#TakeActionForMS
POLICY PRIORITIES
Multiple sclerosis (MS) is classified as an autoimmune disease of the central nervous system (CNS). The immune system attacks myelin (protective covering of the nerves) in the brain, spinal cord, and optic nerve, which disrupts communication between the CNS and the rest of the body. The disease course of MS is unpredictable, often occurring in a pattern of relapses and remissions also known as an episodic disability. In some people, the disease is progressive and will steadily worsen from the onset.

**WHAT ARE THE SYMPTOMS?**

- Weakness or imbalance
- Abnormal sensation (tingling or numbness)
- Fatigue
- Mood and cognitive changes
- Pain
- Mobility issues
- Vision problems
- Mobility issues
- Pain

**WHAT IS MS?**

**WHO IS AFFECTED?**

- Canada has one of the highest rates of MS in the world.
- On average, 12 Canadians are diagnosed with MS every day.
- Over 90,000 Canadians live with MS.
- Onset of MS is typically between ages of 20–49.
- Women are 3x more likely to be diagnosed with MS than men.

**WHAT WE DO**

The Multiple Sclerosis Society of Canada provides information, support and advocacy to people affected by MS, and funds research to find the cause and cure for the disease, bringing us closer to a world free of MS.

As part of the MS community, we are committed to ensuring Canadians living with MS, and their families, can participate fully in all aspects of life. We continue to urge the federal government to remove barriers and improve policies that impact people with MS in several policy priority areas.

**OUR MISSION**

To connect and empower the MS community to create positive change.

**OUR VISION**

A world free of multiple sclerosis.
COVID-19

Impact on the MS Community

The primary concern for the MS Society is for people living with MS and their families. This is a population facing considerable risk from COVID-19 due to the treatments that weaken or alter their immune system, due to episodic yet progressive disability, and due to comorbidities. The increased social isolation from public health restrictions puts them at greater risk for mental health issues such as depression, which is already much higher for people living with MS than the general population as well as longer term health impacts.

The COVID-19 pandemic has compounded the challenges faced by the thousands of Canadians living with MS as well as their families, their friends, their communities, and all Canadians touched by this disease. And just as COVID has had a more pronounced impact on women, so too does MS – 75 per cent of Canadians living with MS are women. This gender dimension intersects with the multiple challenges Canadians affected by MS face every day including employment and income security, access (treatments, and care and housing), and MS research.

Impact on Health Charities

Health charities have been increasingly filling the gaps in the healthcare system – and during the pandemic, these gaps have become chasms. Demand for our services such as equipment has increased just as charitable giving – the backbone of our funding model – has dried up. We are reliant on grassroots, event-related fundraising, yet we can no longer hold in-person events, and online alternatives do not come close to filling the void. Meanwhile, across the health charitable sector, we have seen a fourfold increase of Canadians seeking support services as COVID-19 has impacted their access to care, including the cancellation of hundreds of thousands of surgeries and specialty care. In 2020, the MS Society alone saw a revenue reduction of $14 million while confronting greater demand.

The health charitable sector is crucial to the achievement of many social and economic goals set by the federal government. Thus, health charities need to be a part of the creation of a stronger and more resilient post-pandemic Canada.
PRIORITY: EMPLOYMENT SECURITY

Make Work... Work

Employment is a key factor in maintaining adequate income and reducing poverty. Research shows that people with MS have disproportionately high unemployment rates given their educational and vocational histories. Yet many people living with MS who want to work struggle to do so. Often the problem is one of flexibility, accommodation, and a lack of understanding of episodic disability (periods of wellness followed by periods of disability). It is critical we move past the notion of work as a binary switch of “you can work” (no assistance) vs. “you can’t work” (assistance). With more than 60 per cent of people living with MS eventually reaching unemployment it’s clear more needs to be done to support those who live with episodic disabilities.

“Telling my employer I had multiple sclerosis at the time of my diagnosis didn’t go over well. The diagnosis was a struggle – not only did I have instability in my employment, I had uncertainty in my future. They didn’t understand the episodic nature of MS and I was forced to leave the organization. I felt disenchanted and struggled with making ends meet while I was unemployed.”

