

# Some guidelines on **saving energy**

For people with multiple sclerosis





# Introduction

Nowadays, there are two sentences we hear all the time: “I’m so tired!” and “I have no time!” The challenge of managing one’s everyday activities is so common that every year dozens of magazines present their September back-to-school specials with articles like “100 tips for planning your day” and “25 recipes for busy cooks.” In reality, what these magazines are suggesting is that we learn to manage our energy, because it’s a finite resource for all of us.

For people with multiple sclerosis (MS), it is even more important to learn how to save energy and handle fatigue as well as possible. After all, fatigue is one of the most common symptoms of this disease, and it has negative repercussions on the daily life of many people with MS. That’s why it’s essential for these people to adopt effective energy-saving strategies.

The goal of this brochure is to offer you methods and tools that will enable you to save time and energy. In addition, we encourage you to share them with all the “tired” people you know, whether or not they have MS.

We all know how hard it can be to change a routine. We’re ready to change our house, our job and even our spouse, but we find it difficult to throw out a ratty old pair of slippers! To succeed in acquiring new habits, we first have to adopt an open attitude towards change: this is easier if we believe that we will benefit from changing how we do things. On the other hand, if we’re unreceptive and refuse to change, that makes our task even more difficult.



To acquire new habits, set realistic goals for yourself and take the time to integrate them well. If they improve your everyday life, you’ll be motivated to continue.

And now, it’s up to you!

## Part 1

# Suggestions for simplifying your life and saving energy

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## 1 Set your priorities

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What could be more natural than having to make decisions in life? Never hesitate to review your priorities in light of your current situation.

First make a list of all your activities (everyday activities, housework, job, leisure and rehabilitation) and rank them in order of importance, asking yourself the following questions:

- What do I enjoy doing and what's important to me?
- What absolutely has to be done today, or this week?
- How often do these tasks have to be done?
- Do I have to do everything myself?
- Are my expectations of myself realistic?
- What do the people around me expect of me?
- Are their expectations the same as my own?

Then choose the activities that you would like to continue doing yourself. We will see later that there may be more energy-efficient ways to do them.

If you think that everything is top-priority and nothing can be changed, think about your resistance to change and ask someone you trust for their opinion. This should help you.



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## 2 Know how to share – delegate tasks!

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Identify the tasks that you could delegate and that other people could do, without anyone being worse off. Tell yourself that learning to delegate can be a real step towards wisdom. If you have children, it's natural for them to get involved with household tasks, depending on their age, since that represents an opportunity for them to learn all kinds of things.

You can also make use of various services:

- Bank transactions and a lot of shopping can easily be done by phone or on the Internet. Check catalogues as well: the number and variety of things you can order by mail never ceases to grow. See for yourself!
- Many businesses, such as grocery stores, drugstores and dry cleaners, offer home delivery. Use it!

Being independent doesn't mean doing everything yourself; it also means knowing how to get help.

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### 3 Simplify and eliminate tasks

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Here are a few questions that should help your reflection process:

- Could certain tasks be eliminated altogether? For example, you'll have considerably less ironing to do if you take the clothes out of the dryer as soon as the cycle ends and hang them up right away.
- Could the frequency of certain activities, such as dusting, vacuuming or grocery shopping, be reduced?
- Could other tasks be simplified or done differently? For example, you could choose recipes that don't take much time but are still delicious, or leave the dishes to drip dry instead of drying them.

Simplifying tasks also means...

- Thinking about what hairstyle would be the most practical for you, as well as being attractive.
- Choosing comfortable and appropriate shoes, since you get tired easily.
- Giving yourself permission to have a frozen meal instead of a home-cooked one so that you'll have enough energy to go to the movies in the evening. Similarly, you could invite friends to a potluck dinner, where everyone brings something, instead of cooking everything yourself. People will be happy to help out.

