

Multiple Sclerosis: Its effects on you and those you love



MULTIPLE SCLEROSIS: ITS EFFECTS ON YOU AND THOSE YOU LOVE

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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.

Many resources are available through the Multiple Sclerosis Society of Canada and other agencies in your community.

Connect with a Multiple Sclerosis Society of Canada navigator:

Toll-free: 1.844.859.6789

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Website: www.mssociety.ca

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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 more than 77,000 men and women in Canada have the disease.

The cause of MS is still unknown, but we do know that the myelin sheath – the covering 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, and the nerve fibres themselves can be damaged.

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.

What will happen to me?

MS varies considerably from person to person, and in the severity and course of the disease. 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 MS, depending on the type you have been diagnosed with.

In addition, much can be done to treat particular symptoms as they arise.

Symptoms of MS are unpredictable and vary greatly from person to person, and from time to time in the same person. Multiple Sclerosis can cause symptoms such as extreme fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder problems, cognitive impairment and mood changes. Remember that while many different symptoms can be experienced in MS, it is highly unlikely that you'd experience all of the symptoms listed.

Because multiple sclerosis varies so much, no one can predict what will happen in the future. MS is not a fatal disease for the vast majority of people with MS, and disability is not inevitable. Several studies have shown that people with MS can expect to live 95% of their normal life expectancy. One study, which followed a number of people for 25 years, also indicated that after that period of time, two-thirds were still ambulatory (able to walk with or without the use of walking aids). Another study from Vancouver, B.C. found that disability due to MS develops at a much slower rate than generally believed. For example, it took 28 years, following onset of MS, for 50 percent of those in the study to need a mobility aid to walk a distance of a block.

Are there different kinds of MS?

Yes. The majority of people who develop MS are initially diagnosed with relapsing-remitting MS. Let's take a closer look at the different types of MS:

Relapsing-remitting MS

Characterized by clearly defined attacks (relapses) followed by complete or partial recovery (remissions); most common form (85% at time of diagnosis).

Secondary-progressive MS

Most people with relapsing-remitting will eventually transition to a phase of the disease called secondary progressive. This phase of the disease has progressive worsening and fewer relapses, though sometimes there are occasional relapses and minor remissions and plateaus.

Primary-progressive MS

Less common (15% at time of diagnosis), people with this type of MS have a nearly continuous worsening of symptoms from the beginning usually without clear relapses or remissions. About five per cent of people diagnosed with PPMS experience occasional relapses with steadily worsening disease from the beginning.

What is an MS relapse?

Relapses 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 relapses, there are periods called remissions. During these times, the disease doesn't appear to progress. Sometimes there are years between relapses.

MS relapses can be managed. Some people feel a relapse 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.

People with MS may sometimes experience pseudo-relapses (or pseudo-exacerbations).

A pseudo-exacerbation is a temporary worsening of MS symptoms, that have occurred before. The episode usually results from a trigger such as a rise in body temperature or other stressor (e.g., infection, fatigue, constipation). A pseudo-exacerbation is not related to new inflammation or disease activity within the central nervous system.

It is important to remember that not all health problems will be caused by MS. Depression, anxiety, high blood pressure, high cholesterol, and chronic lung disease have been identified as the most common conditions that exist alongside MS (also called comorbidities).

Getting annual medical check-ups and seeking medical attention for new or persistent health issues is important to a person's overall health. Research is demonstrating that treating comorbidities may help enable people to better cope with the symptoms of MS and the side effects of treatments, as well as improve overall quality of life. Be sure to obtain medical treatment when problems arise and don't assume "it's just MS".

Why did it take so long to be diagnosed?

As yet, there is no one definitive diagnostic test for multiple sclerosis. The scattered symptoms you might have experienced over the months or years may easily have resembled other conditions, and a doctor cannot make a definite diagnosis of MS until other diseases and conditions are ruled out.

To diagnose multiple sclerosis, a neurologist will take a detailed medical history and do a neurological examination. The neurologist will test reflexes and sensations, look at eye movements, and watch a person's gait and coordination. Depending upon what is found, additional tests may be ordered. These may be done to rule out other diseases and/or confirm a diagnosis of MS.

