



# Multiple Sclerosis

Its effects on you and those you love



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Disponible en français.

## **Multiple Sclerosis: Its effects on you and those you love**

This booklet contains a lot of information to help you with some of the questions you might have. Don't feel that you have to read it through from start to finish. Pick out the topics that are of most interest to you right now with the help of the table of contents. You can always go back and look over the other material later.

Some people who have experienced the diagnosis of multiple sclerosis generously shared their perceptions and feelings to make this document as personal and as helpful as possible. In many cases, their exact quotations explained the situation so well, they were included as an integral part of the text.

Many resources are available through the Multiple Sclerosis Society of Canada and other agencies in your community. For more information on where you can turn for help from time to time, contact your local chapter or the nearest division office of the Multiple Sclerosis Society of Canada.

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# **INTRODUCTION TO MS**

## **What is multiple sclerosis?**

Multiple sclerosis (MS) is the most common disease of the central nervous system affecting young adults in Canada. It is estimated that approximately 50,000 men and women in Canada have the disease, and every day about three more people in Canada are diagnosed with MS.

The cause of MS is still unknown, but we do know that the myelin sheath – the coating around the nerve fibres in the central nervous system (CNS) – is affected. Myelin is necessary for the transmission of nerve impulses through nerve fibres. If damage to myelin is slight, nerve impulses travel with minor interruptions; however, if damage is heavy and if scar tissue replaces the myelin, nerve impulses may be completely disrupted.

The name “multiple sclerosis” is derived from this process – **multiple** (many) since it occurs in a number of places within the nervous system and **sclerosis** (scars) which means the hardened patches of scar tissue that form over the damaged myelin.

MS varies greatly from person to person and in the severity and the course of the disease. Some people have few attacks and little disability over time. Others have “relapsing-remitting” MS which means they have a series of attacks (exacerbations) followed by periods of recovery (remissions). Others have what is called “progressive” disease which can be “primary” or

“secondary”. People with primary-progressive MS have steady worsening (or progression) from onset with only minor recovery.

Secondary-progressive MS begins with a series of relapses and recovery but becomes steadily progressive over time with continued worsening. Most people with MS have the relapsing-remitting or secondary-progressive forms.

Symptoms of multiple sclerosis often become apparent in young adulthood. It is most often diagnosed in those between 20 to 40 years of age. It can however be found in people younger and older. The average age at diagnosis is 30. Almost twice as many women have MS as men.

## **What will happen to me? All I can think of is a wheelchair.**

MS varies considerably from person to person. At the time of diagnosis, it is impossible for your doctor to predict what course the disease might take and how you will be affected in the next five or ten years. Fortunately, there are specific treatments for relapsing-remitting MS, and some may be helpful for people with secondary-progressive MS who are still having relapses. In addition, much can be done to treat particular symptoms as they arise. (Please see more information in the section on MS treatments, pages 10-13.)

During an attack (relapse or exacerbation) of MS, the myelin becomes inflamed, and nerve impulses are slowed or stopped. This causes symptoms such as lack of coordination, weakness, tingling, impaired sensation, fatigue, dou-

slightly higher chance of developing the disease. Research now suggests that several genes interact to determine susceptibility to MS (not one single gene). Ground-breaking research in this area continues with hopes that discovery of these genes will lead to the development of new and more effective treatments for the disease.

Many researchers agree that MS is a “multi-factorial” disease, meaning it’s caused by more than one thing. In this respect, the three research areas mentioned above (viral, immune system and genetics) may actually be connected. Researchers suspect that MS is the result of a combination of viral exposure, genetic background and autoimmunity and that an individual must have all three factors to develop MS. It is possible that a common virus may trigger the body’s immune system to attack and damage central nervous system myelin in a genetically susceptible person.

Your local chapter of the Multiple Sclerosis Society of Canada is regularly informed of the latest research and treatment information. You may wish to get in touch with the chapter and become a member of the MS Society to be kept up-to-date. This information is also available on our web site: [www.mssociety.ca](http://www.mssociety.ca).

## **Why did I get it? Why me?**

There are a number of factors that make certain people more susceptible to multiple sclerosis than others. However, they didn’t do anything “wrong” to cause the disease to develop. We

know that Canada is a high risk area for MS. The number of cases in Canada is much higher than in the southern United States or Mexico. Recent epidemiological (population) studies in Canada have found MS rates from 90 to 200 cases per 100,000 population. Autopsy studies in Canada and elsewhere revealed MS in people who did not experience noticeable symptoms in their lifetime. This means that the MS prevalence rate for Canada may be in the range of 175 to 200 cases for every 100,000 people, or one case per 500 to 750 people.

Age is also involved in developing MS. About two-thirds of people with MS have their first symptoms between the ages of 20 to 40. Although sometimes the diagnosis is not made until a person is over 45, a medical history will often reveal that symptoms appeared previously, but were not severe or long-lasting enough for the person to seek medical attention. In the remaining one-third of the cases, the first symptoms appear and are diagnosed before 20 or after 40 years of age. It is estimated that every day three more people in Canada are diagnosed with MS.

## **Can my children get it?**

MS is not contagious, nor is it hereditary in the usual sense of the word. It is likely that a number of factors must exist before MS develops.

It is known that certain genetic populations (northern European backgrounds) have a greater susceptibility to MS. There is also a higher incidence of MS in family members,

particularly in identical twins where there is the same genetic background. But other environmental factors must be present as well, and the vast majority of people with MS do not have another family member with the disease.

Please contact the nearest MS Society office for additional information and articles about genetic research in MS.

## **SYMPTOMS OF MS**

### **Common symptoms of MS**

Symptoms of MS are unpredictable and vary greatly from person to person and from time to time in the same person. They may include: extreme fatigue, vision problems, loss of balance and muscle coordination, slurred speech, tremors, stiffness, bladder and bowel problems, difficulty walking, cognitive problems and even paralysis. This chapter is dedicated to explaining some of the more common symptoms. Be sure to talk with your doctor about any new symptoms you are having. In addition, please see the section on MS treatments, pages 10-13.

### **Bladder problems and MS**

It is fairly common for people who have MS to have some problems with bladder control. You may have to see your doctor a few times to deal with it, and he/she may get help from a specialist. If you are having either frequent urination or just the reverse – if you have difficulty passing urine – you should see your doctor without delay.

