

Connecting with Community

What is multiple sclerosis (MS)?

What does MS Canada do to support people affected by multiple sclerosis?

How can you get involved to support our efforts?

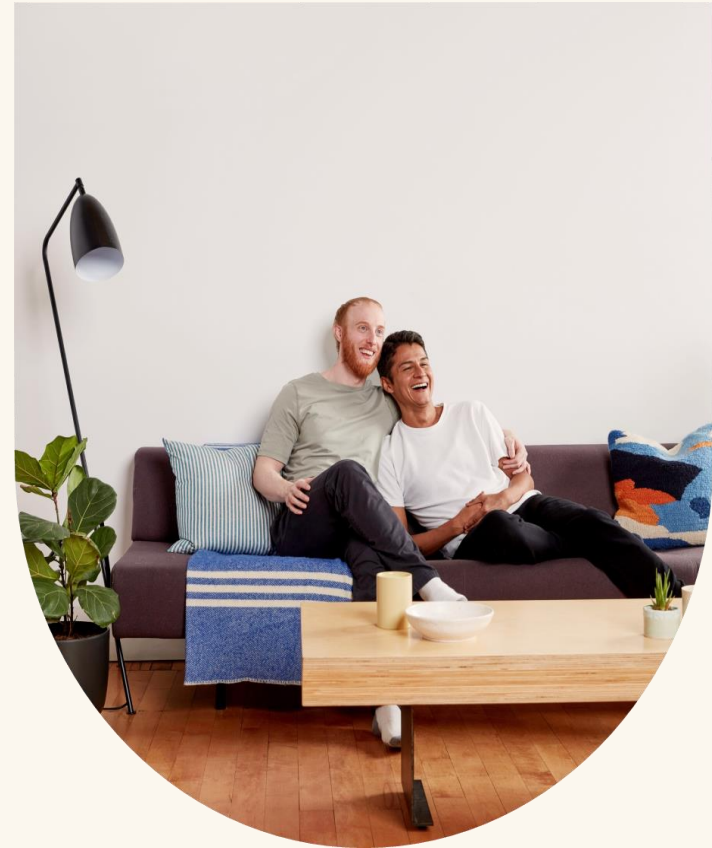
MS Canada

Who We Are

We're here for the estimated 90,000 Canadians living with an MS diagnosis.

Our Vision: **A world free of multiple sclerosis (MS).**

Our Mission: **To connect and empower the MS community to create positive change.**



Richard (right), lives with MS, and husband Marc



MS Facts

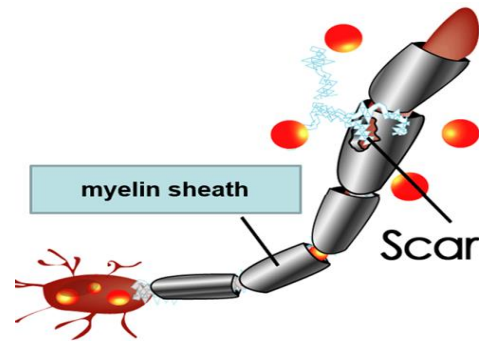
- **Canada has one of the highest rates (per capita) of MS in the world** - over 90,000 Canadians live with multiple sclerosis
- on average 12 Canadians are diagnosed each day
- **MS is the most common, non-traumatic cause of neurological disability in young Canadians**
- 60% of adults who are newly diagnosed are between the ages of 20-49
- **women are three times more likely to be diagnosed than men**
- there are approximately 2.8 million people living with MS around the globe
- **every 5 minutes someone in the world is diagnosed with MS**
- about 3%-5% of people with MS experience their first symptoms before adulthood
- globally, there are approximately 30,000 children and youth, 18 years and younger, living with MS
- If you have a parent or sibling with MS, you have a 1-3% chance of developing it. An identical twin with MS raises your risk to 30%.