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### 4 To improve the organization of your day's activities, plan ahead

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- Plan your movements around the house. Get into the habit of putting everything that needs to go up- or downstairs near the staircase. You'll avoid some climbing that way. Ask for help with heavy objects.
- Put everything you use for a particular activity in one place. For example, before sitting down to watch TV, gather everything you'll need – phone, glasses, remote control – and then take it easy!
- Plan what you will need for your activities during the week and make sure you have all the necessary items. Keep reserve supplies of toilet paper and wrapping paper. Have emergency solutions on hand: frozen meals, a bottle of wine or small hostess gift for a last-minute invitation.
- Hang up a bulletin board in a central location in your home and ask all family members to add to the shopping list.
- Plan your travel outside the house. How many times as you were coming back from your grocery shopping have you suddenly thought, "Oh, I forgot something...?" Before leaving home, take the time to make a list of all the items you need to buy and where you need to go (supermarket, dry cleaner, drugstore). When you leave, use the opportunity to take out the garbage on your way out if it happens to be garbage day.
- Write down the errands you have to run as soon as possible and those that aren't urgent in your datebook. This will allow you to combine certain shopping trips. For example, if you have to go to the mall to buy the kids' school supplies, why not buy a present for your mother-in-law whose birthday is coming up in a few weeks?

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## 5 To reduce fatigue, balance your schedule

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It's important to know your abilities and limits and to learn to live with them in order to prevent exhaustion. It is just as important to respect your personal rhythm. Be aware of the constraints you put on yourself and learn to be critical of them. All those "must do's" aren't always as essential as we'd like to think!

- Figure out the schedule for your activities for the week and then plan your days, maintaining a certain balance among them. Your schedule has to be realistic and take your priorities into account. If necessary, change it! Each week, plan for some quiet times and some especially pleasant activities.
- Learn to recognize the times of day when you feel energetic and take this into account when you schedule your activities. Doing all the housework on the same day isn't smart – it's an unrealistic dream!
- Alternate periods of work and rest, hard work and light duties. Learn to anticipate your fatigue by knowing the limits of your tolerance while sitting, standing and walking. You will then be able to take breaks BEFORE you get tired, and thus avoid overly long recovery periods.
- Plan time in your schedule for leisure activities. We often tend to believe that a leisure period has to be long, but 30 minutes of reading, music, yoga or other exercise will make you feel better.
- Pace yourself during your activities; it is more productive to keep up a reasonable speed rather than tiring yourself out by going too fast.
- Avoid doing several things at once. You risk being ineffective and getting overtired. For example, use your answering machine and return calls when it suits you.
- Don't feel obligated to finish a task at all costs or to do it on a specific day. Whoever said that the vacuum only works on Thursdays?

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## 6 Work effectively

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### Maintain good posture

- When you sit down, choose a straight, firm chair with armrests instead of a soft, overstuffed armchair and make sure your lower back is well supported. Sit right back in the chair, and keep your back as straight as possible and your knees and hips bent at 90° angles. If necessary, put a small footstool under your feet. Avoid the "slumped in front of the TV" position, which gives a false impression of being restful. Even if you aren't accustomed to it, work sitting down as much as possible in order to save energy.
- At a table or desk, ensure that the height of the working surface is appropriate. Face your work head-on instead of sideways; for example, if the telephone is on your left, turn your whole body to answer a call or swivel your chair in order to avoid twisting your back.
- When standing, avoid locking your knees in an extended position and wear low-heeled shoes (about 1 cm or 1/2 inch). If your balance is good enough, change position by swinging your weight from one leg to the other while contracting your abdominal and buttock muscles. Even better, use a small stool to rest one foot at a time; this will reduce the fatigue in your lower back.
- If you have to lift objects, hold them as close to your body as possible, keep your back straight by contracting your abdominal and buttock muscles, and use your thigh muscles to lift yourself up. Avoid leaning, as much as possible. However, if you absolutely have to do so, keep your back straight and bend your knees. Ask for help rather than risking an injury!



