



Information for People Newly Diagnosed with Multiple Sclerosis

Foreword

This booklet is intended to provide people newly diagnosed with multiple sclerosis (MS) with an early overview of information about MS and the people and services that are here to support you in Saskatchewan. It can be a useful starting point for anyone who wants to know more about living with MS.

For more information about professionals and services in Saskatchewan that support people with MS, refer to the web pages of the Saskatchewan MS Care Pathway and the MS Society of Canada, Saskatchewan Division.

Parts of this resource are adapted with permission from “Living Your Best Life with Multiple Sclerosis (MS)” presentation by Dr. Iliia Poliakov, Clinical Director of the Saskatoon Multiple Sclerosis Clinic, March 28, 2018 and MS Wellness Program booklet by Laurie Murphy, MS Society of Canada, Saskatchewan Division, 2018.

The perspectives of people living with MS were solicited by the MS Society of Canada, Saskatchewan Division November/December 2018 and also provided by patient advisors to the Saskatchewan MS Care Pathway. This booklet is evidence based and expert informed. It was assembled by the information subcommittee of the MS Care Pathway Clinical Implementation Committee. This work was further supported by a Saskatchewan Health Research Foundation (SHRF) Research Connections Grant (PI S.Donkers). All content is published with the consent of contributors.

We would love to get your comments on this booklet and suggestions for additions or changes. To contact the MS Care Pathway team, e-mail info@health.gov.sk.ca.

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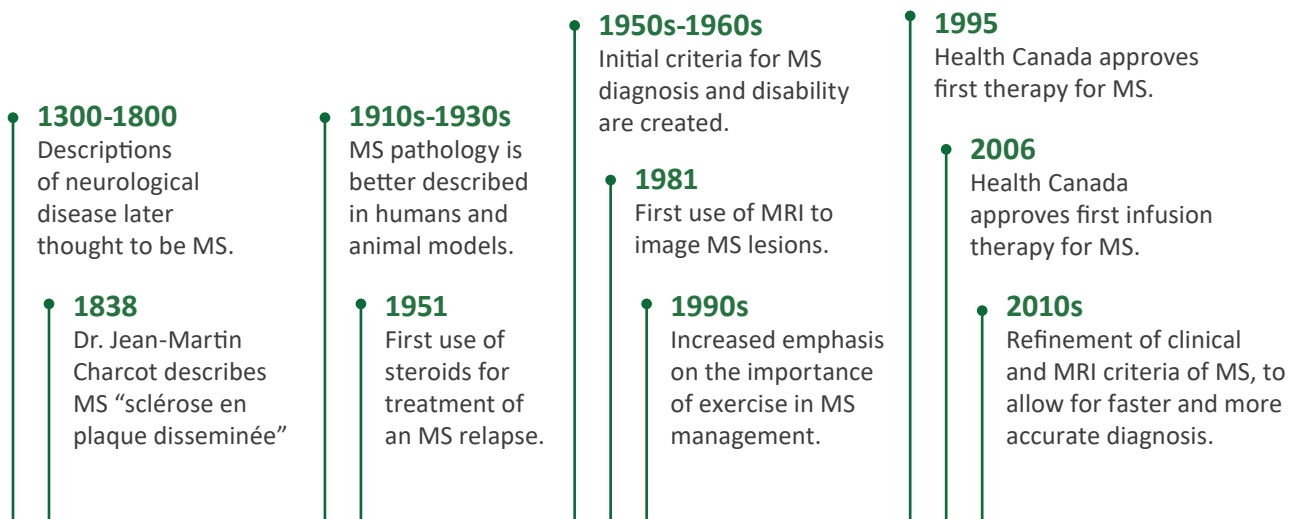
Receiving a Diagnosis of MS

A diagnosis of MS may produce reactions of shock, fear and concern – from you and also from your family, friends, co-workers, teachers or employers. Everyone might have their own idea of what MS is and what it means. It is probably a good idea to leave any pre-conceived ideas aside for now.

MS impacts each person differently over their lifetime, so ensuring you have access to a supportive health care team and reliable information about MS symptoms, treatments and its impact means you can better navigate your own path with MS.

Advancements in MS Care

For a person diagnosed today there are a range of disease-modifying therapies and strategies to improve MS symptoms and the quality of life for people with MS. There is also an improved understanding of the importance of resources that can help to manage a chronic disease such as MS.



“When I was diagnosed I knew very little about MS. My best medicine, without a doubt, was educating myself with the help of peer support and getting involved in all aspects of my disease. MS is a disease of the mind and body, you have to treat both.” ~ Dennis, diagnosed in 2000

“I was diagnosed with MS in June 2016. It came as a shock and transformed my life. Here are things I learned along the way:

- There will be lots of doctors appointments and blood work. It’s helpful to have a spouse/ partner/ friend accompany you to these appointments to help manage all the information you receive and scheduling doctor appointments.
- Take notes. Lots of notes. You will get so much information it can be overwhelming because everything is new to you.
- If you have a spouse/partner, they will experience the stress of the diagnosis as well. Check in with them to make sure they’re okay. Encourage them to seek counselling if they require additional support.
- Remember to laugh. Being diagnosed with a disability is a shock to your brain. Enjoy the small things – sunshine, a flower, a dog’s kiss.” ~ Lois, diagnosed in 2016

2011

Health Canada approves the first oral therapy for MS. This was also the first therapy to show superiority to older treatments.

2014

Health Canada approves first immune reconstitution therapy for MS.

2018

Health Canada approves first therapy for PPMS.

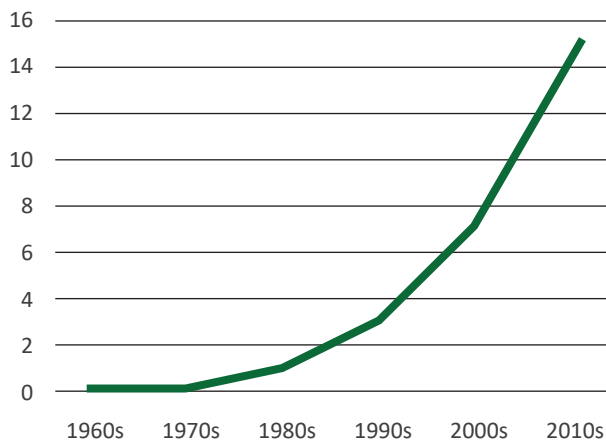
2019

FDA approves a new therapy for SPMS, bringing the total number of approved MS therapies to 15.

2020+

An accumulation of real world evidence showing longer term benefits to early treatment.

Number of medications approved in USA or Canada for treating MS



What is MS?

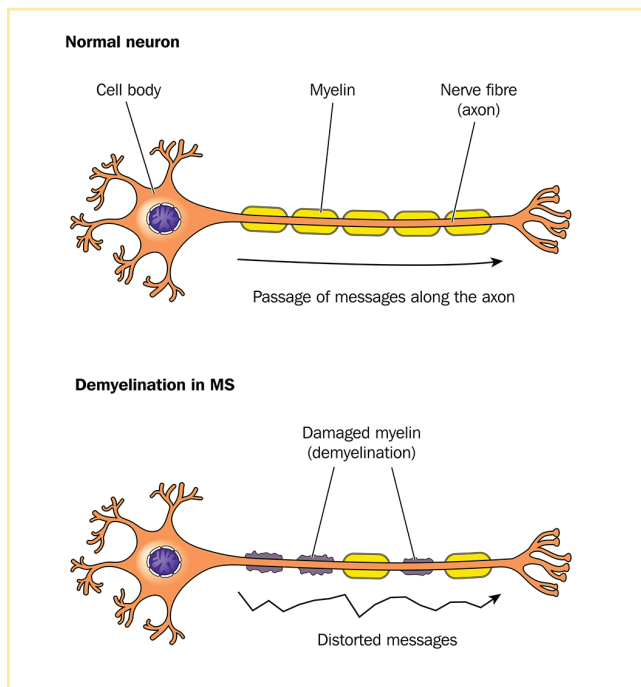
Pathophysiology of MS

MS is an autoimmune disease of the central nervous system (brain, spinal cord). The disease attacks myelin, the protective covering of the nerves. It causes inflammation and often damages the myelin and the nerve underneath. Healthy nerve cells and myelin are necessary for the transmission of impulses through nerve fibers.

