovery, with later attacks followed by partial recovery.

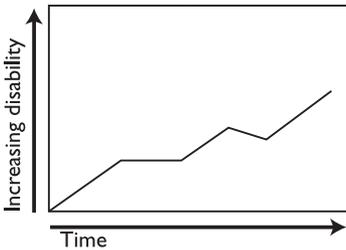
2. **Secondary-progressive MS (SPMS)** starts as RRMS before becoming progressive, where the disease typically gets slowly worse over time. Attacks often continue to occur, especially earlier in the course of secondary progressive MS. The transition from RRMS to SPMS is usually very gradual and is often best recognized in

2. Secondary progressive



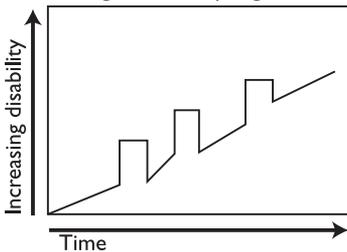
retrospect. An example would be a slow increase in leg weakness occurring in someone who has had attacks of their MS for many years. Notice how the line in Figure 2 increases and continues to climb. This diagram illustrates increasing disability even after an attack is over. Of people starting with RRMS, 50% will have SPMS within 10-20 years.

3. Primary progressive



**3. In primary-progressive MS (PPMS)**, the disease is progressive from the beginning. This type of MS happens in 10–15% of people with MS. It affects men and women equally, often with a slow onset of walking difficulties, and usually appearing after 40 years of age. It is characterized by an increase in disability with or without plateaus and occasional temporary minor improvements as shown in this figure. 4.

4. Progressive relapsing



**4. Progressive-relapsing MS (PRMS)** like PPMS is progressive from the beginning, but it has clear relapses with or without full recovery. Notice how the lines in Figure 4 show increasing disability with intermittent relapses. PRMS is the least common type of MS, occurring in 5% of people.

## **My doctor said there is no test to confirm whether I have progressive MS. How does he/she know I have it?**

There is no test to confirm progressive MS. Instead, this diagnosis is based on monitoring how your MS progresses. This is done by recording a description of how your symptoms have evolved over time together with measuring changes on your neurological exam (your exam is graded according to the EDSS score). Perhaps surprisingly, other tests such as MRI scans or spinal fluid exams do not indicate the phase of your MS. It is important that you let your doctor know if you've noticed changes in your level of functioning. Whether or not such changes represent progression of your illness, discussing them with your doctor will help you to develop the best health care strategy possible.

## **What can I expect with progressive MS?**

It is hard for your doctor to predict what your future holds because MS varies so much between individuals and there is no typical rate of progression or disability. Some people with progressive MS may, at some point, experience a plateau, where their progression seems to level off. Others may become very disabled. Many people fear that they will die from their MS, but this is very unusual. In the small percentage who have a shortened life span, it is almost always due to complications associated with severe progression. Minimizing such complications will be beneficial for an individual's health, quality of life, and ability to function.

The important thing to remember is that there are resources every step of the way to help inform and support you. This information and support will assist you in finding the best ways of managing your illness, both physically and emotionally.

### **IMPROVE YOUR QUALITY OF LIFE**

Before looking at treatments for progressive MS and symptom management, let's look at some general ways for you to improve your quality of life. Coping with a chronic illness such as MS takes planning and can be especially challenging if you experience fatigue, depression, cognitive difficulties, or have trouble getting around. Below are some strategies that might be helpful.

#### **Try to visit a specialized MS clinic**

Located across the country, these clinics offer a wide range of services and supports, provided by a multidisciplinary health care team including a neurologist with advanced knowledge of MS. Most MS clinics also have a specialized nurse, who coordinates initial and long-term management issues, and teaches you about medications (including how to take them) as well as self-care strategies. Ask the MS Society about whether there may be financial assistance to cover some of the costs of a visit to a MS clinic — either through the MS Society or through provincial subsidies.

