# 2024 Policy Priorities

MS Canada

#TakeActionForMS

Sylvie, lives with MS, and her husband Mario, Quebec

# Canada has one of the highest rates of MS in the world.

More than **90,000 Canadians** live with multiple sclerosis

On average, **12 Canadians** are diagnosed each day

A person is diagnosed with MS every **two hours** in Canada.

## Anyone can be diagnosed with MS.

Women are three times more likely to be diagnosed with MS than men.

A majority of adults who are newly diagnosed with MS are between the ages of 20 & 49.

**Almost 3 million people are living with MS worldwide.**

We work with global partners and researchers to find cures for MS.

## Our Vision

A world free of MS.

## Our Mission

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

MS Canada provides information, support, and advocacy to Canadians affected by MS, and funds research to find the causes and cures for the disease. 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.

**MS Canada**

## What is multiple sclerosis (MS)?

MS is a neurological disease of the central nervous system (CNS) which includes the brain, spinal cord, and optic nerves. Each person is affected by MS differently.

In MS, the body's immune system mistakenly attacks myelin, the protective covering of nerve fibres. Myelin is needed to effectively send messages to and from the brain. Damage to the myelin can result in loss of nerve fibres and over time and these changes contribute to disease progression.

The most common MS symptoms include fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder and bowel problems, and cognitive and mood changes.

**MS is caused by a combination of genetic and environmental/lifestyle risk factors.**

- While having a family member with MS increases the risk, environmental and lifestyle factors are major contributors to MS.
- There are a number of risk factors for MS such as vitamin D deficiency, adolescent obesity, smoking, and infection with Epstein-Barr virus (EBV).

# MS Canada Policy Priorities

MS Canada has heard the personal and profound stories of life with MS from Canadians coast to coast to coast — the obstacles to remaining in a job; the sacrifices supporting partners or adult children; the frustrating barriers to access; the struggle to pay bills and make ends meet; and, the ongoing emotional demands of a disabling and unpredictable disease.

Now it's time for Canada to **#TakeActionForMS**. It's time for the federal government to work with MS Canada to mobilize a nation to accelerate MS research breakthroughs and improve policies, legislation, and programs to empower people affected by MS to live their best lives.

## MS Research

### Make MS Research a Priority

Invest $15 million in MS research funding in partnership with MS Canada, leveraging our connections and expertise to focus and further our understanding of MS, pursue leading-edge research on repair and regeneration, and explore strategies to prevent MS (e.g., risk factors, understanding preclinical MS, and develop and test interventions to prevent MS).

## Income Security

### Fully Fund the Canada Disability Benefit

Allocate funding for the urgent implementation of a Canada Disability Benefit that is inclusive of Canadians with episodic disabilities like MS and those not currently receiving government supports.

## MS Treatment and Care

### Boost MS Specialist Care

Invest in funding MS specialist care through federal-provincial health funding agreements to improve timely access to diagnosis, treatment, and rehabilitation.

## Employment Security

### Make Work...Work

Continue modernizing the EI sickness benefit by reducing the hours needed for eligibility from 600 to 400.

## MS Care and Housing

### Invest in Comprehensive, Appropriate, and High-Quality Home Care and Housing

Ensure federal funding investments include comprehensive and high-quality home care for people with long-term chronic health conditions such as MS and a range of appropriate housing and care options that focus on diversity and choice.

# Make MS Research a Priority

MS Canada is an important research partner. The deep integration of MS Canada in both national and international efforts has been essential in ensuring we fund the most promising developments. Over our 76-year history, we have raised more than $218 million to fund research efforts and used that funding to leverage millions more. Annually, MS Canada funds approximately $5-10 million in research to support studies that investigate all aspects of MS. We also support research and training programs that cultivate a network of bright young minds and engage them in activities that enhance their skills and knowledge in MS research.

