



Take Action to Improve Life with MS

**Multiple Sclerosis Society of Canada
2018 Pre-Budget Consultation Submission**

Introduction

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.

The MS Society 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. We need to:

- ✓ **Make Work...Work** by including more flexible employment to allow people with MS and episodic disabilities to **remain in the workforce**
- ✓ **Make Ends Meet** by closing the gaps in income and disability supports for people with MS who are unable to work or can only work on an intermittent basis
- ✓ **Make Health Research a Priority** by providing sustained funding for health research as outlined in the recommendations of the [Naylor Report](#) on the future of scientific research.

MS is Canada's Disease

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. Most people with MS are diagnosed between the ages of 15 and 40. MS is three times as likely to occur in women as in men. The unpredictable effects of MS are physical, emotional, and financial and last for the rest of their lives.

Canada has the highest rate of MS in the world, and consequently, it is often referred to as "Canada's Disease."

1. *What federal measures would help Canadians to be more productive?*

The federal government can make changes to make it easier for people with MS and others with disabilities to **keep their jobs** and **stay in the workforce** as full productive contributors to growth and prosperity in Canada's economy.

Recommendations to "Make Work...Work":

- ✓ **Improve the coordination of basic definitions and program parameters across the income, disability, employment and support system to include those living with episodic disabilities**
 - This includes all 7 programs offered by different providers (federal, provincial, and private).
 - Canada Pension Plan – Disability (CPP-D); Employment Insurance (EI) Sickness Benefit; Employment-based long-term disability (LTD) plans; Worker's Compensation benefit; Veterans' benefits; Tax measures; Provincial/Territorial social assistance programs

- ✓ **Enhance the EI Sickness Benefit program by:**
 - Extending the duration of EI Sickness benefits from 15 weeks to 26 weeks to match compassionate care benefits
 - Reducing/eliminating the clawback
 - Creating a flexible work-sharing program so that a person can reduce work hours while receiving EI income.

- ✓ **Create a system for the expert dissemination of information and hands-on support to employers** on roles, best practices and resources when an employee or family member is diagnosed with a chronic or episodic disability, and requires time away from work.

Employment is a key factor in maintaining adequate income and reducing poverty. However, the average unemployment rate for individuals with MS is almost 60 per centⁱ. U.S. data indicates that people with MS experience some of the highest unemployment rates among groups with severe and chronic disabilities, and have disproportionately high unemployment rates given their educational and vocational histories.ⁱⁱ People with MS want to work, but struggle to continue to work.

The Conference Board of Canada in 2016 published [a report](#) that found: *“The unpredictability and episodic nature of MS make it particularly challenging in the workplace. As symptom types and severity vary greatly, individuals with MS can find it difficult to manage their treatments, let alone maintain a daily routine and meet work commitments within the traditional employment space.”*ⁱⁱⁱ

[A report](#) by the Institute for Research on Public Policy (IRPP) cited as the Mowat Centre’s top public policy paper in 2015, asks how Canada is doing in supporting Canadians who experience a major health issue with their employment and income needs. It points to a *“need for a comprehensive re-examination of how Canadians are able to balance work and income during periods of receiving or giving care.”* It also notes that each year, six per cent of the Canadian workforce adjust its work status for some length of time in order to deal with a health condition.^{iv}

[Research](#) conducted by the Conference Board of Canada identifies Canadians with disabilities as an under-represented group in the Canadian labour force.^v There are, however, substantial numbers of Canadians with disabilities willing and able to work. If not full-time, then at least on an intermittent basis. A recent [IRPP report](#) states 1.2 million working-age Canadians in 2012 reported one or more of the twenty conditions considered episodic. This represents slightly more than half of the 2.3 million working-age Canadians living with a disability.^{vi} Policies and programs targeted at income or employment support focus narrowly on “disability,” assuming a health condition that is either continuous or progresses linearly through time.^{vii} We need to move past these old, binary, conceptions of both disability and employability.

Recommendations to “*Make Ends Meet*”:

Short Term:

- ✓ **Make 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;
- ✓ **Change eligibility criteria** (e.g. Canada Pension Plan – Disability, Disability Tax Credit) to ensure people with episodic disabilities have access to programs and tax credit systems for those unable to work or who can only work on an intermittent basis;
- ✓ **Harmonize the EI sickness benefits duration of 15 weeks to match the 26 weeks’ duration of compassionate care benefits**;
- ✓ Ensure the **national poverty reduction strategy** includes all Canadians including those with episodic and progressive disabilities to have adequate income;
- ✓ **Increase 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.

