Caring and sharing spouses and partners
For the Spouses and Partners of People with Multiple Sclerosis.
More detailed information about multiple sclerosis and its symptoms can be obtained free of charge by contacting the Multiple Sclerosis Society of Canada (see contact information at the end of this booklet) or by visiting the Society’s Web site at

www.mssociety.ca/qc

“There are three unknowns when the diagnosis is given: the disease, your partner’s reaction and your own reactions. Information throws light on these three unknowns, these three dark areas.”

John
Symptoms

Multiple sclerosis (MS) is an unpredictable disease of the central nervous system (spinal cord, brain and cerebellum). The number and severity of symptoms vary considerably from one person to the next and over time for the same person. They may include extreme fatigue, vision loss, disturbed sensation, motor problems, loss of balance, poor coordination, bowel and bladder problems and sometimes, although more rarely, partial or total paralysis. *Every case is unique, so people with MS should avoid comparing symptoms.*

Who Gets Multiple Sclerosis?

This disorder generally occurs in adults between the ages of 20 and 40, but the first symptoms can appear between the ages of 15 and 20. Twice as many women as men have multiple sclerosis.

Although multiple sclerosis is not hereditary, some people are genetically predisposed to it. Research has shown that children who have a parent with multiple sclerosis have a 3% to 4% risk of developing the disorder themselves. To be considered a hereditary disorder, the risk of transmission would have to be between 25% and 50%.

According to the most recent theories, multiple sclerosis may be caused by a combination of genetic and environmental factors – possibly exposure to a common virus – that trigger an autoimmune reaction in a predisposed person, causing the person’s body to mistakenly attack its own cells.

Multiple Sclerosis in Canada

Canada has one of the highest rates of multiple sclerosis in the world. Other high-prevalence areas are the northern United States, central and northern Europe, southern Australia and New Zealand.

An estimated 50,000 Canadians have MS, including about 12,000 people in Quebec.

On the Right Track...

It is important to note that medical research has been making great strides. Scarcely ten years ago, there was no treatment for multiple sclerosis available on the market.

Today, there are treatments that slow the progression of the disease and reduce the number, duration and severity of attacks. Research has shown that these treatments reduce the number of MS attacks and the number of lesions detected by magnetic resonance imaging. Other treatments are currently being developed.

Canadian researchers, many in Quebec, are known worldwide for their expertise and work in this area, as well as for their dedication and commitment to finding a cure for MS.

The mission of the Multiple Sclerosis Society of Canada is to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

Courses

The most common courses, or forms, of multiple sclerosis are: relapsing-remitting, primary-progressive, secondary-progressive and progressive-relapsing.

Relapsing-Remitting MS

This cyclical form of MS is the most common. It is characterized by attacks (also called exacerbations, relapses, or flare-ups) of varying duration, followed by recovery periods, also of varying duration. This form also includes the so-called “benign” type of multiple sclerosis.

Primary-Progressive MS

The disease progresses from onset with no plateaus or recovery periods or with a few plateaus and only temporary, minor improvements. Progression may be slow or fast, and may take many years.

Secondary-Progressive MS

This is a variant of the relapsing-remitting course. After some years, the disease becomes progressive with few exacerbations or remissions.

Progressive-Relapsing MS

In this course, the disease progresses from onset and is punctuated by obvious acute attacks. This form of MS is relatively rare.
This publication by the Multiple Sclerosis Society of Canada (Quebec Division) is designed to answer the questions that the partners of people with multiple sclerosis ask and to show them that they and their loved ones can still lead full, happy, very satisfying lives.

Not only does it provide information about the effects of this often misunderstood disease, it also suggests possibilities, ideas and solutions that can help people cope with their new reality.

This booklet is based on the stories of many couples where one partner has MS, who one day saw their lives hurtling off into the unknown...

“I see two priorities: the first is to learn to deal with it instead of accepting it. It’s more positive and more active. The second is not to see your partner as a person who is ill, but as a person. That’s all.”

Aline

Shock Wave

After weeks of doctor’s appointments and medical tests, the diagnosis fell like a bombshell: multiple sclerosis. “She’s only 30!” Oliver kept saying. “We just bought a house... We were talking about maybe starting a family...”

It’s true that for several months, Sandra had been complaining of intense fatigue, difficulty concentrating, occasional numbness in her limbs that lasted several days. Of course, life had been moving at a frantic pace for the past year: the wedding, the house, Sandra’s promotion to communications manager for a major information technology company, the death of Oliver’s father. They had come through everything with the sense of partnership that had always united them and a great deal of love. But illness? Sandra confused, always tired, maybe even paralysed! She who so enjoyed being active!

