



ADAPTING TO CHANGES IN YOUR MULTIPLE SCLEROSIS

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Living with MS

MSology Essentials Series

Adapting to changes in your Multiple Sclerosis

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INTRODUCTION

Multiple sclerosis (MS) is a chronic neurological condition that affects about 100,000 Canadians. Like other chronic illnesses, MS will change and evolve throughout a person's lifespan. Some symptoms may periodically flare up then improve, while others may steadily worsen over several years. The uncertainty about what symptoms you'll have over the short term, and worrying about the level of disability that may occur over the long term, make living with MS especially challenging.

Fortunately, there are now many medications that can help to reduce the frequency and severity of MS flare-ups ("relapses") and slow the development of disability. These treatments are most helpful early in the course of your MS but appear to lose some of their effectiveness as MS progresses. So as your MS evolves, there will be a need to make some adjustments to your treatment regimen and adopt some creative solutions to overcome any limitations you may be experiencing.

This booklet has been developed in collaboration with nurses specialized in MS to explain some of the changes that can occur as MS progresses. Some of these changes are specific to MS; some are due to the inescapable process of getting older. MS has been described as "accelerated aging", so that some of the difficulties associated with MS – mobility problems, muscle tightness, vision impairment – are also common later in life in people without MS.

It is hoped that this booklet will answer some of your questions about how MS progresses, and provide some useful tips for coping with the illness and living a healthier life.



HOW DOES MS PROGRESS?

MS is believed to be an autoimmune disorder in which a person's own immune system attacks certain tissues in the body. During an attack, immune cells pass from the blood stream into the central nervous system (CNS), causing inflammation and damage to myelin, the "insulation" that normally encases and protects the delicate nerve fibres of the brain, spinal cord and optic nerve.



Throughout your illness the goal of treatment never changes: to maintain your daily function and slow the development of disability.

Most people are diagnosed with relapsing-remitting MS (RRMS). During this initial phase of the disease, inflammatory flare-ups interrupt the signals travelling along the nerves. These inflammatory episodes can be detected on magnetic resonance imaging (MRI) scans and may be apparent to you as a relapse – new symptoms or a worsening of previous symptoms that last for at least a day or two without an obvious cause (such as an infection).

The MS symptoms that you experience provide a clue to the part of the CNS that's affected: sensory symptoms (e.g. pain, tingling, numbness) are caused by lesions affecting sensory nerves; muscle symptoms (e.g. muscle stiffness or weakness, tremor, slurred speech) are caused by lesions affecting motor nerves; and so on. As the inflammation subsides, there's a period of remission during which the symptoms improve or go away completely.

Over time and with repeated attacks, MS causes an accumulating amount of tissue damage and the nervous system is less able to adapt



to the loss of nerve tissue. This causes a process called *disability worsening*. On a day-to-day basis, this means that some of the function that you've lost may not be regained. For example, you may find you can no longer walk through the shopping mall without taking a break, or the bladder symptoms you've occasionally experienced have become the “new normal”.

Throughout this process of inflammatory flare-ups, a second, less noticeable disease process is going on. This is called neurodegeneration, in which disease-related changes to the nerve tissues in the brain cause irreversible damage. The process is difficult to detect even with an MRI and appears to occur somewhat independently of the inflammatory episodes. The cumulative loss of function that occurs because of this process is called *disability progression*.

Inflammation and neurodegeneration are the twin mechanisms underlying the disease process in multiple sclerosis. Inflammation predominates in RRMS. Neurodegeneration predominates in progressive forms of the disease: secondary-progressive MS (SPMS), which develops in most people after the RRMS phase; and primary-progressive (PPMS) MS, in which disability is there from the outset.

MS is very unique to the person who has it. Not everyone with RRMS will go on to develop progressive MS, and not everyone with progressive MS will develop the same degree of disability. Progressive MS is a very individual phenomenon: some people will have disease activity (relapses and/or MRI lesions) with or without progression; some will have no disease activity but will have progression; and some will have no disease activity and no progression (called “stable disease”).



HOW DO I KNOW IF MY DISEASE IS PROGRESSING?