- To carry packages, opt for a backpack or a bag worn slung over your shoulders, and avoid carrying too much at a time.
- If you have several bags to carry, distribute them between both hands, being sure to balance the weight. That will prevent you from straining your back.

### Organize your work space

- Collect all the objects you will need before starting work and put them somewhere where you can easily see and reach them. Eliminate disorder and unnecessary objects.
- Get everything you will need. For example, keep a bottle of household cleanser everywhere where you regularly use it, and have several pairs of scissors strategically placed around the house.

- Ensure that you're working in good conditions: appropriate lighting, good ventilation, suitable noise level (too much noise can disturb your concentration).
- Install telephones in strategic spots around the house: have a regular phone on each floor or carry a cordless phone around with you.

### Choose practical, adapted work tools

- Use "tools" that are easy to handle: lightweight dishes and saucepans, utensils with large, non-skid handles that provide a good grip.
- Choose practical appliances: electric can-opener, hand-held blender and lightweight vacuum.
- Check out items with long handles or wheels: long-handled dusters and tongs, serving tables and suitcases on wheels.



## Prevent falls

- Avoid wearing shoes or slippers that don't support your feet well or that have slippery soles. Long, flowing clothes that could trip you up should also be avoided.
- Think about installing a handrail in staircases.
- Make sure the lighting in corridors and staircases is good. Nightlights are very useful if you have to get up at night.
- Don't let open spaces get cluttered with wires and furniture; stick rugs down firmly with two-sided tape, available in hardware stores.

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## 7 Learn how to analyze an activity and solve any related problems

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In our daily activities, we often act automatically. That's why it's so important to stop now and then and take the time to analyze how we do things.

In this brochure, we obviously can't cover all the problems you might face. But we can suggest an eight-step process for analyzing and addressing difficult issues.

- 1 **Identify the difficulties:** Which activities are causing problems (such as excessive fatigue, pain and risk of falls)?
- 2 **Identify the source of the problem:** – What part of the activity is difficult? When do your problems usually start? Do you feel pain? If so, where? Is the equipment you're using appropriate? Is your work method appropriate? Does the pace of your work suit you?
- 3 **Brainstorm:** – Note down all the ideas that come to mind for improving the situation: eliminate steps, improve your posture at work or the tools you use and delegate tasks. Don't hesitate to ask your friends and family for suggestions!
- 4 **Choose ONE idea** from the list you made and try it out.
- 5 **Evaluate the results:** – Has the problem been solved? Do you see a satisfactory improvement? If not, move on to the next step.
- 6 **Try out** another idea you thought of and continue in this way until you have found a suitable solution.
- 7 If you have reached the end of your idea bank without solving the problem, **consult** an outside resource: occupational therapist or physiotherapist.
- 8 Finally, **accept** that certain problems can't be solved at this point.





## Part 2

# Everyday life

## 1 Through the house, room by room

### Kitchen

- Work sitting down at the table instead of standing up at the counter. If you do work at the counter, sit on a high stool or, if you have to stand for a long time and your balance is good enough, open a cupboard door and put one foot on the bottom shelf in order to reduce tension in the lumbar region.
- Rearrange your cupboards so that the objects you use most frequently are handy: Lazy Susans and sliding shelves can make it much easier to store things accessibly.
- Use lightweight, easy-to-handle dishes.
- To save steps, use “French” service, setting all the food out on the table.
- To set and clear the table, use a trolley.

### Living room

- Before sitting down, collect everything you’ll need: remote control, phone, book and tea.
- Make sure you have good lighting and a comfortable chair that allows you to sit with good posture and thus to rest properly.