Oliver was outraged. He felt overwhelmed, betrayed by life and powerless to do anything. He loved Sandra very much and wanted to help her through this, but how? Would he have the strength and energy he needed? And what would happen to their relationship? What could they expect and where would they find the resources that they would both need to deal with a situation that could develop totally unpredictably, as the doctors said?

Sandra stroked her husband’s face and smiled bravely. “At least we know who the enemy is,” she said. “I know we can get through this together, Oliver, if that’s what you want too. But I think we’ll have a lot to talk about. You’ll love that: you enjoy these relationship discussions so much!” Oliver smiled. “It won’t be our first all-nighter, honey!”

Sandra and Oliver are very much aware that their lives have taken a new turn and that they will have to live one day at a time, with patience, empathy, laughter and love. Sadness as well and, sometimes, despair.

Patience
Empathy
Laughter
Love
A COLOSSAL CHALLENGE

Partnering with someone who has a progressive, unpredictable disease like multiple sclerosis can trigger a flood of painful feelings: anxiety, powerlessness, shame, despair, anger, fear, loneliness, guilt. All these get mixed up together and can quickly turn into distress.

More than the disease itself, your worst enemy is silence. Many misunderstandings are due to the fact that people often think silence will protect them and their partner with multiple sclerosis. On the contrary, silence can easily lead to isolation.

You and your newly diagnosed partner will have to work against this dangerous trap: it is to be avoided at all costs. The opposite of silence is communication. This involves acknowledging the negative feelings that you sometimes have: distress, anger, fear for the present and the future.

Obviously, multiple sclerosis will upset your personal life, your relationship, your professional life and your habits. You will have to face major challenges, profound grief, and constant adaptations to new and unpredictable situations.

People with multiple sclerosis do not always experience it the same way or to the same extent. They do not necessarily become disabled and can continue to function normally for a very long time. Even those with functional limitations can continue to live at home. A number of solutions are available for coping with the various problems that may arise, as you will see in the following pages.

In your relationship, this insidious disease represents a challenge for both of you. It will require both of you to be extraordinarily flexible – but isn’t that part of living together for any couple? You will have to recognize, however, that multiple sclerosis generally requires even faster and more in-depth adaptation and changes.

Many couples manage to overcome the obstacles, avoid coming to grief on the reefs, get around difficulties, and keep their love alive. Despite the fact that one of them has a disease, they contrive to live quite contentedly, in harmony and partnership, in the face of the struggle that they are waging together.

“MS didn’t change my love for her at all. I even love her more now because I admire her. A lot of people would let themselves be overwhelmed by the disease. Not her! She is the most positive girl I know.”

Marc-André
Learning that you have multiple sclerosis is not like learning that you have an expiry date! This is when we started to get actively involved. We received a lot of information and went looking for more ourselves.

Martin

We help each other when we learn.

David

The Three Keys

Everyone we talked to while preparing this booklet mentioned three key factors that can help partners understand what is happening to them and to the person they love, so that they can live together better, despite everything.

These keys, which have no claim to be absolutes, are: information, involvement, and respect.

To begin with, it is imperative that you obtain as much information as possible about what your partner with multiple sclerosis is experiencing. This will help you understand the disease, its symptoms and its impact. This is the first thing you need to do in order to deal with the disabilities that may eventually befall your partner.

In the same vein, it is very helpful if you get involved in all the procedures that support a person with MS. This can be done in various ways, such as participating in self-help groups and accompanying your partner on visits to the doctor. On the home front, you will need to work together to rethink who does what.

Despite your deep desire to devote yourself to supporting your partner with multiple sclerosis, you must, more than ever, learn to respect yourself. You will be far more effective if you are able to preserve your health and conserve your energy. To do this, you must learn to recognize your limits, both psychological and physical. Do not try to do everything yourself or to do too much.

Also, both partners need to continue to have their own interests, activities, goals, roles and dreams...

Avoid These Traps!

Our partner with multiple sclerosis will need your help and support.

This disease mainly attacks women. So the partners who are called upon to provide support are mostly men.

Some studies have shown that men have more difficulty discussing their problems and expressing their emotions freely than women do. They often hesitate to ask for help and fail to use the available resources. However, men generally manage to participate more in social and recreational activities, which certainly contributes to their overall well-being and their ability to deal with this type of context.

In the same situation, women are better at expressing their feelings and taking advantage of support systems. But they tend to neglect their own health, which can lead to physical or psychological problems.