## Get the most out of visits to your physicians

Let's begin this section by clarifying the roles of a few key healthcare professionals:

- ➔ **Family physician:** provides general health care, including check ups, immunizations, and preventative care. Your family doctor can help treat simpler problems (such as urinary tract infections) and can refer you to other specialists.
- ➔ **Neurologist:** as well as determining your initial diagnosis, a neurologist will prescribe MS treatments and medications to manage your MS. Regular annual visits are recommended. The neurologist will refer you to other specialists, such as pain specialists, or urologists (for urinary symptoms not related to a urinary infection) etc.

It's important to work with your health professionals to make sure you get the best care. Maximize the value of each visit by preparing in advance.

- ➔ Think about what you want to accomplish during your upcoming visit.
- ➔ Make a list of important questions or concerns you would like to discuss.
- ➔ Tell your doctor about any changes in symptoms (see the tracking graph at the back of the book).
- ➔ Review which medications you are taking and when/how you are taking them.

- Mention any problems or questions you have about your medications.
- Let your doctor know if you have seen any other healthcare professionals recently that she may not know about.
- Consider bringing a friend or family member to your appointment for support and to help keep track of anything discussed.

Because MS symptoms can be so diverse, people tend to assume that any symptom is related to their MS. But this is not always the case. Be sure to see your doctor about symptoms that are troubling you. Your doctor or community pharmacist is likely a very good source of information, but sometimes he/she may not be as knowledgeable about MS as you. Help your doctor to help you by sharing new information. For instance, sometimes people with MS will bring their doctor information about symptom medications their doctor may not be aware of. The MS Society of Canada can assist by offering you information on existing symptom management medications and techniques. If you've tried to partner with your doctor and find that he/she simply does not offer you the support you need, consider finding another doctor.

## Use rehabilitation services

Rehabilitation, also called rehab, can help you maintain or reach your best physical, emotional, and functional level no matter what disabilities you have. It can play a very important role in enhancing your day-to-day living. One type of rehab, referred to as restorative rehab, aims to regain function after it

is lost, which can be difficult (for example, reducing spasticity or strengthening muscles). It tends to be focused with measurable results (for example, improved mobility in a specific limb).

With progressive MS, maintenance or preventative rehab tends to play a larger role. The goal of this type of rehab is to make up for lost functions with strategies and techniques that let a person function at their highest level despite the severity of their MS. Maintenance rehab focuses on the whole person and is more general (for example, helping an individual to maximize independence). Below are a few specific types of rehab specialists. Be sure to ask your doctor about how each might help you.

- **Physiotherapists (PTs)** evaluate your movement and functioning—including your strength, mobility, balance, posture, fatigue, and pain management. PTs can help you meet the physical challenges and demands of your life. They can also suggest an appropriate exercise regime and should be consulted regarding the proper use of motor aids such as orthotics (shoe inserts or braces), canes, crutches, walkers, wheelchairs, or scooters.
- **Occupational therapists (OTs)** help work on the every day skills that you need to function as independently as possible at home and at work. They target upper body strength, mobility, and coordination and can help you use assistive technologies to increase ease of access and independence. OTs offer ways to simplify work or manage fatigue and stress. They can also teach you strategies for functioning despite thinking, sensation, or vision problems.

- **Psychologists and psychiatrists** may be helpful if you experience cognitive or mood changes. Having to deal with MS can cause depression for some, but the disease process itself can also play a role. Depression can have a powerful impact on a person's estimation of their quality of life. It is important to know that while depression is very common in people with MS, it is also very treatable through medications and psychological therapy.
- **Speech and language therapists** help work on speech or swallowing problems that result from impaired muscle control. Sometimes they are also involved in the evaluation and management of cognitive dysfunction, especially when it affects communication.
- **Social workers** assess social needs and can help refer you to resources about income maintenance, insurance, housing, long-term care options, etc.

There are many other resources to help you, including psychiatrists, neuropsychologists, dieticians, orthotists, and urologists, to name a few. If you think you would benefit from any of these specialists, consider visiting an MS clinic, or speak to your doctor about possible referrals.

## Stay healthy

There's so much you can do to optimize your health.