Tests may include the following:

- ➔ Magnetic resonance imaging (MRI) to scan the central nervous system, without the use of x-rays. More sensitive than the CT scan, MRI can detect areas of demyelination that may not be seen by the CT scanner;

MULTIPLE SCLEROSIS: ITS EFFECTS ON YOU AND THOSE YOU LOVE

- Lumbar puncture or spinal tap to draw out cerebrospinal fluid. The fluid is examined for increased levels of gamma globulin and oligoclonal banding. The results may not definitively pinpoint MS, but they may help confirm the diagnosis;
- Evoked potentials (EP) to measure how quickly nerve impulses travel along the nerve fibres in various parts of the central nervous system.

Many people find the period surrounding diagnosis – and the uncertainty that can be involved – very difficult. Look to your neurologist or nurse for information, but also remember that the MS Society of Canada is here to discuss what you are experiencing and provide information, and support.

A diagnosis of multiple sclerosis can bring many different feelings. Some people may feel shock, anger, anxiety, sadness, or a combination of any or all of these emotions. Some people also experience relief in that there is finally now a diagnosis to explain the strange symptoms that had been occurring. Keep in mind that there is no one 'right' way to feel, and no one right way to cope with something as life-altering as a diagnosis of a chronic illness. Your emotions are natural and normal, and no two people's coping mechanisms are quite alike. You may wish to discuss your feelings with your doctor, family members, friends, clergy or services personnel at the Multiple Sclerosis Society of Canada. Getting your feelings and fears out into the open can sometimes help you come to terms with the diagnosis.

TREATMENTS

There are different kinds of pharmacological treatments for MS. There are medications (disease-modifying therapies) which target the disease itself, and have an effect on disease progression. There are medications to treat relapses – these medications aim to decrease the length of time and severity of the relapse. And finally, there are diverse medications which help relieve the various symptoms which can be experienced in MS. There are many other strategies that can be used in order to improve quality of life, such as appropriate exercise, physiotherapy, massage, stress-reduction techniques, and good nutrition.

Disease-modifying therapies

Disease-modifying therapies are designed to reduce the frequency and severity of clinical attacks (also called relapses or exacerbations), which are defined as the worsening of an MS symptom or symptoms, and/or the appearance of new symptoms, which lasts at least 24 hours and are separated from a previous exacerbation by at least one month. Disease-modifying therapies also reduce the accumulation of lesions (damaged or active disease areas) within the brain and spinal cord as seen on MRI (magnetic resonance imaging), and finally, they slow down the accumulation of disability.

These medications, which are generally taken on a long-term basis, are the best defense currently available to slow the natural course of MS. Decisions about taking a disease-modifying therapy are best made by carefully considering and weighing factors including individual lifestyle, disease course, known side effects, and the potential risks and benefits of the different therapies. A full discussion with a knowledgeable health care professional is the best guide for your decision. Each person's body or disease can respond to these medications in different ways.

For more information on these medications, please connect with an MS Navigator at 1-844-859-6789 or visit the web site at www.mssociety.ca and see the "Treatments" section.

Treatments for Progressive MS

While there are treatments for relapsing forms of 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. That said, there are a few disease-modifying therapies that are approved for some forms of progressive MS.

Assistance with treatment cost varies among provincial, territorial and federal drug plans and private insurance companies. Reimbursement criteria will also vary between drug plans.

Treatments for Clinically Isolated Syndrome

Several of the disease-modifying therapies are approved for those who have experienced a single event suggestive of MS (also called clinically isolated syndrome, or CIS). These individuals must have brain lesions on MRI and alternate diagnoses must have been ruled out.

Relapse management

Relapses (also called attacks, exacerbations or flare-ups) are often treated with steroid-type drugs such as prednisone or intravenous methylprednisolone to reduce the severity of an individual attack of MS and hasten recovery from it, particularly in the earlier stages of the disease. The steroids (also called corticosteroids) work by reducing the inflammation that occurs in the CNS during an MS relapse. They are of no value during the later progressive stages and may even produce harmful side effects. Long-term use should be avoided.