Medications are available that can slow down an overly irritable bladder, and others help activate the bladder when emptying seems slow. Many people have minimal inconvenience once they get help. Keep your doctor informed about your urinary habits and any related problems.

Some people may develop urinary tract infections. Symptoms include: frequent urination, strong smell and discolouration of the urine, and sometimes, abdominal or back pains and fever. The presence of MS makes it more difficult for your urinary system to “get by” without specific medication, so don’t try to handle it yourself. There are also methods of emptying the bladder of as much left over urine as possible – often the cause of infection. Talk to your doctor about this possibility.

Part of the problem may be solved by timing fluid intake. When some people begin having bladder frequency or lack of control, they drink hardly anything. **This is dangerous.** It is very important that the kidneys get two litres of fluid each day to do their work in eliminating waste products efficiently.

The answer is to plan fluid intake. Don’t drink large volumes of fluid just before going out or going to bed. The same amount of fluid might be easily handled spread over a longer period of time. Beverages containing caffeine and alcohol can make urgency and frequency problems worse. You may wish to limit these.

Appropriate clothing, padding and devices for incontinence are available at reasonable cost

and can be useful in coping with lack of control. These are available at drug stores or medical supply companies. Shop around and compare prices since costs may be different from place to place.

Every symptom you get is not necessarily related to MS. Men may develop prostate trouble and women vaginal infections which have nothing to do with MS. Let your doctor sort out the cause and recommend treatment.

For more information, please consult the publication *Understanding Bladder Dysfunction and MS*, available from the Multiple Sclerosis Society.

## **Is bowel function affected by MS?**

It appears that constipation occurs in more people who have MS than in the general population. If this irregularity is a problem, there are several steps you can follow.

First, you should remember it is not necessary for good health to have a bowel movement every day. But, if you don't have one every three to four days, you could have complications. The symptoms of a full bowel could be nausea, headache and a general feeling of being unwell.

Timing, fluid intake, diet and physical activity are four measures that must receive primary consideration.

**1. Timing** – A specific time of day should be selected. Bowels move more readily after a

meal so after breakfast is an ideal time for someone on a morning schedule and after dinner for someone on an evening schedule.

**2. Fluid intake** – Fluid intake of two quarts (or two litres per day) aids in maintaining a soft stool; warm liquid taken before a meal or before trying will also aid bowel movement.

**3. Diet** – You should follow a healthy diet including fibre in the form of bran cereals, vegetables and fruits. Bran is one of the cheapest and most easily available forms of natural laxatives. Add several teaspoons (10 mL) to meatloafs, breads, soups, stews or almost anything that is mixed together and baked or simmered. Prune or lemon juice, an orange, apple or fig could be taken in the evening for someone on a morning schedule and in the morning for a person on an evening schedule.

**4. Physical Activity** – Activity and exercise promote good bowel health. You should exercise to the extent you are able, but not to the point of exhaustion.

If the problem persists, your doctor could recommend temporary measures such as medications, suppositories, laxatives or enemas.

Irregularity may be a symptom of another illness, not necessarily MS. It is important you discuss it with your doctor.

For more information on bowel functions and MS, please contact your MS Society division or chapter office and ask for a copy of *Understanding Bowel Problems in Multiple Sclerosis*.

## How can I cope with fatigue?

Fatigue is one of the least understood and most frequent symptoms of MS. It often causes problems among co-workers, friends or family members who accuse the person with MS of “just being lazy”. But fatigue is a very real symptom and is the result of damage to the nervous system.

If you have fatigue, you should find your own limits and be able to plan your days to make the best use of your energy. You should try to sleep fairly regular hours, have as much physical activity as you can without becoming over exhausted and rest or nap when necessary.

Research on the anti-viral drug amantadine (Symmetrel®) seems to indicate that the drug eases the fatigue level in many people with MS. In addition, sometimes various amphetamines are used to treat MS fatigue. Discuss these options with your doctor.

Fatigue can fluctuate on a day-to-day basis – a phenomenon doctors don’t understand, so don’t expect your family to. You may have to explain frequently how you feel. Otherwise, your behaviour may be mysterious to them.

“I can suffer from extreme fatigue. But by rearranging my daily activities, I can complete everything I want to do. Learning to live within my scope has been one of the most important adjustments I have made.”

What does this mean for daily living? Working in the home (kitchen, workshop), you may find

it easier if you reorganize your work area so you can reach the most used items readily. Have lazy susan storage on cupboard shelves, use a tall stool to sit on while working and do as many chores as possible sitting down – paring vegetables, ironing, hobbies, etc. Use a trolley on wheels for moving several items at a time and have other people carry the heavy items. An occupational therapist could assist you in evaluating activities and making energy saving suggestions.

Whether at home or work, you can plan your day so that the hardest or necessary tasks are done when you have the most energy. Plan an easier task or a break time for the periods when you know you feel less energetic. If your job is very physically demanding, you may have to consider a different kind of employment that will allow you to be productive without exhausting all your energy.

To learn more about fatigue, read the Multiple Sclerosis Society of Canada publication, *Coping with Fatigue in MS*.

## Is pain a symptom of MS? I have quite a lot of pain in my back and legs, but I’ve been told MS is a pain-free disease.

Most people with MS do experience some pain during the course of the disease. Although our knowledge of why people experience pain is limited, we know that conduction in the central nervous system (CNS) can be abnormal and may result in pain.

Backache is the most common complaint and may be due to the strain put on the back muscles when walking with weakened and spastic muscles. There may also be spasms in the legs (if spasticity is severe) which will cause crampy pain periodically while sitting or lying down.

Much can be done to alleviate distressing symptoms. Some physicians recommend substituting another type of sensation for the pain, such as pressure, warmth, cold or massage.

Pain due to spasticity (stiffness) can be aided by stretching exercises or may be caused by faulty walking pattern which can be helped by using a proper assistive device. But if the pain cannot be managed, medications may be necessary. Stiffness can be treated by anti-spasticity drugs such as baclofen or a newer drug called tizanidine (Zanaflex®). Sometimes tranquilizers and drugs for epilepsy (which stabilize nerves) are used. Reactions to medications vary greatly so your doctor may have to try different treatments before obtaining satisfactory results.