The hallmark of MS progression is a sustained loss of ability or function that doesn't improve over time. For example, you may find that balance problems, muscle stiffness and worsening fatigue make it more difficult to walk so that you can no longer cover the distances you were able to manage a year ago. Or you're finding that you're struggling more with the physical and mental demands of what you need to get done at work or at home.

During this progressive phase, you may not be experiencing any relapses. In fact, many people find that their day-to-day function is quite stable for long periods of time. "Progressive" doesn't necessarily mean that you'll feel worse – but your functioning will gradually become worse. When you think back to a couple of years ago, you'll notice there's a change in how well you're able to get about or manage your daily tasks. Some activities will be more difficult or require more effort, and others may feel beyond your grasp.



Physical or mental impairments that don't improve over time may indicate that your MS is progressing.

WILL MY MS MEDICATION STILL WORK?

Many people with MS take a disease-modifying therapy (DMT) to control their disease. These medications primarily target the abnormal inflammatory response seen in MS. This disease activity is readily apparent – you experience relapses, your doctor detects changes in your nerve and muscle function, and an MRI shows





inflammatory lesions in the brain. The purpose of DMTs is to reduce the inflammation so that relapses become less frequent or severe, the MRI picture improves and disability takes longer to develop. So DMTs should be thought of as preventatives rather than medications that relieve MS symptoms.

This disease activity (relapses, MRI lesions) appears to contribute to the neurodegenerative processes that cause much of the disability later in life. That's why it's so important to start a treatment early – to try to prevent inflammatory damage and slow the development of worsening disability. However, once the neurodegenerative process takes hold, it can slowly accumulate tissue damage in the brain even without inflammatory activity.

The processes of inflammation and neurodegeneration are interrelated, so people with progressive MS may continue to have relapses or MRI lesions. In such cases, your doctor is likely to advise staying on your current medication or will recommend that you switch to a DMT that's better able to control your disease. Even if you haven't had a relapse in a while, it may be best to continue taking a medication – your treatment may be suppressing relapses and they may flare up again if you stop your therapy.

Wherever you are in the course of your disease, the goals of treatment remain the same: to try to reduce the damage that MS is causing in your brain and spinal cord, to slow the development of disability and maintain your wellness.



Worsening disability doesn't mean that treatments will no longer work for you. Your doctor may recommend that you change to a medication that's better able to control your disease.



A NOTE ABOUT AGING

The reason that MS changes over the course of your lifetime is due in part to the natural aging process. As we get older our immune systems have a less inflammatory response, which may help to explain why relapses become less frequent with aging. It also means that treatments that target the immune response may become less effective – underscoring the importance of starting treatment as early in the disease course as possible, when you'll get the most benefit from therapy.

An aging immune system also means that older people are more susceptible to infections. MS medications can be associated with a risk of infection, so this may mean you'll need to modify your treatment regimen and take extra precautions against infections.

MS won't prevent you from developing other medical conditions as you get older. So see your family doctor regularly for a complete check-up. If you do develop other health issues, such as high blood pressure or diabetes, these conditions and the medicines you take for them may have an impact on the DMT you're taking. So as you get older, your doctor and MS nurse will need to discuss your changing needs, how your risk profile has changed, and how best to maintain your general health.



Frequent hand washing is the simplest way to avoid infections.



WHAT CAN I DO FOR MY MS?



People are experts at adapting to the inevitable changes that occur in life. They come up with new ideas, view things differently, adopt new strategies to cope with difficulties. There will be new challenges as your MS progresses, but you've faced other problems before and overcome them. Here are a few suggestions that may be helpful as you adapt to changes in your MS and develop your personal wellness plan.

1 Commit to a healthier lifestyle.



- Quit smoking. This is essential. Aside from the many known health problems with tobacco, smoking appears to worsen MS and increases the risk of worsening disability.
- Work on improving your diet. There are countless food temptations and it's all too easy to acquire bad habits. But it's important to avoid fast foods, junk foods and unhealthy snacking for the sake of your overall health. Excess salt in your diet may also worsen your MS.
- Try to maintain a healthy body weight. This can be difficult – especially if you're having problems with mobility or MS fatigue. But aside from the health risks associated with obesity, such as diabetes and heart disease, there is some evidence that obesity will worsen your MS. Obesity also puts an added strain on your muscles and joints, makes it more difficult to remain active and will worsen fatigue.