Globally, MS Canada has declared, along with MS organizations from Australia, Denmark, France, Germany, Italy, MS International Federation, Spain, U.K., and U.S, our collective commitment to a global research strategy to cure MS, known as Pathways to Cures. There are multiple paths to an MS cure and this coordination will effectively address knowledge gaps and avoid duplication to speed progress together.

We remain agile in our efforts and respond to promising opportunities as they arise in the global MS research landscape. With recent research advances, MS prevention has changed from a distant aspiration into an attainable goal, and we are determined to translate this vision into reality.

A recent global MS research landscape analysis found that less than ten per cent of our global research funding is invested in MS prevention. Emerging research has identified the potential for advances in prevention of MS with the landmark study identifying Epstein-Barr virus (EBV) as an early trigger required for MS development and the existence of an MS prodrome, a period of early signs and symptoms that precede a disease, as a window for early intervention. There is a need to build on these recent discoveries with a focus on prevention. To accelerate this research, we are forging partnerships with global MS organizations and research experts who share our unwavering commitment to a world free of MS and we are asking the Government of Canada to join us as a partner.

"There is no question that living with MS is costly to the individual. But the productivity loss and health care cost affect our economy as well. As a 36-year-old woman living with MS, on long term disability with increasing health costs, I am one of 90,000 Canadians already costing our system. The toll MS has on our economy is why research for prevention is imperative for our government to invest in. More Canadians are being diagnosed every day and Canada leads the rates of MS globally. We should be taking the lead in partnering globally to research why MS has become Canada's disease."

**AMANDA, DIAGNOSED IN 2014, ALBERTA**

To drive MS prevention, MS Canada will leverage the global MS community's resources, expertise, and capacity to establish and co-lead a global MS Prevention initiative targeting risk factors, understanding preclinical MS, and developing and testing interventions to prevent MS. In the next year, this includes convening a scientific advisory group to define key priorities for investment, engaging global partners and establishing a partnership model, and launching a global funding opportunity in prevention to build capacity in this area.

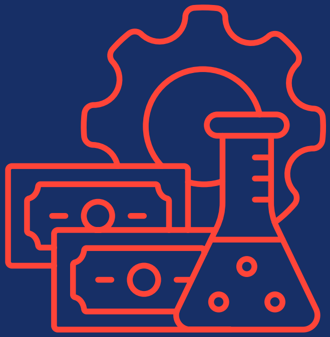
Here in Canada, MS Canada has the leadership, and our research community has the expertise to propel this research forward. We have the track record to build capacity and coordinate funding of MS research as well as the infrastructure. Our organization is committing resources to build this prevention initiative and we are seeking funding partners, including the Government of Canada, to join this initiative.

The time is now to focus on prevention with the high rates of MS in Canada and the economic burden of MS, as a Deloitte Access Economics report estimates the annual cost of MS at more than $3.4 billion and rising. The per person cost of MS for Canadian individuals is estimated to be $42,800 annually.

Investing funding in research in partnership with MS Canada, with the goal of preventing MS in future generations, has the potential to save the Canadian health care system and broader society billions of dollars annually in the future. Cures are possible within our lifetimes, and this investment can take Canada from being known as the country with one of the highest rates of MS to a country that led the way in MS prevention.

## Key Action

**Invest $15 million in MS research funding in partnership with MS Canada, leveraging our connections and expertise to focus and further our understanding of MS, pursue leading-edge research on repair and regeneration, and explore strategies to prevent MS (e.g., risk factors, understanding preclinical MS, and develop and test interventions to prevent MS).**