You may find massage and an Aspirin®-type drug help relieve sore and/or tired muscles including backache before going to bed. Your doctor will advise you on the most appropriate other therapy. Some symptoms such as feeling of tightness or a “girdle sensation” may not be treatable by existing medications, but you should discuss them with your doctor as they may not be caused by MS.

A less commonly felt pain, but which sometimes occurs with MS is trigeminal neuralgia (also known as tic douloureux). It is usually felt as severe pain lasting several seconds at a time, located in one side of the face. Trigeminal neuralgia is treatable and should be discussed with your doctor.

Remember that like everyone else, persons with MS are subject to unrelated conditions, such as arthritis, migraine headaches, and lower back pain. Let your doctor know about the pain you're experiencing so a proper diagnosis can be made.

## **Does MS affect memory? Sometimes I just can't remember anything.**

Sometimes people with MS have problems with memory and concentration. These cause a lot of worry both for the person who has the problems and for the family, sometimes leading to misunderstanding and frustration.

These are true symptoms of MS and are directly caused by the disease. Like other symptoms they can come and go and may be made worse by fatigue, infections or stress.

Some people with these problems can be confused with their thinking, especially when tired, and others find that they are not able to control their feelings as much as they would like. They may cry or laugh for little reason and are afraid of over-reacting in front of others. This can be embarrassing and can lead to social withdrawal and isolation.

People with MS can appear cranky and overly sensitive to others. Relatives and friends may feel hurt and criticized unfairly. They may say that the person with MS has become selfish and is no longer able to see the relatives' problems or point of view. It may also be very hard for relatives to cope with the depression that can happen to people with MS, and at these times counselling for both the person with MS and their relatives might be a good idea.

These direct psychological symptoms are due to MS itself but may be combined with the emotional upset that affects everyone when a family is trying to adapt to living with the disease. Once the symptoms associated with MS are recognized for what they are, positive steps can then be taken to overcome them. For instance, someone who has a problem remembering things will find it useful to keep a note pad close at hand.

Just understanding that these difficulties are due to MS can stop a lot of guilt and frustration, and help people to accept their limits.

Although direct psychological symptoms are not uncommon, many people with MS will never experience them at all.

Courtesy of Dr. Alexander Burnfield, M.B., B.S., M.R.C. Psych., you may also find the booklet, *Multiple Sclerosis and Your Emotions* helpful. It is available from the Multiple Sclerosis Society of Canada.

## **What is an MS “attack”?**

For unexplained reasons, the disease seems to come in relapses or attacks which doctors call exacerbations. They are medically defined as the appearance of new or worsening of old symptoms lasting at least 24 hours. At these times, symptoms may suddenly become worse, or new ones may appear. In between attacks, there are periods called remissions. During these times, the disease isn't progressing and the body is recovering. Sometimes there are years in between attacks.

“I haven't had an attack of MS for several years, but I do have reminders from time to time that it's still there.”

MS attacks can be treated. For more information, see the section on MS treatments, pages 10-13.

Some people feel an attack coming on, and change their lifestyles accordingly by resting more and slowing down until the episode passes. Others may find that the way they feel changes from day to day.

Not all your health problems will be caused by MS. People who have MS are not more susceptible to other ailments, but they can still have – along with everyone else – colds, flu, broken bones, ulcers, diabetes, etc. Be sure to obtain medical treatment when problems arise and don't think “it's just MS”.

## Can anything make MS worse?

Naturally, because of the ups and downs of MS, people try to figure out what sets off an attack or relapse. A number of possibilities have been mentioned including emotional upset, infections, overexertion and fatigue, injuries and surgery. There does seem to be a direct connection between high temperatures and worsening of MS symptoms for many people with MS. A hot bath or shower, a fever or hot weather made symptoms temporarily worse for more than half of the people with MS involved in one study. Avoiding high temperatures when possible would seem to be the sensible route.

For the other items mentioned, there is no general pattern. The only factor that clearly has been shown to be associated with an exacerbation are common viral infections. The relationship of emotional upset and trauma is less certain, and for the majority of relapses no direct cause can be isolated.

## **TREATMENTS**

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For many years, people with MS have been receiving wide-ranging and often helpful treatment to relieve symptoms and enable us to live more comfortably with the disease. More recently, however, four specific therapies for relapsing-remitting MS have become available in Canada. These are described below, followed by a section on therapies for progressive MS and a section on symptom relief.

## Treatments for relapsing-remitting multiple sclerosis

Three beta interferons (Avonex™, Betaseron® and Rebif®) and a drug named glatiramer acetate (Copaxone™) are approved for treating relapsing-remitting MS in Canada. While they do not cure MS, these drugs reduce the frequency and severity of attacks by about one-third in relapsing-remitting MS. Beta interferons are produced naturally in the body and have an effect on immune system regulation. The three drugs are produced using recombinant DNA techniques. Copaxone is a synthetic compound that chemically resembles a component of myelin. Although its mechanism of action is not completely understood, it may act as a “decoy”, diverting immune cells from their myelin targets.

Several studies have found that beta interferons and glatiramer acetate have some impact on progression of disability. For more information on the four drugs, please call 1-800-268-7582 or visit the web site at [www.mssociety.ca](http://www.mssociety.ca) and see the “Research & Medical Library” page.

In addition to these proven treatments, a number of other therapies are being tested. The MS Society reports regularly on the results of treatment studies in the quarterly publication *MS Canada* and on the web site: [www.mssociety.ca](http://www.mssociety.ca).

## Treatments for progressive MS

While there are treatments for relapsing-remitting MS, the development of treatments for primary and secondary-progressive MS has been

slower. It is more difficult for investigators to show that a therapy is actually effective in slowing the progression of the disease.

However, research is making headway, and in June 1999 Health Canada approved interferon beta-1b (Betaseron) for the treatment of secondary-progressive MS based on the results of a European clinical trial. However, a later North American study of Betaseron for secondary-progressive MS resulted in a more negative outcome. A study involving interferon beta-1a (Rebif) for secondary-progressive MS also yielded more mixed results.

Mitoxantrone (Novantrone®) is a drug developed to treat cancer that has been approved in the U.S. to treat people with worsening relapsing-remitting MS, people with secondary-progressive MS and people with progressive-relapsing MS. While not officially approved in Canada for MS, some clinics and neurologists are using the drug especially for people whose MS is rapidly progressing or for people who have not responded well to other therapies. Mitoxantrone is given intravenously (into the vein). There is a lifetime cumulative dose limit because of concerns about cardiac toxicity.