When myelin is damaged, the body is able to make some repairs. But eventually **multiple** patchy areas of scarring (also known as lesions) develop on nerve fibers. The nerve fiber (or axon) may be damaged or broken.

Demyelination may lead to scar tissue formation (**sclerosis**). In a person with MS, sclerosis occurs in multiple places in the central nervous system, and it appears in new areas over time.

MS causes damage to the central nervous system but does not directly attack the rest of the body. However, the damage caused in the brain and spinal cord affects the flow of information from the brain to the rest of the body. This disruption produces a wide variety of neurological symptoms and impaired function in other parts of the body. The most common symptoms are problems with balance, strength, vision, fatigue, muscle control, cognition, or bladder or bowel activity, and odd sensations such as numbness or tingling.



“I always use the analogy of a lamp. Our brain sends electric signals through our nerves the same way electricity follows a wire. With MS, the coating of our nerves (myelin) is damaged when our immune system decides to go a little crazy and attack that insulation. So if you imagine a frayed wire, where its coating has come off, that is how it works with us. The electric signal can’t pass through the damaged area, so the light bulb flickers.”
~ Rhea, diagnosed in 2015

The diagram on the top shows a healthy nerve cell (or neuron) and the diagram on the bottom shows a nerve cell affected by MS. Notice how the nerve fibre in a healthy cell is surrounded by a myelin sheath. Impulses travel down the nerve fiber to communicate with other cells. In the MS-affected neuron, the myelin has been damaged, and impulses are not able to travel as easily.

The Course of MS

The MS course is based on the different patterns of symptoms and signs experienced or observed. There are two basic classifications for the course of multiple sclerosis: relapsing-remitting or progressive MS.

Relapsing-Remitting MS (RRMS)

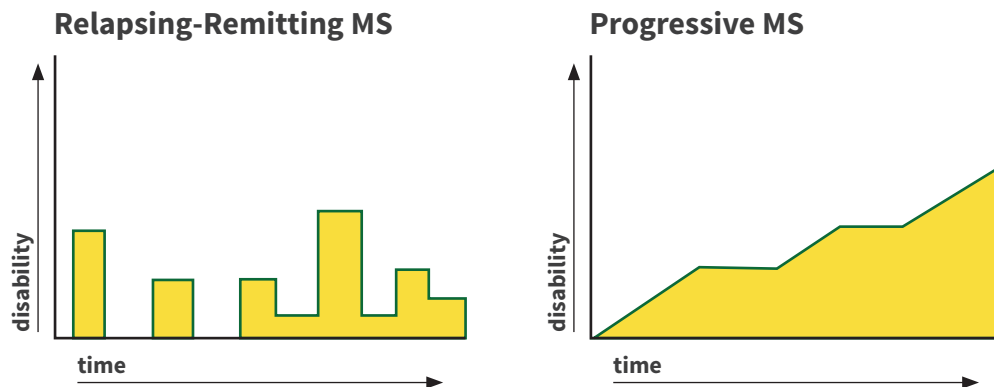
About 85 per cent of people diagnosed with MS will have RRMS at the time of diagnosis. RRMS describes a course of MS characterized by unpredictable but clearly defined episodes during which new symptoms appear, or existing ones get worse. These “episodes” are most commonly referred to as relapses. They may also be called attacks, exacerbations, or flare-ups. Typically, in a relapse, symptoms reach their worst point of severity over a few hours to days. Each relapse lasts anywhere from at least 24 hours to a few weeks after which time the majority of people notice symptoms starting to improve. Incomplete recovery may occur in up to 30-50% of relapses. Improvement after a severe relapse may take many months. People generally experience a period of more stability in their MS symptoms between relapses. The time between relapses is variable but may be months or years.

Most MS treatments are designed to prevent relapses in people with RRMS. If treatment is effective, people may experience relapses quite rarely. People who experience a relapse should follow up with their MS care provider to make sure that the treatment they are on is still the best one for them.

Progressive MS

Primary Progressive MS (PPMS) is characterized by a slow buildup of disability, without relapses. It may stabilize for periods of time, and even offer minor temporary improvement, but overall, there are not periods of significant improvement or return of function. Approximately 10 to 15 per cent of people with MS are diagnosed with primary progressive MS from the start.

Secondary Progressive MS (SPMS) occurs when relapsing-remitting MS begins to worsen, usually in the absence of distinct relapses. The rate of worsening is different for everyone and typically is more gradual than the worsening experienced with MS relapses. About 50 per cent of people with RRMS will develop this form of progressive MS within 20 years of diagnosis.



The left diagram shows how a person with RRMS may experience the disease over time. Initially, symptoms or disability go away after each episode. After a while, people may notice that more symptoms persist after the episode has ended. The right diagram shows how people with progressive forms of MS experience the disease – with slow but continuous worsening of disability. In both scenarios, symptoms and disability build.

Clinically Isolated Syndrome (CIS)

MS can be complicated to diagnose. The diagnostic criteria require evidence that damage has occurred in different parts of the central nervous system over time. Evidence of damage over time involving different parts of the brain and spinal cord may come from your medical history, physical examination or test results. Tests may include a lumbar puncture, visual evoked potentials or brain imaging (such as MRI).

When a patient has a single MS relapse but does not yet meet all the criteria for an MS diagnosis, they may be diagnosed with clinically isolated syndrome (CIS). At this stage, regular follow up and brain imaging may be recommended to ensure appropriate treatments and supports are available at the right time. Early access to MS services and disease modifying treatment options help to minimize the impact of MS over the course of a person's lifetime.

Sometimes MS disease activity is not noticeable to the person with CIS even though brain imaging or the neurological exam may show changes.

Not everyone with CIS will be diagnosed with MS. Over the longer term, many people do develop more MS disease activity – leading to an MS diagnosis.

The course of MS may be confirmed at initial diagnosis, or it may require more time and investigation. Do you know what type of MS you have?

Disease Activity and Progression

MS is a chronic disorder, and over the long term it has a progressive course for most people diagnosed. Progressive means there is a trend for disability to accumulate and get worse over time. A minority of people experience very little progression. People diagnosed with MS today may experience a slower rate of progression compared to people diagnosed 30 years ago. The reasons for this may include the availability of newer disease treatment options, earlier diagnosis and improved disease management. The types of symptoms and the rate at which the disease progresses are different for everyone.

When physicians refer to disease activity, this means that either there have been MS relapses and/or an MRI scan shows an area of new damage. Alternatively, the disease may be labelled non-active if there are no recent MS relapses and MRI scans remains largely unchanged.

Progression may occur independent of disease activity. Progression is usually measured by comparing results of tests that are repeated over time. Repeated testing may include the neurological examination with calculation of the Expanded Disability Status Score (EDSS) and/or a timed 25 foot walk test or other functional tests.

If you know the course of MS that you have, it may give you an idea what to expect as the disease progresses. But multiple sclerosis is still quite unpredictable – the course, duration, severity and impact of symptoms varies greatly from individual to individual. Even within categories of relapsing-remitting and progressive MS there are spectrums from mild to severe disease.