### Bedroom

- To make your bed more easily, arrange the covers as much as you can before you even get up and then sit on the edge of the bed or on a nearby chair to finish the job. Use a duvet instead of blankets and a bedspread. If necessary, put blocks under the bed to raise it up, so that you won’t have to lean over too much. Arrange your bed so that both sides are away from the wall and easily accessible.
- Have a reading lamp placed where you can turn it on easily (some can be activated by touching them or clapping your hands).
- Eliminate all unnecessary objects. Keep circulation space clear, and take a few minutes to analyze how your drawers and closets are organized: get rid of unused clothing that’s cluttering them up! If necessary, lower the clothes rails and shelves in your closets.

### Bathroom

- For safety’s sake, have a good-quality rubber mat in the bathtub and dry it off after each use. Make sure that your bath mat is non-skid.
- If only all bathtubs were equipped with grab bars attached to the wall, how many falls would be avoided by both adults and children! So be smart and install one before you fall. They keep you more stable when you’re standing and make it easier to get into and out of the bath.
- If you find it difficult to get up out of the bath, use a bath bench with an adjustable height; you’ll be able to wash safely while remaining seated. Be sure to buy a safe model that is adapted to your condition. If necessary, consult an occupational therapist at your CLSC.
- A telephone-style shower will allow you to rinse completely, even if you use a bench and remain seated during your shower.

- A bottle of liquid soap or a soap dispenser attached to the wall within easy reach is more practical than a bar of soap that will slide all over floor of the bathtub, just as a bath glove is easier to handle than a washcloth; a long-handled brush will allow you to wash your back and feet easily.
- When you're standing at the sink to brush your teeth, shave or wash, pay attention to your posture.
- To wash your feet or dry yourself, sit on the toilet seat or on a solid, non-skid bench.
- To clean the bathtub, use a "spray and rinse" product immediately after your bath, which reduces the need to scrub it out each time. For more thorough cleaning, kneel down and use a long-handled brush or a mop.

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## 2 Daily activities

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### Hygiene and dressing

- Personal hygiene will require less effort and be safer if these activities are carried out in a functional, properly equipped bathroom (see the "Bathroom" section, on page 8).
- Organize a space where you can sit down in front of a mirror so it will be less tiring to do your hair and makeup.
- Ladies, choose a "wash and wear" hairstyle that requires little or no blow-drying. You will save time and energy that way!
- Choose comfortable clothing and shoes that are easy to put on and do up.
- Before you start getting dressed, get out all the clothes you have decided to wear and put them near the place where you get dressed. To put on pants, stockings, socks and shoes, sit down rather than balancing on one leg; that way you'll avoid falling.
- Choose a backpack-type of purse or select a model that you can wear slung over your shoulders or around your waist.

### Washing and ironing

- Wear clothes that can be machine-washed and -dried and that require little or no ironing: knitwear instead of blouses, for example.
- Avoid scrubbing and use a stain remover that you can spray on your clothes before doing the laundry.
- Do small loads of laundry at regular intervals instead of accumulating a lot of clothes; small loads are easier to handle than large ones.
- Lower the clothesline so that it is at the right height for you and put your laundry basket on a chair instead of on the ground.
- Reduce ironing by placing a wrinkled item in the dryer with a damp cloth for 5 minutes. You'll be surprised to see that it is ready to wear after that.
- Front-loading washers and dryers offer easier access in a sitting position.

### The joy of housework

- To simplify housework, eliminate unnecessary knickknacks and high-maintenance surfaces such as mirrors, and avoid "dirt-attracting" items such as unpatterned carpets in pale colours.
- As mentioned above, alternate heavy and light tasks and plan for rest periods.
- Use easy-to-handle tools such as a light mop that's easy to wring out, and choose spray-on products that mean you don't have to drag a bucket of water around.
- When you vacuum, keep your back in the right position: to avoid twisting your back, work with a front-to-back motion rather than side-to-side, and keep your knees slightly bent.

- Store general cleaning products together and carry them in a bucket or get a gardener's apron with lots of pockets where you can put everything you need.