- No diet has been proven to impact the course of MS. That said, it makes sense to choose healthy, nutritious foods. A diet low in saturated fats (meat, eggs, dairy products) and high in monounsaturated fats (canola oil, olives and olive

oil, nuts, seeds, avocados) and polyunsaturated fats (flaxseed oil, fish and fish oil) may be helpful. Some MS patients believe that avoiding wheat and dairy products helps their symptoms. Eating plenty of fruits, grains and vegetables helps to keep your heart healthy, avoid constipation, and maintain a healthy weight.

In addition, people with MS sometimes wonder whether they should take extra vitamins or food supplements. There is no scientific evidence that they will make a difference with perhaps one exception. Researchers are now looking carefully at vitamin D as a way to possibly reduce the risk of MS developing in the first place. In terms of food supplements, people with MS should avoid those that claim to boost the immune system. That could be a problem in MS, which results because of a misdirected immune attack on myelin within the central nervous system.

As mentioned, vitamin D – whether delivered through sunlight, fish such as salmon or tuna, milk, or in pill form – may play a role in preventing MS. Many physicians now suggest that people with MS themselves might benefit from taking a daily intake of 1,000-2,000 IU of vitamin D because many people in Canada are vitamin D deficient and this deficiency may play a role in the disease. This idea is interesting but unproven.

If you do change your diet radically or increase your intake of vitamins, it is a good idea to consult your doctor or a nutrition specialist. You could also contact the nutrition service of your community health service or provincial health ministry. In addition, the MS Society's *Healthy Eating: A guide for persons with multiple sclerosis* examines what makes up a healthy diet.

- Exercise can be of great benefit in MS, however it is important to find the right balance of activity and rest for you. Studies have shown that appropriate exercise can improve fitness and decrease fatigue. However, this does not mean overdoing it. Too much exercise can result in more fatigue and weakness. It is also important to try to keep your temperature down when exercising, as this can worsen symptoms or produce new ones. For this reason, some people prefer to exercise in a cool pool where possible, or will take a cool bath before and after their exercise. It is best to consult with a professional (such as a physiotherapist) when choosing an exercise regime to ensure that it is suitable for you. There are many different types of exercise: some that increase mobility through stretching and range of motion (helpful for weakness and stiffness), some that improve balance, some that are aerobic, and some for relaxation.

The best exercise regime is balanced and helps you feel better and stronger. The MS Society of Canada offers the publication, *Everybody Stretch*, which approaches stretching and exercise from varying levels of ability.

- Try to decrease your stress levels — stress is generally not helpful to well being. Ensure that you get some time to relax and surround yourself, where possible, with people and things that are fulfilling to you. You might even consider regular meditation practice. Simple practices such as meditating for 15 minutes a day, learning yoga or T'ai Chi, or going for a massage can help relieve tension and have psychological benefit. Ask your local community centre or MS chapter about classes being taught in your neighbourhood. You might wish to refer to the MS Society publication, *Taming Stress in MS*.

## Asking for help can be a strength

Everyone needs help sometimes. Consider your friends, family, doctor, local MS chapter, or trained counsellors when you're looking for support. Your friends and family may appreciate your explaining how they can best support you. Sometimes people want to help, but they don't know how to be the most helpful. Some people with MS want very specific support (for example, help getting groceries every couple of weeks). In other cases, the situation may be quite the reverse. Sometimes people with MS have to ask well-meaning family or friends not to rush to help every single time they have difficulty doing something.

Whatever 'help' means to you, asking for it does not need to make you feel less capable. Instead, asking for support can enable you to be more functional, by freeing up more energy, time, or emotions for other priorities.

## Consider group support

Talking about MS with others can offer you the support you need to get through difficult times. It can also connect you to a huge network of people who are coping with MS. By getting involved with support groups, you not only increase your network of knowledge, but you may find others that can relate to your struggles, and who may help you to uncover resources (both inner and outer) that can improve your situation. The MS Society of Canada has many self-help groups. Call your local chapter for more information.

## Educate yourself

Educate yourself about MS, but always consider the source of information. Check with your doctor, nurse, or the MS Society to find out if the information you've found is correct. Here are different sources of information available to you:

- **MS Society of Canada** – is accurate, up-to-date, and can help you assess the information you've found.

Updated information on research can be found by visiting the Society's Web site and clicking on MS Research.