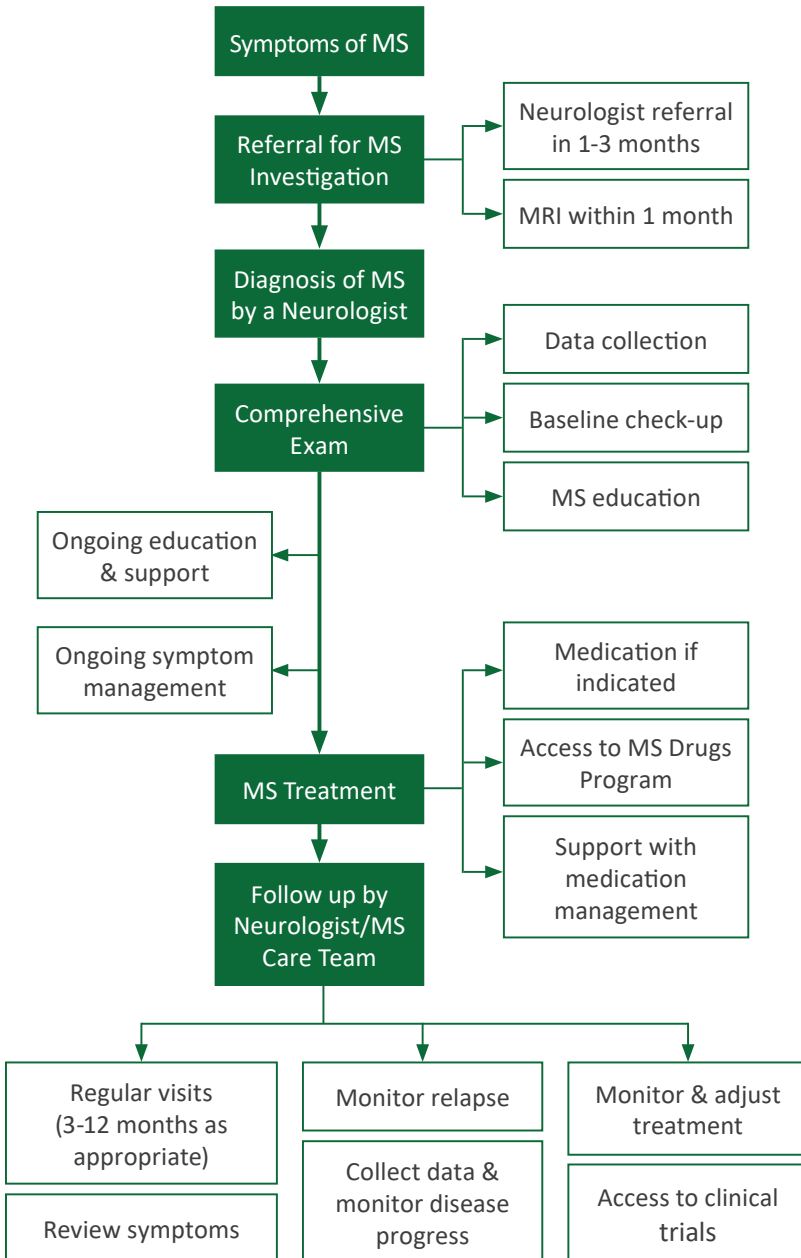
The prospect of progressive disability may be scary, especially as a person newly diagnosed with MS. In spite of this uncertainty, many people with MS continue to have children, go to school and have careers. People living with MS have a statistical life expectancy only six to seven years less than people without MS (MS Trust UK). Still it can be helpful to get as much information as you can about programs and services that support people with special needs. The MS Society of Canada is an excellent resource.



MS Care

The MS Care Pathway

The MS Care Pathway is a Saskatchewan initiative that maps out the main steps along the care continuum. The goal of the pathway is to help organize services and information so every person with MS gets the care that is right for them.



MS care falls under two main categories – MS treatment (monitoring and managing the progress of the disease in your central nervous system) and symptom management (responding to the effects of the disease on the rest of your body). Going forward, a primary neurologist and a primary health care provider are recommended at a minimum to meet your care needs.

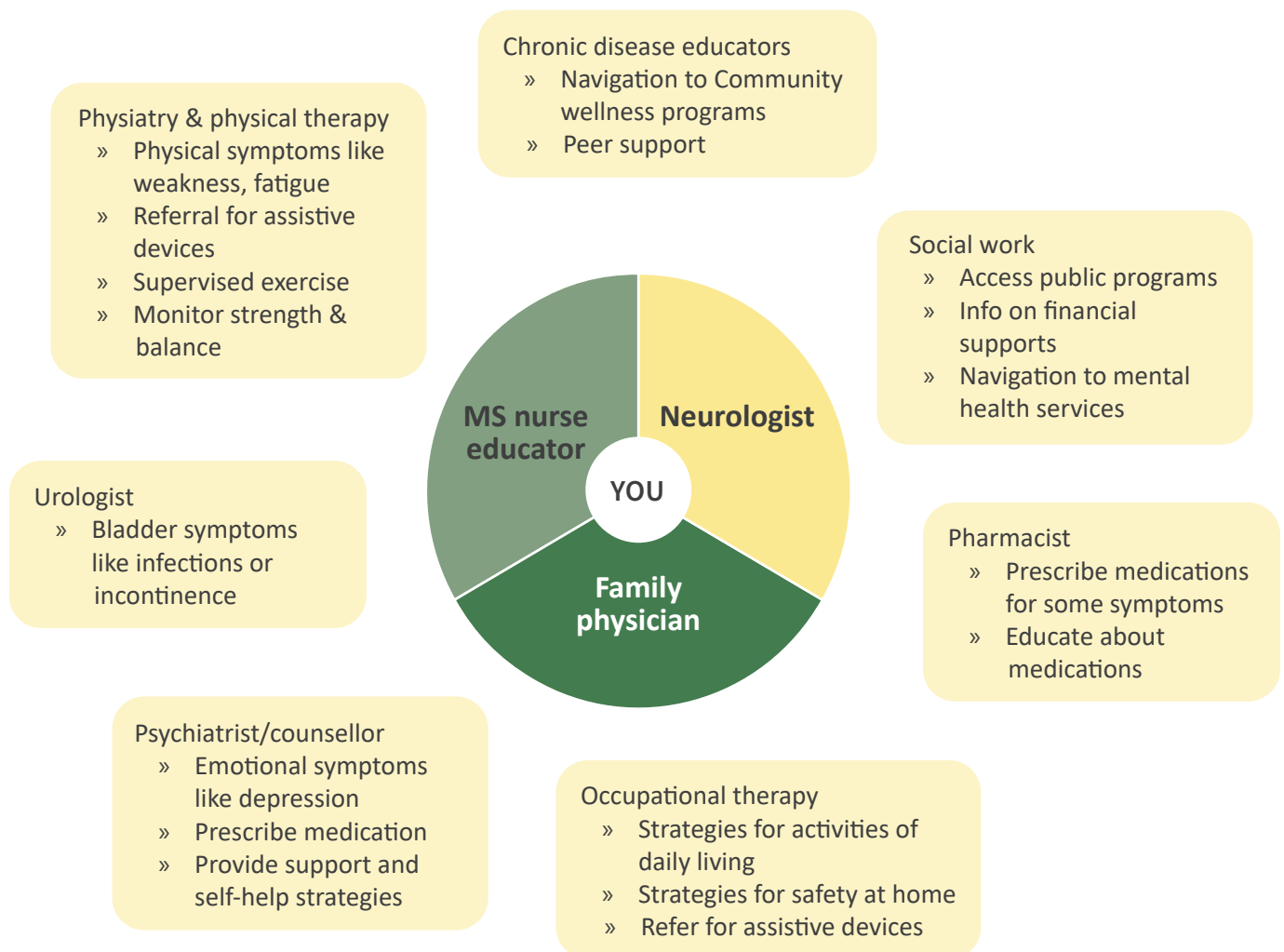
A neurologist (in the MS Clinic or the community) may direct your care, but you are encouraged to involve your family doctor, nursing and rehabilitation professionals, community resources and the MS Society of Canada in helping you access care and find the resources you need. If you are uncertain where to start, an MS nurse specialist can help you navigate the next steps. You can reach an MS nurse at any time via the MS Drugs Program at 1-866-655-7966.

It is important that you surround yourself with a health care team that you trust and that meets your needs. If you are uncomfortable with a care provider, it is okay to switch. For consistent care, one primary neurologist and one family physician who you are able to see most of the time are recommended.

MS Symptom Management

MS care and the management of MS symptoms can involve a diverse group of care providers from massage therapists to neuropsychologists. Some clinical centers such as the MS Clinic in Saskatoon or Wascana Rehab Centre in Regina can provide access to a few providers in one place such as physiatrists (physical rehabilitation specialists), pharmacists and nurses, but there are many other supports in the community that can help someone with MS during the course of their disease.

