



TAKING ACTION TO END MS - CANADA'S DISEASE

PRE-BUDGET CONSULTATION SUBMISSION

SUBMITTED JANUARY 2016

The Multiple Sclerosis Society (MS) of Canada is pleased to provide input to the 2016 pre-budget consultation. Canada has the highest rate of multiple sclerosis in the world. MS is truly Canada's disease. As Canadians, our risk of developing MS is two times greater than if we lived in France, 13 times greater than if we lived in Argentina and 27 times greater than if we lived in Pakistan.

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. The unpredictable nature of MS has a profound impact on a person's ability to maintain financial security and navigate healthcare and community support systems. In many cases, the role of family caregiver is vital for physical and emotional support of a person living with MS.

The MS Society hosted a quality of life initiative/survey in 2013 and heard from thousands of Canadians affected by MS. We heard that 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 may be lower than that of your friends and other Canadians 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. This feedback was echoed in 2015 during our federal election campaign.

Our outreach and consultations have led to a number of policy innovation ideas that when implemented, can make a real and lasting impact on people affected by MS. The recommendations presented in this submission reflect the importance of ensuring no one is left behind.

RECOMMENDATIONS

The MS Society is asking the federal government to take action now to improve quality of life for Canadians affected by Canada's disease – MS. This includes improvements to programs to support job retention and better coordinate income and disability benefits for people affected by MS and other disabilities, improve caregiver supports, and accelerate MS research.

Recommendation: *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. 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 convening a national dialogue to identify feasible solutions to ensure **no one is left behind**.*

- *Change the Employment Insurance program to make it more flexible and provide incentives to stay in the workforce.*
- *Consider work sharing program for individuals on sickness leave.*
- *Expand the federal-provincial labour market agreements and other employment funding programs to provide early intervention and other services to help support job retention. Provide counselling and information support for employers on how to accommodate and to promote disability management practice*

Background

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 symptoms, let alone maintain a daily routine and meet work commitments within the traditional employment space. It has been estimated that the average unemployment rate of individuals with MS is almost 60 per cent. Some reports have estimated this number as high as 80 per cent as the disease progresses. More employers need to address the challenges caregivers of individuals with MS face in the workplace.

Half of working age Canadians with disabilities have a disease which is episodic in nature. Many employers do not understand episodic illnesses and disabilities like MS, where severe symptoms come and go in unpredictable ways. We know from our Listening initiative/survey that only half of those still working said their employer had made accommodations to help them stay in their jobs. Most jobs are not flexible enough to accommodate their needs and government programs do not support intermittent part-time work.

"The issues in question are confronted by more than one million Canadians living with episodic or some form of chronic illness: you want to work, you can work, but the income and social support systems governing our labour market are designed with a binary switch — you're either in the workforce and off assistance, or you're out of the workforce completely and on assistance."

[iPOLITICS](#)—September, 16, 2015

Employment Insurance (EI) sickness benefits are designed for people who are sick and unable to work. They do not take into account the situation of people with MS and other episodic illnesses, whose ability to work varies greatly over time. The EI program makes a gradual return to the job or intermittent work very difficult, since benefits are reduced dollar for dollar by any job earnings and working a few hours per week means losing a week of benefits.

Employment programs provided by the provinces with federal funding under current Canadian Labour Market Agreements are designed to create new jobs and promote recruitment for people with disabilities. They do not provide the services that would really help people with MS and other episodic disabilities keep working, e.g., early on-the-job support or encouragement to employers to make needed workplace accommodations.

Recommendation: *Canada's governments should 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 should:*

- *Increase existing federal benefits (i.e. EI sickness benefit amount) and credits (i.e. caregiver tax credit, family caregiver tax credit, disability tax credit) for people with disabilities.*
- *Make disability tax credits fully refundable to put badly needed income directly in the hands of low-income people with MS and other disabilities.*
- *Change eligibility criteria to ensure people with episodic illness and disability have access to disability tax credits and benefit programs.*

Background: 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.

The impact is real for people like Alex who was diagnosed with primary-progressive MS in 2011. He was forced to leave his career because of his disease and now relies on income support to provide for himself, his wife and three children. Alex and his family often went months without any income while trying to access disability benefits. Alex states "You have to jump through hoops to access employment insurance, social assistance and disability supports. It takes many hours and lots of visits to doctors, health professionals and government offices just to apply for the financial help you need. The process takes many months, and while you are doing this you have to go without a diagnosis, income, and medications and at times, even food on the table."

Recommendation: *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.*

Background: Multiple sclerosis affects the entire family. Spouses, mothers, fathers and children as well as friends become caregivers — integral to the health and well-being of people with MS and they too struggle financially. 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. Canada does not have a federal action plan to support caregivers, unlike other countries such as Great Britain, United States, and Australia that have national caregiving strategies or supports for caregivers. 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: *Increased investment to speed up research to develop effective disease-modifying therapies for progressive MS. Canadians with this highly damaging and challenging form of MS need answers urgently.*

Background: 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. There are no effective treatments available for progressive MS that target the disease process, only those that assist with symptom management. This means that people who live with this form of multiple sclerosis experience 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.

Michelle has lived with progressive MS for over 30 years. Over the past two decades she has seen treatment after treatment become available for those with relapsing-remitting MS, and while she is grateful for advancements in the field of MS research, she is still waiting for a treatment that could help her. She explains "Research takes time, I get that...but it's a challenge to exercise patience when you're the one living with this disease — calls to action like this give me hope, which is a very powerful thing when you're living with progressive MS."

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 work, attend social events, and doesn't have the side effects from older medications. People affected by MS would like to see treatments for progressive forms of MS as well to enable them to lead productive lives in their communities.

TAKING ACTION

Canada has the highest rate of MS in the world. The MS Society heard from Canadians affected by MS and have now shared these recommendations. Since MS is Canada's disease, we should be the country to pioneer new policy approaches to meet the needs of those affected by the disease. Increased research investments for progressive MS are key in the fight to #endMS. Better income, job, and caregiver support will make a huge difference to the quality of life of people living with MS. It's now time to take action to end Canada's disease.

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