



**Written Submission for the Pre-Budget Consultations in
Advance of the 2020 Budget**

**By: Julie Kelndorfer, Director, Government and Community Relations,
Multiple Sclerosis Society of Canada**

Recommendations

Employment Security – *Make Work...Work*

People with MS want to work but struggle to continue to work. A staggering 60% are unemployed and that needs to change. We need to update the definition of disability to include episodic (periods of wellness followed by periods of disability).

Income Security – *Make Ends Meet*

The cost of paying for medication, services, equipment, and treatment is a significant burden for people with MS and their families. When MS stops someone from working, they should be able to access adequate income and disability support.

Access - *Make Access a Reality*

MS is unpredictable, episodic and progressive which means the needs of people with MS change over time. Access throughout our communities and access to comprehensive treatment, care and appropriate housing is a must.

Accelerating Research – *Make Health Research a Priority*

Research is key to new treatments, better quality of life, and ultimately a cure.

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.

The MS Society has heard the personal and profound stories of life with MS from Canadians coast to coast – the struggles in the workplace, the financial difficulties families are facing to make ends meet, the frustrating barriers in accessing Health Canada approved therapies, appropriate care, housing, and social supports, and the hope research provides.

Now it's time for Canada to #MakeMSMatter! It's time for the federal government to join our collective effort towards our mission of connecting and empowering the MS community to create positive change that helps realize our vision of a world free of MS. We are committed to ensuring Canadians living with MS, and their families, can participate fully in all aspects of life. This means asking the federal government to remove barriers and improve policies which impact people with MS in several areas.

Employment Security

People with MS want to work but struggle to continue to work. A staggering 60% are unemployed and that needs to change. We need to update the definition of disability to include episodic (periods of wellness followed by periods of disability).

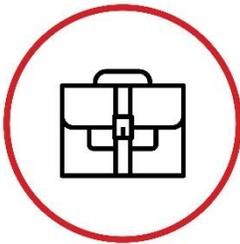
Canada has one of the highest rates of MS in the world!

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.

Key Actions for the federal government:



- Implement the 11 recommendations regarding episodic disabilities in the HUMA Parliamentary Committee's [Motion M-192 report](#)
- Increase Employment Insurance (EI) Sickness Benefits from 15 weeks to 26 weeks

The **evidence** to improve employment security is in alignment with the following:

- Report of the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA) (2019) [Taking Action: Improving the Lives of Canadians with Episodic Disabilities](#)
- Disabled Women’s Network of Canada (DAWN Canada) (2019) - [More Than A Footnote: A Research Report on Women and Girls with Disabilities in Canada.](#)
- Conference Board of Canada (2018) report: [MS in the Workplace: Making the Case for Enhancing Employment and Income Supports](#)
- Public Policy Forum (2017) report: [Condition Chronic](#)
- Conference Board of Canada (2016) report: [Multiple Sclerosis in the Workplace: Supporting Successful Employment Experiences](#)
- [Multiple Sclerosis International Federation \(2016\): Global MS Employment Report](#)
- Institute for Research on Public Policy (2015) report: [Leaving Some Behind: What Happens When Workers Get Sick.](#)

Income Security

The cost of paying for medication, services, equipment, and treatment is a significant burden for people with MS and their families. When MS stops someone from working, they should be able to access adequate income and disability support.

Key Actions for the federal government:



- Make the Disability Tax Credit refundable
- Implement the 11 recommendations regarding episodic disabilities in the HUMA Parliamentary Committee’s [Motion M-192 report](#)
- Change eligibility criteria (e.g. Canada Pension Plan – Disability, Disability Tax Credit) to include those with episodic disabilities building in the changes from Bill C-81 for those unable to work or who can only work on an intermittent basis

The **evidence** to improve income security is in alignment with the following:

