



**Written Submission for the Pre-Budget Consultations in
Advance of the 2022 Budget**

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Recommendations

Recommendation 1: Make Work...Work

Update the EI sickness benefit by reducing the hours needed for eligibility from 600 to 400, by removing the one week waiting period, and by eliminating the clawback in the Working While on Claim provision.

Recommendation 2: Make Ends Meet

Implement the Canada Disability Benefit to make direct payments to individuals who live with a disability, specifically including episodic disability as defined in the Accessible Canada Act.

Recommendation 3: Make Access a Reality

Accelerate current reforms to pharmaceutical policy (i.e., PMPRB reforms, national pharmacare, national drug agency), and incorporate patient-centred perspectives to make access to MS treatments equitable, affordable and timely.

That the government create an age-appropriate care and housing approach in the COVID-19 recovery including the perspective of adults under 65 with disabilities.

Recommendation 4: Make MS Research a Priority

Make MS research a priority by investing critical funds in health research in partnership with health charities, by continuing to invest in basic scientific research, and by connecting with health charities like the MS Society to ensure the lived experience and patient voice are part of research priority setting.

Introduction

Due to its high rate in Canada, multiple sclerosis (MS) impacts all Canadians not just the people who live with MS – their family, their friends, their community and country are all touched by this disease. The unpredictable, episodic, yet progressive nature of MS makes it particularly challenging to maintain an adequate quality of life. MS is a disability which has both visible and invisible symptoms, and barriers in government support programs add immense financial and practical challenges for Canadian families who struggle with the realities of living with MS.

Today's uncertain and difficult times resemble what it's like to live with MS – every single day. Every day, people with MS wake up to adversity and do everything in their power to persevere. Now, the COVID-19 pandemic has compounded the challenges faced by the thousands of Canadians living with and impacted by MS. And just as COVID has had a more pronounced impact on women, so too does MS – 75 per cent of Canadians living with MS are women.

The MS Society of Canada provides information, support and advocacy to people affected by MS. This submission highlights recommendations for the federal government to join in 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. Together, we can ensure Canadians living with MS, and their families, can participate fully in all aspects of life.

Recommendation 1: Make Work...Work

Update the EI sickness benefit by reducing the hours needed for eligibility from 600 to 400, by removing the one week waiting period, and by eliminating the clawback in the Working While on Claim provision.

Employment is a key factor in maintaining adequate income and reducing poverty. Yet many people living with MS who want to work struggle to do so. Research shows that people with MS have disproportionately high unemployment rates given their educational and vocational histories.

Often the problem is one of flexibility, accommodation, and a lack of understanding that episodic disability means periods of wellness followed by periods of relapse. It is critical we move past the notion of work as a binary switch of “you can work” (no assistance) vs. “you can't work” (assistance). With more than 60 per cent of people living with MS eventually reaching unemployment it's clear more needs to be done to support those who live with episodic disabilities.

The extension of the EI sickness benefits from 15-26 weeks in Budget 2021 is an important first step in updating the EI Sickness benefit, but without further updates, some who live with MS will still be left behind. Many people with MS are still excluded from EI sickness benefits because they have precarious employment that fails to meet the minimum hours requirement. During the COVID-19 response, the government quickly and aggressively experimented with policy innovation to give individuals and businesses the support they needed.

The removal of the waiting period and reduction in hours to qualify for the benefit addressed a lack of flexibility in the EI sickness benefit and it needs to continue to apply moving forward. Additionally, eliminating the clawback in the working while on claim provision specific to the EI sickness benefit will

enable Canadians with episodic disabilities to access much needed income while maintaining their connection to the workforce.

Recommendation 2: Make Ends Meet

Implement the Canada Disability Benefit to make direct payments to individuals who live with a disability, specifically including episodic disability as defined in the Accessible Canada Act.

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 must be able to access adequate income and disability supports.

[According to the National Advisory Council on Poverty](#), “Persons with disabilities, immigrants, refugees, ethno-cultural and racialized groups, LGBTQ2S individuals and many others remain at a high risk of living in poverty compared to the general population.”

Just as COVID-19 has had a more pronounced impact on women, so too does MS – 75 per cent of Canadians living with MS are women. When it comes to income security in particular, the challenges are further amplified for women. They have on average, lower incomes and earnings thus making them more susceptible to poverty. As noted in the report [Disability Inclusion Analysis of Lessons Learned and Best Practices of the Government of Canada’s Response to the COVID-19 Pandemic](#) based on [Statistics Canada 2020](#) findings, “Many people with disabilities faced disproportionately high decreases in income since the start of the pandemic, with impacts more severe among:...women with disabilities.”