Symptom management

There are many different symptoms that can be experienced in MS. There are also many pharmacological treatments for MS symptoms. Other strategies may be very important here, such as physiotherapy in the case of spasticity, or energy-saving techniques in the case of fatigue. Speak with your healthcare team to see if it would be of benefit for you to see rehabilitation specialists such as physiotherapists, occupational therapists, speech and language therapists or others.

SYMPTOMS AND THEIR MANAGEMENT

How can I cope with fatigue?

Fatigue is one of the least understood and most frequent symptoms of MS. It can cause problems among co-workers, friends or family members should they 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 experience fatigue, learn your own limits and plan your days to make the best use of your energy. You should try to sleep fairly regular hours, engage in as much physical activity as you can without becoming over exhausted, and rest or nap when necessary.

Various medications are available that may help manage fatigue in MS – discuss the options with your doctor.

Fatigue can fluctuate on a day-to-day basis. You may have to explain to your family and friends how you feel. Otherwise, your behaviour may seem mysterious to them.

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 most tiring or most 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.

Is pain a symptom of MS?

Most people with MS 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.

Dysesthesia is a burning, aching, tingling discomfort which can be experienced in the limbs. It may be treated with various classes of medications including antiepileptic and anticonvulsant agents as well as low dose antidepressants.

Pain due to spasticity (stiffness) can be aided by stretching exercises or, if caused by a faulty walking pattern, an assistive device may help. If the pain cannot be managed via these means, medications may be necessary. Stiffness can be treated by anti-spasticity drugs and sometimes tranquilizers and drugs for epilepsy (which stabilize nerves) are used. More severe cases can sometimes be treated with injections of botulinum toxin which helps weaken the muscle and thereby reduce its stiffness. Reactions to medications vary greatly so your doctor may have to try different treatments before obtaining satisfactory results. Cannabis for medical purposes is also available for the treatment of MS-associated pain in adults.

Back pain is a common complaint and may be due to the strain put on the back muscles when walking with weakened and/or spastic muscles. You may also experience spasms in the legs (if spasticity is severe) which can cause periodic cramping while sitting or lying down.

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

You may find massage and an over the counter pain reliever helps relieve sore and/or tired muscles including backache before going to bed. Your doctor will advise you on the most appropriate therapy. Some symptoms such as a feeling of tightness or a "girdle sensation" may not be treatable by existing medications, but you should discuss them with your doctor.

A less commonly felt pain, 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 with carbamazepine or phenytoin, among other medications.

Remember that like everyone else, people 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.

Bladder problems and MS

It is fairly common for people who have MS to have some problems with bladder control. If you are having either frequent urination or if you have difficulty passing urine – you should see your doctor without delay. He or she may refer you to a specialist to help manage this symptom effectively.

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, burning with urination, strong odour and discolouration of the urine. Sometimes individuals will also experience 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 to help empty the bladder of any left over urine. Residual urine, or left over urine in the bladder is often the cause of infection. Talk to your doctor about these methods and which might best suit your lifestyle.

Part of the problem may be solved by timing fluid intake. When some people begin having bladder frequency or lack of control, they drink less to avoid these symptoms. 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, absorbent padding and devices for incontinence 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 vary from store to store.

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.

Is bowel function affected by multiple sclerosis?

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. Consult your doctor or physiotherapist before commencing an exercise program.

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.

Does MS affect my thinking?

Sometimes people with MS have problems with memory, concentration, problem-solving, and/or other cognitive functions. These symptoms are usually caused directly by the disease's damage to myelin and the nerve cells. However, cognitive symptoms can also be indirectly affected by depression, anxiety, stress, or fatigue. Fatigue, for instance, may make your mind feel sluggish, and stress can decrease your ability to concentrate.

Like other symptoms, cognitive symptoms vary from person to person, and can come and go. Only five to ten percent of people with MS develop cognitive problems that interfere in a significant way with day to day functioning.

