ACT NOW TO IMPROVE

#LIFEWITHMS

POLICY PRIORITIES
About MS and the MS Society of Canada

When you or a loved one is diagnosed with multiple sclerosis (MS), life can suddenly turn on a dime: one day your body behaves normally, and the next it refuses to listen to you. MS can happen to anyone, without warning, and often in the prime of life. Over 77,000 Canadians live with MS; that’s one of the highest rates in the world.

- On average, 11 Canadians are diagnosed with MS every day.
- An estimated 1 in every 385 Canadians are living with the disease.
- Women are three times more likely to be diagnosed with MS than men.
- MS is the most common neurological disease affecting young adults in Canada.
- 60% of adults diagnosed with MS are between the ages of 20 and 49 years old – the prime family- and career-building years.
- Total annual health sector costs for MS are expected to reach $2.0 billion by 2031.

MS is a chronic, often disabling, disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance, and mobility. MS impacts all Canadians – not only the affected individuals, but also their families and friends. And it affects everyone differently.

The MS Society believes a future free of MS is achievable. We have contributed over $175 million towards MS research since 1948. Our research investment has enabled Canada to create a network of exceptional MS researchers and become a leading contributor to discovery in the field of MS. We provide programs and services including information, support, education, wellness, and other resources for people with MS and their families.

Along with our members, volunteers and staff, we work to ensure Canadians living with MS, and their families, have the opportunity to participate fully in all aspects of life by advocating for improvements in government legislation and policies, private industry practices and/or public attitudes.
The MS Society has heard the personal and profound stories of life with MS from Canadians coast to coast – the obstacles to remaining in a job; the sacrifices supporting spouses 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 improve #LifeWithMS! It’s time for the federal government to work with the MS Society to mobilize a nation to accelerate the pace of MS breakthroughs and improve policies, legislation and programs to empower people affected by MS to live their best lives.

### POLICY PRIORITIES

**[1] EMPLOYMENT SECURITY**

*Make work...work* by making employment supports and programs more flexible and inclusive by including episodic disability in the definition of disability to allow people with MS and other episodic disabilities to remain in the workforce.

**[2] INCOME SECURITY**

*Make ends meet* by improving income and disability supports for people affected by MS such as making the Disability Tax Credit refundable.

**[3] ACCESS**

*Make access a reality* by implementing the Accessible Canada Act, increasing access to treatments, and investing in comprehensive care and housing.

**[4] ACCELERATING RESEARCH**

*Make health research a priority* by continuing to invest in fundamental research, recognize and support the unique role health charities and patients play in the health research ecosystem, and support innovative partnerships with health charities.
[POLICY PRIORITY]
EMPLOYMENT SECURITY
Make Work…Work!

PRIORITY — EMPLOYMENT SECURITY

The federal government should continue to help “Make Work…Work” by:

- Fully implementing the recommendations in the report made by the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA) with respect to their study on Motion M-192 (Episodic Disabilities).

- Improving the coordination of and program eligibility by fully implementing Bill C-81 changes, which includes episodic disability in the definition of disability across the income, disability, and employment programs (e.g. Employment Insurance (EI) Sickness Benefit, Canada Pension Plan – Disability (CPP-D), and Disability Tax Credit (DTC)).

- Enhancing the EI Sickness Benefit program by:
  - Extending the duration of EI Sickness benefits from 15 weeks to 26 weeks to match compassionate care benefits.
  - Eliminating the clawback.

- Ensuring effective implementation of the amended federal labour code formally allowing requests for flexible work arrangements from employers. Additionally, working with provinces and territories on the implementation of similar changes in provincially regulated sectors.

Employment is a key factor in maintaining adequate income and reducing poverty. The average unemployment rate for people living with MS is a staggering 60%. Research shows that people with MS have disproportionately high unemployment rates given their educational and vocational histories.

Yet people with MS want to work and struggle to continue to work. Often the problem is one of flexibility and accommodation and an 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).
[POLICY PRIORITY] INCOME SECURITY
Lack of secure, adequate income intensifies the hardship caused by MS and keeps people affected by the disease from participating fully in their communities. This situation is amplified for women with disability. In Canada, MS affects women three times as often as men. They also have, on average, lower incomes and earnings thus making them most susceptible to poverty.

Canadians affected by MS face the challenges of paying for medication, services, equipment, treatment, and transportation – and these can be a significant economic burden. Intertwined with this burden are complicated application processes, requirements for numerous verified medical forms, and strict eligibility criteria for programs.

PRIORITY – INCOME SECURITY

Make Ends Meet!