# Costly Disease… Costly Delays

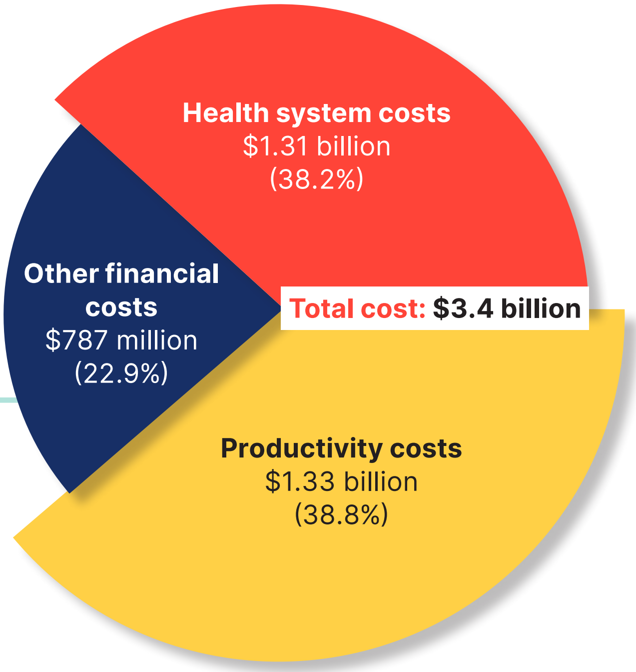
MS is a costly disease for individuals, their families, our health systems, and Canadian society more broadly. A recent study by Deloitte Access Economics highlighted the significant socioeconomic cost of MS to Canada, estimating the total annual cost of illness to be more than $3.4 billion in 2019.

Furthermore, the study investigated the impact and economic cost of the pandemic on MS care in Canada and found a significant reduction in health service access among people with MS resulting in a health services backlog and an accumulation of unmet health needs.

This reality will have a long-lasting negative impact on health outcomes of people living with MS, due in large part to delayed diagnosis and delayed, altered, or halted treatment and care that occurred during the pandemic. As well, it was noted that a reduction in rehabilitation, coupled with a lack of social and cognitive stimulation during the pandemic, is expected to result in increased disability progression for some individuals.

Unless action is taken now, bottlenecks in an already strained healthcare system threaten to form. As healthcare providers attempt to address the backlog of needs, Canadians continue to receive new MS diagnoses, putting added strain on the specialists who provide treatment and care. The MS community knows that time is brain. The faster an individual can receive a diagnosis, and the faster they can get effective treatment, the longer they can preserve function and avoid disability.

# Cost of MS to Canada



In a normal (non-disrupted) year, the annual cost of MS to Canada is significant, totalling more than **$3.4 billion in direct health costs, productivity loss, and other financial costs**.

Productivity loss accounts for **$1.3 billion** of the cost of MS to Canada – that includes reduced employment, absenteeism, presenteeism, premature mortality and informal care.

The annual cost of MS per person is estimated at **$42,880**, much higher than other chronic diseases like diabetes and heart disease.

The COVID-19 pandemic caused delays in both MS diagnosis and MS treatment, **resulting in worse outcomes for Canadians living with MS**.

Delayed diagnosis and disrupted treatment will generate an additional **$578.2 million** in MS-related **health system expenditure, productivity losses**, and **lost wellbeing** between 2020 and 2024.

**These additional health and economic pandemic costs are expected to continue into the future, unless we take bold action now.**

# Fully Fund the Canada Disability Benefit

Income security is a top priority for the MS community. Canadians are facing an affordability crisis. People with disabilities are disproportionately impacted — they are twice as likely to live in poverty as those without disabilities. Accessing financial support and managing the high costs of MS is a challenge. People living with MS often require expensive medication, rehabilitation treatments, and transportation, as well as feeding, mobility, and bathing aids.

A 2020 report from the Conference Board of Canada found that when a family member is affected by MS, that household faces a greater financial burden than the average Canadian household. The data from 2018 indicates Canadians living with MS and their families paid more than $39 million out-of-pocket for critical treatments to manage their disease. Canadians living with MS aged 20 years and older sustain additional costs that are approximately three to eight times higher than Canadians without a neurological condition. By 2031, out-of-pocket expenses for Canadians living with MS are expected to reach $170 million.