Call toll-free in Canada: 1-800-268-7582

Email: [info@mssociety.ca](mailto:info@mssociety.ca)

Website: [www.mssociety.ca](http://www.mssociety.ca)

- **Medical journals** – a source of credible and current information on MS, but may be difficult to understand.
- **Medical or science magazines** – explain the findings in recent medical journals and how this information affects your life. You may find these sources easier to understand.
- **Articles in newspapers** – information may be worth looking into further, but often sensationalized, and not always accurate.
- **Books or websites** – can be good sources of information but be careful that the authors aren't trying to sell you an idea or product.

## **Surround yourself with people and things that give you pleasure and energy**

Happiness can come from something very simple like a conversation with people you love, enjoying a new craft or hobby, laughing with a friend, listening to music, or being outdoors. With a progressive illness such as MS, you may need to re-examine your dreams and plans as there may be new limits that challenge you. But having a chronic illness with disability does not have to mean that you have less meaning, activity, or enjoyment in your life.

## **Are disease-modifying therapies available for progressive MS?**

Disease modifying-therapies have been shown to reduce the number of relapses in MS. They do this by interfering with the immune system's attack on the CNS. Currently there are five approved therapies in Canada for RRMS: Avonex<sup>®</sup>, Betaseron<sup>®</sup>, and Rebif<sup>®</sup> (which are beta-interferons) Copaxone<sup>®</sup> (glatiramer acetate) and Tysabri (natalizumab). Because these drugs are aimed at reducing relapses, they are less helpful for progressive MS (where relapses are not as common or well-defined). The cost of therapy may be covered by your or your spouse's private or employer-paid health insurance. Or, depending on which province you live in, you may be reimbursed for the cost of these medications.

There are currently no other approved drug treatments for progressive MS in Canada. Drugs have to be approved by Health Canada before doctors can give them to you. Once a drug is approved for one use, your doctor can sometimes prescribe it for another use if they believe it will help you.

In the rare case of very rapidly progressive MS, typically occurring in patients under age 40, doctors will sometimes prescribe drugs approved for the treatment of cancer such as Novantrone® (mitoxantrone) or Cytosan (cyclophosphamide). In these cases, it is critical that the person with MS is carefully monitored, given the risks associated with these treatments. It is important to have an informed conversation with your physician regarding any questions you have about your treatment.

There are hundreds of clinical trials occurring at all times on different aspects of MS. Some of these are specifically for progressive MS (for example immunosuppressive drugs), but most of the clinical trials for MS tend to focus on relapsing forms.

This is because progressive MS is harder to study: the clinical trials take longer, are more expensive, include older and therefore less healthy individuals, and have a higher risk of failure. For these reasons trial sponsors are less likely to study this form of MS. Nonetheless many drugs that suppress inflammation have been looked at in progressive MS and so far they have not worked very well, if at all.

Clinical trials should not be viewed as a substitute for treatment because they are experimental and need to continue for an extensive length of time before they can be deemed to be therapeutic. Ultimately, the understanding gained from research and clinical trials helps everyone with MS. You can find out more about current trials from the MS Society of Canada or MS Clinics. You can also ask your neurologist or family doctor about the possibility of participating in a clinical trial.

## Symptom Management

Whether or not disease modifying therapies are an option for you, there are many pharmaceutical and non-pharmaceutical options for your symptoms. Symptom management is important for helping you live as comfortably and as productively as possible. If your doctor prescribes a medication for you, be sure to discuss any side effects.

Often there is more than one medication for any particular symptom. You need to work with your doctor to find the medication or non-pharmaceutical therapy most suitable for you.

## Treatments for MS symptoms

Here's a look at some of the most common symptoms of progressive MS and information on how these symptoms can be treated. Please note that it is rare for people with MS to have all of these symptoms.

**Fatigue**, the most common symptom of MS, is a sense of tiredness, lack of energy, or feeling of exhaustion that can seem overwhelming, and which can interfere with daily activities. In MS, there are two types of fatigue. Primary fatigue, is related to the underlying disease process in MS. Secondary fatigue is caused by factors such as depression, medication side-effects, heat, lack of exercise, sleep difficulties, and stress. Speak with your physician about what might be causing your fatigue and available treatment options.