Man or woman, the well partner has to develop his or her own strategies and express his or her own desires.

The three keys, founded on the wealth of experience of those who have already been through it all, are starting points. Use them to unlock the secrets of coping with MS and make both your lives the best they can be.
Ilness generates a sort of interdependence for everyone: the person with MS, their partner, children, parents… Everyone suffers when they see suffering and don’t know what to do.

The first solution is to learn or relearn to talk to one another. In a word, communicate! Isn’t this the cornerstone of any successful relationship, one that is healthy, balanced, and happy?

Open, direct, honest communication will make it easier to redefine the relationship as necessary, while respecting personal activity levels and the dignity of the person with MS. All relationships involve constant adaptation to the many changes inherent in living together. Multiple sclerosis imposes changes on a relationship that are new and totally unpredictable. Both partners have to adapt to this reality.

Some men whose wives have MS confide that they no longer recognize their spouses, themselves, or their relationship. Multiple sclerosis has upset the whole applecart, almost overnight, without warning. Note that multiple sclerosis is never the sole cause of all of a couple’s problems. But it can accentuate them.

As we will see later, an impressive number of couples have found effective, original ways to “live with” multiple sclerosis. One way or another, life goes on…

These couples, from the start, have made communication their best weapon against the disease. They show, with enthusiasm and sometimes real ingenuity, the importance of living in the present to the fullest, of living day by day, and focusing on what they can do, even if it has to be done differently, rather than what they can no longer do.

The unpredictable nature of multiple sclerosis certainly creates a lot of stress, but it can be managed on a daily basis, for instance, by redistributing the workload. This may include domestic chores like housework, errands, cooking, laundry and child care.

Similarly, a couple should look at routine activities such as work, recreation, outings, hobbies and intimacy. One way or another, they also need to be prepared to review task allocation as needs and circumstances change. This, in itself, constitutes another challenge for the relationship. Long-term financial planning for the family is also recommended: it can help people feel more secure, regardless of what the future holds in store.

Any couple dealing with an illness of one of the partners needs to be able to communicate, adapt and live in the present moment.

Our values as a couple have changed.
We rethought our priorities because of the disease.
Our quality of life has changed, but I think it’s a good thing.
We may be less materialistic and more attentive to what is around us. We have time.
Louise always says that now, we take the time to watch time go by.
Before, we didn’t see it.

Self-confidence is fundamental.
Both partners have to take charge of their lives.

Renew Your Relationship

Communicate
Redefine
he presence of a disease like multiple sclerosis can have an impact on sexuality.

Studies show that at least 80% of women with MS report problems or changes in their sex lives. The specific causes mentioned are fatigue, decreased desire, painful genital sensations, insufficient vaginal lubrication, and the absence of orgasms.

In men, over half have erectile difficulties, decreased genital sensation, fatigue, ejaculation problems and reduced libido or sex drive.

The ways in which multiple sclerosis can affect sexuality have been divided into three types of dysfunctions. **Primary sexual effects** are directly related to the neurological changes caused by the disease. In both women and men, these may include a reduction or loss of libido, decreased genital sensation, and inability to reach orgasm.

**Secondary sexual effects** result from multiple sclerosis symptoms that are not sexual in nature but may affect sexuality. These include bowel or bladder problems, fatigue, spasms, decreased muscle tone, tremors in the hands or body, and difficulty concentrating.

**Tertiary sexual effects** are related to the psychological impact of the disease on intimacy and sexual desire. Changes in self-esteem or body image, demoralization, depression, or mood swings can all inhibit sexuality. Furthermore, role changes, changes in professional status or lifestyle may, sometimes temporarily or to a greater or lesser extent, hamper sexual relations.

There are drugs and treatments that can help people deal with sexual problems. Don’t hesitate to discuss this issue with your medical advisors and consult a psychologist or sex therapist if need be.

Recommended reading: the booklet titled “Sexuality and MS,” by Michael Barrett, Ph.D., published by the Multiple Sclerosis Society of Canada.

Sex is only one form of intimacy. Love is also expressed with cuddling, caressing and touching.

Open communication with a lover, communication that is effective and intimate, is absolutely the best way to deal with the problems in a sexual relationship that are caused by multiple sclerosis. Explore new ways of doing things, be creative, express what you feel and what you would like, redefine your sexuality: your sex life will be more pleasurable despite the disease.
Multiple sclerosis is difficult to diagnose right away. This disease, which can be thought of as a sort of imbalance of the immune system, takes various forms. The severity and progression of MS vary from one person to the next, as do the related symptoms.