The goal of the MS Care Pathway is coordinated multidisciplinary care. Your care team (your family physician/NP, neurologist, MS nurse and you) will manage referrals to other specialists in the community, and share information to coordinate care.



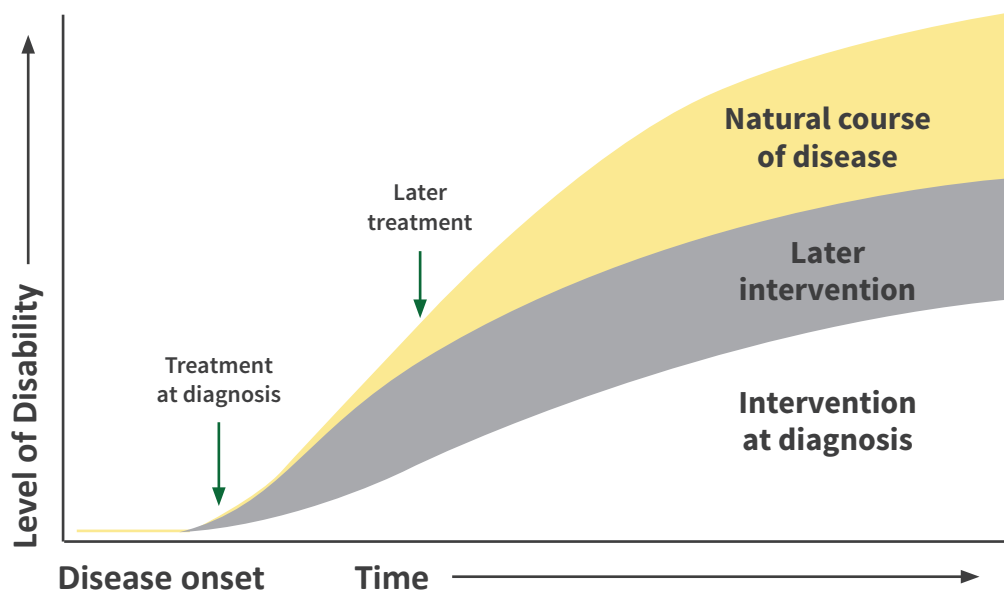
**Do you feel that your care providers communicate well with you and with one another?
Do you know how to find information about other services and supports?**

MS Treatment

When health care providers talk about MS treatment, they are usually referring to treatment for the underlying disease process. This type of treatment is typically pharmacological therapy (drug treatment) commonly referred to as disease-modifying therapy (DMT).

DMTs for MS aim to prevent further damage to the central nervous system. Most treatments work by targeting some aspect of the inflammatory process of MS, with the goal of preventing inflammation and thus reducing the number of relapses and their severity. DMTs do not usually reverse disability that already exists. MS symptoms (such as weakness or fatigue or other MS symptoms) are not generally expected to improve with DMT treatment. DMT treatment may be thought of as a preventative approach to delay the onset of further relapses or disability.

There is strong evidence that DMT can slow down brain atrophy in the short term and decrease disability at the two-year mark. While more research is underway to verify the long-term benefits of DMT, observational studies utilizing data from large databases indicate a decrease in the burden of long-term disability. Current consensus guidelines from experts working in MS support treatment with DMTs as soon as possible for people diagnosed with active MS. Guidelines also recommend continued re-assessment and an individualized treatment strategy that optimizes treatment effectiveness for each person living with MS (MS Brain Health 2017).



This graph shows that people who start disease-modifying treatment early in the course of their disease may experience a lower lifetime burden of disability than people who start medications later in the disease course.

Your neurologist or an MS specialist neurologist may suggest a DMT treatment plan based on your individual health status and the course of your disease, but the decision to undertake treatment must be made by you. You are encouraged to access information about the proposed treatment and consider factors such as known side effects, potential risks and benefits, how the drug regime fits with your lifestyle, and how it compares to similar products (if any). Once you start a therapy, it is recommended the medication be taken as directed. You should also learn the specific side effects associated with your treatment and monitor for the known side effects. It is also important to monitor for relapses or changing MS symptoms. Changes may indicate a need to review if the treatment you are on is still the right one for you.

As you learn more about MS, you may learn about alternative MS treatments (products or therapies that are outside conventional medicine). Many people with MS use alternative therapies to manage symptoms of their disease, which is usually okay if they make you feel better. But there are no known alternative therapies that can treat, cure or control the disease itself. If you are interested in alternative therapies, you may wish to approach them as complementary (additional) to conventional treatment. Be sure to discuss alternative treatments with your health care team, and make them aware of what you are taking or are thinking about trying.

If you are interested in trying something new, you may wish to consider participating in clinical trials of new MS therapies and interventions. Let the MS clinic or your neurologist know that you would like to learn more about opportunities that become available. You can also register on the MS Society website to get more information about clinical trials.

Financial assistance for MS drugs

In Saskatchewan, funding for MS drugs is provided through the Saskatchewan MS Drugs Program. The Ministry of Health may cover partial or full cost of drugs for people with MS who meet specific criteria. Coverage for drug costs are adjusted based on income status. Financial support for the cost of MS drugs from compassionate programs provided by industry or private health insurance may also be options for some people.



Questions about criteria, costs and coverage for disease modifying MS drugs can be discussed with the SK MS Drugs Program Coordinator. Questions about MS drugs or lifestyle changes that could impact your MS can also be discussed with the MS Drugs Program Nurse Educator. Both the program coordinator and the nurse educator can be reached at 1-866-655-7966.

Living with MS

Common Symptoms of MS

The effects of MS vary a great deal from person to person, but there are symptoms that are more common than others. Even though there is not a cure for MS, there are often therapies and treatments that can provide relief or partial relief of symptoms.

The best strategy for managing symptoms of MS is to have open and frank conversations with your health care providers about the symptoms you experience and their impact. Symptoms may impact very personal matters and be difficult to discuss. It can also be challenging to figure out if the symptoms are related to your MS or some other cause.

This section provides an overview of common symptoms and approaches to symptom management. For more detail, there are excellent on-line resources that provide up to date, evidence-based information and answer common questions about MS symptoms. You can access quality, trustworthy information about symptoms and management from the MS Society of Canada (www.mssociety.ca).

There can be many variations in MS symptoms and differences in how they are experienced by each individual. If you have a symptom that does not seem to fall into one of these categories, you should make note of it to raise with your MS care team.

Fatigue



Fatigue, the most common symptom of MS, is a sense of tiredness, lack of energy, or feeling of exhaustion that can seem overwhelming, and which can interfere with daily activities. Despite fatigue being very common, not everyone with MS experiences fatigue. In MS, there are two types of fatigue. Primary fatigue is related to the underlying disease process in MS. Secondary fatigue can be caused by other factors such as depression, medication side effects, heat, lack of exercise, sleep difficulties, thyroid disease and stress. MS-related fatigue tends to get worse as the day goes on, is often aggravated by heat and humidity, and comes on more easily and suddenly than normal fatigue. Approaches to managing fatigue are usually centered on identifying and controlling secondary causes, and developing individualized self-management programs and goals.

“Remind yourself that even if your neurologist is a medical genius, he or she cannot read your mind or see what is happening with your symptoms outside of his office unless you tell him or her. Know that most docs prefer the kind of patients that get involved in their own health care and try to help figure out mysteries or solve problems.” ~Michelle, diagnosed in 1992

Paresthesia



Paresethesia means altered or unusual sensation, such as tingling, tickling, pricking ('pins and needles'), numbness, itching, burning, squeezing or electrical shocks. These bizarre symptoms typically occur in hands, arms, legs and feet but may also be experienced in bands around the chest, or in the face and mouth. They tend to have a 'come and go' pattern and may get worse after periods of exertion. The presence or worsening of these unusual sensations does not necessarily mean your MS is progressing. If symptoms are severe, affecting your sleep or functional ability, you should discuss with your MS specialist.