- Report of the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA) (2019) [Taking Action: Improving the Lives of Canadians with Episodic Disabilities](#)
- Disabled Women’s Network of Canada (DAWN Canada) (2019) - [More Than A Footnote: A Research Report on Women and Girls with Disabilities in Canada.](#)
- Neurology (2019) - [Disability progression in multiple sclerosis linked to income, education](#) (Low socioeconomic status (SES) at symptom onset was associated with a higher risk of reaching 2 important disability milestones (EDSS 4.0 and 6.0) as well as secondary progressive MS)

- The Standing Senate Committee on Social Affairs, Science and Technology (2018) report: [Breaking Down Barriers: A critical analysis of the Disability Tax Credit and the Registered Disability Savings Plan](#)
- Conference Board of Canada (2018) report: [MS in the Workplace: Making the Case for Enhancing Employment and Income Supports](#)
- [Statistics Canada - Canadian Survey on Disability, 2017](#)
- Public Policy Forum (2017) report: [Condition Chronic](#)
- Institute for Research on Public Policy (2015) report: [Leaving Some Behind: What Happens When Workers Get Sick.](#)
- Caledon Institute (2010) report: [A Basic Income Plan for Canadians with Severe Disabilities](#)

Access

MS is unpredictable, episodic and progressive which means the needs of people with MS change over time. Access throughout our communities and access to comprehensive treatment, care and appropriate housing is a must.

Key Actions for the federal government:



- Implement the Accessible Canada Act to ensure a barrier-free Canada and specifically with regards to:
 - Programs and service delivery – ensure services are accessible to all (e.g. Canada Pension Plan – Disability (CPP-D), Employment and other programs and benefits revise their definitions of disability to align with the Accessible Canada Act definition.)
 - Employment – ensure access to employment opportunities and accessible workplaces (include an episodic disability lens)
 - Built environment – ensure Canadians can move freely in around buildings and public spaces
 - Transportation – ensure a barrier-free federal transportation network
- Through intergovernmental health agreements invest in comprehensive homecare (includes personal and nursing care and in-home supports) and for those unable to remain at home, fund the development of appropriate housing through the national housing strategy
- Increase access to Health Canada approved treatments as early intervention is vital

The **evidence** to make access a reality is alignment with the following:

Accessibility

- Government of Canada: Accessibility Legislation Consultation Report – [What We Heard](#)
- Angus Reid Institute in partnership with the Rick Hansen Foundation report - [Accessibility: A source of future anxiety and a significant consideration for Canadian consumers today](#)

Access to Treatments

- Conference Board of Canada (2016) report: [The Value of Specialty Medications: An Employer Perspective](#)
- Evidence-based international consensus report: [Brain health: time matters in multiple sclerosis](#) (recommends a strategy to maximize lifelong 'brain health')

Care and Housing

- Statistics Canada Health Report (2017): [Needs for mobility devices, home modifications and personal assistance among Canadians with disabilities](#)
- [Clinical Profile of Persons with Multiple Sclerosis Across the Continuum of Care](#) (2018- Canada)- *Conclusion - the prevalence of MS in community, institutional and hospital-based care settings exceeded that of the general population.*

Accelerating Research

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 is focused on accelerating research and since 1948 has provided over \$175M of funding for MS research and researchers in Canada.

Key Actions for the federal government:



- Continue to invest in basic scientific research
- Connect with health charities to ensure the patient voice is part of the research priority setting
- Partner with health charities to turn innovative research into real-life treatments

The **evidence** to make health research a priority is alignment with the following:

- [Investing in Canada's Future: Strengthening the Foundations of Canadian Research](#) (Naylor) report
- Motion M-132 Federally Funded Health Research – Report of the Standing Committee on Health - [Report 20 - Towards Open Science: Promoting Innovation in Pharmaceutical Research and Development and Access to Affordable Medications both in Canada and Abroad](#)
- [Canadian Proactive Cohort Study for People Living with MS \(CanProCo\)](#)

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 and services for Canadians affected by MS. Ultimately implementing these recommendations will enhance Canada's competitiveness as we are a diverse, accepting, inclusive, and accessible country – not just for MS, but for all Canadians living with chronic illness and disability.