Julia Stewart, diagnosed in 2004, New Brunswick

Unfortunately, the EI Sickness Benefit designed to address this very issue has been virtually unchanged since the 1970s. To put this into context, it was set up at a time when smoking on planes was legal, bell-bottoms were king, and universal Medicare was just getting on its feet. The program provides insured employees up to 15 weeks of financial assistance if they can’t work for medical reasons, provided they’ve qualified with over 600 hours already worked. While it is an important safety net, it also has outdated design flaws, most notably a rigid “on or off” switch that doesn’t work for those who need a gradual workforce reintegration or for those living with episodic disabilities.

For the 13 million Canadians identified as not having short-term disability insurance in a 2015 report from the Institute for Research on Public Policy, Leaving Some Behind: What Happens When Workers Get Sick, at the end of 15 weeks, they can either have recovered, or receive nothing further as they continue to recover. The 2019 EI Roundtable Report noted that three of the four major parties recognized in their 2019 platforms that it’s time to extend the benefit from 15 weeks to at least 26 weeks. Now, in 2021 with the impacts of the pandemic ravaging our economy and the livelihoods of Canadians, the time for action has come.

KEY ACTION

Expand the Employment Insurance (EI) Sickness Benefit from 15 weeks to at least 26 weeks
**PRIORITY: INCOME SECURITY**

*Make Ends Meet*

The cost of paying for medication, services, equipment, and treatment is a significant burden for people with MS and their families. When MS stops someone from working, they should be able to access adequate income and disability supports.

The COVID-19 pandemic has further compounded existing challenges faced by the thousands of Canadians living with MS and their families. As described by the National Advisory Council on Poverty in their first report *“Persons with disabilities, immigrants, refugees, ethno-cultural and racialized groups, LGBTQ2S individuals and many others remain at a high risk of living in poverty compared to the general population.”*

“The effects of poverty on people with MS, especially women, are pronounced and occur far too frequently. I regularly speak to women who are no longer able to work and have no avenues for income once their medical EI is finished. They are not seen as “disabled enough” to qualify for provincial disability assistance programs, they have not built-up sufficient contributions in the CPP-D system and certainly could not survive on CPP-D alone, even at its maximum payment. The system is failing them.”

**KEY ACTION**

Implement the new Canadian Disability Benefit ensuring it is inclusive of episodic disabilities and integrates with other income and disability programs to lift Canadians with disabilities out of poverty

Just as COVID-19 has had a more pronounced impact on women, so too does MS – 75 per cent of Canadians living with MS are women. When it comes to income security in particular, the challenges are further amplified for women. They have on average, lower incomes and earnings thus making them more susceptible to poverty. As noted in the report *Disability Inclusion Analysis of Lessons Learned and Best Practices of the Government of Canada’s Response to the COVID-19 Pandemic* based on *Statistics Canada 2020* findings “Many people with disabilities faced disproportionately high decreases in income since the start of the pandemic, with impacts more severe among:... women with disabilities.”

Michelle Hewitt, diagnosed in 2008, lives with MS, British Columbia
Socioeconomic status has profound effects on health outcomes. Research supported by the MS Society of Canada and published in Neurology (2019), the journal of the American Academy of Neurology, demonstrated that less socioeconomically advantaged people living with MS tend to have greater disability. Furthermore, at the 2021 Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum, new findings were presented by Eleni Vasileiou, MD, that suggest people with MS who are less socioeconomically advantaged tend to have faster rates of nervous system damage. Hence, the urgency in ensuring income security through such programs as the Canadian Disability Benefit for Canadians living with MS.
PRIORITY: ACCESS
Make Access a Reality

Access to Treatments

Canadians affected by MS know research is key to new treatments and ultimately a cure. In the meantime, access to Health Canada approved disease-modifying therapies (DMTs) is key to maintaining positive health outcomes for people with MS. Early intervention and treatment are vital to avoiding many of the long-term economic and personal costs that result from unnecessary irreversible disability.