Help is available for those who find that their cognitive symptoms are getting in the way. Your doctor may be able to refer you to professionals who can introduce you to strategies for dealing with cognitive dysfunction. For instance, someone who has a problem remembering things may find it useful to keep a note pad or personal device close at hand. In some cases medication may be helpful.

Can MS affect my mood?

MS can be difficult to deal with, and the circumstances that surround a diagnosis can make people feel many different emotions, such as sadness, anxiety, frustration, anger, and/or uncertainty. This is understandable: a diagnosis of MS can present some losses which you'll need to grieve. In this sense, such feelings are a part of a healthy (even if difficult) coping strategy.

However, for many people with MS, mood changes are due to more than circumstance. The disease process itself can sometimes cause changes in mood such as depression. It can be difficult to determine the root of depression, however, whether it is due to circumstance, the disease process itself, or both, it is treated in the same way. If you are feeling down, depressed, or hopeless, and have lost pleasure or interest in the things you normally enjoy, see your doctor. As well as pharmaceutical treatments there are also options such as counselling which can be very helpful. Your doctor can help you decide what might be best for you. Don't suffer in silence: help is available to you.

Occasionally, MS can cause emotional instability. The 'pseudobulbar affect' (also called pathological laughing and crying), is a condition in which people manifest emotions which may have little to do with what they're actually feeling. For instance, someone with pseudobulbar affect may find themselves laughing uncontrollably when they don't actually find something funny, or being unable to stop crying when they are not sad. There are medications which may be helpful.

Other Common Symptoms

1. **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.
2. **Speech** – MS can sometimes cause several types of changes in normal speech patterns. These can range from mild difficulties to severe problems that make it difficult to speak and be understood. Speech disorders are also called dysarthrias. Speech and language therapists can be of help. There are also assistive devices available for more severe cases of speech disorder.
3. **Spasticity** – Spasticity is a common symptom that results from MS lesions in the nerves that control movement. It may result in pain that feels like severe cramping, tightening, aching, or pulling.
4. **Vertigo** – Some people experience a dizziness or vertigo (spinning sensation). There are a number of medications which can help control this troubling symptom.

5. **Numbness** – Numbness of the face, body, or extremities (arms and legs) is one of the most common symptoms of MS, and is often the first symptom experienced by those eventually diagnosed as having MS. There are no medications to relieve numbness. Fortunately, however, most instances of numbness are not disabling, and tend to remit on their own. In very severe cases, the neurologist may prescribe a brief course of corticosteroids, which is often useful in temporarily restoring sensation.
6. **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.
7. **Sexual difficulties** – MS may affect sexual functioning in some people. It could be a temporary problem or it might require some treatment.

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. Vitamin D deficiency at some point earlier in a person's life may be a factor in having triggered the MS.

Age and gender are also factors involved in developing MS. About two-thirds of people with MS have their first symptoms between the ages of 15 and 40 and it is three times more likely to occur in women than in men.

Can my children get it?

MS is not contagious. Since several different genes play a role in creating the risk of getting the disease, that increased risk is only very rarely transmitted on to your children because it is unlikely that you would pass down all the 'risky' genes to the same child. 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 rate of MS in family members. The general population has approximately a 0.25% risk of developing MS. An immediate family member of someone with MS (e.g, a child or sibling) has a 3-5% chance of developing MS. While statistically significant, this is still a relatively low risk. An identical twin of someone with MS has a one in three chance of developing MS. The fact that both identical twins – who share identical genes – don't always get MS, and that the vast majority of people with MS don't have another family member with the disease demonstrates that while genes may play an important role, other environmental factors must be present as well.

Can anything make MS worse?

Naturally, because of the ups and downs of MS, people try to figure out what sets off a relapse. A number of possibilities have been explored, such as trauma (including surgery), stress, vaccinations and infections.

A fair amount of research has been conducted on these possible associations with relapses. The factor with the strongest association with relapses is the common viral infection. For this reason, it is prudent for people with MS to treat infections (such as bladder or chest infections) early and even better to avoid them in the first place by getting lots of rest and, if practical, avoiding other people with infections such as the cold or flu.