While not yet at the large clinical trial stage, researchers are also studying such experimental drugs and techniques as T-cell vaccination, peptide therapy, thalidomide and bone marrow transplantation. It won't be known whether any of these potential treatments will work until the clinical trials have been completed and results analyzed, however there is increasing optimism that treatments will be available soon for progressive MS.

## Treatments for MS attacks

Attacks (also called exacerbations or relapses) are often treated with steroid-type drugs such as ACTH, prednisone or intravenous methylprednisolone to reduce the severity of an individual attack of MS, particularly in the earlier stages of the disease. They are of no value during the later progressive stages and may even produce harmful side effects. Long-term use should be avoided.

## Treatments for MS symptoms

**1. Spasticity** – Muscle stiffness is a common problem in people having a severe attack of MS. There is no one drug that is totally effective, but often a combination of drugs (baclofen is widely used and tizanidine [Zanaflex®] is now available) and physiotherapy may be helpful. Other drugs are being tested for increased effectiveness.

**2. Bladder problems** – This can be a problem for some people, but medical treatment can help. The Multiple Sclerosis Society of Canada has a publication called *Understanding Bladder Dysfunction and Multiple Sclerosis*, which you may find helpful. Bowel problems may also appear but can often be solved by changing eating habits (see pages 5-6).

**3. Tremor** – In more severely affected people, tremor can be a disabling problem interfering with the ability to carry on daily activities. Sometimes, medication can be helpful.

**4. Fatigue** – Many people with MS experience fatigue. Some people find the drug

amantadine (Symmetrel®) to be useful. Adjusting one's lifestyle can be helpful as well (see page 7). You may also want to contact the MS Society for the publication, *Coping with Fatigue in MS*.

**5. Vision problems** – Temporary loss of vision, double vision and jerky eye movements are frequent MS symptoms. Fortunately, these problems often clear up spontaneously. Sometimes treatment, usually with a steroid-type drug, is used. You should see your doctor for a thorough evaluation if you develop any vision problems.

**6. Sexual difficulties** – MS may affect sexual functioning in some people. It could be a temporary problem or it might require some treatment. The Multiple Sclerosis Society of Canada has a booklet, *Sexuality and Multiple Sclerosis* see page 16, which provides more information.

**7. Emotional problems** – Naturally, a diagnosis of MS may lead to anxiety and depression, and such emotional factors may actually aggravate the MS symptoms you have. The MS Society has a booklet called *MS and Your Emotions* that you may find helpful. Or you may wish to have your doctor refer you to a counsellor, psychologist or psychiatrist to help you work through your feelings.

**8. Memory and concentration problems** – Again, like other problems associated with MS, difficulties with memory and concentration can come and go, see page 8.

## **Should I exercise/ have physiotherapy?**

You and your doctor should decide whether physiotherapy will be of value to you. Following an attack of MS, it may be useful for you to be referred to a rehabilitation department of a hospital for an assessment.

It is important to understand what physiotherapy is and what it is not. Physiotherapy is a way of examining your present abilities and learning how to make the most of them. A physiotherapist can help you maximize your present energy, and along with an occupational therapist, instruct you in energy-saving techniques. The rehabilitation staff may suggest specific exercises and aids for your home program to help you remain independent. If you wish, an occupational therapist could visit your home to talk about ways to change things to make it easier for you to get around and conserve energy.

A regular exercise program or appropriate recreational sport will benefit you in the long run by maintaining good physical condition. This does not mean terribly strenuous sports unless, of course, you are able to. Many people have found a regular swimming or yoga program helpful in maintaining muscle tone without becoming overly tired. Once you gain experience in living with MS, you will be able to judge how much you can exercise before becoming fatigued.

“One of the reasons I developed an interest in yoga was that I'd read it was a form of exercise that put the least amount of strain on the

body, particularly the spine. I found it to be a tremendous tension release which helped me cope better with MS and helped me learn to relax.”

Many MS Society chapters offer exercise programs, such as yoga, tai chi, swimming and horseback riding. If there is no chapter in your area, other community groups may have beneficial programs.

## **How often should I see my doctor? Are visits to specialists recommended?**

You should see your doctor at regular intervals. You and your doctor can work out how often this will be depending on how healthy you are in general. You should also establish that you can telephone your doctor in between regular appointments for any crisis that might come up, because you could develop medical problems that are totally unrelated to MS. These should be treated as they would be with anyone else.

You should find a doctor who is knowledgeable about MS and on whom you can rely to treat you as a whole person.

You and your family doctor aren't the only ones involved in your treatment and care. You may require periodic visits to a neurologist for reassessment of your neurological condition. Your family doctor or neurologist may refer you to an MS clinic, where you will have the benefit of neurologists and health care professionals who are experts in the diagnosis and

management of MS. Please contact the MS Society of Canada for the phone number of the MS Clinic nearest you.

If there is any sign of bladder or bowel problems, you should see your family doctor and be referred to a specialist if necessary. The staff of a rehabilitation department – physiatrist (doctor of physical medicine), occupational therapist, physiotherapist and others – may also be involved from time to time with your assessment and overall care. Psychiatrists or psychologists may be consulted to help deal with cognitive or emotional problems.

Getting along with a disability is a team effort, and you are the most important member of the team.

## **RESEARCH**

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### **What is happening in research?**

MS is a complex disease and research involves a number of medical specialties including the study of the immune system, myelin regrowth and repair, genetics, virus research and epidemiology.

Researchers who study viruses think MS may be caused by any one of a number of common virus infections such as measles or one of the herpes viruses. The virus may not actually invade the central nervous system, but may trigger the abnormal autoimmune response.

Much research is underway to determine how this actually takes place.

MS is a disease of the immune system. The body's immune system destroys bacteria, viruses and other foreign substances that invade it. Sometimes a change in the way it finds and destroys foreign matter sets off an autoimmune response, and the body begins attacking some part of itself, treating it like it is foreign. This probably happens in MS.

Scientists are looking for ways to make myelin repair itself and regrow after it has been damaged by MS attacks. Usually adult myelin does not regrow easily but researchers are finding ways to overcome this problem. Much of MS research is so-called "basic" or "fundamental" research. Scientists are trying to understand how the complex central nervous system works and how and why parts of it stop working. Once these questions are answered, finding the cause and cure of multiple sclerosis will be much easier.

