



## **World Leader in Hockey, Maple Syrup and MS**

**Multiple Sclerosis Society of Canada Pre-Budget Consultation Submission  
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## About the Multiple Sclerosis (MS) Society of Canada

The MS Society provides services to people with multiple sclerosis and their families and funds research to find the cause and cure for this disease. We have a membership of 17,000 and are the only national voluntary organization in Canada that supports both MS research and services. Since our founding in 1948, the core support of the MS Society has been from tens of thousands of dedicated individuals, companies and foundations in communities across Canada.

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. It is the most common neurological disease affecting young adults in Canada. Most people with MS are diagnosed between the ages of 15 and 40. The unpredictable effects of MS are physical, emotional, and financial and last for the rest of their lives. MS impacts all Canadians - not only the affected individuals, but also their families who come together to manage the realities of MS.

Canada has the highest rate of MS in the world.

### Introduction

The MS Society hosted a quality of life initiative/survey in 2013 and heard from 6000 Canadians affected by MS. The data-based conclusions:

- If you live in Canada with MS, you may face the reality that you will no longer be able to work because of the unpredictability of your disease, and the barriers that exist in our support systems.
- Your quality of life will be lower due to a lack of access to financial support and not easily accessible employment and income programs.
- Your family may also be your caregivers.
- And if you live with progressive MS, there are currently no disease-modifying treatments.

***The MS Society is asking the federal government to take action to improve quality of life for Canadians affected by this particularly Canadian disease.*** This includes improvements to programs to **support job retention** and better coordinate **income and disability benefits** for people affected by disabilities; improved **caregiver supports**, coordinated quality **lifelong care**; and accelerated **MS research**.

1. What federal measures would help **Canadians** generally – and such specific groups as the unemployed, Indigenous peoples, those with a disability and seniors – maximize, in the manner of their choosing, their contributions to the country’s economic growth?

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 which will help to sustain and grow Canada’s economy. This includes considering the recommendations in the Institute for Research on Public Policy (IRPP)’s recent ground-breaking report [Leaving Some Behind: What Happens When Workers Get Sick](#) and recently published report *MS in the Workplace* from the Conference Board of Canada.

**Recommendation: Better Employment Supports means:**

- Improve the coordination of basic definitions and program parameters across the disability support system and enhance the breadth and quality of disability insurance coverage within the labour market;
- Extend the duration of EI benefits (from 15 weeks to 26 weeks to match compassionate care benefits), reducing/eliminating the clawback, and 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 illness, and requires time away from work.

The recently published report, *MS in the Workplace* by the Conference Board of Canada, states: “*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.*”<sup>i</sup>

The Institute for Research on Public Policy (IRPP) report “*Leaving Some Behind: What Happens When Workers Get Sick*”, 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 the “*need for a comprehensive re-examination of how Canadians are able to balance work and income during periods of receiving or giving care.*” The report 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.<sup>ii</sup>

**Recommendation: Improved Income Supports**

We recommend that the federal government take action to improve income supports for people with MS who are unable to work or can only work on an intermittent basis. The federal government can:

- **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;**
- **Reduce and/or eliminate the EI sickness benefits waiting period;**

- **Make disability tax credits fully refundable 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 conditions have access to public insurance 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.**

People with MS who can't work have trouble getting by on the limited financial assistance offered under current government programs. 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.

In a recent paper, *“The Disability Tax Credit: Why It Fails and How to Fix It,”* 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.”*<sup>iii</sup>

2. What federal actions would assist **Canada's businesses** – in all regions and sectors – meet their expansion, innovation and prosperity goals, and thereby contribute to economic growth in the country?

**Recommendation: *Increased investment to speed up research to develop effective disease-modifying therapies for progressive MS, to reduce attrition, reduce sick-leave costs, and reduce workplace volatility through better treatments.***

People diagnosed with progressive MS currently face an extremely difficult and precarious future. Approximately 85% of people with MS are diagnosed with a relapsing-remitting course, but half of them will go on to develop secondary progressive MS. Around 15% of people with MS are diagnosed with primary progressive MS, meaning their disease declines steadily from onset – a slow, devastating accumulation of neurological damage and disability.