Depression



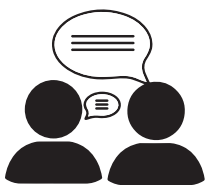
Like fatigue, depression may be a primary symptom of MS as well as a secondary symptom. That means it can be part of the disease process (primary) as well as a result of difficult circumstances of living with a chronic disease (secondary). In either case, there are a range of treatment options for depression. If you are feeling depressed or hopeless, or have noticed a change in your sleeping or eating patterns, be sure to consult your physician. No one needs to cope with depression alone.

Cognitive Changes



Some degree of cognitive changes are common in people with MS. Mild cognitive changes may occur early in the MS disease course. These changes can include problems with attention, processing information quickly, multi-tasking, memory, problem-solving, and new learning. Cognitive symptoms may worsen with increased MS-related fatigue. Cognitive changes are not always obvious to the person living with MS, yet may be noticed by others. Cognitive changes can also occur normally as people age. Talk to your physician if there is concern about cognitive changes. It is important to rule out preventative or treatable causes for cognitive symptoms. There may be strategies that can be put in place to decrease the risk or impact of cognitive symptoms on your health and safety.

Speech



Speech disorders may occur in MS because speech is controlled by many areas in the brain. Lesions can cause different types of changes in speech such as pauses or slurred speech.

Speech difficulty can range from mild to severe problems that make it difficult to speak and be understood. Speech therapy for people with MS may focus on strengthening speech muscles and learning adaptive strategies.

Pain



On research questionnaires about MS symptoms, about half of people surveyed have reported pain that is severe enough on a pain scale to be considered “clinically-significant.” That may translate into pain that interferes with quality of life or activities of daily living.

Neurological pain can present in many different ways but is more typically burning, tingling or shooting in quality. It may fluctuate in intensity over seconds, minutes or days. People with MS can also experience muscle pain. This kind of pain can be a result of muscle spasms and is directly caused by damage to the central nervous system. Pain in the muscles, joints, tendons and bursa may also be related to immobility, over-use injuries or arthritis. An evaluation to pinpoint the source of the pain is essential to help find the best treatment or preventative approach to minimize pain. Pharmacotherapies (drugs), keeping a positive mental attitude and regular physical activity all help to manage pain and reduce the impact of pain on your life.

Muscle Spasticity and Weakness



Spasticity refers to a sense of muscle stiffness or tightness, and sometimes painful muscle spasms. Muscle weakness is a primary symptom of MS caused by damage to the central nervous system. The signal from the brain to properly activate the muscle is disrupted, causing weakness. Muscle weakness is also often secondary to lack of use of a limb or muscle. People may develop a routine of not using a limb or muscle if it is already weaker, fatigues quickly, is painful or clumsy. Weakness from lack of use is often reversible with physical activity (exercise) while severe weakness caused by direct damage to the central nervous system less often improves with exercise. Spasticity can be managed using a variety of treatment approaches including stretching and medications.

Balance and Coordination



These problems can be a primary symptom resulting from damage to a part of the brain called the cerebellum. Problems with balance or trouble walking can also be secondary, caused by other things happening in your body such as muscle weakness or tightness, fatigue, or sensory problems like numbness in your legs or feet. A physical therapist may give you special exercises to help you adjust to sensations of loss of balance. Other management strategies

“Sometimes I feel like we are whining or complaining, when generally we are just trying to explain. For example when we say fatigue – it doesn’t really explain to people how we feel. Fatigue honestly sounds like tired. Exhausted works better. Feeling like a bag of wet cement maybe. My support group was just talking about how we are so short with our spouses some days and it tends to be not only because of the fatigue we feel, but also the guilt. The guilt we feel about having MS – that we are weighing down our families and friends with it.”

~Rhea, diagnosed in 2015

may include medications, exercise and stretching, and proper use of mobility aids like canes or walkers. Falls can be a serious health risk for people with MS, so people having trouble walking should get help and advice from health care providers.

Vision



Vision problems are often among the first symptoms that people with MS notice, sometimes even before MS has been diagnosed. Possible problems include uncontrolled eye movements, blurred vision, double vision, or spots that seem to partially obscure vision. Vision problems may be due to damage to the optic nerve. Vision difficulties such as double vision may also be affected by fatigue, increases in temperature, stress, or infection. Treatments for vision problems are usually quite effective.

Sexual Dysfunction



Changes in sexual function can occur in MS. For women, these can include impaired genital sensation, diminished orgasmic response, loss of interest, weak vaginal muscles, and a lack of lubrication. For men, these can include impaired genital sensation, decreased sex drive, difficulty achieving an erection, and delayed or decreased ejaculation. There can also be a significant impact on a person's sexual self-esteem and body image. Depression and fatigue can also impact a healthy sexual life. Much can be improved through medication and counseling. Although it may be embarrassing, it is important to discuss with your care team.

Bladder & Bowel Problems



Problems such as urinary urgency, incontinence (leaking urine), retention (not being able to empty the bladder) and recurrent bladder infections may occur in MS. Constipation is common and diarrhea is less common but also occurs in MS. While there are several medications available, proper nutrition plus adequate fiber and fluid intake can be very helpful.

Difficulty Swallowing



Difficulty in swallowing is a symptom that is more common in advanced disease, but it can occur at any stage. If you persistently cough after drinking liquids, or choke while eating certain foods, it should be brought to the attention of your health care team.

Treating Symptoms

	THINGS YOUR DOCTOR CAN DO	THINGS YOU CAN DO	OTHERS WHO CAN HELP
FATIGUE	<ul style="list-style-type: none"> » Investigate and manage other causes (depression, hypothyroidism, anemia, drug effects) » Prescribe medication 	<ul style="list-style-type: none"> » Regular exercise » Planning and pacing strategies » Lifestyle changes » Get adaptive equipment 	<ul style="list-style-type: none"> » Occupational therapists » Psychologists » MS nurse specialists » Physiotherapists
MOOD	<ul style="list-style-type: none"> » Investigate and manage other causes (drug effects, financial stress) » Prescribe medication 	<ul style="list-style-type: none"> » Participate in group mental health programs or peer support groups » Talk to family and social supports » Regular exercise 	<ul style="list-style-type: none"> » Psychologists » Psychiatrists » Social workers » Community mental health services
COGNITION	<ul style="list-style-type: none"> » Investigate and manage other causes (mood disorders, poor sleep, fatigue) » Rule out current medications as cause of change in cognition 	<ul style="list-style-type: none"> » Regular exercise » Mental activity (puzzles, novel mental tasks) » Awareness and compensatory strategies (note-taking, alarms or reminders to compensate for poor memory) 	<ul style="list-style-type: none"> » Occupational therapists » Psychologists » MS nurse specialists
PAIN	<ul style="list-style-type: none"> » Investigate and manage other causes (infection, co-morbidity) » Prescribe medication 	<ul style="list-style-type: none"> » Regular exercise » Coping strategies (meditation, increasing sense of control over pain) » Topical creams for areas of local muscle or joint pain 	<ul style="list-style-type: none"> » Physiotherapists » Psychologists » Psychiatrists » Pain specialists » Massage therapists
WEAKNESS	<ul style="list-style-type: none"> » Refer to physiatrist for assistive devices (cane, brace, shoe inserts, walker) » Prescribe exercise 	<ul style="list-style-type: none"> » Regular exercise » Stretching » Strategies for safety and fall prevention at home and work 	<ul style="list-style-type: none"> » Physiotherapists » Physiatrists » Occupational therapists
PARESTHESIA	<ul style="list-style-type: none"> » Investigate other causes » Prescribe medication 	<ul style="list-style-type: none"> » Regular exercise » Keep track of patterns or positions linked to altered sensations » Strategies to safely compensate for altered sensation 	<ul style="list-style-type: none"> » Physiotherapists » Physiatrists » Occupational therapists

“Learn what energizes you. I have more energy when I’m around people, but others need alone time to recharge. Aim for consistency in sleep, activity levels, and eating, but let yourself break the rules sometimes so you feel normal and can stick to it long term.”
 ~Nicole, diagnosed in 2012

