

MOVING TOWARD INCLUSION AND PROSPERITY

BRIEF TO THE STANDING COMMITTEE ON FINANCE PRE-BUDGET CONSULTATION SUBMITTED AUGUST 12, 2011

EXECUTIVE SUMMARY AND RECOMMENDATIONS

The Multiple Sclerosis Society of Canada (MS Society) is pleased to provide input to the Standing Committee on Finance for its pre-budget consultation. Our perspective is that of people affected by MS: the estimated 55,000 to 75,000 people who have the disease, their families and caregivers, health care professionals, researchers and MS Society of Canada supporters.

The MS Society recognizes significant progress has been made in the past few months on issues that impact people affected by MS and thanks all Members of Parliament who championed them. This includes the commitment to fund a clinical trial of CCSVI¹ and MS and the establishment of the Canadian Multiple Sclerosis Monitoring System. We believe these two initiatives are very much in the spirit of the Strategy for Patient-Oriented Research (SPOR) being led by the Canadian Institutes of Health Research. The MS Society was pleased to see additional funding for SPOR in the June 2011 budget. Finally, we are grateful for the commitment to a new Family Caregiver Tax Credit which will include spouses – an inclusion the MS Society has been urging for a number of years.

The MS Society recognizes the need for spending restraint given the current uncertain economic climate. Our recommendations, therefore, are targeted at helping people return to and keep their jobs, increasing the income security of low-income Canadians and ensuring the health care system is there for people with MS and other episodic disabilities and brain conditions.

1. **Recommendation:** That the Government of Canada first, immediately addresses the needs of caregivers of people with MS by making existing and future caregiver tax credits refundable to help them in their day-to-day lives of looking after loved ones and second, work with the provinces, territories, caregivers and caregiver organizations on the development of a pan-Canadian approach to supporting caregivers.
2. **Recommendation:** That the Government of Canada makes Employment Insurance sickness benefits more flexible so people can work part-time and receive partial benefits. In addition, making the Disability Tax Credit refundable would help address the income needs of low-income Canadians. Finally, develop – in consultation with the provinces, persons affected by MS, as well as other stakeholders – a pan-Canadian income security program to replace the current hodgepodge of disability pensions, social assistance programs and tax credits.
3. **Recommendation:** That the Government of Canada begins in 2012 a robust, nation-wide dialogue about the health care system and what a new Health Accord should look like and commit to the inclusion of people with chronic conditions such as MS. In the meantime, the six percent ongoing commitment to health care funding should continue.

ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis is an unpredictable and often 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”**.²

MS symptoms are unpredictable and vary greatly from person to person. Symptoms may include: visual disturbances such as double or blurred vision, extreme fatigue, loss of balance and coordination, muscle stiffness, speech problems, bladder and bowel problems, short-term memory problems and partial or complete paralysis. Very recently, a new and intriguing theory about MS has emerged. It suggests that MS may be related to a possible narrowing of veins in the neck and chest area. This has been called chronic cerebrospinal venous insufficiency or CCSVI. The MS Society is funding research into CCSVI and MS to advance scientific knowledge as quickly as possible.

Canada has one of the highest rates of MS in the world with an estimated 55,000 to 75,000 people affected by MS. It is the most common neurological disease affecting young adults and is most often diagnosed between the ages of 15 and 40, during prime career and family building years.

THE IMPACT OF MULTIPLE SCLEROSIS

Multiple sclerosis is a costly disease. MS has a significant economic impact on the health care system because of increased visits to a doctor, longer stays in hospital and the need for often costly medications. One study, done in the late 1990s, estimated the lifetime cost of the disease is \$1.6 million per each person with MS.³ In other research, the Public Health Agency of Canada estimated the total costs associated with MS in 2000-2001 were almost \$1 billion: \$139.2 million in direct costs (hospital care, physician care, drugs) and \$811.3 million in indirect costs (dollar value of production costs due to long-term disability or premature death).⁴

MS has a profound impact on the ability to earn a living. Many people are diagnosed between the ages of 15 and 40, just when they are finishing school, starting careers and beginning families. As the disease progresses, it takes a toll on a person’s ability to stay in the work force full-time. Over time, up to 80 percent of people with MS can no longer work. Sometimes, this is because the disability caused by MS becomes more severe, but at other times, it’s because of a lack of understanding and accommodation by employers and insufficient government supports. While not all of these costs noted above can be avoided, the MS Society believes the cost to society could be reduced if greater assistance were provided to people with MS and other episodic disabilities and neurological conditions to assist them in remaining or returning to work.

RELATIONSHIP TO OTHER EPISODIC DISABILITIES AND BRAIN CONDITIONS

The MS Society works with other organizations representing people who live with other episodic disabilities and brain conditions⁵ and their caregivers. Our recommendations reflect the needs of those communities as well. Thus, our recommendations, if acted upon, would benefit the wider population of Canadians with episodic disabilities and brain conditions. The MS Society works closely with the Canadian Caregiver Coalition, Episodic Disabilities Network, Health Charities Coalition of Canada and Neurological Health Charities Canada.

