



LISTENING TO PEOPLE AFFECTED BY MS AND TAKING ACTION

BRIEF TO THE HOUSE OF COMMONS STANDING COMMITTEE ON FINANCE

PRE-BUDGET CONSULTATION

SUBMITTED AUGUST 6, 2014

The Multiple Sclerosis Society (MS) of Canada is pleased to provide input to the Standing Committee on Finance as part of the 2015 pre-budget consultation. Canada has the highest rate of MS in the world. 100,000 Canadians live with the disease and thousands more are affected by it. It is a costly disease both directly and indirectly to our Canadian health, social, and economic systems.

In 2013, more than 6,000 Canadians affected by MS responded to the Listening to People Affected by MS initiative (Listening survey), hosted by the MS Society of Canada, allowing us to better understand the impact of multiple sclerosis on quality of life (QOL) needs, gaps and barriers. We heard from a broad range of people including those diagnosed with MS, people waiting for a diagnosis of MS, informal caregivers of a person with MS, family members and close friends of people with 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. If you have MS, you likely spend free time trying to navigate a complicated health and social support system, to access the resources that are available to you as a Canadian living with a chronic illness. Ultimately, we heard that if you live with MS in Canada, you want to see governments take ACTION on MS.

Based on the gaps and barriers identified in the Listening Survey noted above we recommend the following:

- (1) The federal government needs to create and expand more flexible employment programming to improve job retention rates for those affected by episodic disabling diseases like MS.**
- (2) The federal government needs to improve income security programs for people affected by MS and other episodic and chronic diseases and disabilities.**
- (3) 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, improve access to resources, create flexible workplace environments, and recognize caregivers' vital roles.**

The MS Society works collaboratively with the Health Charities Coalition of Canada, the Episodic Disabilities Network and the Neurological Health Charities Canada to enhance employment and income security for people with episodic disabilities and for neurological conditions as well as advocate for improved caregiver supports.

ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis is an often progressive and disabling disease of the brain and spinal cord. The disease attacks the protective myelin covering of the central nervous system, causing inflammation and often destroying the myelin in patches. In its most common form, MS has well defined attacks followed by complete or partial recovery — sometimes described as an “episodic disability”.

MS symptoms are unpredictable and vary greatly from person to person. Symptoms may include vision disturbances such as double or blurred vision, extreme fatigue, loss of balance, problems with coordination, stiffness of muscles, speech problems, bladder and bowel problems, short-term memory problems, and even partial or complete paralysis.

Canada has the highest rate of MS in the world. 100,000 Canadians live with the disease and thousands more are affected by it. MS is the most common neurological disease affecting young adults. It is most often diagnosed between the ages of 15 and 40, during the prime career and family building years.

RECOMMENDATIONS

One of the themes highlighted by the Finance Committee for this pre-budget consultation is “support for families and helping vulnerable Canadians by focusing on health, education and training.” The recommendations presented in this brief not only reflect this focus but the other themes of economic growth, and maximizing the number and types of jobs for Canadians.

Specifically, the MS Society is asking the federal government to invest in programs that will improve job retention and better coordinate income and disability benefits for people affected by MS and other disabilities as well as improve caregiver supports.

1. **Recommendation:** The federal government should make immediate changes to make it easier for people with MS and others with episodic illnesses and disabilities to keep their jobs and stay in the workforce.
In the short term:
 - Pursuant to Motion No. 430 the federal government implement recommendations to increase the flexibility and adaptability of employment programs.In the long term:
 - Change the Employment Insurance program to make it more flexible and provide incentives to stay in the workforce.
 - Pursuant to Motion No. 430, expand federal-provincial labour market agreements and other employment funding programs to provide early intervention and other services to help support job retention.

Canadians living with MS face severe difficulties coping with a challenging illness. They also struggle to survive financially and deal with the high costs that go along with MS. People with MS struggle to continue working, and we know from research as their MS progresses, nearly 80 per cent of Canadians

impacted by the disease may find themselves unemployed. 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 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.

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.

Yet experience has shown that many Canadians with MS and other episodic disabilities want to work and can stay in the workforce with the right supports.

2. **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 and credits 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.
 - Change federal legislation to prevent private insurance companies from cutting back Canada Pension Plan — Disability Children's Benefit from people receiving long-term disability. This money is targeted for children of people with disabilities and it's unfair to deduct it from the parent's income.

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

Lack of secure, adequate income intensifies the hardship caused by MS and keeps people affected by the disease from participating fully in their communities. 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, medications and at times, even food on the table."

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 the MS Society's Listening survey we heard from Canadians that:

- almost 1/3 had to rely on financial help outside their personal resources to deal with issues related to MS;
- almost 1/2 had difficulty getting financial assistance to meet their medical and support needs;
- almost 1/2 of the people receiving disability benefits found this income was not enough to maintain a decent quality of life.

3. **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, improve access to resources, create flexible workplace environments, and recognize caregivers' vital roles.

- 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.

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.

The Listening survey highlighted the great challenges faced by caregivers:

- The greatest worry for people affected by MS is the impact the disease has on their family — their well-being, financial security, and general quality of life.
- Only 28% of caregivers can find the support they need as a caregiver.
- Only 23% of caregivers feel they have someone to talk to when they feel tired or negative.
- Only 28% of caregivers have access to respite care to give them a break from caregiving when they need it.

While we are pleased to see the launch of the Canadian Employers for Caregivers Plan (CECP) this past June with the focus on the need to address caregivers and the workplace we will look forward to seeing improvements in these other areas noted above as well.

TAKING ACTION

Canada has the highest rate of MS in the world. Not only do 100,000 Canadians live with MS, their families, friends and communities live with MS too. The MS Society heard from Canadians affected by MS and have now shared that information with this committee. It's now time to take action.

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