	THINGS YOUR DOCTOR CAN DO	THINGS YOU CAN DO	OTHERS WHO CAN HELP
BLADDER	<ul style="list-style-type: none"> » Prescribe medication 	<ul style="list-style-type: none"> » Kegel exercises » Bladder care strategies (timed toileting, double voiding, avoid bladder irritants) 	<ul style="list-style-type: none"> » Urologists » Pelvic floor physiotherapists
BOWEL	<ul style="list-style-type: none"> » Recommend stool softeners, laxatives or anti-diarrheals 	<ul style="list-style-type: none"> » Healthy bowel habits (hydration, regular fiber intake) » Regular exercise and Kegel exercises 	<ul style="list-style-type: none"> » Pelvic floor physiotherapists » Gastroenterologist
SPASTICITY	<ul style="list-style-type: none"> » Rule out or treat conditions that can worsen spasticity (e.g. pain, urinary tract infections) » Prescribe medication » Refer for special procedures (e.g. Botox) » Refer for pain pumps or intrathecal pumps 	<ul style="list-style-type: none"> » Regular exercise » Regular stretching of affected muscle groups 	<ul style="list-style-type: none"> » Physiotherapists » Physiatrists
SEX	<ul style="list-style-type: none"> » Investigate and manage other causes (pain, mood) » Prescribe medication » Refer patient/partner to sexual health clinic 	<ul style="list-style-type: none"> » Discuss problem with doctor and with therapists » Sexual aids (vibrators, lubricants, stimulators) 	<ul style="list-style-type: none"> » Psychologists » Physiatrists » Sexual health specialists
SLEEP	<ul style="list-style-type: none"> » Rule out sleep apnea, or treat sleep apnea (CPAP) » Recommend medication (short term only) 	<ul style="list-style-type: none"> » Sleep hygiene (regular sleep and wake times, avoid screens before bed, avoid caffeine after 2 p.m., etc.) 	<ul style="list-style-type: none"> » Respiriologist

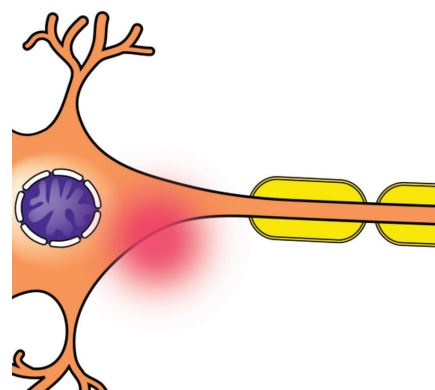


What MS symptoms have you experienced? Keep notes about your symptoms, when they started, what affects them, and what kinds of treatments work best for you.

Managing a Relapse

A frequent concern for people newly diagnosed with relapsing-remitting MS is the prospect of having a relapse. A relapse is a relatively sudden episode of new symptoms or worsening symptoms lasting more than 24 hours, in the absence of other factors such as heat, illness, infection, stress, or fatigue. The episode may last for a period of time (days, weeks or months) and then improve partially or completely. Relapses are most common in the first few years after being diagnosed with MS, but people can experience a relapse at any time.

A relapse is caused by inflammation in the fibers of the central nervous system. Inflammation usually goes away by itself, and then the relapse subsides. If your relapse is quite severe, your neurologist may prescribe a dose of steroids or other treatment. In general, treating inflammation leads to faster recovery from the relapse, but does not affect the course of the disease in the long term.



This illustration shows inflammation in a nerve cell. Most MS medications are designed to prevent inflammation and therefore prevent relapses.

You may be having a relapse if your MS has been relatively stable for at least 30 days and then:

- **You notice a change in symptoms -- old MS symptoms become worse or new symptoms appear. (It does not feel like part of the normal day-to-day fluctuation in how you feel.)**
- **The symptoms (or worsening) last for more than 24 hours**
- **There is no other explanation for the symptoms (like stress, exertion, cold or flu, arthritis, etc.)**

Any MS symptom could be associated with a relapse, but the most common ones include optic neuritis (blurry vision in one eye, poor colour vision or pain with eye movement), weakness or sensory changes in one or more limbs, relatively sudden onset of dizziness and incoordination, bladder or bowel changes, and noticeable changes in cognition such as memory and concentration. You may experience one or several of these symptoms together during a relapse.

Whatever symptoms you experience, they often get gradually worse over a period of a few days, or longer, and then level off. Eventually, the symptoms will usually subside, and you will start to gradually recover. Sometimes the symptoms of a relapse go away completely but, in other cases, they may not fully disappear.

What should I do if I have a relapse?

If you are not sure whether you are having a relapse, consider if there may be an external factor other than MS contributing to your symptoms (such as illness or infection). If the symptoms are not severe, it is reasonable to wait for a day or two to see if your symptoms improve.

Relapses can be a sign that your MS is more active, so it is important to report each one. If your MS is becoming more active, your medical team may want to change your treatment.

Ask your neurologist who to contact if you think you are having a relapse. It is important that you have a plan and know what to do if you experience worsening symptoms, even if you are not sure it is a relapse. It may be possible for you to see someone in an MS clinic or talk to someone on the phone on short notice.

Whomever you speak to will ask you about the symptoms you are experiencing, when they started, what has changed and how severe the effects are. You may not see the neurologist in person every time you have a relapse, but your MS team will keep a full record of your relapses and symptoms, and advise you on who to see for symptom management.

It can be worrying when you experience a relapse, but don't panic. It will usually settle down on its own. You may feel unwell and more tired than usual, so let your family and friends help you out. Be aware of sick leave provisions at work and talk to a social worker about other types of support programs that might be available.



Do you know who to contact if you think you are having a relapse?

Wellness

Most people newly diagnosed with MS want to know what they can do to maintain their own health. That is an excellent question. There are steps you can take that improve MS outcomes and let you take more control of the disease. Many people find they can improve their quality of life and sense of well-being by focusing on aspects of health that can be controlled and changed. Knowledge about MS is growing, including knowledge about how physical and mental wellness can influence the disease course.

Use credible on-line resources, peer networks, the MS Society and your health care providers to stay up-to-date about new recommendations and ideas for wellness activities.

Healthy Body

Diet



Eating a healthy diet and maintaining a healthy weight is, of course, good advice for everyone. People with MS may additionally find that diet plays a role in managing symptoms such as fatigue, constipation, pain or weakness. There is no clear evidence to date that specific dietary restrictions (of gluten or dairy products for example) are beneficial for MS. However, it is possible to have food allergies or other conditions, apart from MS, that affect your tolerance of certain foods. Pay attention to the kind of diet that works best for you personally.

Research into the properties of individual nutrients such as fats, phytochemicals or vitamins and how they interact with processes related to MS is a topic of great interest to people living with MS. It can be complicated to translate this research into dietary recommendations (outside a laboratory) but it contributes to increasing knowledge about the relationship between nutrition and MS. To date, research supports Vitamin D supplementation of around 4000 IU per day, which may be linked to fewer relapses. Discuss supplementing your Vitamin D with your doctor.

There are several popular claims about what diet is best for MS. In the absence of consistent scientific evidence, most health care providers will recommend a common-sense diet with lots of fruits and vegetables, and controlled intake of fat, salt and overall calories. If you decide to try a specific diet plan just be sure that essential nutrients are not overly restricted or omitted from your diet, and keep your health care team informed.

“My life hack is to start exercising. You may feel fatigued at first but slowly build up your cardiovascular, flexibility and balance. It is like putting money in the bank. Someday you are going to need it.” ~Debby, diagnosed in 2000

Exercise



Thirty years ago, if you were diagnosed with MS, you would have been told to stay away from any physical exertion, but we now know it is very important to remain physically active. The Canadian exercise guidelines for people with mild to moderate MS recommend a minimum of 30 minutes of aerobic activity twice a week and resistance training of the major muscle groups twice a week. More recent evidence suggests maintaining core strength is especially important for maintaining walking function and independence.

Sometimes exercise may temporarily worsen fatigue or weakness in the short term. However, in the longer term (over weeks or months) most studies support that exercise improves walking function and may reduce pain, fatigue and mood symptoms. Exercise is safe for individuals living with MS, and increased strength, mobility, bowel and bladder function are just some of the benefits shown in research. Exercise has also been found to be neuroprotective (prevents or slows down destruction of nerve cells).