WHAT IS NEEDED

The MS Society asks the Standing Committee on Finance to consider the needs of people with MS and caregivers and examine approaches for employment and income supports that would directly

improve the lives of people affected by MS and other episodic and neurological conditions as well as their caregivers. Such changes would have a positive result, in many cases, by helping people living with MS and other episodic and neurological conditions and their caregivers return to jobs where they can once again help contribute to a prosperous Canada.

1. Support for caregivers

Canada's support for caregivers is limited, while the need for caregiving is increasing. Millions of Canadians provide much needed care to their loved ones with chronic illnesses and disabilities, and these caregivers save our health care system billions of dollars each year. Caregivers provide more than 80 percent of care needed by individuals with long-term conditions and contribute more than \$5 billion of unpaid labour annually to the health care system.⁶ Unfortunately, caregiving can have negative consequences on the health of caregivers themselves and can drastically affect their own financial security since they may have to leave work.

The MS Society is pleased the federal government has recognized this pressing need with the introduction in the June 2011 federal budget of the Family Caregiver Tax Credit, which will allow spouses who are caregivers to claim some tax relief. For a number of years, the MS Society has been urging that spouses be able to claim a tax credit for caregiving. This is a positive step forward.

But more can and should be done. Moving forward immediately, the MS Society urges a small adjustment to **make the new Family Caregiver Tax Credit and the existing Caregiver Tax Credit refundable** so low-income Canadians who pay low or no taxes will also benefit.

In addition, we suggest Canada must move to a more comprehensive approach to caregiver supports. Right now, the patchwork of caregiver supports unfairly dictates that where individuals live governs what help they will receive. We applaud Manitoba and Nova Scotia for making caregivers a priority and urge the Government of Canada to examine these approaches. Canada can also learn from others. The United Kingdom provides a modest, but highly welcomed Carer's Allowance for people who assist others who are disabled or have a chronic condition. A new support is the Carer's Credit which enables caregivers to build up qualifying years for the British equivalent of CPP.

The MS Society suggests the federal government look at a pan-Canadian approach to caregiver support by engaging the provinces and territories, caregivers and organizations that represent caregivers in a dialogue about how caregivers can truly be supported including refundable tax credits, protection of jobs and recognition of their vital role.

Recommendation: That the Government of Canada first, immediately address the needs of caregivers of people with MS by making existing and future caregiver tax credits refundable to help them in their day-to-day lives of looking after loved ones and second, work with the provinces, territories, caregivers and caregiver organizations on the development of a pan-Canadian approach to supporting caregivers.

2. Income security for people with MS and other chronic conditions

Income security for people living with MS is of utmost importance. Many people with MS are no longer able to work full time after they develop MS, and they and their families primarily bear the significant costs of the disease.⁷ This is true of other people who have either episodic or chronic conditions, especially those caused by brain disease or injury. The result is that many Canadians with MS and other disabilities and chronic conditions and their families live on extremely limited incomes and find it difficult to keep and find work. To live, they turn to the current hodgepodge of federal, provincial and territorial disability pensions, social assistance programs and tax credits, which often cannibalize each other and discourage people from working. The result: individuals who can work some of the time do not return to jobs and, ultimately, are trapped in poverty.

The MS Society urges both short-term and long-term approaches to tackle these problems. In the short-term, the Government of Canada could initiate changes to two existing programs under its jurisdiction which would help more people stay in the work force as active contributors to the Canadian economy and help low-income individuals receive some much needed financial support.

The first change would be to allow people who have an episodic disability such as MS to choose to work part-time and receive **partial Employment Insurance sickness benefits** if they are able to return to work on a part-time basis. Currently, individuals who qualify for EI sickness benefits receive them for 15 weeks. By allowing people to receive benefits for 150 half days instead of 75 days (i.e., 15 weeks), individuals with an episodic disability would be able to maintain a strong attachment to their jobs and receive an adequate income even when they have to take time off. Employers would pay a lower salary during the benefit period but still retain the services of an experienced employee. There would be no additional cost to EI.

MS provides an excellent example of an episodic disability. Most people with MS have the relapsing-remitting type of the disease which is characterized by unpredictable but clearly defined episodes or attacks during which new symptoms appear, or existing ones get worse. The time between attacks is variable but can be weeks, months or even years. During a relapse, an individual may have to take time off from the job for an undetermined amount of time, or he/she may be able to manage by reducing the number of hours worked during the week. The employer may be understanding and keep the job open and offer flexible hours with no reduction in pay. Or, unfortunately, the employer may decide accommodation would be too costly and the individual should apply for long-term disability benefits. In the MS Society's view, when an individual leaves a job under pressure, the community also loses since it no longer benefits from the contributions of a skilled worker and valued taxpayer.