There are two major aspects to MS research: (1) to discover the cause of MS and how to prevent it, and (2) to find a treatment that will stop MS from progressing once it strikes. Research into MS treatments is advancing steadily although the underlying cause of the disease is still unknown. Treatments are tested in clinical trials to determine if the drug or therapy actually works – a difficult task in a disease like MS, which has spontaneous remissions. While no one can predict when the answers will come, researchers are increasingly optimistic as they

learn more and more about the way the nervous and immune systems work.

The Multiple Sclerosis Society of Canada has been a strong supporter of MS research since it was founded in 1948. Funds go to carefully selected research projects at universities and hospitals across the country. Research is also a priority of other MS Societies around the world. The Multiple Sclerosis Society of Canada is a member of the Multiple Sclerosis International Federation. Comprised of 38 national societies, the Federation coordinates and distributes information on MS research at the international level.

From time to time, reports about breakthroughs in MS research appear in newspapers, on TV, radio and on the Internet. While most of the information is factual, sometimes it is out of context or incomplete. Your local chapter or division office receives information about research in Canada, and other countries, regularly. If you hear or read any news about MS research, you may wish to check it out with your local chapter, or go to the MS Society web site: [www.mssociety.ca](http://www.mssociety.ca).

## **LIVING WITH MS**

### **Are there special diets for people with MS?**

Although a number of special diets for MS have received attention in the news in recent years, the Multiple Sclerosis Society of Canada does not endorse any particular diet for MS, nor is there any scientific evidence that mas-

sive doses of vitamins affect the course of the disease. It is important to have a balanced diet.

Because in the beginning stages of the disease, the majority of people will recover from attacks whether they are treated or not, it is very difficult to establish a cause and effect relationship with a particular diet or megavitamin therapy. If you do change your diet radically or increase your intake of vitamins, you should consult a nutrition specialist or doctor to ensure that you are receiving all the necessary nutrients.

To stay in good health, it is important to eat a well-balanced diet consisting of a variety of foods. If you have any questions about the kind of diet you should be following, contact the nutrition service of your community health service or provincial health ministry for further information. The MS Society's *Healthy Eating: A guide for persons with multiple sclerosis* examines what makes up a healthy diet. Like all other publications, it is available from chapter and division offices.

## **Should I give up alcohol?**

You should consult your doctor, but unless forbidden, an occasional social drink will do no harm. If you do experience fatigue, balance or bladder problems, you may find that liquor increases these problems, and it may be wise to limit consumption.

If you are taking any medications, check with your doctor to find out whether it is safe to drink in moderation. Alcohol in quantity is unsafe for anybody.

## **Should I use some kind of mobility aid? It makes me feel as though I'm giving in.**

If an aid will help you live a fuller life and conserve energy, use it. If it will enable you to do something better and more easily, use it. You may need an aid for one month and not the next since MS is a variable disease. Aids are not necessarily a sign of progression of the disease, but they could be a way of coping with your present situation.

“A wheelchair doesn't confine, but allows me to go out into the world. Wheelchairs and canes are means of letting you out of a cage. They allow you to do things you couldn't do before you used them.”

The point is to be independent using whatever devices you need. Your doctor, with the assistance of the staff of a rehabilitation department, will prescribe the appropriate aid, tailored to your specific needs.

Aids can take many forms. For those having trouble walking up or down stairs or along a hall or pathway, a railing is needed for safety. Grab bars in a bathroom will add a safety feature when using the bathtub and toilet. A walk-in shower is easier to manage than a bathtub. A safety non-slip mat in the bathtub is a necessity for everyone. Medical equipment supply companies often have showrooms where you can view their products.

Hand controls make it easier to drive a car if you are having trouble with your legs. These can be added to most car models and are available from many medical equipment supply companies.

Several automakers offer programs to help people better afford adaptations for their vehicles.

If you are considering renovating or building a house, plan on making it totally accessible and usable. Building plans for accessible housing are available from Central Mortgage and Housing Corporation, or you may wish to consult an architect who is knowledgeable about planning for total accessibility.

Other aids are just a matter of common sense. There are many sources and suggestions for adapting all sorts of objects. Aids are sometimes available free-of-charge through provincial government programs. The MS Society can help put you in touch with the appropriate government agency. Your local chapter may also provide aids on loan. For more information, contact your local chapter or the nearest division office, for contact information, please see the back cover of this booklet.

### **Sexuality and MS. I have heard there may be sexual problems associated with MS. Is this true?**

Many people with or without MS have sexual problems at some point in their life. Problems are different from person to person. For men it

could be not getting an erection when they want one. For women, it could be not feeling aroused when previously they would be.

Since sexuality is a part of our total personality and cannot be separated from the rest of life's experiences, it is not surprising that external pressures such as feeling depressed or anxious affect sexual relationships. Even when a satisfying sexual relationship is a source of reassurance, self-esteem and tension release, the problems of having MS may affect communication. Couples will need to maintain and improve positive communication in all aspects of their lives to overcome these problems.

As a spinal cord injured woman said: "Your sexuality is relationships with other people. It is how you feel about other people. It is everything. It is you."

It is also possible that MS will affect the parts of the nervous system involving sexual function. This can be checked by your doctor. But even if this is the case, it can be a temporary problem since MS has remissions, and a problem you have today may be gone a month from now. In addition, the recent medication sildenafil citrate (Viagra®) may be helpful for men with MS. So far, studies have not found it useful for women.

We all know that having an enjoyable sex life is not necessarily the same as having sexual intercourse. Even if intercourse is no longer possible or satisfying, there are many options for committed, loving partners. The Multiple

Sclerosis Society of Canada has a more detailed booklet, *Sexuality and Multiple Sclerosis*, which you may find helpful. It is available through division offices. Marriage counsellors and others specializing in relationship problems are available for consultation in your community as well.

## **What about contraception?**

The vast majority of women who have MS continue to ovulate and, therefore, can become pregnant unless they use some method of birth control.

Oral contraceptives, IUDs, diaphragms, condoms or foams and jellies can be used depending on the couple's choice and advice of their doctor. If the desired number of children has been reached, or the couple decides not to have children, sterilization may provide an answer. A full discussion with a doctor is a good idea.