What is multiple sclerosis (MS)

MS is a chronic autoimmune disease of the central nervous system (CNS) – brain, spinal cord and optic nerve.

It is thought that the immune system malfunctions and attacks cells and tissues within the CNS, which orchestrates an inflammatory response that damages and/or destroys:

- **myelin** – *the insulating substance wrapped around the nerve fibers (axons)*
- **axons**
- **oligodendrocytes** - *the myelin-making cells*



What causes multiple sclerosis?

Causes are *not* fully understood, but current research increasingly points to a complex interplay of genetics combined with lifestyle and environmental risk factors.

We do know:

- ✓ MS is *NOT* considered hereditary
- ✓ MS is *NOT* contagious
- ✓ life expectancy is near normal for vast majority
- ✓ adjustments to lifestyle can help disease outcomes

Lifestyle: smoking, obesity, deconditioning, poor diet

Environment: Vitamin D deficiency, Epstein-Barr Virus



Diagnostic Process



Medical History: signs, symptoms, family history

Neurological Examination: eyes/facial movements, reflexes, limb strength, sensation, coordination

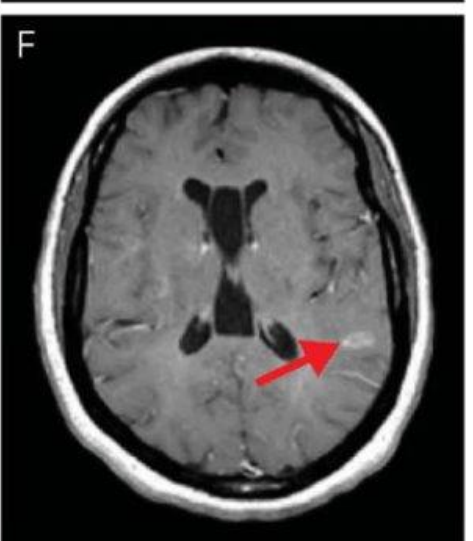
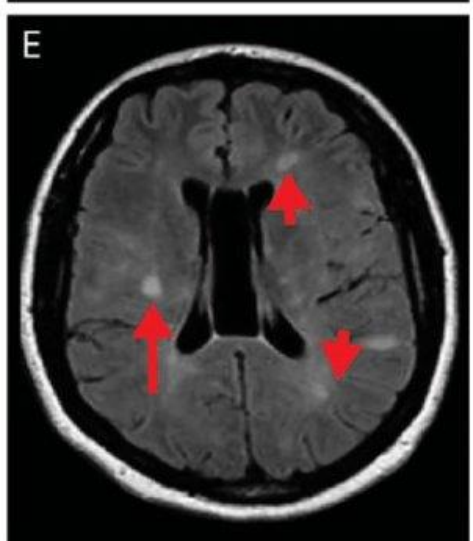
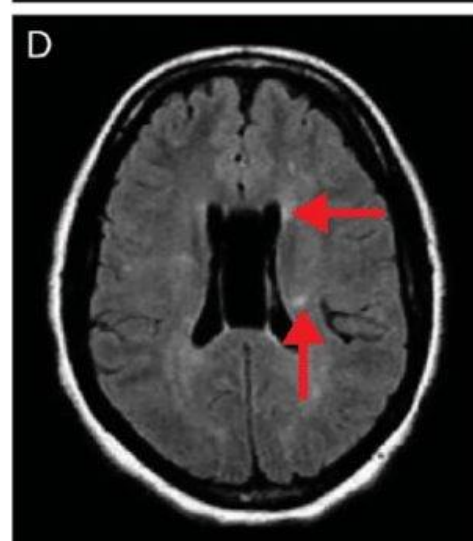
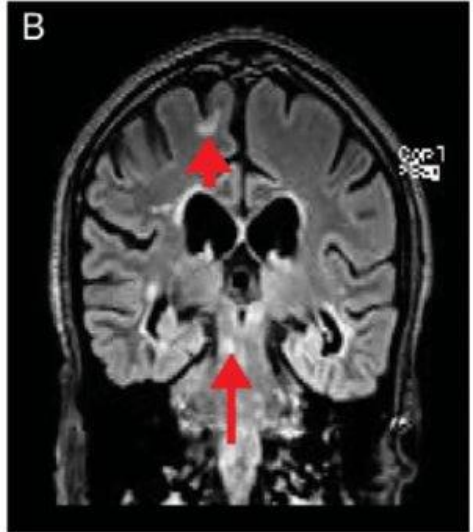
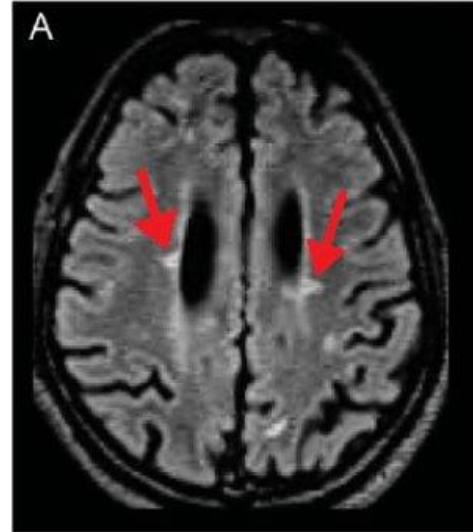
Evoked Potentials: measure how quickly nerve impulses travel along the nerve fibers in various parts of the central nervous system, after receiving different stimulus