The association between relapses and stress is a complicated subject because stress can be both physical and psychological and just about everybody feels like they are under stress of some sort all the time. Even more confusingly, when people with MS feel 'stressed', this experience tends to amplify symptoms that already exist, which can blur the line between symptom fluctuations and true relapses. The best advice is, as far as is practical, to keep the stress level in your life under control.

Whether or not vaccinations can trigger relapses has been the subject of much discussion. In general, the value of a vaccination far exceeds the tiny risk that it will trigger a relapse.

RESEARCH

What causes multiple sclerosis?

While the cause of MS is still not known, research indicates that a combination of several factors may be involved.

1. **IMMUNOLOGIC:** It is now generally accepted that MS involves an autoimmune process – an abnormal immune response directed against the central nervous system (CNS); the brain, spinal cord and optic nerves. The exact antigen, or target that the immune cells are sensitized to attack, remains unknown. In recent years, however, researchers have been able to identify which immune cells are mounting the attack, some of the factors that cause them to attack, and some of the sites, or receptors, on the attacking cells that appear to be attracted to the myelin to begin the destructive process. The destruction of myelin – as well as damage to the nerve fibre themselves, cause the nerve impulses to be slowed or halted and produce the symptoms of MS. Researchers are looking for highly specific immune-modulating therapies to stop this abnormal immune response without harming normal immune functions.
2. **ENVIRONMENTAL:** Migration patterns and epidemiologic studies – those that take into account variations in geography, socioeconomics, genetics, and other factors – have shown that people who are born in an area of the world with a high risk of MS and then move to an area

with a lower risk before the age of 15, acquire the risk of their new home. Such data suggest that exposure to some environmental agent that occurs before puberty may predispose a person to develop MS later on.

MS is known to occur more frequently in areas that are farther from the equator. Some scientists think the reason may have something to do with vitamin D, which the human body produces naturally when the skin is exposed to sunlight. People who live closer to the equator are exposed to greater amounts of sunlight year-round. As a result, they tend to have higher levels of naturally-produced vitamin D, which is thought to have a beneficial impact on immune function and may help protect against autoimmune diseases like MS.

- 3. INFECTIOUS AGENT:** Since initial exposure to numerous viruses, bacteria and other microbes occurs during childhood, and since viruses are well recognized as causes of demyelination and inflammation, it is possible that a virus or other infectious agent is the triggering factor in MS. More than a dozen viruses and bacteria, including measles, canine distemper, human herpes virus-6, Epstein-Barr, and Chlamydia pneumonia have been or are being investigated to determine if they are involved in the development of MS, but as yet none has been definitively proven to trigger MS.

- 4. GENETIC:** While MS is not hereditary in a strict sense, having a first-degree relative such as a parent or sibling with MS increases an individual's risk of developing the disease well above the risk for the general population. There are studies that show there is a higher prevalence of certain genes in populations with higher rates of MS. Common genetic factors have also been found in some families where there is more than one person with MS. Some researchers theorize that MS develops because a person is born with a genetic predisposition to react to some environmental agent that, upon exposure, triggers an autoimmune response. Sophisticated new techniques for identifying genes may help answer questions about the role of genes in the development of MS.

What is happening in research?

MS is a complex disease, so the research that is taking place involves a number of medical and research expertise, including the study of the immune system, myelin regrowth and repair, genetics, viruses and epidemiology. Over the past 10 to 15 years, there has been a remarkable increase in scientific knowledge about MS. Every day, seven research papers are published on MS internationally – that's more than 2,000 a year.

In the 1990s, research yielded the first generation of treatments directly targeting MS. Today, people with MS can choose from a number of therapies which have been shown to reduce relapses and slow the progression of disability. Currently there are no therapies on the market that can repair damage to the nervous system or protect nerves from degeneration. There is growing interest in this area of research, and therapies resulting from this work may have significant implications for the treatment of progressive MS.

Research supported by the MS Society of Canada is focused on several major areas – both investigator driven and targeted – that focus on progression and therapies, cause and risk factors of MS, nerve damage and repair, and symptom management and quality of life. Approaches include laboratory research, clinical trials and research on aspects of healthy living. Much of MS research is so-called “basic” research, with researchers trying to understand how the complex central nervous system works and how and why parts of it stop working.