## **Effects of pregnancy on MS.**

Some scientific research has been done on this question, and in general, pregnancy is not considered to be harmful in the long run for the women who have MS. There may be a slightly increased risk of attacks in the period after giving birth, however, studies have shown that most women have a decreased risk of attacks during pregnancy. It is unlikely that pregnancy has any negative effects on the long-term course of the disease.

Before making a decision, these questions should be discussed with your doctor. Feel free to contact the MS Society for more information.

A couple planning for a child should also consider whether the affected partner will have the energy and stamina to help care for the child after it is born and in the years ahead. Will help be available from relatives or paid assistance? Financially, can the couple cope? Is it possible for one partner to support the family if he/she is the only one working?

While severe disability is not always, or even usually, associated with multiple sclerosis, the couple should think about the possibility while planning a family. For more information, contact your local chapter or division office and ask for a copy of *Becoming a Parent: A major decision when MS is in the family*.

## **Can we maintain our usual lifestyle?**

If you have little or no physical disability, your family lifestyle may not change at all, but many people with MS report they have to cut back some of their activities, choose ones that aren't so physically demanding and get more rest if they are going to stay out late. This may be disturbing to your family because your disability is affecting them as well.

Therefore, some compromises may have to be made. Instead of pushing yourself to the point of exhaustion, maybe you can find activities

that aren't so demanding physically, yet are fun for the rest of the family. You may have an expertise at playing bridge or chess. Games like Monopoly® and Scrabble® can be fun and are a good excuse for a get-together in the afternoon or evening.

“If we are invited out for the evening, I rest before we go, or plan in advance to come home early. Sometimes I arrange to come home by taxi while my husband stays on a bit longer. This way I don't feel like I'm spoiling the evening out.”

Many public places like art galleries, museums, and shopping malls have wheelchairs available. It may be hard emotionally to use one for the first time, but it will conserve your energy and allow you to participate more fully and for much longer.

## **Should I make preparations to change my lifestyle for the future?**

It is wise to plan ahead, even though you may never have to fall back on that planning.

“At the time of my diagnosis the planning had to happen immediately because we were going to build our dream house on the lake. It had to be accessible for a wheelchair even though I might never need one. It would have broken my husband's heart to have to move at a later date from a house I couldn't run. We have lived happily in our house for seven years. I have no disability, but I am comfort-

ed by the fact that if I did, our lives would not change greatly.”

There's nothing wrong with planning for the best and worst case scenarios. It is perfectly reasonable to consider the possibility of becoming disabled while planning your home and your job, or while planning a trip around the world.

One of the more difficult problems for a couple is the possible change in their roles. This requires much discussion between partners. The possibilities for the future must be looked at together. A family with two incomes may have to learn to cope on one. One person may have to be employed as well as taking on more responsibility for running the home and caring for the children. It is important for the affected partner to offer as much moral and physical support as possible. This will ease the burden and help maintain feelings of co-operation.

A job that is less physically demanding may be more suitable and may have to be planned for.

“When I found out I had MS, I decided never to marry. Now I realize if the right person came along, I would want to become involved, but I would certainly talk about having MS first.”

Some hospitals may have counsellors who can offer advice on adapting styles of living and career planning. There are also professional career counselling firms in larger cities.

Vocational retraining is available through provincial vocational rehabilitation departments and Human Resources Development Canada career counsellors should be helpful in making you aware of options for the future.

Participating in an MS Society self-help group may put you in touch with people who are dealing with similar problems or who have overcome certain difficulties. (See “What is a self-help group” on page 24 for more information.) The MS Society has information on remaining in the workforce and options to make it easier. Call your division or local chapter for a copy of *Assets and Abilities: Your Guide to Work, Income Security and Multiple Sclerosis*.

## Where can I get financial help?

Financial matters will become important whether you are physically disabled or not. You may want to think about your future employment goals, your present financial needs and the availability of insurance plans.

If you become unable to work, some employers provide a group insurance disability program for their employees. You should have been advised of this coverage when you started work and the benefits under the plan should be explained to you in some type of employee’s handbook. If you do not have this information ask for it from your employer. Your employer should also outline the proper procedure to submit a claim for benefits, if needed.

You could be eligible for long-term disability benefits upon satisfactory proof of disability. You may be able to work part-time and still receive all or part of these benefits, so discuss your individual situation with the insurance company that provides the benefits. **Medical coverage and group life insurance premiums** may also continue, depending on the terms of the policy. These should be explained by the handbook or by your employer.

If you have worked a minimum number of hours, you should be eligible for **Employment Insurance (EI)** from Human Resources Development Canada. Claimants who have worked at least 600 hours are normally eligible for a maximum of 15 weeks of sickness benefits. Contact your local Canada Employment Centre for further information. Some group insurance plans provided by an employer replace EI benefits, so ask your employer if you are eligible.

You may have contributed to a **private income protection** plan, or there may be such a benefit attached to a **personal life insurance** policy that you own. As with group insurance, you may be able to qualify for monthly income benefits with either of these. You should contact your insurance agent or the company that issued the policy for the details and proper procedure for claiming benefits.

If you have contributed to the **Canada Pension Plan** for a specified period of time and are no longer able to work because of MS, you are probably eligible for a disability pension. The

**Canada Pension Plan (CPP)** and the **Quebec Pension Plan (QPP)**, for residents of Quebec, are social insurance programs that protect workers and their families against the loss of income due to retirement, disability or death. The plans cover nearly all employed and self-employed people in Canada who are between the ages of 18 and 70 and who earn more than a minimum level of earnings each year. CPP disability benefits are available to people who are between the ages of 18 (20 under QPP) and 65 (when your CPP retirement pension begins), have contributed to the CPP and/or QPP for a minimum number of years, and are disabled according to CPP or QPP legislation. Neither program covers health-related expenses, such as the cost of MS treatments or medical supplies. For more information about disability benefits, contact your nearest division or chapter office and ask for a copy of the publication *Assets and Abilities: Your Guide to Work, Income Security and Multiple Sclerosis*.

If your total income is insufficient to meet your needs, you may be eligible for **financial assistance** from your provincial social services department. A means test is required.

For **short-term help**, assistance may be provided by your municipal social services office. Once again, a means test is necessary.

