



10 Tips

for People Living with MS



Multiple Sclerosis
Society of Canada





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1-800-268-7582
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Introduction

For thousands of Canadians, living with multiple sclerosis is a daily challenge of symptoms and uncertainty. How will I feel today? What will I be like tomorrow?

Until recently, little could be done to treat MS. That picture has now changed, bringing with it new hope that the disease can be controlled and, perhaps, reversed in the future.

In the meantime, there is the day-to-day. In the hope of providing some practical advice and guidance for people with MS, the Multiple Sclerosis Society of Canada, with the assistance of an unrestricted educational grant from Teva Neuroscience, organized a series of educational sessions called *Living Well with MS*. This booklet is based on the information provided by the series speakers — neurologists, psychologists, allied health professionals, the MS Society and people with MS. We hope you find it helpful in your daily life as a person, and as a person with MS.

1 Be Educated about MS

When you first hear the words, “We think you have MS,” many people run a gauntlet of emotions such as shock, anger, sadness and fear. Why me? Why now? You may have had troubling symptoms for months or years but now your fears have been confirmed. You have an illness. Your body has turned on you. You are no longer in control of your health, your future, and your life.

It is frightening to enter into the unknown. But the best weapon to ease your anxieties and regain your sense of control is education. Learn all you can about MS. The keys are information and education — two services of the MS Society. It is hoped that in arming people with the information they need, they can regain their sense of control and independence. It is the starting point for accepting the diagnosis and adjusting to a life that now includes MS.

Some of the information that you will need is practical. What are the possible symptoms I may experience? How do I manage fatigue or heat sensitivity? What resources are available to me in my community? Some information is important to your ongoing health. How do I know if I’m having a relapse? Will an infection make my symptoms worse? And some information is important so you can plan your life. Will I be able to continue working? Can I become pregnant? How will I manage parenting? Is treatment effective in controlling the disease? What new therapies are on the horizon?

There are many sources of information: your neurologist, your family doctor, MS clinic staff, the MS Society, the Internet, people you may know who are living with MS. But be aware that not all information has equal value. Be selective. There are many false cures and unfounded claims.

The most valid information about treatments comes from randomized, placebo-controlled trials, which compare the therapy to no therapy. Open-label studies* are also important because they are performed by leading physicians in reputable MS centres. Such studies can help to answer many important questions about a medication — does it seem to be effective after many years of use? Is it safe? Will it continue to keep me from having relapses? Some studies are also important because they compare treatments. This is useful because it gives some idea of which medication is more effective, which has side effects that may lead you to stop taking the therapy, and which treatment may be the better choice for you.

As a general rule, the best placebo-controlled and open-label studies are published in medical journals or are reported at medical conferences. Ask your doctor or the MS Society about new research and what it means to your specific circumstances. This information will be vital if you must decide on which therapy is right for you.

Good information is the key. With it in hand, you can start to make the best possible decisions about your life and your future.

** An open-label study is a type of scientific trial in which all people receive the medication being studied. It does not compare the efficacy of the medication with placebo (no treatment). Open-label studies may be extensions of placebo-controlled studies, enabling people who have responded to the medication to continue on therapy, and people in the placebo group to switch over to active treatment. Or they may simply compare patients on one therapy with those in another.*

2 Listen to Your Body

When you have relapsing-remitting MS, the symptoms you experience will come and go. You will have good days and bad days. Days when you are feeling especially fatigued, or the tingling and numbness are worse.

Your body is trying to tell you something: listen. If you are feeling tired, take it more slowly and rest periodically. You will still get the job done — it just may take a little longer. If the heat is bothering you, cool down. Find a shady spot or an air-conditioned place. Have a cold drink. Take a cool bath. If you feel tired while exercising, don't overexert yourself.

Try to achieve some balance in your life. Learn to pace yourself. Get the rest your body needs when it needs it.

Rediscover what makes you happy — and do it.

3 You are the Same Person as You Were Before MS

When you have a chronic illness, you can fall into the idea that you are your illness. A diagnosis can feel like a label: You are that person with MS. You can start thinking of yourself as different somehow. Even on good days, there may be symptoms to remind you that MS is still there in the background. You worry that people look at you differently now.

There may be days when your symptoms limit your activities, or you find there are some things you can just no longer do. But often we define ourselves by how we feel and what we do. So who am I now that I have MS?