Avoiding heat (if you find your fatigue is heat-sensitive), resting regularly, ensuring adequate sleep, engaging in moderate exercise, consulting an occupational therapist regarding energy management techniques, or visiting a sleep clinic are all things you could do to try to improve your fatigue.

Perhaps you've been thinking about mobility aids, but feel reluctant to become reliant on them. Remember that sometimes they can actually improve your quality of life by reducing the energy you use to get around, freeing up energy to do other things. For more information, contact your physician, make an appointment at an MS Clinic, or call the MS Society of Canada.

**Depression** can be very common in MS. While it is not hard to see how a chronic illness might make someone feel depressed, there is also evidence that depression may be a primary symptom of MS; that is, part of the disease process and not simply a result of difficult circumstances. If you are feeling depressed or hopeless or have noticed a change in your

sleeping or eating patterns, be sure to call your physician. Call immediately if you are having thoughts of death or suicide. The important thing to remember is that depression is very treatable in MS and there is help available. Medications, counselling, or support groups may be of great benefit. You do not need to suffer in silence. Other mood changes, such as uncontrollable laughing and crying (known as the 'pseudobulbar affect') can also occur and can be treated.

While **cognitive changes** occur in about half of the people with MS, they are fairly mild for most people. These changes can include problems with attention, memory, problem solving and learning. Approximately 5-10% of people with MS experience more severe cognitive difficulties. Whether the symptoms are mild or more severe, it is important to tell your doctor so that he/she can make an appropriate referral or help you find the best way to manage. Specialists such as neuropsychologists, speech and language pathologists, or occupational therapists can help you learn how to compensate for cognitive difficulties you are having. Sometimes small lifestyle changes or memory devices can be very helpful. There is some evidence that some medications may be useful.

**Pain** was previously not recognized as a symptom of MS. Now, however, health professionals acknowledge various types of pain in MS and are aware that pain can have a negative impact on quality of life. If you are experiencing pain, see your doctor about medications available for acute or chronic pain. It is very important that an accurate diagnosis of the cause of any type of pain be made to make sure it is treated appropriately.

Non-pharmaceutical therapies such as physiotherapy, acupuncture, meditation, biofeedback, massage, orthotics, walking aids, and hot or cold compresses can also help to control pain.

### **Muscle spasticity and weakness are common**

**symptoms.** For spasticity, your doctor may prescribe one of the numerous medications available and may also suggest physical therapy, exercise, stretching, and adaptive devices. Untreated spasticity can cause serious mobility problems and interfere with personal care. Reducing spasticity can make movement easier and lessen fatigue. On the other hand, spasticity can sometimes help compensate for weakness. For example, it's easier to stand on a weak leg if the muscles are stiff. Rehabilitation specialists can help you manage your spasticity in a way that provides you with the greatest productivity. Consider seeing if aquatherapy, yoga or T'ai chi classes, all helpful for spasticity, are available in your community.

**Balance and coordination problems** can be a primary symptom resulting from damage to a part of the brain called the cerebellum. They can also be secondary, resulting from vertigo or dizziness, tremors, or numbness in your legs or feet. Speak to your physician about the possible reasons for your balance or coordination problems and ask about available medications that might help. Physiotherapists can suggest exercises to help compensate for vertigo or lack of balance. Braces and weights are sometimes used to help manage tremors that aren't alleviated by medication.

**Vision problems** are due to damage to the optic nerve and weakness in the eye muscles. Talk to your doctor about medications for acute attacks of vision problems. Assistive devices such as eye patches and prism lenses may be helpful for vision problems which persist. Vision difficulties such as double vision may also be affected by fatigue, increases in temperature, stress, or infection. Managing these conditions where possible may help improve your symptoms.

**Bladder symptoms** such as difficulty holding urine, emptying the bladder, and frequent bladder infections often occur with progressive MS. If you have any problems with urination, tell your doctor. He/she may refer you to an urologist who can determine which type of bladder dysfunction you have. This information will then allow your doctor or specialist to prescribe the appropriate medications. In some cases, self-catheterization may be necessary. Biofeedback and regular scheduled times to urinate may help improve bladder function.