A number of expenses associated with the extra cost of having a physical disability are **deductible from federal income taxes**. Some deductions that may be claimed by the disabled taxpayer or the supporting spouse are: the dis-

ability tax credit, medical expenses, attendant care, transportation devices and equipment and child care expenses (under certain conditions.) For details, contact the nearest office of the Canada Customs and Revenue Agency. Unfortunately, the Multiple Sclerosis Society of Canada is not authorized to provide direct financial assistance. But other services are often provided that may help ease the burden. Check with your local chapter or the nearest division office.

## **Emotions and MS**

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### **My family seems too over-protective.**

Your family obviously loves you, and your spouse and parents are distressed to know you have this disease. They are trying to do everything they can to ensure that the disease does not progress. They want you to look after yourself, and they also want to look after you.

Can you imagine how your parents feel? They think to themselves: "What did we do wrong? What didn't we protect against?" Your spouse might be wondering: "Was I too demanding? Maybe I didn't give enough attention. What can I do now to make up for it?" The way many people show love and affection is to look after others.

"I want to go on with life, and do what I can do. I'm not having any symptoms right now. My wife is constantly reminding me that I

have MS. She says, ‘Don’t mow the lawn, don’t trim the hedge’ because a nurse in the hospital said something about conserving energy. My parents are always looking at me too and saying, ‘Are you getting enough rest?’ My friends seem to be worried as well. Everyone is looking at me as a sick person all the time.”

Try to sit down with your family or friends and explain what is bothering you. In order to reduce their fears, explain exactly what you can do physically. Point out that you want to be as independent as possible and would like their help and co-operation. Tell them it is important for you to maintain your self-esteem.

If you find this difficult to do, counselling should be available in your community to help you and your family work through these problems and to learn how to communicate better.

## **Sometimes I feel depressed.**

It is natural to feel depressed at times. Sometimes you may fear you are losing your health, your dreams and your plans for the future. You are bound to grieve at this, and you are bound to feel miserable at times. It takes time to adjust to a changed situation. In addition, several studies have found that depression can be a symptom of MS, and that it can be treated with medications and/or counselling.

When most people are grieving, they want someone to comfort and love them. But when people are depressed, they tend to pull away

from others, so loved ones leave them alone when, in fact, their support is most needed. It is also important to remember that your family members are upset and depressed, as well. Talking about how everyone is feeling is very important at this time.

“I find it really hard to talk to my family when I’m depressed. I just like to be alone, and when they say to me: ‘What’s wrong?’ I don’t let them know. Should I let them know? Or would it just make them more worried?”

Don’t think your spouse doesn’t love you, or that your parents don’t love you because you’re feeling miserable and no one is comforting you. How are they to know you are feeling miserable if you don’t tell them? Communication is something that has to be worked on all the time. Your family cannot guess what you are feeling or what you want. You have to talk about it.

“I was very bitter, and I was still feeling that I could finish my degree. But I finally came to the conclusion that I had to withdraw because of my physical limitations. It was a big step for me at that time. It was during this period that I sought counselling. Although there seems to be a stigma attached to going to see a psychiatrist or psychologist, I found the experience very helpful. It helped me put my needs and aspirations in perspective and made me feel comfortable with my eventual decision.”

If you are feeling particularly “down” or distressed, you should let your doctor know so

he/she can consider various types of anti-depressant medications and/or counselling. It might be helpful to seek counselling from a professional (psychologist, psychiatrist, social worker, clergy) or to have a discussion with a close friend. Alexander Burnfield, a physician who has MS, deals with many of these problems in his book *Multiple Sclerosis: A Personal Exploration*. Check with your local library or contact the MS Society about how to borrow or purchase the book. Also available from the MS Society is a booklet called *Multiple Sclerosis and Your Emotions* that you may find helpful.

The MS Society also helps organize self-help groups for people with MS, their spouses and children to meet and discuss problems, see page 24. To learn about one that might be right for you, contact the nearest MS Society division office or chapter.

## **How and what do I tell my children?**

What and how you tell your children depends upon their ages and level of maturity. If they are quite young, it might be best to answer questions about what is wrong with mother or father as they come up. This approach would be less frightening than a formal announcement and explanation of MS.

Older children should be told in simple, truthful terms. Children are very quick to notice changes and may feel the security of their home threatened unless they know what is happening. Children often worry that their parent

with MS will die. When they are reassured that MS won't cause death, the anxiety is relieved.

“I make a conscious effort to get out of the house often so my son's friends will see me and understand that I am exactly like their mothers – except I'm in a wheelchair.”

You may find it difficult to keep doing some of your former activities with your children: playing hockey with them may have to be replaced by coaching them at hockey, and canoe trips replaced by fishing.

But many parts of family life don't need to change. You have much to offer your children in understanding and love. The important thing is the quality of the relationship, not what you can or cannot do. Family members need to work together, sharing good times and responsibilities, in order to maintain a happy household.

The Multiple Sclerosis Society has a number of helpful publications for children and parents including a booklet called *How to Talk about MS with Your Children*. Contact your nearest division office or local chapter for more information.

## **What do I tell people about having MS?**

Your community includes people who are close to you, and those whom you know casually. Your relatives, friends and employer naturally will want to know what has happened to

you, especially if you have visible symptoms. They may also want to know what they can do to help.

You can start with a simple explanation of the disease and how it is affecting you at this time. (The MS Society has some leaflets and brochures that will make the task easier.) In a way, you will be learning together. Your employer will want to know if you can carry on with the job. It would be a good opportunity to reassure him or her that you can, or perhaps discuss some changes that might make it easier for you to cope physically. The MS Society can help you begin discussions with your employer. A booklet called *Assets and Abilities* is available from your chapter or division office.

You may or may not wish to tell casual acquaintances if it comes up in a conversation. There is probably no reason for a formal explanation.

## **THE MS SOCIETY OF CANADA**

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### **How can the MS Society help me?**

The Multiple Sclerosis Society of Canada is a national voluntary organization, which supports research into multiple sclerosis, provides services to people who have MS and conducts public and professional education programs on MS. Through the Multiple Sclerosis International Federation, it is connected with other national MS Societies with the same goals around the world.

The MS Society of Canada consists of a national office located in Toronto, seven divisions across the country and approximately 120 chapters. The primary role of the national office is coordination of research, individual and family services, fund raising programs, social action and public education. Divisions and their chapters are directly responsible for providing services to people with MS and their families, for putting awareness programs into effect, providing social action and also for raising funds to support MS Society activities.