Lumbar Puncture (Spinal Tap): examines spinal fluid, for increased levels of immunoglobulin and oligoclonal banding

MRI: looks for areas of abnormality in the brain and spinal cord

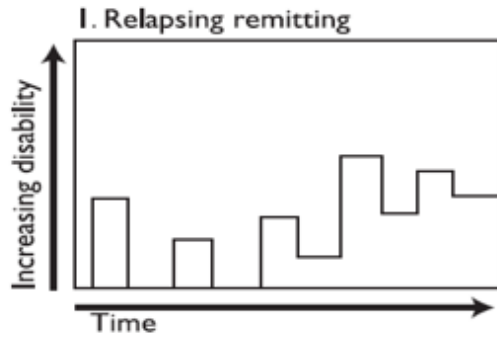


A world free of MS

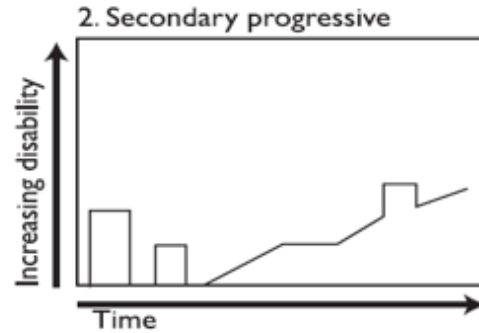


MRI Imaging

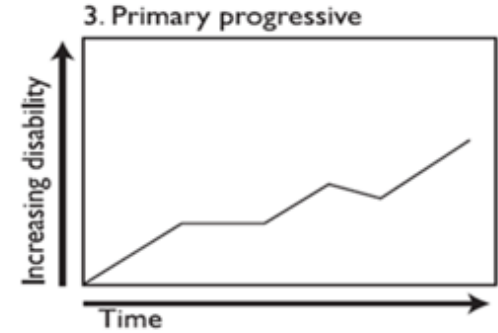
Types of MS



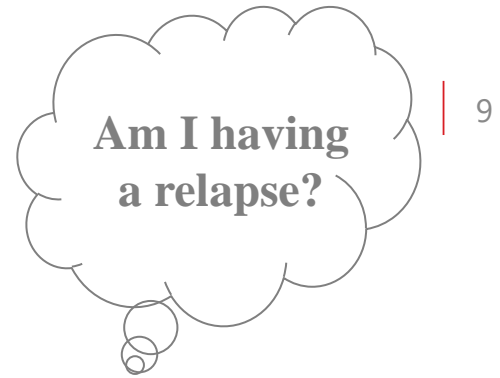
~ 85% of newly diagnosed have this type



~ ½ diagnosed with RRMS will move to SPMS within 20 years



What is an MS relapse?