Better treatments for progressive MS would mean increased mobility, less pain and fatigue, improved productivity (i.e. fewer lost work days), lower health care costs, and full and active participation in many spheres of social and economic life by people affected by MS. It's time to focus additional scientific and financial resources on progressive MS so that we can accelerate the search for disease-modifying treatments and cures.

Advances in treatments for relapsing-remitting MS over the past decade have been remarkable and have assisted individuals to remain in the workforce and use the healthcare system less. Amanda,

diagnosed with MS in 1999 is now on a new oral therapy and says it has been “freeing” and she is able to once again go to work. This helps her, her family, and her employer.

3. What federal measures would ensure that urban, rural and remote **communities throughout Canada** enable residents to make their desired contribution to the country’s economic growth and businesses to expand, prosper and serve domestic and international customers in order to contribute to growth?

### **Recommendation: Care for the Caregiver**

The federal government needs to initiate the development of a National Caregiver Action Plan working with provinces, territories, caregivers, employers and organizations to: reduce financial burden (e.g. refundable caregiver tax credit, and enhanced credits), improve access to resources, create flexible workplace environments, and recognize caregivers’ vital roles. The federal government can:

- **Make caregiver tax credits (family caregiver and caregiver tax credits) fully refundable to help provide essential income for people sacrificing time and income to care for people with MS and other disabilities;**
- **Increase the caregiver tax credit amounts (family caregiver and caregiver tax credits) to help alleviate the immense financial burden faced by Canada’s caregivers;**
- **Expand the “gravely ill” criteria in the Compassionate Care Benefits to include caregivers of people with progressive diseases such as MS.**

Multiple sclerosis affects the entire family. Many find it very difficult to keep full-time jobs while they carry out their vital duties as caregivers – and government support is not adequate or flexible enough to cover their basic living costs.

The Family Caregiver Tax Credit is providing necessary recognition and support of caregivers. However, because the credit is non-refundable, it does not provide adequate support to low income families. Supporting caregivers in Canada is vital to strengthening the social infrastructure of communities across our country to meet the needs of their residents.

### **Recommendation: Coordinate Quality Lifelong Care and Support**

People with MS and people with disabilities need equitable access to a continuum of appropriate, high-quality housing and care. This means governments need to:

- **Increase investments in comprehensive home care for people with long-term chronic health conditions such as MS. Through negotiations of the Health Accord, ensure provinces and territories are accountable to deliver measurable improvements for those who need home care because of a long-term chronic disease and not only to those whose access to homecare is for short period of time as is the case for those requiring post-acute or palliative care at home.**
- **Create a range of age-appropriate housing and care options for people who cannot remain at home;**

- **Fund rehabilitation services in the community (e.g. physiotherapy, occupational therapy, vocational rehabilitation) for people living with MS;**
- **Ensure people with MS have timely access to affordable treatments. This includes access to immunoablation and autologous hematopoietic stem cell transplantation (IAHSCT) at the Ottawa Hospital for those who meet the eligibility criteria. Additionally, medical facilities across the country need to utilize these findings in order to work together to offer this treatment locally – to provide the benefit of this procedure to as many people as possible.**

Quality healthcare in the community for people with complex disabling chronic disease such as progressive MS is woefully inadequate. The current system offers community-based care to those who are terminally ill in the form of palliative care.

Currently, disease-modifying therapies (DMTs) approved for multiple sclerosis (MS) appear to work by blunting the destructive autoimmune response that targets tissues in the central nervous system (CNS). For many individuals living with MS, DMTs offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, delaying the accumulation of disability.

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<sup>i</sup> *Thy, Dinh, Philip Astles, and Karen Turpin. Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences. Ottawa: The Conference Board of Canada, 2016.*

<sup>ii</sup> *Meredith, T., and Chia, C. Leaving Some Behind: What Happens When Workers Get Sick. Institute for Research on Public Policy, 2015.*

<sup>iii</sup> *Simpson, W., and Stevens, H. The Disability Tax Credit: Why It Fails and How to Fix It. University of Calgary, School of Public Policy, 2015.*