Discoveries are now moving much faster from the laboratory to the person with MS. Potential treatments are tested in clinical trials to find out if the drug or therapy is safe and effective – a complicated process in a disease like MS which has spontaneous remissions. Currently, there are hundreds of different clinical trials for MS therapies taking place around the world. New and promising areas of MS research include the search for treatments that can block attacks on the myelin and nerve fibres (neuroprotection) and the repair of myelin and nerve function (neuroregeneration).

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 (MSIF). Comprised of more than 40 national societies, the MSIF 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, often it is out of context or incomplete which has the effect of overstating its importance. The fact is that true medical 'breakthroughs' are rare, and most scientific progress occurs in small steps. If you hear or read any news about MS research, you may wish to confirm the details with an MS navigator by calling 1-844-859-6789 or emailing **msnavigators@mssociety.ca**

LIVING WITH MS

Should I have physiotherapy?

You and your doctor should decide whether physiotherapy will be of value to you. Following a relapse 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. An occupational therapist can make suggestions about ways to make it easier for you to get around and function in your home, as well as conserve energy.

Is it safe for me to exercise?

A regular exercise program or appropriate recreational activity or sport will benefit you in the long run by maintaining good physical condition. The Canadian Society for Exercise Physiology (CSEP) released the *Canadian Physical Activity Guidelines for Adults with MS* to provide the minimum frequency, intensity, duration and type of physical activity necessary for improved fitness among adults with MS.

For more information on the Guidelines please call an MS navigator at 1-844-859-6789 or visit the website at mssociety.ca/physicalactivity.

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.

Many MS Society offices have information about adapted exercise programs in your area. 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?

Visiting your doctor at regular intervals is recommended, but you and your doctor can work out how often this will be depending on how healthy you are in general. It is helpful to establish an understanding whereby you can telephone your doctor in between regular appointments for any issue or 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.

It is ideal, if you can find a doctor who is knowledgeable about MS and on whom you can rely to treat you as a whole person. Sometimes your doctor may not know everything about MS – you may at times even feel more of an expert on the disease. If that is the case, try to ensure that you have a doctor who is open to reviewing the material or information that you may bring to them.

You and your family doctor shouldn't be the only ones involved in your treatment and care. You may also 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.

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.

Managing a chronic condition is a team effort, and you are the most important member of that team.

Are there special diets for people with MS?

Although a number of special diets for MS receive attention from time to time, the Multiple Sclerosis Society of Canada does not endorse any particular diet for MS. But it makes sense that a healthy approach to eating can keep the body in the best shape possible. In practical terms, many dietitians recommend an overall diet that is high in vegetables and fruit, whole wheat grain products, low fat dairy products, lean meats, poultry and fish.

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 one exception. Researchers are 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.

Vitamin D – whether delivered through sunlight, fish such as salmon or tuna, milk, or in pill form – may play a role in reducing the risk of MS. Many doctors now suggest that people with MS themselves might benefit from taking a daily intake of 2,000-4,000 IU of vitamin D because some people may be vitamin D deficient.

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 visit Health Canada's website for a copy of *Canada's Food Guide* at **canada.ca**

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 alcohol intensifies these problems, so it may be wise to limit consumption.

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

Should I use some kind of mobility aid?

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 can be 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 cane or a wheelchair is an aid to getting around better, not a personal defeat. And if you have a relapsing form of MS, you may need the aid only temporarily, until the relapse eases.

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. Building plans for accessible housing are available from Canada Mortgage and Housing Corporation, or you may wish to consult an architect who is knowledgeable about planning for total accessibility.

There are many sources and suggestions for adapting all sorts of objects. Aids are sometimes available free-of-charge through provincial government programs. Your local chapter may also provide financial assistance or loan of necessary equipment or devices to assist with daily living.

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. Men may have difficulty in getting an erection, and women may experience difficulty in becoming aroused.

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.