- also called attack, exacerbation, flare-up
- during a relapse new symptoms appear, existing ones get worse, or perhaps previously experienced symptoms re-occur
- lasting at least 24-48 hours in absence of other illness or infection
- can last days, weeks, or several months

** each person will have attacks that vary in symptoms and duration*

MS Symptoms

Invisible:

- fatigue
- pain
- visual problems
- sensory dysfunction
(numbness, tingling, pins & needles, itch)
- cognitive impairment
- mood alterations
- depression
- bladder and bowel problems
- dizziness
- headache
- sexual dysfunction



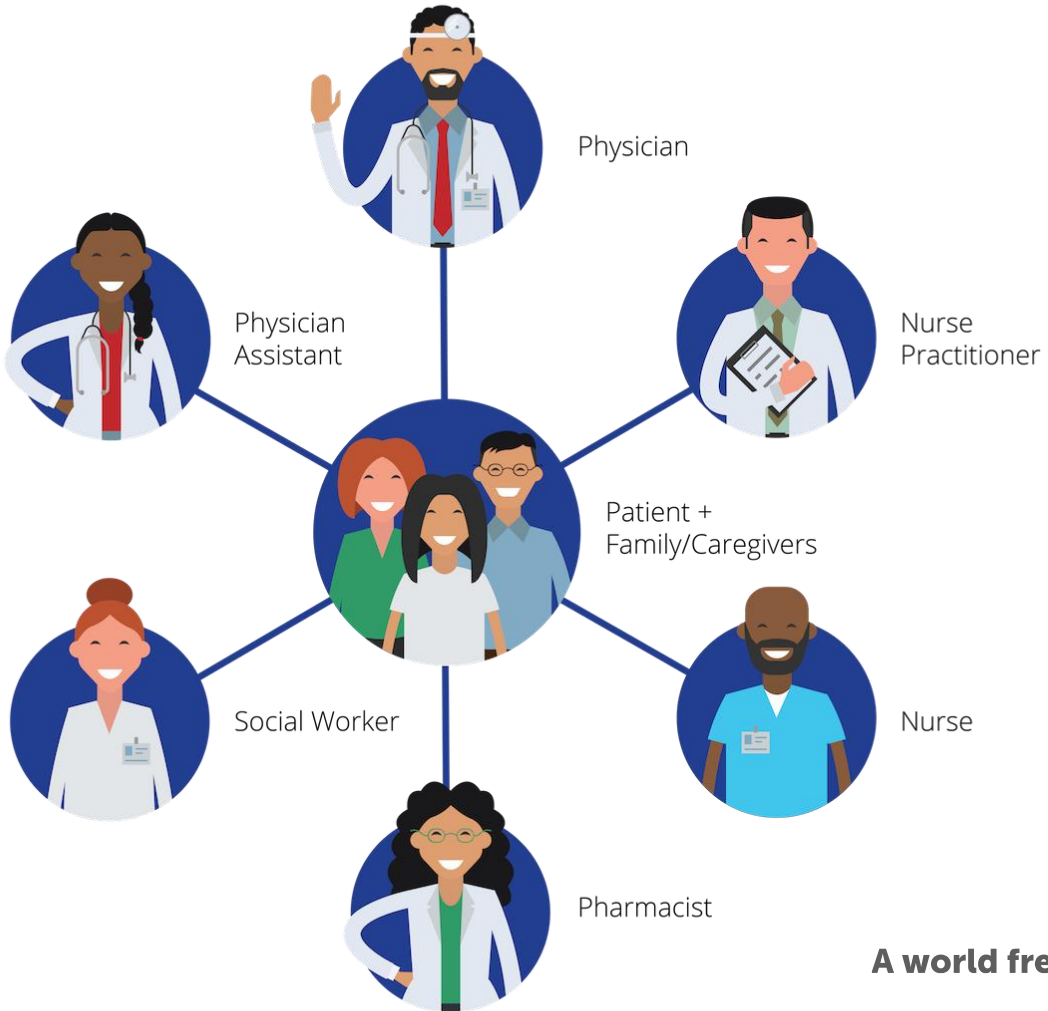
Visible:

- motor functions
 - walking
 - muscle weakness
 - spasticity
 - tremor
 - drop foot
- speech problems
- lack of balance and coordination



No one will have all these symptoms, and likely won't have symptoms all the time

Building Your Healthcare Team



Disease Management

- **maintain contact with your healthcare team**
- **disease-modifying therapies (DMTs/MS Drugs)**
- **relapse management medications (steroids)**
- **symptom management medications**
- **complementary therapies**

Complimentary therapies can include sleep hygiene strategies, Vitamin D supplements, massage and physical therapy, counselling, exercise, stress management, cooling strategies

Vitamin D is a Complementary Therapy

Age group	Recommended daily intake	Maximum daily intake
Infants 0 – 6 months old	400 IU	1000 IU
Infants 7 – 12 months old	400 IU	1500 IU
Children 1 – 3 years old	600 IU	2500 IU
Children 4 – 8 years old	600 IU	3000 IU
Children and adults 9 – 70 years old	600 IU	4000 IU
Adults >70 years old	800 IU	4000 IU
Pregnant and breastfeeding women	600 IU	4000 IU



It is important to remember that too much vitamin D can be harmful – daily intake should not exceed the maximum recommended by Health Canada for each age group.

Wellness Strategies

- plenty of sleep, even resting, plus schedule breaks for ‘me-time’
- healthy eating
- take your medications as prescribed
- keep connected with your healthcare team
- ask for help if you need it
- stay connected with family and friends
- participate in therapy when you need it including counselling, exercise and rehab
- when able, go outside or visit a different environment
- perhaps enjoy some pet time
- physical activity

Identify your priorities and set goals. But forgive yourself and move forward if you get a bit side-tracked or need to revamp a goal.



Keeping a Health Journal

Things to keep track of in your journal:

- when symptoms started/ended
- what symptoms were experienced (had before?)
- did you have a fever
- how was your life affected by attack/symptoms
- when symptoms ended, was there any deficits in your abilities (*ie. vision did not recover to previous prescription*)
- other?



“When I was first diagnosed, I made three phone calls: one to my family, one to my partner, and one to MS Canada.”

Karen
Living with MS, Toronto



What does
MS Canada
do to
support
people
affected by
multiple
sclerosis?

MS Knowledge Network

Education & Awareness

Peer Support Programs

Wellness Programs

Quality of Life – Equipment
Program

MS Knowledge Network

MS information and support for anyone in Canada

MS Navigators provide trusted information on all aspects of life with MS. Whether you're living with the disease, working with or caring for someone with MS, tapping into current, reliable information will enable you to make informed choices.

MS Navigators are available to assist from 8am–8pm ET, Monday to Friday by:

- **Phone:** 1-844-859-6789
- **Email:** msnavigators@mscanada.ca
- **Live chat:** mscanada.ca



Selassie, MS Navigator

Education & Awareness

- **Hear From The Experts** webinars
- **MS 101 Newly Diagnosed** sessions
- Community Education Presentations
- **e-Newsletters**
- printable resources
- MS Canada website: mscanada.ca
- **YouTube**
- Facebook, Instagram, Twitter & TikTok



Marilyn Werseen-Lenzen

MS Ambassador

Community Support

1:1 Peer Support Program



You are not alone in living with MS or being a caregiver

I need someone to talk to about MS

I have some questions and want to connect with someone who's been there

Caregivers can now connect with a Peer Support volunteer who is also a caregiver!