**Bowel problems** generally involve constipation and diarrhea. If you have problems with your bowels, tell your doctor so that he/she can suggest the most appropriate therapies. While there are a number of medications available, proper nutrition and adequate fibre and fluid intake can be very helpful.

**Changes in sexual function** are common in MS. For women, these can include impaired genital sensation, diminished orgasmic response, loss of interest, weak vaginal muscles, and a lack of lubrication. For men, these can include impaired genital sensation, decreased sex drive, difficulty achieving an erection, and delayed or decreased ejaculation.

There can also be a significant impact on a person's sexual self-esteem and body image. Depression and fatigue can also impact a healthy sexual life. Much can be improved through medication and counselling.

If these symptoms are concerns to you, it is important to try to overcome any shyness around discussing these issues. Locate the health professionals who are receptive to your concerns and who are willing to refer you appropriately. The MS Society of Canada can also refer you to its publication, *Sexuality and MS*, as well as other publications on sexuality and disability which may be of help.

**Speech and swallowing difficulties.** There are currently no medications available, but rehab specialists such as speech and language therapists or occupational therapists may be able to provide you with some very helpful exercises and techniques for improving your speech, swallowing, or eating. These symptoms can certainly affect quality of life and addressing them is very important. Contact your doctor for a referral.

## **Complementary and alternative medicines (CAMs) are widely used, but it is important to make informed choices.**

Many people with MS use CAMs. When considering the use of CAMs, it is best to discuss the issue with your physician, particularly when you are on any other prescribed medications or treatments. Weigh the pros and cons and ask yourself the following questions:

- ➔ What does the treatment involve?
- ➔ How and why is it supposed to work?
- ➔ What are the risks?
- ➔ Are there possible interactions with your current medications?
- ➔ Is the alternative healthcare professional regulated?
- ➔ How much does it cost?

CAMs may be helpful for managing your symptoms, but remember to have a healthy skepticism. For instance, a claim that a particular substance 'boosts the immune system' may sound positive, but if so, this might be a risky CAM for someone with MS. It is the activity of the immune system in MS that leads to myelin damage, therefore increasing immune activity could possibly be harmful. This is not to scare you away from considering CAMs, but rather to remind you that just because something is 'natural' does not mean it is necessarily safe or effective. If you need some assistance in researching the claims of a particular CAM, contact your local MS Society.

The MS Society will be able to provide you with information on that CAM, or can refer you to other resources such as books or Web sites that may help you make an informed decision.

### **A note on family**

MS can have an impact on the entire family. Try to be aware of how the changes brought about by MS affect each member of your family. Everybody will react to these changes in their own ways, and often not everyone is 'on the same wavelength' in terms of how they cope. With all the changes that progressive MS can bring, it is very natural to expect some disruption in your normal family dynamics. Figuring out how best to communicate can be an ongoing challenge, but is well worth the effort. The MS Society of Canada has publications about families, be it caregiver issues, information on speaking with children about MS, or books for children of parents with MS. Speak with your doctor about referrals, such as counselling, that might be helpful. While MS can place stress on a family, it can also reveal a family's unique gifts, such as compassion, sense of humour, or resourcefulness.

## Thinking long-term

When dealing with a chronic illness such as MS, there are a lot of long-term issues which can present concerns and questions. How will my disease progress? Where will my source of income come from? What are my insurance options? Will I be able to remain in my home? What are the options for making my home more accessible for me? Who will care for me if I become more disabled? These kinds of questions can be overwhelming, particularly when MS is newly diagnosed. While it may seem a scary exercise, it may help you in the long run to consider some of the possible scenarios that you find most frightening. Despite some peoples' superstitious feelings, thinking about or planning for 'worst-case scenarios' will not make them happen to you. Instead, this kind of 'planning for the worst, but hoping for the best' may help you to feel you have a measure of control over your life. You can feel comfortable knowing that you have a safety net set up for you and your family, which in many cases you will not need.