The answer is surprisingly simple: You are the same person as you were before. You have an illness — the illness doesn't have you.

Your life may be different now, but it isn't less than it was. Before your diagnosis, your life was rich and complex — filled with people and plans and hopes for the future. It still is. It is true that you have been forced to confront the uncertainty of life, but the future is no more certain for someone without MS. No one knows what lies ahead.

The process of life is one of redefinition. As we get older, we discard some roles and take up new ones. We are not children or students, we are spouses and parents and grandparents. And what it means to fulfill each of these roles also changes. Perhaps you see the role of a parent as one of rushing your children from a soccer match to a swimming meet, but now you can't do that anymore because you are too fatigued. Does that mean you are a failure as a parent? Or does it mean that it's time to redefine what a good parent is? Is there someone else who can take the kids to soccer and help share the load? And aren't there other things that children need from their parents? Talk to your children. Find out what they truly need from you.

A painter who loses his sight may become a sculptor. Learn to cope with the curveballs that life throws. Change what you can. Accept what you must. Live your life as richly as you did before.

4 Stay Healthy

When MS is uppermost in your mind, it is easy to forget about the rest of your health. But having an illness doesn't prevent you from getting another illness. Like people who don't have MS, you still have to guard against heart disease, diabetes and all the other health concerns.

Stop smoking. Eat sensibly. Try to exercise regularly at a pace and level of exertion that you can manage. Exercise will help you maintain an ideal body weight, alleviate stress, maintain cardiovascular fitness and lower cholesterol. For people with MS, keeping your muscles in tone will also help to maintain your strength and balance.

See your family doctor for an annual physical exam. Practice preventive medicine: get a Pap smear, do breast self-examination, have a prostate exam, have your cholesterol and blood sugar checked, etc. Do all the things that other people do to maintain their health.

Some health conditions, such as infections, will actually make your MS symptoms worse. So if you get an infection, make sure you treat it promptly.

Keeping healthy is an important goal, but it's especially important for people with MS. Staying fit and healthy will help your body and your mood in your day-to-day struggle with MS.

5 Manage Your Mood

It isn't uncommon for people with MS to develop clinical depression. Clinical depression is different from "feeling down" or "having the blues". Depression is an illness that can appear as depressed mood, irritability, loss of appetite, poor sleep, inability to concentrate, or a lack of enjoyment in doing the things you previously liked to do.

Don't ignore depression. It is more than just a passing mood that will get better on its own. Often it doesn't and the symptoms may get worse with time. A depressive episode can last for weeks or months, draining your energy and corroding your relationships and quality of life.

No one knows why people with MS are more prone to depression. It may be due to life changes that come with MS, or actual changes in the brain caused by MS lesions. Some medications used to treat the symptoms of MS may also be associated with depression. So you should talk to your doctor about this issue when you are choosing the right treatment for you.

If you are feeling especially down and think you've got depression — see your doctor. Depression can usually be treated effectively with medications or therapy. Medications (one or more pills taken daily) can relieve the anxiety and depressed feelings you have, restore your normal sleep and eating patterns, and help you to feel like your old self again. Therapy can help you identify your stresses and problems that may be affecting your emotions, and can help you develop a new perspective on your life.

Depression is an illness that requires treatment. Don't suffer in silence. Get the treatment you need.

6 Involve Your Whole Family

You are the person with MS. But MS affects your whole family. Talk to them. Involve them in the decisions that have to be made. Ask for their help.

Share some of your responsibilities. If you are too tired or physically unable to do all the things you used to do, divide up the chores and let them do their part. As your role changes, theirs will too — and everyone can grow in the process. Change does not have to be a bad thing.

Communication is the key — with your spouse and your children. Kids need to know what's going on in your life so you will need to educate them about the symptoms you may get and how they may affect the family.

What you tell your children will depend on their age. Younger children (ages 3-6) need to understand that you haven't gotten MS because they've done something bad. Reassure them that they've done nothing wrong. Older children (ages 6-12) understand that MS is an illness, that you will have symptoms, and what you need to do during those times to make the symptoms better. Ask them how your MS makes them feel. Give them the comfort, reassurance and support they need.