"As a young woman, diagnosed with MS at the age of 17, I have been depending on my DMT to lessen my disability burden for the past 14 years. I have found a treatment that works for me, this is a difficult process. This treatment is key to my success in life and the thought of being unable to afford or even access this drug, due to a loss of employment or simply a move between provinces, is terrifying.”

Julie Petrin, diagnosed in 2007, Ontario

The MS Society strongly believes that a population health perspective may not reflect the needs of individual patients especially as it relates to a heterogenous disease like MS. No two people have the same course of the disease or respond in the same way to the same medication, hence the need for access to all Health Canada approved treatments for MS and a wide-array of therapeutic options.

A 2020 Conference Board of Canada report - Accessing Disease-Modifying Therapies for Multiple Sclerosis: A Pan-Canadian Analysis finds that many Canadians living with MS can’t get sufficient, equitable, or affordable access to DMTs. The report shows that too many of them face regulatory, administrative, and financial barriers to access, stopping them from using these life-changing therapies.

KEY ACTION

Improve access to Health Canada approved treatments for MS by working with provincial/territorial partners to ensure equitable and affordable access to all treatments across Canada
PRIORITY: ACCESS
Make Access a Reality

Access to Appropriate Care and Housing

Canadians living with MS often require housing and care support – in home settings and in long-term care (LTC) facilities. Unfortunately, there are many examples of inappropriate responses to this need, related to age, ability level, culture, family visitation, connection with the community and optimizing support for independence. Despite the current unprecedented spotlight on LTC facilities in Canada brought on by the COVID-19 pandemic the perspective of younger adults with disabilities living in LTC continues to be largely ignored. This is in direct contrast to the Government of Canada’s COVID-19 and people with disabilities in Canada guidance document, which notes “Special considerations, adaptations and accommodations should be considered and provided for people with disabilities within the healthcare and public health systems... This applies to acute care hospitals, long-term care homes, congregated residential settings...”

“As COVID-19 spread across Canada, it was alarming to see outbreaks and deaths in LTC facilities in Ontario and Québec. The facility where I live, went into lockdown on March 9 [2020] and it quickly became apparent just how serious this outbreak was. Our facility was ‘militarized’. Family, friends, companions, and the family dog were prohibited from visiting; all recreation and physical therapy activities stopped; and in-house amenities, such as the hairdresser and a small tuckshop remain closed to this day. My hair has not been cut since February! It was not until the beginning of June, that we were allowed 90 minutes of sunshine and fresh air a day. It wasn’t until August that we were allowed out of the facility and given permission to leave the property.

Build an inclusive care and housing approach as part of the COVID-19 recovery both within and outside of long-term care facilities, specifically including the perspective of adults under 65 with disabilities

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PRIO\(\text{RITY: ACCESS}\)

Make Access a Reality

Access to Appropriate Care and Housing

Persons affected by MS must be accorded the opportunity to remain in their own homes and in the community with the appropriate supports. Comprehensive home care needs to focus on the family and include: nursing and personal care, supplies (e.g. incontinence supplies) and equipment, homemaking, meal preparation, childcare, rehabilitation, technology (e.g. home monitoring), and meaningful respite services. According to a study commissioned by the Canadian Medical Association by Deloitte released in March 2021 the inability to provide these supports in the community is causing the rapid growth in the need for LTC.

As our country moves forward with COVID-19 recovery and addressing the challenges exposed with LTC it will be imperative to include the perspectives of younger adults with disabilities who call these facilities home. To exclude them and their lived experience will only exacerbate their current situation.

I became depressed when the economy started to re-open and most people were able to get out for a walk, shop for flowers, and prepare for summer projects. I became collateral damage of the pandemic, when I had to spend weeks in the hospital with lower back pain, because I was unable to see my chiropractor when they opened. I want people to know that we, the younger people in LTC, should not be forgotten as the pandemic recovery moves forward. We need to be included in these discussions and solutions.”