No one understands what I'm going through

The MS Society of Canada is pleased to offer a confidential peer support program to connect you with trained volunteers who live with MS or are caregivers.

Contact msnavigators@mssociety.ca or 1-844-859-6789 for more information.

"The MS Peer Support Program made me feel comfortable in my own skin again. It gave me back the confidence I lost after my diagnosis and allowed me to develop a friendship that I will cherish forever."

Jessie,
1:1 Peer Support participant

Community Support

Virtual Peer Support Groups

Caregiver – second Sunday of the month @ 3pm ET

Newly Diagnosed – first Wednesday of the month @ 7pm ET

South Asian – fourth Sunday of the month @ 7pm ET

BC & Yukon – fourth Friday of the month @ 10am PT

Alberta & NWT – first Thursday of the month @7pm MT

Central Canada (Ontario) – 2nd and 4th Tuesday of the month @5 pm ET

Prairies (SK/MB) – second Thursday of the month @ 5pm CT

MS Warriors – first, third and fifth Tuesday of the month @ 1pm ET

Let's Talk MS (*open to women or those identifying as women living with MS*) – last Monday of the month @ 5pm ET



Join a volunteer led MS support group and connect with your community.

Self-Directed Online Connections



We Talk MS is our new online social community for people living with MS, providing guided discussions to help them work through difficult conversations and strengthen bonds with family and friends.

Wellness Programs & Resources



MS GET FIT TOOLKIT
A RESOURCE TO HELP ADULTS LIVING WITH MULTIPLE SCLEROSIS (MS) MEET THE CANADIAN PHYSICAL ACTIVITY GUIDELINES

YOUR ability:
Do what you can to work towards meeting the guidelines

YOUR way:
Pick moderate intensity activities that feel good and that you enjoy

GUIDELINES AT A GLANCE

For important fitness benefits, adults with multiple sclerosis who have mild or moderate disability need at least:

- 30 minutes of aerobic activity, 2 times per week, AND
- Strength-training exercises for major muscle groups, 2 times per week

WHO CAN BENEFIT?

If you are between the ages of 18 and 64 and have mild to moderate disability resulting from relapsing or progressive forms of MS, these guidelines are for you.



Quality of Life Program

Promoting personal independence and contributing to an enhanced quality of life.

Quality of Life - Equipment Grants are designed to provide financial assistance to those requiring support with the purchase of mobility equipment and safety devices, up to \$1000/person in a calendar year.

Quality of Life - Cooling Products Grants provide financial assistance to those requiring support with the purchase of cooling products, such as cooling fans (e.g., Dyson), air conditioning units (e.g., window or portable), and central air units. The Cooling Products Program is open year-round.