Adolescents need to exercise their independence but may feel angry because they have to do extra chores, or because they feel different from their friends because they have a parent with MS. Try to explain why their help is so important to you and the family. Allow them enough time for themselves and encourage them to become fully involved in their own lives with sports or social activities.

Involving your family in MS can truly be a growth experience. Family members can mature and assume new roles, develop better empathy and understanding, and gain newfound respect for you in your struggle with the illness. For your whole family, talking about MS and living with the illness is an ongoing process as they — and you — learn to cope better with your condition.

7 Develop a Support Network

People with MS need to access a variety of medical services to help them manage their disease. A family doctor, neurologist, nurses, MS clinic staff and the MS Society are all invaluable sources of care and support for the newly diagnosed.

In the longer term, however, it is usually necessary to expand and broaden this network as your needs and circumstances change. Perhaps you need to hire someone to clean the house. Maybe you can no longer drive. Or you'd benefit from psychological counselling.

This point — when you need to ask for help — can be a difficult time. It may be demoralizing as you recognize that you can no longer “do it alone” or with the help of your immediate family. And it may take some effort to rethink things and see how you can enlist the support of others to share the load.

What you need is to make a conscious choice of how you are going to continue living day-to-day with MS. It is important to realize that you are not alone. There is a support network out there that is ready to assist you.

There are many resources and services available to people with MS. Talk to the MS Society, MS clinic staff and people in your community. Find out what is available. Depending on your circumstances, you may want to source out:

- Homemaker support
- Mental health services
- Dietitians
- Occupational therapists
- Physiotherapists or physiatrists
- Other health professionals (e.g. massage therapist, acupuncturist, etc.)
- Social organizations
- Church or community groups
- Government services and programs.

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Ask about social and recreational services, such as adapted exercise programs (e.g. Tai Chi, Yoga, Pilates) or adapted swimming programs.

During the course of your illness, it is important to develop ties that will give you social and recreational outlets so you don't have to rely exclusively on family members and friends. Your network of new contacts will help you with coping, provide you with the support you need, and help you develop new interests and activities so you can continue participating fully in your life.

8 Plan for the Future

Having MS does not mean you have to abandon your dreams and goals. Many, if not most, of your goals can still be achieved. But it may take a little time and a little planning.

Decide what are your priorities. What is most important to you? Then work out some strategies that will get you there. If your path seems blocked, don't give up. Try to think of a new way to reach your goal.

It is difficult facing an unknown future. But the future is unknown to all of us. You don't know how your disease course will progress — if you will have frequent symptoms, how limiting they will be, if they will lead to disability. So figure out what you want to achieve with your life, then take active steps to make it happen.

Go after what is most important to you. There are greater tragedies than MS — like giving up on the future or looking back with regret at a dream you abandoned.

9 Stay Positive and Take Control

You have been hit with devastating news: you have MS. Now what? You have to go on. You still have a life. It may not be exactly the way you imagined. But there are still lessons to be learned and experiences to be lived that may be far richer and rewarding than you could have foreseen.

What can you achieve today? What is important to you? Each day is a gift that shouldn't be taken for granted.

Stay positive. Find the humour in situations. Try to have a good laugh every day. Spend more time with people who make you happy.

Learn to accept your limitations, but revel in your accomplishments.

10 Stand Up for Yourself

There are many people and resources you can call on to get the help you need. Unfortunately, finding out what is available can be a difficult and time-consuming process. What services are in your area? What government funding is there? What is reimbursed by provincial health plans or insurers?

For this kind of information, there is no one source to turn to. You may want to begin with a call to the MS Society, which can then direct you to other resources such as an MS clinic, government offices, an MS Society support group, or resources on the Internet. But to be completely successful you have to be a detective, pulling scraps of information together to complete the picture.

Don't get discouraged. Stand up for yourself. Go on the offensive and get the information you need about the benefits to which you are entitled.

This can be difficult — calling different places, asking people about things you know nothing about. Finding out your eligibility for certain benefits based on your financial or disability status. There may be questionnaires to fill out, letters to write, people to track down.

But persistence pays off. Stay with it. Ask questions. Make the calls. If you don't get the information you need, call again. Be your own ombudsman. Keep pressing for answers until you get the answers you need.

There may be days when you feel lost in the labyrinth of hospitals, social agencies, insurance companies, and government offices. But stay focused and you will get through it — a better informed, entitled and stronger individual. Despite MS, and because of it.