Parliament unanimously passed Bill C-22: the Canada Disability Benefit Act in June 2023, which commits the federal government to creating a new income support to reduce poverty among low-income, working-age Canadians with disabilities. The government is now working on the regulations, which will define who is eligible for the benefit, the benefit amount, and how it will be administered. As the benefit is designed in the regulatory process, it must have eligibility that is inclusive of Canadians with episodic disabilities and those not currently receiving government supports. It is critical forthcoming budgets include full funding for the urgent implementation of the Canada Disability Benefit.

Time is of the essence – people with disabilities, including Canadians living with MS, cannot afford to wait.

**What our community has told us about the urgent need for the Canada Disability Benefit:**

“Things that are essential, like home renovations/improvements, vehicle modifications, medical care, and health insurance, are **more expensive** for people affected by MS. It is **extremely difficult** to live off disability payments if you have a low-income job to begin with.”

“The cost of everything continues to go up and that includes the cost of medications and any extra help required. A person on disability supports living alone often has to **choose between rent or food** for the month.”

“I simply **cannot afford the expenses** of basic living and the extra expenses of chronic disease.”

“Since encountering MS in my life, I have found the costs of having such an illness to be **very expensive**. From everyday usage of incontinence diapers to mobility equipment, **it has taken a considerable amount of money away from me**. Money that normal people would probably spend on vacations that I never get to go on.”

## Key Action

**Allocate funding for the urgent implementation of a Canada Disability Benefit that is inclusive of Canadians with episodic disabilities like MS and those not currently receiving government supports.**

# Boost MS Specialist Care

Canadians across the country are concerned about our health care system. A recent report by Deloitte Access Economics raised significant concerns, including a reduction in health service access during the pandemic that resulted in the accumulation of unmet health needs, including delayed diagnosis, disrupted treatment, and a reduction in rehabilitation.

The MS community knows that time is brain. The faster an individual can receive a diagnosis, and the faster they are able to get effective treatment, the longer they can preserve function and avoid disability.

We know that timely access to diagnosis by an MS neurologist is necessary for access to early intervention and treatments, which are vital to avoid many of the long-term economic and personal costs that result from unnecessary irreversible disability. Disease-modifying therapies (DMTs) can dramatically alter the course of the disease by reducing annual relapse rates, slowing disability progression, and reducing the number of lesions. Exposure to any DMT was found to be associated with up to 33 per cent lower risk in mortality when compared to no DMT exposure.

Rehabilitation is essential for many people with MS to maintain various functions and improve their general day-to-day wellbeing. Rehabilitation targeted towards halting decline and restoring function has the potential to slow progression and enhance quality of life for people living with MS.

Let's boost MS specialist care by funding additional MS healthcare professionals - from MS nurses to neurologists and rehabilitation professionals. This will lead to faster diagnosis and improve timely access to treatment and rehabilitation, which will have a direct impact on reducing the backlog of care created by the pandemic and address the rising costs of MS in Canada.

**BARB, DIAGNOSED IN 2011, MANITOBA**

**"During the pandemic, I experienced extreme delays at my MS clinic – appointments were re-scheduled or canceled – and limiting in-person contact meant appointments with my neurologist went from being in-person to being a phone appointment. I knew my doctor was doing their best, but I also knew that I wasn't getting the best possible care I could.**

**Now, I can see my neurologist in person again, but staffing shortages remain and delays are common. I know the pandemic put a huge strain on our healthcare system, but those trying to fix it have to understand that we need to close the gap by boosting MS specialist care and fund additional MS healthcare professionals so people's disabilities don't get worse."**

## Key Action

**Invest in funding MS specialist care through federal-provincial health funding agreements to improve timely access to diagnosis, treatment, and rehabilitation.**

# Make Work...Work

Many people living with MS want to work, but the unpredictable and episodic yet progressive nature of MS symptoms often leads to reduced employment and eventually a premature exit from the workforce. Far too often, the problem is one of inflexibility in the attitudes of employers and the design of illness and disability leave policies. Overcoming these obstacles necessitates enhanced flexibility in employment support systems, fostering a workplace culture that embraces accommodation, and cultivating a deeper understanding of episodic disabilities that characterize a disease like MS.