Long Term:

- ✓ Give serious consideration to a **basic income program** that would replace provincial/territorial social assistance for most working-age persons with severe disabilities. The Basic Income program would be a close model of the Old Age Security (OAS) and Guaranteed Income Supplement (GIS) programs for seniors. This policy option is recommended in a [report](#) of the Caledon Institute of Social Policy.

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. MS is three times as likely to occur in women as in men. When looking at the distribution of gender of working age Canadians with severe or very severe disabilities *“women outnumber men both in absolute number and incidence (i.e., the percentage of the population with disabilities) among those with severe/very severe disabilities and those with mild/moderate disabilities.”* Women also have on average lower incomes and earnings, thus making them most susceptible to disability-induced poverty.^{viii}

Accessing financial support and managing the high costs of MS is a challenge. [Research](#) shows MS seriously affects the economic life of those diagnosed, even within a few years of onset.^{ix} Medication, services, equipment, treatment and transportation all become additional unexpected costs of living. Many indicate that they need more money and have difficulty navigating support systems to find financial support, be it for medications, income replacement, or claiming tax deductions related to disability.

Qualifying for these programs 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. Additionally, many Canadians with MS cannot qualify for disability-related public or private insurance programs because eligibility is obtained through employment, or is a workplace benefit, and many people impacted by MS in the prime of their lives are no longer able to maintain employment.

While the Disability Tax Credit (DTC) is designed to provide equity to compensate at least roughly for the added non-itemizable and non-reimbursable costs of disability, qualifying is challenging for people with progressive and episodic disabilities.

For those who do qualify, to benefit, an individual must have an adequate amount of income. Many Canadians with episodic disabilities, and women with disabilities, cannot work enough to generate the minimum income required. A refundable tax credit -- that even those with the lowest incomes may access -- would offer a solution to this problem.

In a [recent paper](#), researchers Wayne Simpson and Harvey Stevens calculated that 301,458 of the 499,302 adult Canadians who qualify for the credit cannot receive any benefit from it because they don't have enough income. To turn this around, the authors suggest:

“turning this non-refundable credit into a refundable credit, would increase the average benefit for Canada’s poorest families with a disabled person from \$29 to \$511, increasing their total income by a meaningful 4.1 per cent. Just as importantly, where a meagre 0.2 per cent of these families now get any benefit at all from the credit, a refundable credit would now see a majority, 56.4 per cent, receiving benefits.”

2. What federal measures would help Canadian businesses to be more productive and competitive?

Recommendation to “*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 therefore asks the federal government to make health research a priority.

Federal investment to the Canadian research ecosystem is urgently needed. The MS Society of Canada, as a member of the Health Charities Coalition of Canada, calls on the Government of Canada to make health research a priority by providing sustained funding for health research as outlined in the recommendations in the [Investing in Canada’s Future: Strengthening the Foundations of Canadian Research](#) report.

While the Naylor Report’s recommendations provide a blueprint for elevating Canada’s capacity to be a world leader in research and innovation, we would like to highlight the importance of sustained funding for research from the perspective of the people living with MS.

Fundamental research is imperative to improving the lives of people living with MS and other health conditions as it creates new avenues of discovery and improves the shared knowledge base of science. Canadians rely on advances in fundamental research to explore questions about how a disease develops, determine whether a new treatment may be effective, and help to identify optimal care. Investments made in research serve a dual purpose of not only impacting health outcomes and

promoting innovation, but to also stimulate the economy through employment opportunities, which leads to the commercialization of products and the development of intellectual property.

Fundamental research in Canada is key for generating new knowledge, driving innovation, training the next generation of scientists, for globalization as well as for socio-economic impact leading to improved lives for all Canadians. Responsive and committed federal funding of fundamental research in Canada will provide the stimulus needed to bolster our economy, support innovation, and attract and retain talent to our country. Investments in research today provide jobs and stimulate the economy, setting the stage for improved prosperity and innovation in the future. Health research funding is an investment that attracts and retains talent and, ultimately, improves health outcomes and supports economic growth.

About the MS Society of Canada

The MS Society of Canada is dedicated to finding a cure for MS by funding leading-edge research and improving the quality of life of those affected by the disease. The MS Society offers programs and services for people with MS and their families, and its affiliated MS Scientific Research Foundation is among the largest funders of MS research in the world.

i Schiavolin, S. et al., 2013

ii Sweetland et al., 2012

iii Conference Board of Canada, 2016

iv Meredith, & Chia, 2015

v Brisbois, 2014

vi Furrie, 2010

vii Furrie, 2010

viii Mendelson et al., 2010

ix Pflieger et al., 2009