### **How do I become a member?**

It is easy to become a member and membership brings several advantages. Members of the MS Society receive newsletters and other information on a regular basis including research updates and information on available services. Members also have the opportunity to share experiences and concerns with other people who have MS. Many consider this last reason one of the best reasons for joining the MS Society. All records, of course, are confidential, so no one need know you have MS unless you tell them.

Contact your nearest chapter or division office for a membership form, or visit [www.mssociety.ca](http://www.mssociety.ca)

There is no problem in maintaining an informal contact with the MS Society, perhaps calling from time to time to learn about research advances and services that are available. You can attend workshops and seminars, as well, without being a member.

## **What kinds of services are available?**

Services vary across the country depending on the kind of provincial government and community programs available. The MS Society does not duplicate services already in existence.

Information, Funding and Support provide the framework for the services available through Individual and Family Services. These major services areas are comprised of core services that provide the basic structure of Individual and Family Services for divisions and chapters across Canada.

### **Information**

- MS Society of Canada publications
- ASK MS information resource centre
- Lending libraries
- Conferences and workshops

### **Funding**

- Equipment purchase or loan
- Special assistance

### **Support**

- Individual advocacy
- Support counselling
- Consultation and referral
- Support and self-help groups
- Recreation and social programs

People who have multiple sclerosis have the opportunity to help decide what kinds of services are available by becoming involved at the chapter, divisional and national levels of the MS Society. In this way, the Multiple Sclerosis Society of Canada is able to offer programs that truly reflect the needs of people with MS.

The MS Society is ready to offer as much or as little help as you may need within its range of services. Contact your local MS Society chapter or one of the division offices.

## **What is a self-help group?**

Self-help groups are informal associations of people who meet, often for a limited period of time, to help each other work through shared concerns and problems. In a way, people have been doing this for centuries, but now organizations such as the Multiple Sclerosis Society of Canada provide help to get people, who have the same concerns, together.

In self-help groups, people come to realize they are not alone and share ways to cope with life that includes MS. Groups exist for people with MS, spouses and caregivers. For more information, please contact the nearest MS Society division office or chapter.

## Publication Evaluation Form

Please visit [www.mssociety.ca/en/help/evaluation.htm](http://www.mssociety.ca/en/help/evaluation.htm) on the web to fill in our on-line evaluation form. If you do not have access to the Internet, please take a moment to fill in this form and mail it to our National Office.

TITLE of this PUBLICATION: \_\_\_\_\_

1. Was the topic covered in this publication helpful to you? Please circle one:

- Not at all       Somewhat Helpful       Very Helpful

Why? \_\_\_\_\_

2. How would you rate the overall publication? Please circle one:

- Poor       Fair       Good       Excellent

Why? \_\_\_\_\_

3. What topics would you like to see covered that are not already in print by the MS Society of Canada? (Please see below for a current listing)

\_\_\_\_\_  
\_\_\_\_\_

4. Any additional comments?

\_\_\_\_\_  
\_\_\_\_\_

Which of the following publications have you **read**? Please indicate by checking the appropriate boxes.

### MS Society of Canada Publications

- |  |   |
|--|---|
| <input type="checkbox"/> ASK MS Information Resource Centre brochure                         | <input type="checkbox"/> My Mommy has MS  |
| <input type="checkbox"/> Assets and Abilities (work, income security and multiple sclerosis) | <input type="checkbox"/> Myelin is Getting on My Nerves (workbook for children whose parents have MS) |
| <input type="checkbox"/> Becoming a Parent   | <input type="checkbox"/> Plaintiff (for families affected by MS)                                      |
| <input type="checkbox"/> Coping with Fatigue   | <input type="checkbox"/> Psychological Symptoms and Relationships Under Stress                        |
| <input type="checkbox"/> Doctor-Patient Dilemmas in MS                                       | <input type="checkbox"/> Sexuality and MS   |
| <input type="checkbox"/> Don't Lose Your Balance (for adolescents with a parent who has MS)  | <input type="checkbox"/> Solving Cognitive Problems   |
| <input type="checkbox"/> Healthy Eating  | <input type="checkbox"/> Someone You Know has Multiple Sclerosis: A Booklet for Families              |
| <input type="checkbox"/> How to Talk about MS with Your Children                             | <input type="checkbox"/> Taking Care: A Guide for Well Partners                                       |
| <input type="checkbox"/> Insuring Your Future: Your Guide to Life Insurance and MS           | <input type="checkbox"/> Taming Stress in MS  |
| <input type="checkbox"/> MS: Facts for Persons Recently Diagnosed                            | <input type="checkbox"/> The Sharing Network (for self-help groups)                                   |
| <input type="checkbox"/> MS: Its Effects on You and Those You Love                           | <input type="checkbox"/> Things I wish Someone Had Told Me  |
| <input type="checkbox"/> Multiple Sclerosis and Your Emotions                                | <input type="checkbox"/> Understanding Bladder Dysfunction  |
| <input type="checkbox"/> Multiple Sclerosis is... (information pamphlet)                     | <input type="checkbox"/> Understanding Bowel Problems   |
|  | <input type="checkbox"/> When a Parent Has MS: A Teenager's Guide                                     |

(see over)

Please note that providing any information below is OPTIONAL. This information will be used to determine if these publications are meeting the needs of the target audience, as well as to respond to your comments, if requested.

Please check which categories best describe you:

- Person with MS
- Family member
- Caregiver
- Health Professional
- Other (please specify): \_\_\_\_\_

Name: \_\_\_\_\_

Email: \_\_\_\_\_

Address: \_\_\_\_\_

Daytime Phone: \_\_\_\_\_

Thank you for taking the time to provide us with your valuable feedback.

Please cut out this form using the dotted line and mail it to the following address:

MS Society of Canada, National Office  
c/o Publications Coordinator, IFS  
250 Bloor Street East, Suite 1000  
Toronto, Ontario  
M4W 3P9

If you would like to receive any of the publications listed here, please contact your local division office listed on the back of this booklet or call 1 800 268-7582.

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H3A 1E7  
(514) 849-7591

## Ontario Division

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## Manitoba Division

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**Multiple Sclerosis  
Society of Canada**

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

**Web site** [www.mssociety.ca](http://www.mssociety.ca)

The Multiple Sclerosis Society of Canada is an independent, voluntary health agency and does not approve, endorse or recommend any specific product or therapy but provides information to assist individuals in making their own decisions.