Your local MS Society and resources such as Society publications can help you deal with these large and often complex long-term issues. It requires effort to sort through these issues, but doing so will give you a greater sense of control within the uncertainty. Some people like to get informed as much as possible right away, while others need to do this more slowly to avoid feeling overwhelmed. So pace yourself and respect your own coping mechanisms.

Changes in MS and particularly progressive MS can be constant. They can represent losses of all kinds and you should not underestimate the kind of grieving you might need to do. At the same time, no matter what your situation is, if you remain open to possibilities, there will always be ways for you to share yourself, ways for you to tap into new interests or talents, or contribute to the lives of those around you.

## **APPENDIXES**

### **Resource tools**

Here are some tools that you can use to manage your disease. Feel free to photocopy them and take them to your next visit with your doctor.

<b>Symptom Diary</b>					
Symptom	Note date symptom started	Note date symptom ended or whether it is ongoing	Does it interrupt your life or affect activities of daily living	Rate the symptom on a scale from 1 (mild) to 5 (severe)	Is this a new or recurring symptom?
			Yes No	1 2 3 4 5	New Recurring
			Yes No	1 2 3 4 5	New Recurring
			Yes No	1 2 3 4 5	New Recurring
			Yes No	1 2 3 4 5	New Recurring
			Yes No	1 2 3 4 5	New Recurring
			Yes No	1 2 3 4 5	New Recurring
			Yes No	1 2 3 4 5	New Recurring
			Yes No	1 2 3 4 5	New Recurring

## Glossary

**Assistive technologies:** a term used to describe the range of tools, products, and devices which can assist in making a given function or activity possible or easier to perform.

**Autoimmune illness:** an illness in which the body's immune system mistakenly attacks healthy cells, organs, or tissues. Multiple sclerosis is believed to be an autoimmune disease in that the body's immune response becomes directed against its own myelin.

**CAMS:** see Complementary and alternative medicine.

**Central nervous system:** the part of the nervous system consisting of the brain, the spinal cord, and the optic nerves.

**Cerebellum:** the part of the brain involved with balance, coordination, and posture.

**Chronic progressive:** a term (now largely outdated) formerly applied to progressive forms of MS.

**CNS:** see Central nervous system.

**Cognition:** includes high level brain functions such as comprehension, information processing, memory, reasoning, and problem-solving.

**Cognitive dysfunction:** term referring to an unspecified degree of impairment in cognitive functioning (can be mild to severe). Due to disease process. See Cognition.

**Complementary and alternative medicine:** a term incorporating two associated areas. 'Complementary' medicine is the use of nonconventional therapies in conjunction with conventional medicine. 'Alternative' medicine is the use of nonconventional therapies in the place of conventional medicine.

**Demyelination:** loss of the protective myelin layer around nerves.

**EDSS (Expanded Disability Status Scale):** used to measure overall disability, as based on the neurologic exam. It is a 20-point scale, with a scope from 0 (normal exam) to 10 (death) by half points. The EDSS is often a key factor in determining future medical treatments, rehabilitation aims, eligibility for clinical trials, and/or eligibility for disability subsidies.

**Evoked potential:** see Visual evoked potential.

**Immune system:** an intricate system made up of glands, tissues, circulating cells, and processes which acts to protect the body from foreign substances and infections.

**Immunomodulatory treatment:** a form of treatment which modifies or alters the body's natural immune system response. In the case of MS, this modification results in a decreased number of MS relapses.

**Immunosuppressive treatment:** a form of treatment which reduces the body's immune responses. In MS, a reduction of immune response could mean less damage to the myelin. An example of an immunosuppressive treatment, which is sometimes prescribed off-label in MS is Novantrone<sup>®</sup> (mitoxantrone).

**Incontinence:** also sometimes called spontaneous voiding. The inability to keep urine in the bladder or the inability to control bowel movements.

**Lesion:** an area of inflamed or demyelinated tissue in the central nervous system. Also called a 'plaque'. Some lesions become permanent 'scars', while others repair themselves spontaneously and disappear.

**Lumbar puncture:** a diagnostic procedure that uses a hollow needle in order to remove cerebrospinal fluid from the spinal canal. The cerebrospinal fluid is examined for changes in its makeup that can be associated with MS (eg, elevated white cell count, elevated protein content, the presence of oligoclonal bands).