Socioeconomic status has profound effects on health outcomes. [Research](#) supported by the MS Society of Canada and published in Neurology (2019) demonstrated that less socioeconomically advantaged people living with MS tend to have greater disability. Furthermore, at the 2021 Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum, new [findings](#) were presented that suggest people with MS who are less socioeconomically advantaged tend to have faster rates of nervous system damage. Hence, the urgency in ensuring income security through the implementation of the Canadian Disability Benefit.

Recommendation 3: Make Access a Reality

Accelerate current reforms to pharmaceutical policy (i.e., PMPRB, national pharmacare, national drug agency), and incorporate patient-centred perspectives to make access to MS treatments equitable, affordable and timely.

That the government create an age-appropriate care and housing approach in the COVID-19 recovery including the perspective of adults under 65 with disabilities.

While there is no cure for MS, access to Health Canada approved disease-modifying therapies (DMTs) is key to maintaining positive health outcomes for people with MS. Early intervention and treatment are vital to avoiding many of the long-term economic and personal costs that result from unnecessary irreversible disability.

The MS Society strongly believes that a population health perspective may not reflect the needs of individual patients especially as it relates to a heterogenous disease like MS. No two people have the same course of the disease or respond in the same way to the same medication. As a result, addressing patient concerns regarding the PMPRB changes, which to date have not been, while ensuring equitable access to all Health Canada approved treatments for MS and a wide array of therapeutic options is crucial.

A 2020 Conference Board of Canada report - [Accessing Disease-Modifying Therapies for Multiple Sclerosis: A Pan-Canadian Analysis](#) finds that many Canadians living with MS can't get sufficient, equitable, or affordable access to DMTs. The report shows that they face regulatory, administrative, and financial barriers to access, stopping them from using these life-changing therapies.

Canadians living with MS often require housing and care support – in home settings and in long-term care (LTC) facilities. Unfortunately, there are many examples of inappropriate responses to this need, related to age, ability level, culture, family visitation, connection with the community and optimizing support for independence.

Despite the current unprecedented spotlight on LTC facilities in Canada, the perspective of younger adults with disabilities living in LTC continues to be ignored. This is in direct contrast to the Government of Canada's [COVID-19 and people with disabilities in Canada guidance document](#); "Special considerations, adaptations and accommodations should be considered and provided for people with disabilities within the healthcare and public health systems...This applies to acute care hospitals, long-term care homes, congregated residential settings..."

Persons affected by MS must be accorded the opportunity to remain in their own homes and in the community with the appropriate supports. Comprehensive home care needs to focus on the family and include: nursing and personal care, supplies (e.g. incontinence supplies) and equipment, homemaking, meal preparation, childcare, rehabilitation, technology (e.g. home monitoring), and meaningful respite services. According to a [2021 study](#) from the Canadian Medical Association the inability to provide these supports in the community is causing the rapid growth in LTC populations.

As our country moves toward COVID-19 recovery, including the perspective of young adults in LTC while addressing the challenges exposed is imperative. To exclude them and their lived experience will only exacerbate their current situation.

Recommendation 4: Make MS Research a Priority

Make MS research a priority by investing critical funds in health research in partnership with health charities, by continuing to invest in basic scientific research, and by connecting with health charities like the MS Society to ensure the lived experience and patient voice are part of research priority setting.

Virtually no other disease has seen the kind of life-altering advancement that MS treatment and research has seen in the past two decades. We are progressing by leaps and bounds, but there is far more that needs to be done. We need more research on why one person's MS progresses and another's does not. We are on the cusp of treatments that target cellular and nervous system repair, actually

reversing the effects of MS. This is the game-changing research and innovation we have been funding – and due to COVID-19 it's slowing to a trickle.

Typically, the MS Society invests \$6-10m annually in MS research. In 2020, however, given COVID-19, we could only invest \$4.7m in research funding to support 13 research projects in MS and 38 trainees. In 2021, that number has been substantially reduced to just the Personnel Award program that supports trainees in MS research – up to a maximum of \$1.5m. Our research funding will continue to fall short of the much-needed investment in MS research without further support from the Government of Canada.

The Government of Canada's partnership with health charities will keep important breakthroughs within our grasp. The MS Society has a longstanding track record of bringing the right priorities, partners, processes, and funding together to deliver breakthroughs. For example, the MS Society's partnership with the Brain Canada Foundation, industry (Roche Canada and Biogen Canada), and the Government of Alberta – the Canadian Prospective Cohort Study to Understand Progression in MS (CanProCo), is key to turning innovative research into real-life treatments.

The MS Society supports fundamental research as we still don't know what causes MS, or how we could prevent it. The research we fund directly includes the voice of Canadians living with MS. We have effectively integrated people affected by MS into the research review process and inform the MS community about advances in the latest MS research. This is the example we would like to see implemented across the entire health research ecosystem.

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 disease and disability.