It is also possible that MS will affect the parts of the nervous system involved in sexual function. Your doctor can likely verify this for you. But even if this is the case, bear in mind that it is possible that this is only a temporary problem. In addition, there are some medications that are often helpful for men with MS who have erectile dysfunction.

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.

Marriage counsellors and others specializing in relationship issues are available for consultation in your community as well.

What about contraception?

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.

It is critical that women using disease-modifying treatments or symptom medications speak with their doctor about pregnancy. In the case of disease-modifying treatments, it is recommended that women stop taking medications if they are actively trying to get pregnant. It may also be important to stop some symptom management medications prior to conception. Speak with your doctor to clarify what would be healthiest for you and your baby.

What are the effects of pregnancy on MS?

Research has been done on this topic, and in general, pregnancy is not considered to be harmful in the long run for women who have MS. There may be a slightly increased risk of relapses in the period after giving birth, however, studies have shown that most women have a decreased risk of relapses during pregnancy. Research indicates that post-pregnancy relapses do not increase long-term levels of disability. In other words, pregnancy does not have an effect on the progression of MS in the long-term.

Before making a decision, these questions should be discussed with your doctor.

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.

Can we maintain our usual lifestyle?

If you have little or no physical disability, your family lifestyle may not change at all, but some people with MS report they have to cut back some of their activities, choose ones that aren't as physically demanding and get more rest if they are going to stay out late. The adjustments you may have to make in your life may cause disruptions to your family members as well, because schedules and roles within the family may change. 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 as physically demanding, yet are fun for the rest of the family. You may become an expert at playing bridge or chess. Games like Cranium® and Scrabble® can be fun and are a good excuse for a get-together in the afternoon or evening.

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.

There's nothing wrong with planning for the best and worst case scenarios. It is perfectly reasonable to consider the impact future MS symptoms may have 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.

Occupational therapists 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 Employment and Social Development Canada career counsellors should be helpful in making you aware of options for the future.

Participating in an MS Society support or self-help group may put you in touch with people who are dealing with similar problems or who have overcome certain difficulties. The MS Society has information on remaining in the workforce and options to make it easier.

Where can I get financial help?

Financial matters may become important following a diagnosis of MS. You may want to think about your future employment goals, your present financial needs and the availability of insurance plans.

While it is not possible to predict how MS might affect you, the reality is that the majority of people with MS lead fulfilling lives and have years of productive work life ahead of them. If however, 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 Employment and Social Development Canada (ESDC). Claimants who have worked at least 600 hours in the last 52 weeks, or since their last claim, are normally eligible for a maximum of 15 weeks of sickness benefits. Contact Service Canada 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. 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 may be 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.

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 living with a physical disability are deductible from federal income taxes. Some deductions that may be claimed include: the disability 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 Revenue Agency.

EMOTIONS AND MS

My family seems over-protective.

Each person in the family will have different ways of relating and coping with a diagnosis of MS. It's important to recognize that while dealing with your own diagnosis of MS can be very difficult, it can also be hard on other family members. Their coping strategies may not always be the same as yours. Open communication and understanding can help bridge some of the misunderstandings or difficulties that may arise.

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 a level of independence and your self-esteem.

If you find this difficult to do, counselling may 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. For some people, the diagnosis of a chronic illness such as multiple sclerosis can represent a real loss in their life. You will need to take time to grieve the diagnosis and changes it has brought into your life.

However, while it is natural to be upset about your diagnosis, there is a difference between this and depression. Depression can be either caused directly by the effects of MS on the brain as well as by a person's reaction to the problems that MS causes. Either way it can be treated with counselling with or without medications.

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 may also be upset. Talking about how everyone is feeling is very important at this time.

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. Sometimes airing your concerns can make these feelings less of a burden. You may feel better having discussed what is troubling you. Those who care for you may feel better that you have taken them into your confidence, or that they know what it is concerning you and can work together with you to manage these issues.

If you are feeling particularly "down" or distressed, 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) or to have a discussion with a close friend.

The MS Society helps organize support and self-help groups for people with MS, caregivers, and others impacted by MS to meet and discuss concerns.

How and what do I tell my children?