**Maintenance rehab:** see Preventative rehab.

**MRI (magnetic resonance imaging):** a procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show areas of demyelination.

**Myelin:** the insulating layer that surrounds nerves, and allows for the effective conduction of nerve impulses.

**Nerves:** bundles of nerve fibres that transmit electrical messages around the body.

**Non-pharmaceutical therapy:** treatment that does not involve medication.

**Off-label:** a term referring to the use of a given medication which is different from that medication's approved parameters around dosage, population, or indication. In MS for example, some physicians will prescribe cancer treatments such as Novantrone® (mitoxantrone) off-label in some cases.

**Orthotic:** a device used to mechanically assist, restrict, or control muscle. They come in many shapes and sizes for different parts of the body. Also called orthosis.

**Pharmaceutical therapy:** treatment using medication.

**Plateau:** a levelling off of the progression of symptom severity.

**PPMS:** see Primary-progressive MS.

**Preventative rehab (also called maintenance rehab):** a type of rehab using strategies and techniques to compensate for lost function allowing the individual to function at their highest level.

**Primary fatigue:** fatigue resulting from the underlying disease process in MS.

**Primary-progressive MS:** a form of MS which is progressive from the beginning, which has no plateaus or remissions, or an occasional plateau and minor improvements.

**Progressive-relapsing MS:** a form of MS which is progressive from the beginning, but with clear, acute relapses, with or without full recovery from those relapses.

**PRMS:** see Progressive-relapsing MS.

**Pseudobulbar affect:** excessive and unstable emotions such as inappropriate laughing or uncontrollable crying. The individual's mood may have no influence on the emotions expressed. Also called 'affective release'.

**Relapse:** the appearance of new symptoms or the reoccurrence of old ones, lasting at least twenty-four hours. Also called attack, exacerbation, flare-up, or worsening. Usually associated with inflammation and demyelination in the brain or spinal cord.

**Relapsing-remitting MS:** a form of MS with clearly defined relapses, with full or partial recovery and no disease progression between attacks.

**Remission:** a period when symptoms are reduced (partial remission) or disappear (complete remission).

**Restorative rehab:** a type of rehab focusing on regaining function after it is lost (for example, reducing spasticity or strengthening muscles).

**RRMS:** see Relapsing-remitting MS.

**Secondary-fatigue:** fatigue caused by factors such as depression, medication side-effects, heat, lack of exercise, sleep difficulties, and stress.

**Secondary-progressive MS:** a form of MS which is initially relapsing-remitting, but which over time changes to a steadily progressive pattern (though the rate of progression is variable). Relapses may still occur, especially early on. Most MS patients will experience at least some progression in their lives, but it may not occur for 10-20 years or more.

**Sign:** objective physical abnormality identified by the physician during a neurologic examination. Neurologic signs may be identifiable only with specific tests and may cause no overt symptoms. Common examples of neurologic signs in MS include altered eye movements, altered reflexes, and weakness.

**Spasticity:** abnormal increase in muscle tone in the limbs. It can manifest as extreme stiffness in the muscles.

**Spinal cord:** the bundle of nerves running from the brain down the spine providing a pathway for transmitting messages to and from the rest of the body.

**Spinal tap:** see Lumbar puncture.

**SPMS:** see Secondary-progressive MS.

**Symptom:** an indication of illness which is experienced or felt by a person, and which is not necessarily observable by others (eg, pain).

**Visual evoked potential (VEP):** a diagnostic tool in which the brain's electrical activity is measured in response to visual stimuli. Demyelination can result in a slower response time. VEPs are abnormal in approximately 90% of people with MS; however, an abnormal result does not in itself indicate a diagnosis of MS.



## How to reach the MS Society of Canada

Current as of August, 2008

Call toll-free in Canada: 1-800-268-7582  
[www.mssociety.ca](http://www.mssociety.ca)

### **British Columbia Division**

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## Contact the Multiple Sclerosis Society of Canada:

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Email: [info@mssociety.ca](mailto:info@mssociety.ca)

Website: [www.mssociety.ca](http://www.mssociety.ca)

### Our Mission

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.