



## **Written Submission for the Pre-Budget Consultations in Advance of the 2019 Budget**

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## Recommendations

- ✓ **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.
- ✓ **Income Security – Make Ends Meet** by improving income and disability supports for people affected by MS such as making the Disability Tax Credit refundable.
- ✓ **Make Access a Reality** – by passing the proposed Accessible Canada Act, increasing access to treatments, and investing in comprehensive care and housing.
- ✓ **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.

## Introduction

Multiple sclerosis (MS) impacts all Canadians - not only the affected individuals, but also their families and friends. The unpredictable, episodic, yet progressive nature of MS makes it particularly challenging in maintaining an adequate quality of life. MS is a disability which has both visible and invisible symptoms, and barriers in support programs across levels of governments add immense financial and practical challenges for Canadian families who struggle to manage the realities of living with MS. Moreover, some of our social support programs are out of date, artificially pulling people who *can* work out of the workforce. Each time that happens, our overall economy suffers.

The MS Society of Canada is focused on ensuring Canadians living with MS, and their families, have the opportunity **to participate fully and productively in all aspects of life**. To get there, federal policy help is required to address the recommendations outlined on the previous page.

### Employment Security - Make Work...Work!

- 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.
- People with MS want to work and often can work yet are forced to leave the labour force because of insufficient accommodation for flexible work arrangements. We need to move past the notion of work as a binary switch of “*you can work (no assistance) / you can’t work (assistance)*.”

Many support programs in Canada designed to support persons with disabilities are built with a binary switch: either you can work or you cannot work. The reality for a great many Canadians, however, is different. MS is one of a number of conditions that present differently in different individuals. For some, it is progressive with continued worsening of symptoms such as speaking, seeing, walking, and learning over time. For others MS can be episodic – periods of good health interrupted (often unpredictably) by periods of illness or disability that affect one’s ability to work. This also applies to other conditions, including but not limited to, arthritis, HIV, epilepsy, diabetes, some forms of cancer and some mental health conditions. Yet, our support programs such as the Employment Insurance (EI) system does not differentiate, thereby forcing many Canadians out of the workplace entirely and prematurely. This has a massive cost to the economy overall, and the employers who lose corporate memory and experience, and are forced to retrain employees.

***Canada has one of the highest rates of MS in the world!***

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.

Over 77,000 Canadians live with MS. Approximately 1 in every 385 Canadians live with MS. 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. On average, 11 Canadians are diagnosed with MS every day.

We are encouraged to see the amendments to the federal labour code allowing for formal requests for flexible work arrangements. Additionally, we commend the 2018 federal budget changes to the EI Act relating to the Working While on Claim pilot rules, to make them permanent and extend the pilot to include EI Sickness Benefits.

It's time to make flexible and inclusive employment security a priority to allow people with episodic disabilities to remain in the workforce. This is in alignment with the Conference Board of Canada's report "[MS in the Workplace: Making the Case for Enhancing Employment and Income Supports](#)" and their 2016 report [MS in the Workplace](#) as well as the Institute for Research on Public Policy (IRPP)'s report "[Leaving Some Behind: What Happens When Workers Get Sick.](#)"

**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.*

**Income Security – Make Ends Meet!**

- 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 more 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.

We commend the development of a national poverty reduction strategy, which we participated through its consultation, as many of the issues encompassing poverty are unfortunately everyday experiences for people living with MS and their families.

It's time to make income security for people with MS a priority to enable them to make ends meet. This is in alignment with multiple reports including: The Standing Senate Committee on Social Affairs, Science and Technology's recent report "[Breaking Barriers: A critical analysis of the Disability Tax Credit and the Registered Disability Savings Plan](#);" The Conference Board of Canada's report "[MS in the Workplace: Making the Case for Enhancing Employment and Income Supports](#);" the Institute for Research on Public Policy (IRPP)'s report "[Leaving Some Behind: What Happens When Workers Get Sick](#);" and the Caledon Institute's report "[A Basic Income Plan for Canadians with Severe Disabilities](#)."

**Federal policy should help "Make Ends Meet" by:**

- ✓ **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. 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 all Canadians including those with episodic and progressive disabilities to have adequate income.

### **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.

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

- ✓ **Passing the proposed Accessible Canada Act** which 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.

**Accelerating Research – Make Health Research a Priority!**

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 encouraged 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.

**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.

**Conclusion**

Action on the recommendations outlined in this submission will make Canada the world leader not just in its rate of MS, but in the supports needed to improve #LifeWithMS and ultimately enhancing Canada's competitiveness because we are a diverse, accepting, inclusive, and accessible country – not just for MS, but for all Canadians living with chronic illness and disability.