ACT NOW TO IMPROVE

#LIFEWITHMS

POLICY PRIORITIES
About multiple sclerosis

Canada has one of the highest rates of multiple sclerosis in the world, with an estimated 1 in 340 Canadians living with the disease. While it is most often diagnosed in young adults, aged 15-40, we know that it can affect younger children and older adults. MS is the most common neurological disease affecting young adults in Canada.

Women are three times more likely to develop MS than men.

MS is thought to be an autoimmune disease, which means the immune system – designed to protect against intruders such as viruses and bacteria – attacks tissues in the body. In the case of MS, the tissue that is targeted is myelin. Without myelin the communication between nerve cells is disrupted, and the body does not receive the instructions necessary to perform basic functions like speaking, seeing, walking, and learning.

Symptoms

MS symptoms depend upon what part or parts of the central nervous system are affected, this includes the brain, spinal cord and optic nerve. For this reason, symptoms of MS are unpredictable and vary greatly from person to person, and can fluctuate within the same person from one time to the next.

MS commonly manifests itself as impairment of vision, memory, balance, and mobility.

Everyone’s experience with MS is different

Relapsing-remitting MS (RRMS) is characterized by unpredictable but clearly defined periods during which symptoms are apparent. Relapses can last for varying periods (from a few days to several months) and are followed by periods of remission during which many functions return.

Progressive MS occurs in three broad categories: secondary-progressive, primary-progressive, and progressive-relapsing. These have variable degrees of consistency and progression, but all see a worsening of symptoms over time.
Canada has one of the highest rates of MS in the world. Canadian researchers are world leaders in MS research. Now it’s time for Canada to lead the world in improving #LifeWithMS.

MS impacts all Canadians – not only the affected individuals, but also their families and friends. The unpredictable and often episodic nature of the disease makes it particularly difficult for people affected by MS to maintain an adequate quality of life. People also often face serious barriers in the support programs across all levels of governments. This reality creates immense financial and practical challenges for Canadian families who live with MS.

**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 with MS who are unable to work or can only work on an intermittent basis.

3. **Make Access a Reality**
   - By implementing federal accessibility legislation that includes episodic in the definition of disability, 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 and by recognizing and supporting the unique role health charities and patients play in the health research ecosystem.
[PRIORITY]
EMPLOYMENT SECURITY
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. We need to move past the notion of work as a binary switch of "you can work (no assistance)/you can’t work (assistance)."

It’s time to make flexible and inclusive employment security for people with MS a priority to allow people with MS and other episodic disabilities to remain in the workforce.

**RECOMMENDATIONS**

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

- **Improving the coordination of and program eligibility by including episodic disability in the basic definition of disability across the income, disability, 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, we recommend the federal government consult with provinces and territories on the implementation of similar changes in provincially regulated sectors.
[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 living with MS face the challenges of paying for medication, services, equipment, treatment, and transportation – and these can be a significant economic burden.

Qualifying for income and disability supports is challenging for people with MS due to the episodic nature of the disease. Complicated application processes, requirements for numerous verified medical forms, and strict eligibility criteria pose significant problems.

**MAKE ENDS...MEET!**

Federal policy should help “Make Ends Meet” by:

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

- **Changing eligibility criteria** (e.g. Canada Pension Plan – Disability, Disability Tax Credit) to include those individuals living with episodic disabilities 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 national poverty reduction strategy includes episodic and progressive disabilities** to help all Canadians, including those with a diverse range of employment-impacting conditions, achieve 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.
[PRIORITY] MAKE ACCESS A REALITY
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.

**RECOMMENDATIONS**

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

- **Ensuring the Accessibility Legislation** includes all Canadians with disabilities whether their disabilities are visible or invisible, and whether they are permanent or episodic (periods of wellness followed by periods of disability). The definition of disability needs to include the notion of the changing dynamic of disability including episodic, which is the case for individuals living with progressive neurological diseases like MS.

- **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.
[PRIORITY]
ACCELERATING RESEARCH
For Canadians living with MS, research is key to new treatments, better quality of life, and ultimately a cure. The MS Society is focused on accelerating research and since 1948 has provided over $175M of funding for MS research and researchers in Canada. Therefore, we ask the federal government to make health research a priority by continuing to invest in fundamental research and by recognizing and supporting the unique role health charities and patients play in the health research ecosystem.

The MS Society supports the recommendations in the Investing in Canada’s Future: Strengthening the Foundations of Canadian Research (Naylor) report and sees great value in investing in fundamental research. We are pleased to see progress with these recommendations in the announcements made in the 2018 Federal Budget and feel there is still more investment needed. Additionally, the perspective of people living with health conditions (i.e. the patients) are not included in this discussion. This needs to change.

**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.

- **Meaningfully 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.