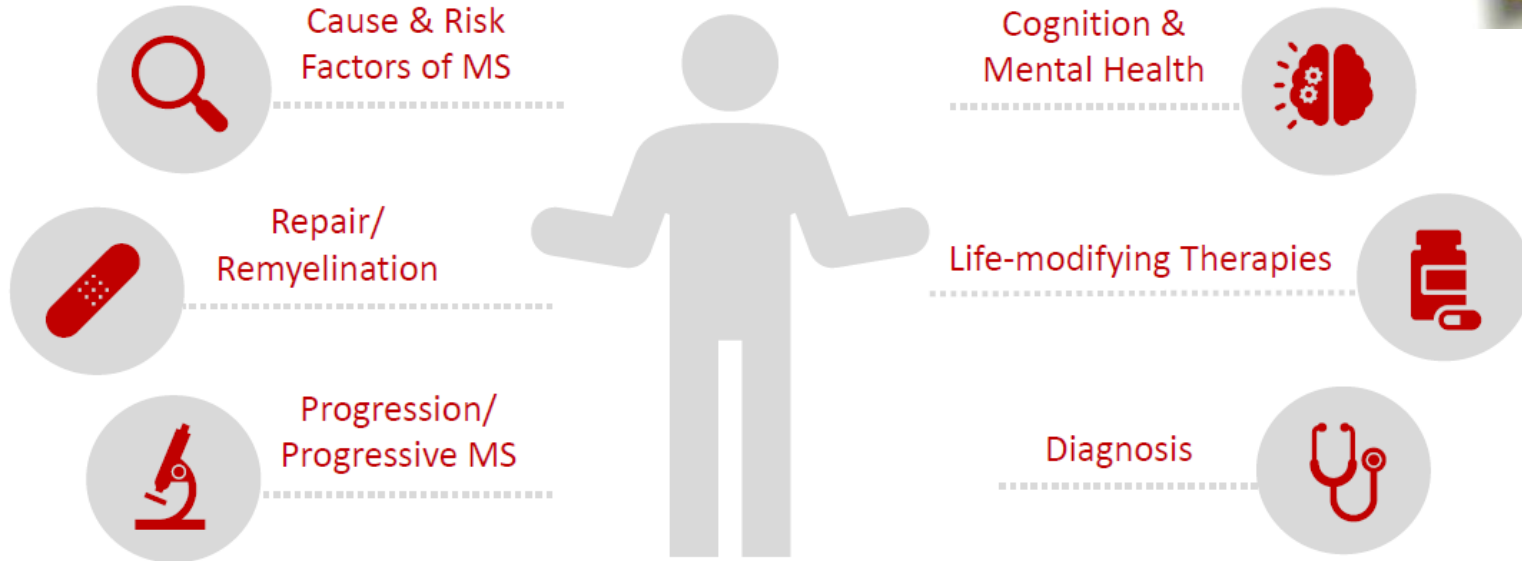
CPP-D Application Support (CAS)

CPP-D Application Support (CAS) aims to help individuals with MS applying for the Canada Pension Plan Disability Benefit (CPP-D) successfully receive their benefits.

We may be able to help determine eligibility for the benefit and, if eligible, pair applicants with trained volunteers. Volunteers guide applicants in completing sections of their applications to better clarify the impact MS or an allied disease has on their ability to work.

MS Research = Hope

~ \$212 million
invested in research
since 1948



<https://mscanada.ca/about-ms-research>

MS

A world free of MS

Get Involved

Fundraising and donations are key to our work.



Christina, lives with MS, Toronto

Ways to Give:

one-time donation

memorial gifts

monthly giving

sponsorships & workplace giving

Get Involved

Fundraising and donations are key to our work.



Sylvie, lives with MS
Chibougamau, QC

Special Events:

MS Walk

MS Bike

MS Read-A-Thon

Burgers to Beat MS

Savour: A Culinary Festival

We Challenge MS

Get Involved

Working together to create positive change



MS Walk Volunteer, Toronto

Volunteer:

1:1 Peer Support Program

Peer Support Groups

Wellness Programs

Community Engagement - Gratitude Calling Team

Day-of-Event Execution: MS Walk

Day-of-Event Execution: MS Bike

Get Involved

Advocacy: government relations & social action

We lobby governments for change to help shape policies and programs that impact people affected by MS.

Example: *Campaign in support of the Canada Disability Benefit (Bill C-22)*

- Federal government launches **Disability Inclusion Action Plan** - MS Canada has been involved for years
- We want Canada's government to lead in improving **#LifeWithMS**

Take Action

MS Advocacy Policy Priorities



MS Research

Make MS Research a Priority



Income Security

Make Ends Meet



Employment Security

Make Work... Work



MS Treatments

Make Access a Reality



MS Care and Housing

Invest in the Right Support

#TakeActionforMS

Connect With Us

MS Canada website: www.mscanada.ca

Knowledge Network: msnavigators@mscanada.ca

Education Team: education@mscanada.ca

1-800-268-7582

info@mscanada.ca