However, right from the onset, people with MS struggle with invisible symptoms on a daily basis. These can be a major source of frustration for both the person with MS and their partner. Inevitably, it is a major challenge for both partners to understand that the symptoms, although invisible, are real.

Extreme fatigue is a major symptom of this disease. Fatigue is observed in the great majority of cases and is thought to be caused by disrupted nervous function. It is important to understand that fatigue caused by multiple sclerosis requires a longer period of rest than ordinary fatigue. MS-related fatigue is also different from fatigue due to hard work, depression, tension, or lack of muscle tone, or nervous fatigue due to effort, heat, hot water, or fever.

To this is added a reduction or loss of sensation in the limbs, numbness, cognitive problems such as memory loss and difficulty concentrating, as well as pain. There are treatments that alleviate some of the invisible symptoms of multiple sclerosis.

The fatigue induced by this disease is insidious, especially before the diagnosis is confirmed. Some spouses doubt their partners’ claims that they are tired. Until the illness is recognized and understood, the partner, family, friends and employer may believe that the person with multiple sclerosis actually has psychological problems.

Partners need to know the facts, recognize the invisible enemy and begin the adjustment process right away. This process, of course, is an ongoing one. It begins with the diagnosis and continues throughout the progression of the disease.

Recommended reading: the booklet called “Coping with Fatigue in MS Takes Understanding and Planning,” by Alexander Burnfield, MB, BS, FRC Psych., DPM, produced by the Multiple Sclerosis Society of Canada.

“At some point, reality sinks in.
You have to face up to the situation. The more you bury your head in the sand, the harder it gets. I say that the sooner you face up to reality, the sooner you can find ways to function differently, function better, and adapt.
Also, you mustn’t be afraid to talk.
Time spent talking isn’t a waste, it’s an investment.”

Dennis
It’s a tall order. As the partner or spouse of a person with multiple sclerosis, you need a number of exemplary qualities. At the top of the list is patience. You will also need empathy, vitality, joie de vivre, a sense of humour, optimism, respect, perseverance, tact, and understanding.

This list is certainly not exhaustive and may seem needless or unrealistic. However, the stories told by many partners show which qualities helped them personally. These are things that you would do well to think about from time to time.

With communication and the will to live each day to the fullest, these attributes will enable you to deal more easily with the challenges that confront you.

*Why doesn’t anyone ask how I am?* Partners are justified in asking this question. Their work is not particularly visible, nor is it recognized. Attention is focused on the person with the disease, very little on the healthy caregiver. That can be frustrating for a partner.

Don’t be afraid to acknowledge and express your emotions. Above all, you shouldn’t feel guilty about them. Guilt can become your worst enemy. You are not guilty because you are healthy, because you think of yourself, or are worried or angry, nor are you guilty or a victim of a situation that you cannot control.

Unfortunately, there are no miracle solutions to help you negotiate all these changes in your life. But, again, remember the importance of communication and living one day at a time.

The people who have been through this emphasize the importance of talking to specialists, asking for help, and never hesitating to accept a helping hand. For example, why not inquire at your local CLSC clinic about available services that could help you, even temporarily, if your partner has an attack (help with housekeeping, meal preparation, etc.)?

Also, there are self-help groups in some parts of Quebec for the partners of people with MS. Their goal is to encourage people living in similar situations to share their experiences. Many people have obtained useful advice from their groups that has helped them deal with the challenges inherent in their partner’s MS. Contact your chapter of the Multiple Sclerosis Society of Canada for information about self-help groups for partners near you.

---

**Partner Profile**

*Of course she has to respect her limitations and I have to accept mine. A sense of humour takes the drama out of many situations and makes things go more smoothly.*

*Philippe*

*What I hate is pity. It certainly wouldn’t work if I felt sorry for her. What I feel for Marie-Claude is empathy. I want to help her. I’ll be with her 100% and I’ll respect her decisions.*

*Chris*

*People who come to the house always ask about my husband, never about me.*

*Brigitte*
You and Your Work
Insofar as possible, it is important to let your employer and your co-workers know that your partner has multiple sclerosis. This way, it will be easier for you to get permission to be away from work from time to time to accompany your partner on visits to the doctor, change your working hours, or sometimes work from home. Clear, specific agreements on these issues with your employer will spare you a lot of additional stress.

You and Your Free Time
You must take time out regularly for recreation and relaxation. If necessary, schedule such moments in advance on a regular basis. This will enable you to find someone to fill in for you at home while you are out. Never feel guilty about having your own activities and sticking with them. Remember that your emotional and physical health are necessary for you to stay the course.