We believe our solution of making EI sickness benefits more flexible would relieve financial pressure on both employers and employees at no additional cost to the system. Our conclusion is supported by a recent paper which was commissioned by the Office of Disability Issues within Human Resources and Skills Development Canada. While the work is still ongoing, it concluded successful employment by people with disabilities are related to 1) the degree of control over the disclosure of disability, 2) whether there is a job to return to, 3) whether there are appropriate workplace accommodations.⁸

The second change we suggest would put actual dollars in the pockets and purses of low-income individuals. The MS Society recognizes that existing programs are important for people with severe disabilities and chronic conditions including those that are linked to brain conditions. These include the Working Income Tax Benefit disability supplement, CPP disability benefits, Medical Deductions, the Disability Tax Credit and the Registered Disability Savings Plan (RDSP).

While these programs are generally working well, the **Disability Tax Credit would have more impact if it were refundable** so a person whose income is low would actually benefit. Currently if a person cannot use the credit because his/her income is too low or if he/she cannot transfer the credit, the credit is lost. This change would provide some modest income for a group of people who unfortunately have some of the lowest incomes in Canada.

Finally, in the long-term, the MS Society suggests it is time for the Government of Canada to work with the provinces, persons affected by MS and other episodic disabilities and brain conditions and supporting organizations to **develop a pan-Canadian income security program** to replace the current hodgepodge of disability pensions, social assistance programs and tax credits. The MS Society would be pleased to be part of this important initiative.

Recommendation: That the Government of Canada makes Employment Insurance sickness benefits more flexible so people can work part-time and receive partial benefits. In

addition, making the Disability Tax Credit refundable would help address the income needs of low-income Canadians. Finally, develop – in consultation with the provinces, persons affected by MS, as well as other stakeholders – a pan-Canadian income security program to replace the current hodgepodge of disability pensions, social assistance programs and tax credits.

3. Health care and the Health Accord

During the recent federal election campaign, people with MS were heartened that the major political parties made strong commitments to continue six percent annual increases in health care funding transfers on an ongoing basis beyond the duration of the current Health Accord. People living with MS and other episodic disabilities and brain conditions rely heavily on the health care system. They worry about having access to physicians and nurses when they need them as well as access to proven and effective drugs and other therapies.

The MS Society applauds the commitment to funding as an excellent start, but echoes the concerns of people with chronic conditions about the current system. It is imperative to begin the dialogue on a new Health Accord since the current Accord ends in 2014. The MS Society recommends a nation-wide dialogue with meaningful opportunities for people who are living with chronic conditions to provide their input about what a second Health Accord should include based on the principles of universal access. The MS Society would be pleased to help facilitate input from people with MS.

Recommendation: That the Government of Canada begins in 2012 a robust, nation-wide dialogue about the health care system and what a new Health Accord should look like and commit to the inclusion of people with chronic conditions such as MS. In the meantime, the six percent ongoing commitment to health care funding should continue.

In closing, the Multiple Sclerosis Society of Canada appreciates the opportunity to provide recommendations that will help meet the needs of people affected by MS. We believe that these modest steps will contribute to the health and well-being of people with MS and other episodic disabilities and neurologically-disabling conditions.

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- 1 CCSVI chronic cerebrospinal venous insufficiency refers to narrowed veins in the neck possibly related to MS.
 - 2 An episodic disabling condition or disease is life-long, but unlike permanent or progressive disabling conditions, these can result in episodes of disability with varying severity and duration. Examples of conditions that are episodically disabling are mental illness, arthritis, HIV/AIDS, multiple sclerosis, crohns and colitis, asthma, psoriasis.
 - 3 The Canadian Burden of Illness Study Group, "Burden of Illness of Multiple Sclerosis: Part I: Cost of Illness," *The Canadian Journal of Neurological Sciences*, 1998, 25: 23-30.
 - 4 "Multiple Sclerosis," Canadian Institute for Health Information, *The Burden of Neurological Diseases, Disorders and Injuries in Canada*, 2007: 72-81.
 - 5 Brain conditions refer to chronic, often progressive, neurological and/or neuromuscular diseases, disorders, conditions and injuries, Neurological Health Charities Canada website: www.mybrainmatters.ca
 - 6 Torjman, Sherri, Caledon Institute of Social Policy, *Caring for the Carers*, June 2011,
 - 7 The Canadian Burden of Illness Study Group
 - 8 Smith Fowler, Heather, "Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario, Report to Office of Disability Issues, Human Resources and Social Development Canada, March 2011 http://srcd.org/en_publication_details.asp?id=253&kw=intermittent+work+&theme=&project=&author=&year=2011&type=1&monthf=1&yearf=1994&montht=8&Submit.x=32&Submit.y=15