If you aren't already doing so, start an exercise regime as soon as possible after receiving a diagnosis of MS as part of improving your overall wellness and quality of life. Starting an exercise regime slowly and increasing activity over time will increase your chance of success. It is common to need support to stay physically active or to find a routine that works with your MS. Referral to a physical therapist or exercise therapist with experience in MS can help you get started and stay on track.

Brain Health



Loss of brain tissue or atrophy occurs to all of us as we age; it is also part of MS as a disease. However, the brain can compensate for some of this damage by rerouting signals or adapting healthy areas of the brain to take on new functions. This built-in repair mechanism is known as “neurological reserve” or “brain health.” Current medical consensus emphasizes the importance of preserving healthy tissue in the central nervous system in order to support the brain’s natural ability to compensate for damage caused by MS.

One way of preventing deterioration is by early treatment to prevent and reduce disease activity. Another way is by taking steps to maintain general wellness – including a healthy weight, positive attitude and active lifestyle – which is associated with a healthy brain. In addition, there are some types of mental activity that promote brain health, such as reading books and magazines, writing in a diary, playing games or doing puzzles, learning to use new tools and technologies, playing a musical instrument, socializing, or taking up new hobbies.

Any mental activity is good, but learning and trying new things is best.

Primary Health Care



People who have MS are unfortunately still just as likely as anyone else to suffer from other common health conditions in Canada – such as hypertension (high blood pressure), obesity, high cholesterol, or viral infections like colds and flus. Comorbid conditions (more than one condition at the same time) can have a negative effect on the progression of MS. So people with MS need to be careful to get regular preventative care, get the vaccines recommended by your health care team, and take medications as prescribed to control any other health conditions.

Smoking Cessation



People with MS should not smoke. Yes - it can be very difficult to quit. Speak to your physician or pharmacist for access to medications and resources to help you make and stick to your plan. But most research says that no matter how long you have smoked, you will see immediate and lasting benefits to your health and finances and eventually you will be happy that you quit. Smoking not only worsens several MS symptoms but also worsens the course of other comorbid conditions such as heart disease and stroke, which are common causes of death for people with MS.

“To manage my MS I used to feel that staying physically fit was the most important thing. Though, yes, it is important, I have learned that maintaining your mental health is equally as important, if not more. Whether it be acupuncture, a body talk session, coffee with a friend, yoga, a nap, reading a book, a hot bath, writing in a journal....Things like that help to remind me that life is good.” ~Lacey, diagnosed in 2004

Healthy Mind

A wellness-oriented lifestyle involves the recognition that you have physical, emotional, social, and spiritual needs that are all necessary for optimal functioning. The good news is that just like physical health, there are things you can do to improve your mental health and to stay mentally well whatever your situation or diagnosis.

Mental Health Care



Research suggests at least half of people with MS will experience mental health symptoms at some point, most commonly depression or anxiety. People with a family or personal history of these conditions are more vulnerable. It is important not to ignore these symptoms, as they can become part of a cycle of worsening physical and emotional health.

If you feel low or anxious most of the time, have trouble sleeping and have little or no interest in life, you may benefit from medication or other treatment approaches. If your symptoms are more variable or you are already on medication, research shows that mental health therapies such as counselling, group therapy or on-line therapy are also beneficial. You can also explore mental fitness strategies such as positive self-talk.

MS can affect regions in the brain that control emotions, so people living with MS may also experience changes in mental health that are neurological rather than the result of life events.

Spirituality



Different people prefer different sources of support. Religious faith is important to some people. Spirituality, in its broadest sense, will be important to others and can include practices such as meditation, yoga, tai chi or mindfulness. These practices can help to induce calmness and mental clarity. They can focus attention on the present moment rather than worrying about what has happened in the past or might happen in the future. Spiritual practices can also help with managing stress and symptoms including pain, anxiety and depression.

Social Engagement



Social isolation and loneliness are not uncommon in MS (and many other chronic conditions that cause disability or depression). Keeping in regular contact with friends and meeting other people helps to keep difficulties in proportion. Connecting with resources like the MS Society of Canada peer support groups, online or social media groups, or MS group exercise classes can help to build your support network and connect with others who live with MS.

Skills and Tips for Managing MS

How to get the Most out of Your Appointments

Seek out good information about MS and its management—the more you know, the more prepared you'll feel to make the treatment and lifestyle choices that work for you. Find a physician with whom you are comfortable. Any doctor can prescribe medication and provide periodic examinations. Having a physician who can discuss personal matters and explain complex issues is another matter. It is legitimate to shop for a doctor who is knowledgeable about MS and able to spend time listening and educating patients.

These are some tips to help get the most out of your neurologist appointment:

- **Keep a diary in between visits.** If you are only seeing your neurologist once every six months or once a year, keeping a diary or notes can to remember what was discussed.
- **Prepare an update for your doctor on what has happened since your last visit.** Write out a few short points that summarize how you have been feeling since your last visit. Be short and to the point, but don't leave out anything that might be of importance.
- **Make sure to tell your doctor about:**
 - » how your MS symptoms are affecting you and/or your quality of life.
 - » any lifestyle adjustments you've made, including diet, exercise, and supplements.
 - » any alternative providers you are seeing, such as acupuncturists, chiropractors, massage therapists.
- **Make a list of questions.** You may have heard the saying, "There is no such thing as a stupid question." There is no question about your health that you should be afraid to ask your doctor. Even if there is something happening that is potentially embarrassing, remember that your doctor has seen and heard everything you could possibly say. List all your questions, including possible follow-ups because not asking can cause anxiety down the road.
- **Ask your most important questions first.** Make sure that you prioritize your questions or concerns so that the most important things get addressed in case time runs out.
- **Have someone come along with you to appointments.** This person can not only take notes, he or she can also remind you of questions and give you the courage or support that you need to ask the question and any clarification that you might need. Also, if this person is a family member, they may have very important details about you to contribute to the discussion.

"Make a list of your symptoms that you hope to improve before you talk to your doctor. There are many symptoms that can be helped, and you may be surprised what can happen if you just ask. For example, if you let your doctor know that you are having trouble sleeping, he or she may simply change the time of day you take a medication, which may make a big difference."
~Michelle, diagnosed in 1992

- **Take notes.** If you will be going to your appointment alone, make sure that you bring a pen and paper. You can also ask your doctor permission to record his answers to the questions you have. Taking notes on your smartphone or mobile device can also be very handy. Do not hesitate to ask the doctor to repeat important information or spell words that you don't understand. It may take an extra 30 seconds or so, but it's important that you get it right.
- **Be respectful and advocate for yourself.** Your care providers are often busy and may seem like they are hurried, but it is important for you to advocate for your health.

Maintain Strong Bonds with Family and Friends

Strong connections with others are an important ingredient in a fulfilling life whether one has MS or not. Most of us need to know we are loved and cared for, and we also need to love and care for others who are important to us. Although MS may alter some of the things you're able to do with and for other people, it's important to maintain meaningful relationships in which you're on both the giving and receiving end.

“About two months post diagnosis a friend of mine linked me to someone who had been living with MS eight years already. He felt comfortable talking about his journey and I was comfortable asking him all those questions I was finally ready to ask. It's comforting to talk to someone who knows what you are going through.

“I found prayer, meditation and journaling very helpful while coping with the news. I'm also very fortunate to have the most supportive family and friends!” ~Jill, diagnosed in 2018

Sharing Your Diagnosis

Sharing your diagnosis is a very personal decision. It is OK to take some time to think about who you share your diagnosis with. If and when you decide to do so, you can start with a simple explanation of the disease and how it is affecting you at this time. “Someone you know has MS” (MS Society USA) is an example of a booklet that helps to explain MS to children. In addition to sharing your diagnosis with family and friends, you may need to have important conversations with your employer. Resources also exist to help with this. Legally, you are not required to disclose your diagnosis unless you are asking for job accommodation.