RECOMMENDATIONS

Federal policy should help “Make Ends Meet” by:

- Fully implementing the recommendations in the report made by the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA) with respect to their study on Motion M-192 (Episodic Disabilities).

- Making disability tax credits fully refundable and increase them to put much needed income directly in the hands of low-income people with MS and other disabilities.

- Changing eligibility criteria (e.g. CPP-D, DTC) to include those living with episodic disabilities building in the changes from Bill C-81 to have access to public insurance and tax credit systems for those unable to work or who can only work on an intermittent basis.

- Harmonizing the EI sickness benefits duration of 15 weeks to match the 26 weeks duration of compassionate care benefits.

- Ensuring the implementation of the national poverty reduction strategy incorporates all Canadians including those with episodic and progressive disabilities to have adequate income.

- Increasing existing federal benefits (e.g. EI sickness benefit amount) and credits (e.g. caregiver tax credit, family caregiver tax credit, disability tax credit) for people with disabilities.
[POLICY PRIORITY] ACCESS
The unpredictability and episodic yet progressive nature of MS makes it particularly challenging not only in accessing the built environment, but also in accessing treatments, care, and appropriate housing.

For many individuals living with MS, disease-modifying therapies (DMTs) offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, delaying the accumulation of disability. The needs of people with MS and their families should be at the centre of health and drug policy decisions.

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.

The federal government should help “Make Access a Reality” by:

- **Effective, timely, and full implementation of the Accessible Canada Act, which includes episodic in the definition of disability.** The federal government demonstrated real leadership, and now it’s time to work with the provinces, territories, and private sector to encourage accessibility across all governments and sectors.

- **Ensuring timely and affordable access to all Health Canada approved treatments** for MS as early intervention is vital to avoid many of the long-term economic and personal costs that result from unnecessary irreversible disability. People living with MS and their unique perspective need to be proactively involved throughout the drug review process from Health Canada to the pan-Canadian Pharmaceutical Alliance.

- **Investing in comprehensive care and appropriate housing that includes:**
  - Comprehensive home care, which focuses on the family and includes nursing and personal care, supplies (e.g. incontinence supplies) and equipment, meal preparation, home making, child care, rehabilitation, technology (home monitoring), and meaningful respite services.
  - Support for home modifications through the development of a nation-wide funding program as part of the implementation of the National Housing Strategy.
  - For those unable to remain in their home, the development of and sufficient funding for age-appropriate housing, care and supports needs to be created.

The unpredictability and episodic yet progressive nature of MS makes it particularly challenging not only in accessing the built environment, but also in accessing treatments, care, and appropriate housing.

For many individuals living with MS, disease-modifying therapies (DMTs) offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, delaying the accumulation of disability. The needs of people with MS and their families should be at the centre of health and drug policy decisions.

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.
[POLICY PRIORITY] ACCELERATING RESEARCH
PRIORITY – ACCELERATING RESEARCH

Make Health Research a Priority!

RECOMMENDATIONS

The federal government should make “health research a priority” by:

- **Continuing the investment of fundamental research** in Canada and include health charities as key partners of government, universities, and private industry.

- **Creating a framework for enhanced coordination** among these four groups to better leverage health charity research investment with additional public and private investment dollars for research.

- **Meaningly engaging patients in setting health research policy.** Federal research funding programs should be informed by the perspectives of patients, their caregivers, and healthcare providers.

- **Implementing research agenda priority setting approaches that include patients and health charities across granting programs.** Health charities are leaders in this area and have extensive experience in using a variety of mechanisms to shape the health research agenda, including direct engagement with patients and international collaborations.

- **Support innovative partnerships** with health charities like the MS Society to turn research findings into life-saving outcomes for people living with MS.

For Canadians living with MS, research is key to new treatments, better quality of life, and ultimately a cure. In Canada, we’re on the cusp of game-changing discoveries in the fight against MS and have a network of some of the world’s most brilliant scientists, who are actively working on breakthroughs.

The MS Society, along with funding partners Biogen Canada, Brain Canada Foundation, which receives financial support from Health Canada through the Canada Brain Research Fund, and Hoffmann-La Roche Limited (Roche Canada) have invested in a multi-million-dollar study to understand the MS population here in Canada over time. In addition to the funding partners, the MS Society also received support from lead donors PCL Construction and Bennett Jones LLP. It is only through these important and innovative partnerships across different sectors that we can achieve a better understanding of what MS is, and how treatments can impact Canadians living with MS and the community. This Canadian Proactive Cohort Study for People Living with MS (CanProCo) will provide research solutions that will not only offer hope for those living with MS here in Canada but around the world.