## Get cooking!

- Plan your menus for the week before going grocery shopping to avoid last-minute trips. Take advantage of bargains in the frozen food section; they will come to your rescue on days when you're tired.
- Choose one-dish meals: hearty soups and casseroles that contain meat and vegetables. Make a large amount of the dish you're cooking and freeze a portion. You'll have meals prepared in advance when you need them.
- When you cook, put everything you will need within reach.
- Use non-stick frying pans and saucepans. Leave your saucepans and other cooking pots to soak before washing them.
- To minimize exertion, place a piece of non-skid material, which you can buy in rolls at department stores, under your mixing bowl; your bowl will be more stable. Use utensils with easy-grip handles.
- Use a food processor to cut fruits and vegetables, or buy them pre-cut. To make puréed soups, use a hand blender which is easy to use and clean.
- If you haven't already done so, buy a microwave oven. Put it in an easily accessible place; you'll find it very useful.
- When you wash the dishes, let them drip dry in the rack.



## Good night, sleep tight!

- Before going to bed, put everything you might need during the night on your bedside table and turn a nightlight on.
- A good mattress is the key to restful sleep.
- Sleep in a comfortable position: lie on your side with one pillow under your head and another between your bent knees, or lie on your back with a pillow under your head and another under your knees. It is not recommended that you sleep on your stomach, since this position is not good for your back and neck.
- Avoid drinking in the evening in order to cut down on your trips to the bathroom during the night. Usually, if you stop drinking two hours before you go to bed, that will do. However, for some people, it is preferable not to drink after 6 p.m.



- If you find it difficult to get to sleep, try various relaxation techniques. You can buy relaxation CDs or cassettes that you can listen to when you go to bed.
- Keep the temperature in your bedroom quite cool (around 68°F or 20°C), which will allow for restful sleep.
- Avoid watching stressful TV shows or getting into stormy discussions before going to bed.
- To get out of bed, turn over onto your side, slowly slide your legs out of the bed and push your trunk upright with your arms.

## Leisure

- Leisure activities are not a luxury! They provide relaxation, fun and self-esteem. It is important to be creative in your leisure activities. Explore new ones: you could make some interesting discoveries. Don't let the first obstacle you encounter put you off.
- Don't hesitate to apply the information in this brochure to your preferred recreational activities, such as a problem-solving method, choice of appropriate equipment and good posture. For example, get accessories that will limit your expenditure of energy: a cushioned lap desk for when you read, a gardener's bench on which you can sit in the garden and in which you can keep all the tools you need.

- Regular exercise is important for people with MS. Choose an activity you enjoy and a time of day that suits you. Pay particular attention to the intensity of your exercises and your own tolerance threshold. A rehabilitation therapist or massage therapist can advise you in this regard. Consult the Multiple Sclerosis Society of Canada about adapted physical activities available near your home; just call 1 800 268-7582.
- Avoid getting overheated. It has been proven that this can aggravate or trigger MS symptoms. To beat the heat, seek out cool areas, protect yourself from the sun, take regular showers or baths, stay in the shade, and think about installing air conditioning (contact the MS Society to find out more about this topic).
- If necessary, contact organizations that arrange recreational activities for people with special needs such as Kéroul and Loisirs Alpha.

### Driving

- Adjust your seat so that you're sitting in the right position (see the "Maintain Good Posture" section, on page 5).
- If necessary, use a cushion that provides good back support.
- Before buying a new car, make sure that the seats are comfortable, the doors are easy to handle and the trunk is easily accessible.

### At work

- Think about your work methods and any habits you could change, bearing in mind the suggestions made in the first part of this brochure.
- Place your telephone, computer keyboard and any other equipment that you use regularly in a location where they are easily accessible.

- Ensure that you are maintaining good posture as you work, and change your position regularly. Every half hour, stretch, get up and walk a few steps.
- Plan your schedule for the day and the week to maintain a certain balance.
- Of course, there are lots of things you can't change, but there are also lots of things you simply don't think about changing. Could you negotiate with your employer to obtain a schedule that is adapted to your needs (for example, work part-time or have shorter days) or work at home from time to time?