Children can often sense when something is different at home. Because their imagination can cause them worries and fears that may be unfounded, it is very important that you address your illness with them. In general, openness and honesty are good guiding principles when speaking with your children about MS. Beyond this, what and how you tell your children might depend upon their ages, level of maturity, and individual personalities. If they are quite young, it might be best to answer questions about what is wrong with mom or dad 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 most people with MS live as long as everybody else, and that MS is not a fatal disease most of the time, their anxiety is relieved. 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.

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.

Deciding who and what to tell about your MS is a personal decision, and one that you might want to take a bit of time to think through and/or discuss with trusted people in your life. You may or may not wish to tell your employer. You are not legally required to disclose your diagnosis or discuss your medical condition with an employer – current or prospective.

There may be some reasons to consider telling your employer about your symptoms or disability such as:

- Some MS symptoms, such as blurred vision or lack of balance may be mistaken for substance problems.
- You may need additional time off for medical appointments or for recovering from a relapse. Your employer will want to know why you are absent so often.
- You may have difficulty in performing your job because of MS symptoms. In this case, it may be a good idea to explain the situation to your employer before he or she takes any disciplinary action.

If you decide to apply for employer-paid disability benefits, your employer must know about your MS.

Before you disclose any information about your MS or symptoms to your employer or colleagues:

- Know your rights concerning disclosure.
- Consider the possible consequences of making your diagnosis public.
- Learn about job accommodation – workplace changes that make it easier for you to do your job.
- Know your rights about accommodation.

Disclosure to other people in your life – friends, acquaintances, people you are dating etc, is similarly a personal decision that deserves some thought. Some people will respond with understanding, and some may provide you with much appreciated practical and emotional support. Others may not respond as well. It helps to be prepared for both possibilities.

If you decide to disclose, you can start with a simple explanation of the disease and how it is affecting you at this time. The MS Society has resources that will make this task easier.

You may or may not wish to tell casual acquaintances if it comes up in a conversation. It is a personal decision, but in many cases there is probably no reason for a formal explanation.

THE MS SOCIETY OF CANADA

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 programs and services for people with MS, their families, caregivers, and others affected by MS. The Multiple Sclerosis Society of Canada is also a funding member of the Multiple Sclerosis International Federation, whose work connects national MS societies around the world with the same goals.

The primary role of the MS Society is coordination of research, programs and services, fundraising efforts, government relations and public education. Local MS Society offices provide services to people with MS and their families, deliver community programs, provide advocacy, engage in government relations activities, and also raise 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 information on a regular basis including research updates and information on available services.

Contact your nearest MS Society office for a membership form, or visit 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?

The work of the MS Society that relates to the latter half of its mission – “enabling people affected by MS to enhance their quality of life” – is conducted by volunteers and staff in Programs & Services.

What does Programs and Services refer to?

The MS Society of Canada supports people:

- Living with a diagnosis of MS;
- Waiting for a diagnosis with respect to MS;
- Close to a person with MS, such as family and friends;
- Caregivers to a person with MS, who may also include family and friends.

The MS Society also provides information and support to health professionals, employers, institutions and students.

The MS Society offers a variety of programs and services to help people affected by multiple sclerosis effectively manage and cope with the disease. Please note that programs and services vary from province-to-province.

- ➔ Information and referral
- ➔ Support and self-help groups
- ➔ Recreation, social and wellness programs
- ➔ Conferences, workshops and education programs
- ➔ Quality of Life Grants
- ➔ Government relations and advocacy.

MS Knowledge Network

The MS Knowledge Network is the MS Society of Canada's hub of knowledge, lead by a team of MS navigators, who provide trusted, consistent, quality MS information and support. MS Navigators are available to assist anyone in Canada, from 8am to 8pm ET, Monday to Friday.

Phone: 1-844-859-6789

Email: msnavigators@mssociety.ca

Live Web Chat also available by visiting the **mssociety.ca**.

Outside of the navigator service hours, or if you prefer finding information on your own, you can use our website to find reliable information & support 24/7.

Multiple Sclerosis Society of Canada

Toll-free in Canada: 1-800-268-7582

Email: info@mssociety.ca

Website: 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.

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