“Learning to manage your energy is important. If you have more on your plate than usual or you are planning a late night out, don't plan anything else for that day and give yourself recovery time after. When it comes to exercise, anything is better than nothing. Have physical activity goals and follow guidelines, but don't get down on yourself or give up if you can't meet them every day. ~Nicole, diagnosed in 2012

Pace Yourself

Taking everything one day at a time allows you just to focus on how you are feeling that day and what you need to accomplish. If it's a “good” day, then try enjoying it and do what you can. If it's a “bad” day, then you just need to prioritize and only do what you really have to. Anything that doesn't need to get done that day can wait for another day.

Accept Help

Learning to accept help from others is important to lessen your burdens and increase the quality of your life. Stay safe, reach out, and let people in -- especially if you are struggling mentally or physically. Others know you are dealing with an MS diagnosis and just want to help however they can.

Keep a Sense of Purpose by Setting Goals

Personal goals help point you in the direction you want to go and provide a feeling of accomplishment and pride when you get there. An unpredictable disease that saps your energy and alters your ability to get things done can make progress towards your goals more difficult. It may even make it necessary for you to re-think previous goals and develop new goals over time. Whatever course your MS takes, it's important to set your sights on things that are important to you. Working toward your personal goals—whatever they may be—will help you maintain your self-confidence and self-esteem, and feel more in control.

“The big thing I tell everyone when they say I am pretty upbeat about my diagnosis is that I have one life. And I deserve to still have a great version of it. But I had to grieve my old dreams, my old plans, and I had to come to terms with the idea that I would need to find new goals and new ways to achieve a really satisfying life.” ~Rhea, diagnosed in 2015

“When I was diagnosed with MS I was initially very mad and sad. I thought what kind of life will I have now? But when I learned to pace myself, not overdo it, I found I could manage this MS monster.

I competed for rodeo queen contests and won two titles. Another one of my dreams was to be a flight attendant and I went on to do this too. I flew all over the world and saw so many amazing places. I also met the man of my dreams. Mutual friends of ours set us up on a blind date and we hit it off instantly.

“After being diagnosed for over 26 years, I now live with worsening disability. My advice is to set your pride aside and use the devices that are available to make your quality of life a little easier. This will help your stress levels too. Once I got past my pride and realized I needed the cane/walker/scooter to get around with, it made my life so much easier.”

~Michelle, diagnosed in 1992

Work together

You and the neurologist are both experts on your MS, but in different ways. It is possible that you may not always see eye to eye. It is important to maintain a good relationship and be respectful of each other, even though your opinions about your MS and treatment may differ.

■ Progressive Disease

There are a few different scenarios where you could be dealing with a progressive form of multiple sclerosis. If you get an initial diagnosis of primary progressive MS (PPMS), you can expect accumulation of disability, without any defined relapses. The rate of the disability accumulation is unique to you but generally the accumulation is gradual over years. With secondary progressive MS (SPMS), the distinctive relapses and remissions become less apparent. The disease progression may be more obvious and steady or it may be slow and subtle for some people.

The disease-modifying drugs that are prescribed for relapsing remitting MS are, unfortunately, usually not helpful for people with progressive MS. That is because most MS drugs control the disease by controlling inflammation that causes relapses, and progressive MS doesn't have much inflammatory disease. However, cases of progressive MS with superimposed inflammation may benefit from treatment. More research is being done. Since there are currently few therapies for progressive MS, some people at this stage start to feel that there is nothing to help them. It is important to remember that even if there is not a way to change the course of the disease, there are many resources available to help people with progressive forms of MS reduce the risk of losing function and live the best life possible with MS.

People facing a diagnosis of progressive disease may wonder if they are going to become disabled. Progressive MS often goes along with stiffness or weakness in legs that starts out causing minor problems with leisure activities or climbing stairs, but over time can get worse and interfere with basic mobility and activities of daily living. Rehabilitation resources are particularly important for helping people with progressive MS to maintain physical function.

Starting from the time of diagnosis, rehabilitation professionals (such as physiatrists, physiotherapists, and occupational therapists) can be involved in developing wellness, conditioning and preventative strategies to promote and maintain health, reduce fatigue, and help you function optimally at home and at work. If symptoms begin to interfere with everyday activities, rehabilitation can address problems with mobility, dressing and personal care, driving, functioning at home and work, and participation in leisure activities.

People with progressive MS should also do their best to maintain their general health through diet and exercise, be proactive about managing any health concerns, and take advantage of all services available for symptom management.

Even your MS neurologist or doctor cannot predict what will happen in your future. Every person's disease course is different. However, no matter your scenario, accessing the resources right for you can help make each day a better day.

Glossary

Cerebellum – a specialized part of the brain (located at the back of the skull between the cerebrum and brain stem) largely involved in controlling muscle coordinate and balance

Cognitive function (cognition) – the process of thinking and understanding. It refers to multiple mental abilities including attention, problem solving, reasoning, perception, and remembering.

Chronic disease – In medicine, a chronic disease is an umbrella term for a number of conditions that typically cannot be prevented or cured, have a complex causality (multiple factors lead to onset), and result in functional disability over time

Demyelination – the loss or breakdown of myelin

Myelin – an insulating layer of tissue that surrounds and protects nerve pathways and serves to increase speed of nerve conduction/signal communication

Neurodegenerative – the progressive loss of structure or function of the nervous system over time

Neurologist – a medical doctor who specializes in treating diseases of the nervous system. The nervous system is made of two parts: the central and peripheral nervous system. It includes the brain and spinal cord. Illnesses, disorders, and injuries that involve the nervous system often require a neurologist's management and treatment

Neurology – the science of the nerves and the nervous system, especially of the diseases affecting them

Pathophysiology – the science of cause, effects and behaviour of disease that aims to describe the condition as well as the functional changes associated with or resulting from that condition.

Physiatrist – A medical doctor who specializes in rehabilitation and restoring optimal function to people with impairments of muscles, bones, tissues, or the nervous system

Spasticity – a type of increased muscle tone causing muscles to feel stiff, heavy and difficult to move.

List of abbreviations

MS – multiple sclerosis

MRI – magnetic resonance imaging (brain imaging)

RRMS – relapsing-remitting MS

PPMS – primary progressive MS

SPMS – secondary progressive MS

CIS – clinically isolated syndrome

DMT – disease-modifying therapy

Resources

MS Comprehensive Information

- www.mssociety.ca
- www.msology.ca
- www.nationalmssociety.org (USA)
- www.mstrust.org.uk
- www.msbrainhealth.org
- [Saskatchewan MS Care Pathway \(search “Sask MS pathway” in your web browser\)](#)

Contacts for Care Providers and Supports

- Saskatchewan MS Care Pathway at www.sasksurgery.ca/patient/MS.html
- Saskatoon MS Clinic phone 306-655-7742
- Sask MS Drugs Program Nurse Educator phone 306-655-8673/ Fax 306-655-8404, e-mail Shirley.macgowan@saskhealthauthority.ca or call the MS Drugs Program toll free at 1-866-655-7966
- For assistance in finding a neurologist or other specialist, consult the MS Society or see the College of Physicians and Surgeons directory at www.cps.sk.ca.
- For assistance in finding primary health care physicians and services, contact the Saskatchewan Health Authority <https://www.saskhealthauthority.ca/Services-Locations/Pages/Home.aspx>.
- Multiple Sclerosis Society of Canada’s MS Knowledge Network phone 1-844-859-6789 or e-mail: msnavigators@mssociety.ca or web chat with navigators from 8 a.m. to 8 p.m. ET at www.mssociety.ca

Peer Support Groups

- Southern Saskatchewan contact: info.sask@mssociety.ca 1-306-522-5600 or province-wide toll free 1-800-268-7582
- Central/Northern Saskatchewan contact: info.sask@mssociety.ca 1-306-244-2114

Clinical Trials Accepting New Participants

- www.msresearch.ca

Other Resources

You can do online searches for any topic in this booklet and you will find almost unlimited information, news, recommendations, suggestions and opinions. Some tips for evaluating internet resources are:

- Who are the authors and what is their expertise?
- Has this information been published and if so where?
- Is this a “one-off” or are there other reliable sources that seem to back up this information?

In general, the most credible Internet resources are those associated with health agencies and medical organizations. If you are in doubt, ask your health care team or people you trust.