Katie Gerke, Alberta
PRIORITY: MS RESEARCH
Make Health Research a Priority

Virtually no other disease has seen the kind of life-altering advancement that MS treatment and research has seen in the past two decades. We are progressing by leaps and bounds, but there is far more that needs to be done. We need more research on why one person’s MS progresses and another’s does not. We are on the cusp of treatments that target cellular and nervous system repair, actually reversing the effects of MS. This is the game-changing research and innovation we have been funding – and due to COVID-19 it’s slowing to a trickle.

Typically, the MS Society invests $6-10m annually in MS research. In 2020, however, given COVID-19, we could only invest $4.7m in research funding to support 13 research projects in MS and 38 trainees. In 2021, as COVID-19 has had a significant impact on our overall revenues we could only launch the Personnel Award program that supports trainees in MS research – up to a maximum of $1.5m, a substantially reduced commitment. Our research funding will continue to fall short of the much-needed investment in MS research without further investments from the Government of Canada.

“To me, prioritizing research would mean that in the long run, we could find a cure to MS. If research isn’t a priority, then eventually, progressively, my condition will deteriorate, I might eventually be a less active citizen and stop contributing to society. The government needs to see research as an investment that will help reduce the costs and financial burden in the public healthcare system. Research is a long term solution.”

Vincent L-Dionne, diagnosed in 2007, Quebec

KEY ACTION

The Government of Canada needs to:

- Invest critical funds in health research in partnership with health charities, significant contributors to Canada’s health research ecosystem
- Continue to invest in basic scientific research
- Connect with health charities to ensure the lived experience and patient voice are part of the research priority setting
**PRIORITY: MS RESEARCH**

*Make Health Research a Priority*

The Government of Canada’s partnership with health charities will keep important breakthroughs within our grasp. The MS Society has a longstanding track record of bringing the right priorities, partners, processes, and funding together to deliver breakthroughs. For example, the MS Society’s partnership with the Brain Canada Foundation, industry (Roche Canada and Biogen Canada), and the Government of Alberta – the Canadian Prospective Cohort Study to Understand Progression in MS (CanProCo), is key to turning innovative research into real-life treatments.

The MS Society supports fundamental research as we still don’t know what causes MS, or how we could prevent it. The research we fund directly includes the voice of Canadians living with MS. We have effectively integrated people affected by MS into the research review process and inform the MS community about advances in the latest MS research. This is the example we would like to see implemented across the entire health research ecosystem.
The COVID-19 pandemic has compounded the challenges faced by the thousands of Canadians living with MS as well as their families, their friends, their communities, and all Canadians touched by this disease. And just as COVID has had a more pronounced impact on women, so too does MS – 75 per cent of Canadians living with MS are women. These key actions are of critical importance to addressing the inequities amplified by COVID-19.

**KEY ACTIONS**

**EMPLOYMENT SECURITY**

Make Work...Work  
• Expand the Employment Insurance (EI) Sickness Benefit from 15 weeks to at least 26 weeks

**INCOME SECURITY**

Make Ends Meet  
• Implement the new Canadian Disability Benefit

**ACCESS**

Make Access a Reality  
• Improve access to Health Canada approved treatments for MS  
• Build an inclusive care and housing approach including the perspective of adults under 65 with disabilities

**MS RESEARCH**

Make Health Research a Priority  
• Partner with health charities to turn innovative research into real-life treatments  
• Continue to invest in basic scientific research  
• Connect with health charities to ensure the lived experience and patient voice is part of the research priority setting

**ABOUT MS**

Multiple sclerosis (MS) is an autoimmune disease of the brain and spinal cord.  
• It is unpredictable.  
• Its effects are physical, emotional, and financial.  
• Currently, there is no cure.

**CANADA HAS ONE OF THE HIGHEST RATES OF MS IN THE WORLD**

1 in 400 CANADIANS LIVE WITH MS

**MS STATS**

• On average, 12 Canadians are diagnosed with MS every day.  
• Women are 3x more likely to be diagnosed with MS than men.  
• Canada is home to some of the world’s leading MS researchers.
#TakeActionForMS