- Exercise regularly. It's important to be active on a daily basis. All that's required is to set aside 20 minutes a day – every day – for an activity you enjoy: take a walk after dinner, go for a bike ride, putter in your garden or sign up at the local pool or gym. The activity doesn't have to be intensive (or expensive). What's important is to get your heart pumping, to stretch your muscles and tendons, and to keep your body moving.

2 Get advice from a physical (PT) or occupational therapist (OT).



There are many health professionals who can provide practical advice on how to make your daily tasks easier. PTs focus on your physical functioning. For example, if there's a difficulty with mobility, people often try to compensate by changing how they walk, which can put added strain on the hips and back and can lead to injuries. A PT can correct your gait and can provide walking aids so you can get around with less strain and fatigue. They can also suggest activities and exercises to keep your body in tune. An OT can offer advice on how to modify your tasks and can provide adaptive devices for work, school or in the home so you can remain active and productive.





3 Don't neglect any emotional or cognitive difficulties you're having.



MS is a mental as well as a physical challenge – so it's not surprising that people with MS have a higher risk of developing symptoms of depression or anxiety. While people often focus their efforts on their physical health, it's also important that you don't neglect your mental well-being. Explore the many activities that can instill a sense of calm and improve your mood: walking or swimming, mindfulness training, yoga, meditation. Find what helps you feel better in your own mind – then do it whenever you need to give yourself a little reward. If you're still struggling with mood symptoms, get help from a health professional (your family doctor, therapist, psychologist). They can discuss the best therapies for you, such as counselling or medications, to help you cope with the challenges.

MS can also have effects on cognition – your ability to concentrate, plan and remember. So be sure to give yourself a regular mental workout to keep your mind in tune: read a book, do a crossword puzzle, jot down your thoughts in a journal, or put some time into studying a topic that you find interesting. Jotting down dates in a calendar, making notes to yourself and smart phone reminders can also be helpful if you're having difficulty remembering things.



Cannabis can provide some relief of MS symptoms. But frequent, daily use can cause problems, such as cognitive difficulties and worsening anxiety.



Get the support you need from the people around you.



MS is a very personal illness. There's a natural inclination to withdraw into yourself with the feeling that you're all alone in your struggles. It's essential that you break out of that sense of isolation – not just for you but for the sake of your loved ones. It's important for you to remain interested and engaged in the business of living.

There are many people – your family, friends, colleagues, people in your community – that you can turn to for emotional support, help with your chores or just a quick chat. Take part in community activities, join a book club, arrange to meet friends for coffee. With phone, text, social media and video chat, there are many channels available to you to stay connected with the people in your life.

At first your family and friends won't understand MS – unless you take the time to explain it to them. Share with them how you're feeling, what you're experiencing, what thoughts make you anxious or depressed. And don't be shy about asking for their help if you need it! You don't have to shoulder the burden alone.





FUTURE CHALLENGES

Multiple sclerosis (like life itself) is filled with uncertainty – about how you'll feel tomorrow, whether you'll still be able to manage your responsibilities, about how you'll be in a year from now. Unfortunately, no one can predict what difficulties you'll encounter as you get older or the limitations you'll face as disability becomes more apparent.

What does remain within your control is how you choose to live day-to-day and how you cope with changes in your MS. If you can adopt a healthier, less stressful lifestyle, make the most of the treatments available to you, and embrace the people around you, you can overcome the challenges ahead.





QUESTIONS TO ASK YOUR MS NURSE

CONTACTS

MS clinic:

Family doctor:

Physiotherapist:

Occupational therapist:

Other numbers:





The MS Essentials series provides the latest information on multiple sclerosis medications, research, and lifestyle issues such as health, nutrition and exercise. All of the booklets are developed by Lind Publishing, publishers of MSology, to help people affected by MS remain active and informed.

MS Essentials is provided free of charge. The full series of publications is available for download at www.MSology.com



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