“...It was important for me to get involved in things other than multiple sclerosis. I have a number of activities. You have to reinvent yourself, consider your own needs. You have to give yourself the means and the time to do what you like too.”

Albert

“...My friends, his friends, everybody knows he has multiple sclerosis. Nobody has any problems with it. And if they did, that would be their problem, not ours.”

Isabelle
You and Your Friends

Your friends are important. Maintain and expand your social network. Go out with your friends as usual. If need be, accept their help and support. Friends often hesitate to offer a helping hand because they do not want to intrude, especially if things appear to be going well. Let them know that their help is appreciated.

You and Your Children

Talking openly about multiple sclerosis with your children will help reduce their anxiety over their parent’s disease and enhance their feeling of security and their well-being. While it is positive for children to share certain household chores and responsibilities, their needs must be carefully balanced with the amount of help and caregiving that is expected of them. Teenagers are able to handle more responsibility. But remember that they need to spend a lot of time with their peers. Young adults have their own lives to live.

Recommended reading: The guide called “How to Talk about MS with Your Children,” published by the Multiple Sclerosis Society of Canada.

You and Your Families

Members of one or both families can easily be part of your primary self-help network. Make a list of the services they can render. Invite them to perform specific, time-limited tasks, such as asking a relative to spend three hours at your home on Saturday afternoon so that you can have time for your favourite hobbies or run errands.

This kind of self-help network may not be necessary for everyone. One way or another, these are arrangements that should first be discussed and agreed upon by you and your partner.

“I’ve learned to appreciate the little things, live more day to day, make fewer big plans for the future. But I make better use of the present and appreciate what life offers every day. You have to look at what you have, not what you could have or can’t have. Once you’ve understood that principle, everything is so much easier. And it’s more fun too.”

Nick

“Listening, observing, choosing the best time to say things – that is so important. Tact takes talent.”

Monique
<table>
<thead>
<tr>
<th>Resource</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologist</td>
<td></td>
</tr>
<tr>
<td>MS Clinic</td>
<td></td>
</tr>
<tr>
<td>Family Physician</td>
<td></td>
</tr>
<tr>
<td>CLSC</td>
<td></td>
</tr>
<tr>
<td>Rehabilitation Centre</td>
<td></td>
</tr>
<tr>
<td>Ordre des psychologues du Québec</td>
<td><strong>1 800 363-2644</strong></td>
</tr>
<tr>
<td>Chapter of the Multiple Sclerosis Society of Canada</td>
<td></td>
</tr>
<tr>
<td>Multiple Sclerosis Society of Canada</td>
<td><strong>1 800 268-7582</strong></td>
</tr>
<tr>
<td>Other Important Telephone Numbers</td>
<td></td>
</tr>
</tbody>
</table>
We developed some techniques for our daily routine. We also learned not to be afraid to say when something is wrong. You need to be proactive. But to get through it, you have to talk to each other and not be afraid of making the other person angry or hurting them. The disease is there, you have to be aware of it. And if you can’t do something today, you’ll do it tomorrow. That’s all.

Maria

You have to try not to suffer from the disease but to adapt to it. When you take this approach, there are no problems. I think that we have found the right approach for us. We don’t lie to ourselves and we don’t have any illusions.

Francine

Last weekend, we did a lot of yard work. We planted flowers, mowed the lawn and picked up things that were lying about. She filled the bird feeders. I watched her and saw that she was happy. And I was so happy to see her happy. That was worth millions.

Paul

Your partner will understand better what the disease involves if he is part of the process from the beginning.

Mona

With multiple sclerosis, we’ve gotten really good at adapting, because things are always changing.

Patrick
We wish to thank all those who so generously participated in the individual meetings and group discussions and provided the comments used to develop the content for this booklet.

Please let us know what you think about this booklet. Was it useful? Please e-mail or write the MS Society at the following address:

Note: The masculine gender has sometimes been used simply to make the text more readable.

ISBN 2-921910-04-7

Multiple Sclerosis Society of Canada (Quebec Division) 2002
Registration – 2nd quarter 2002
Bibliothèque national du Québec
National Library of Canada

© Multiple Sclerosis Society of Canada (Quebec Division) 2002
Imagine that someone takes the bus every morning to go to work. For years, the bus stop has been right in front of the house. One day the bus company decides to move the bus stop three streets away. There is still a bus stop, but the person now has to walk three blocks to get there. So the person has to do a bit more to take the bus. I think that the way life changes with an illness is like that. It takes a bit more effort to achieve the same results as before. That’s just the way it is.

Louis

Life Goes On!