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## 3 And what about the kids?

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### Childcare

- To pick up children, hold them close to your body, keep your back straight and use your thigh muscles.
- To carry your baby around, inside and outside the house, attach the baby seat to the stroller and use that as often as possible. It's much less effort than carrying the seat in one hand.
- As soon as your children are big enough, get into the habit of having them climb onto a chair to be picked up or let them scramble up on you when you're sitting down.

## Children and housework

- Getting even young children to take part in household tasks has the benefit of helping them develop a sense of responsibility and sharing, as well as become more independent. Get together with them to decide which tasks they will be responsible for. In that way, you can delegate some tasks while also fulfilling your role as an educator.
- Avoid falling into the trap of feeling guilty about asking your kids for help because you have MS. It's natural and important for children to take part in the housework. That's how they learn about life and discover the pleasure of helping others.

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## 4 Some closing words on resources

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There are many specialized devices that could make your life easier. You can find these kinds of aids to daily living at the pharmacy or in medical equipment stores.



Here are a few examples: a bath bench or board to prevent you from having to climb over the edge of the bathtub, sock pullers, a wrist rest for when you're working on the computer, items that have easy-grip handles, a raised toilet seat and long-handled tongs to pick up objects off the floor.

You can also consult an occupational therapist working at your local CLSC or a rehabilitation centre. She or he could suggest equipment or accessories that would suit you and ways of doing things that meet your specific needs.

Some rehabilitation centres also organize meetings for groups of people with MS.

Finally, the Multiple Sclerosis Society of Canada recommends a wide range of physical and recreational activities for its members. To find out which chapter of the MS Society is located closest to you, call 1 800 268-7582 (toll-free).

We have made a lot of suggestions in this brochure. However, it is up to you to find out the best methods for facing the requirements of your daily life and to cope with your specific strengths and challenges.

Good luck putting these suggestions to work for you!



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## Thanks

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Pierre Depocas et al., Centre de réadaptation Lucie-Bruneau, 1998.

### *Help Yourself! Hints for Persons with Disabilities*

Human Resources Development Canada (Status of Disabled Persons Secretariat), 1994.

### *Aids to Independent Living: Breaking through the Barrier*

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### *The Arthritis Helpbook: A Tested Self-Management Program for Coping With Your Arthritis*

Kate Lorig and James F. Fries, Addison-Wesley, 1991.

### *Multiple Sclerosis, The Facts You Need*

Paul O'Connor, Key Porter Books, 2002.

### *Managing Fatigue: a Six-Week Course for Energy Conservation*

Tanya L. Packer, Nicky Brink and Adèle Sauriol, Therapy Skill Builders, 1995.

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## Other suggested reading

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### *Understanding and Managing MS Fatigue*

Diane Forrest, *MS Canada*, February 2003.

### *Bien vivre avec la SP – Prise en charge de la fatigue. Educational series by the Multiple Sclerosis Society of Canada*

Dr. Lauren B. Krupp, 2003.

### *Everybody Stretch – A Physical Activity Workbook for People With Various Levels of Multiple Sclerosis*

Multiple Sclerosis Society of Canada, 2003.

### *Assets and Abilities – Your Guide to Work, Income Security and Multiple Sclerosis*

Multiple Sclerosis Society of Canada, 2001.

### *How to Talk About MS With Your Children*

Multiple Sclerosis Society of Canada, Quebec Division, 2000.

### *MS and Fitness – Guide for People With Multiple Sclerosis*

Multiple Sclerosis Society of Canada, Quebec Division, 2004.

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## Video

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### *Au mieux de sa forme... tout en douceur! A physical activity program (in French only), in VHS or DVD format*

Multiple Sclerosis Society of Canada, Quebec Division, 2003.

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## Credits

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## Our Mission

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

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