MS costs Canada $1.3 billion annually in indirect costs relating to reduced productivity, according to the 2023 Deloitte Access Economics report. MS can significantly impact an individual's ability to participate in the workforce. Even among those who are employed, the disease can affect their ability to attend work and their productivity while at work. These impacts lead to real costs to the economy that are borne by the individual, their employers, and different levels of government.

With more than 60 per cent of people living with MS eventually reaching unemployment, it's clear that more needs to be done to support those who live with MS. Many people with MS have precarious employment that fails to generate the minimum hours requirement to receive EI sickness benefits. By reducing the hours needed for eligibility, we can enhance the flexibility of our current system to support those living with MS to remain in the workforce.

**"Employment is a critical part of many Canadians' lives, contributing to their well-being and their financial security. Living with MS can make working a challenge. One of the questions I hear most often is, "what kinds of support can help me at my job?"**

**Partnering with MS Canada and a team of experts, we created the Job Demands and Accommodation Planning Tool (JDAPT). The tool guides people through different job demands and provides practical workplace support strategies. In addition to useful advice, people with MS tell us that the JDAPT improved their confidence in problem solving and in managing their work and health demands."**

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## Key Action

**Continue modernizing the EI sickness benefit by reducing the hours needed for eligibility from 600 to 400.**

# Invest in Comprehensive, Appropriate, and High-Quality Home Care and Housing

Canadians living with MS often require housing support – in home, transitional and/or long term. They should be afforded the opportunity to remain in their own homes and in the community and have care that focuses on options, diversity, and choice. People with MS need equitable access to a continuum of comprehensive, appropriate, and high-quality home care and housing.

Comprehensive home care for Canadians with long-term chronic health conditions such as MS must include nursing and personal support at home, medical or quality of life products such as incontinence supplies, mobility equipment, meal preparation, childcare, rehabilitation, and technology (e.g. home monitoring). It means care and support that includes the whole family, like respite and mental health supports.

MS affects the entire family. Spouses, partners, mother, fathers, and children as well as friends become caregivers – integral to the health and well-being of people with MS.

When we're able to live in our own home in our communities, with our families we have healthier outcomes. Research, like the 2021 Deloitte study, has shown that providing home care supports, even for those with high personal care needs, is considerably less expensive than the costs of long-term care (LTC) facilities.

For those unable to remain in their home, the development of and sufficient funding for appropriate housing, care and supports must be created. We need to move away from a LTC facility as the only option, as the services, programs, and supports provided are almost exclusively focused on seniors.

The federal government can, for example, as recommended by the federal housing advocate, ensure that all the options provided to builders in the catalogue of blueprints that were announced to address the housing crisis are based on universal design principles and are either accessible or adaptable. Additionally, they can expand the accessibility and adaptability requirements in the National Building Code so that all future dwellings are built without barriers.

**MARIO, HUSBAND OF SYLVIE, WHO WAS DIAGNOSED WITH MS IN 2003, QUEBEC**

**"Juggling one's personal, professional and social life and one's caregiver role can be very hard for one person. Multiple sclerosis is progressive and unpredictable, so caregivers also need to adapt to this difficult reality and hope for a social safety net to support them when necessary.**

**The programs and services offered by MS Canada are essential to help enhance caregivers' well-being. In addition, caregivers should also be able to access different adapted options when the time comes to determine how to care for a person with MS in terms of housing and homecare."**

## Key Action

**Ensure federal funding investments include comprehensive and high-quality home care for people with long term chronic health conditions such as MS and a range of appropriate housing and care options that focus on diversity and choice.**

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