



**MULTIPLE SCLEROSIS SOCIETY  
OF CANADA**

**BRIEF TO THE STANDING COMMITTEE  
ON FINANCE**

**SEPTEMBER 2006**

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## **EXECUTIVE SUMMARY AND RECOMMENDATIONS**

The Standing Committee on Finance has asked for input on how best to ensure the prosperity of Canadian citizens and businesses in the future, securing Canada's place in a competitive world. The Multiple Sclerosis Society of Canada is pleased to respond.

In our brief, we have focused on three broad themes that impact people affected by MS as related to ensuring healthy citizens and ensuring affordable spending measures to promote prosperity: income security, health care/ health research and charitable sector issues.

### **MS Society of Canada Key Recommendations**

#### **Income Security**

- Re-define EI sickness benefits in terms of 75 days or 150 half days to allow for part-time work for individuals who can manage some employment.
- The terms "severe and prolonged" in section 42 of the Canada Pension Plan and the term "prolonged" on the Disability Tax Credit Certificate should be amended to take into account episodic and remittent mental and physical conditions.
- Develop a more flexible approach to the current contribution rule for CPP-Disability of four out of the last six calendar years.
- Make more flexible the rules regarding part-time or occasional work so CPP-Disability recipients can do more work without risking their eligibility for benefits.
- Grant authority to the CPP to allow for pilot projects testing new approaches that could target people with episodic disabilities.
- Work with provincial governments to stop the offsetting of CPP children's benefits.
- Harmonize the application forms for DTC and CPP-D to simplify the process for people with disabilities and to realize administrative cost savings and individual taxpayer savings.
- Move to refundable tax credits for persons with disabilities.
- Human Resources and Social Development Canada and the CPP Review Tribunal should continue their outreach to Canadians regarding CPP-D. All of the recommendations in *Listening to Canadians* concerning administrative improvements should be followed.
- Recommend that a task force be established to study the issue of income support for people with episodic disabilities with consultation, within the context of the government's proposed National Disability Act.

#### **Support of Caregivers**

- The CPP should provide dropout provisions for caregivers that are the same as the child-care dropout provisions.
- Extend the caregiver tax credit to spouses of "infirm" individuals.

## Multiple Sclerosis Society of Canada 2007 Federal Budget Recommendations

- Actively pursue measures to support the financial needs of caregivers of people who are severely disabled, including extension of EI benefits.

### **Health Care**

- Expand the home care program agreements to address the needs of people who are chronically ill and/or disabled.
- Work with the provinces to provide access to catastrophic drug coverage across Canada as soon as possible.
- Immediately implement improvements to Health Canada's drug review process to make it more timely and transparent to stakeholders

### **Health Research**

- The federal government further enhance government investment in the Canadian Institutes of Health Research through increased multi-year funding commitments to provide opportunities for stability and planned growth.

### **Charitable Sector Issues**

- Remove the requirement that tax receipts be sent by first-class mail (which would provide a 40 percent savings in mailing costs to registered charities.)
- Exempt registered charities from the requirement of issuing receipts for income tax purposes for donations of less than \$250.

## **INTRODUCTION**

The Standing Committee on Finance has asked for input on how best to ensure the prosperity of Canadian citizens and businesses in the future, securing Canada's place in a competitive world. The Multiple Sclerosis Society of Canada is pleased to provide input on issues that are of concern to Canadians who are affected by multiple sclerosis (MS). Many Canadians are impacted by this often disabling disease of the central nervous system: the estimated 55,000 to 75,000 people who have MS; their families and caregivers; health care professionals; MS researchers and MS Society of Canada supporters.

The Multiple Sclerosis Society of Canada applauds the Conservative government for recognizing the importance of disability issues through its promise to introduce a National Disability Act "*...designed to promote reasonable access to medical care, medical equipment, education, employment, transportation and housing for Canadians with disabilities.*"

In response to the Committee's specific questions to inform its pre-budget consultations, the Multiple Sclerosis Society of Canada will focus on the following three broad themes that impact people affected by MS and relate them to the Committee's first and fourth questions, having to do with ensuring healthy citizens and ensuring affordable spending measures to promote prosperity:

- Income Security and Supports
- Health Research and Health Care
- Charitable Sector Issues

## **INCOME SECURITY AND SUPPORTS**

Multiple sclerosis has a profound impact on the ability to work. Most people with MS are diagnosed between ages 15 and 40 with the average age of diagnosis of 30, just when they are finishing school, starting careers and beginning families. The disease is often episodic in nature, especially in the first 10 to 15 years, when it is characterized by unpredictable relapses (also called attacks) followed by periods of remission. Nearly 80% of people with MS are eventually unable to work full time because of the severity and unpredictability of the disease.

The two main federal programs that provide some income assistance to people with disabilities – the Canada Pension Plan – Disability (CPP-D) and the Disability Tax Credit (DTC) – are both tied to earning an income. Unfortunately, a substantial proportion of people with episodic disabilities experience difficulty participating in the workforce, making it difficult or impossible for them to access the help they need to live.

While there has been some progress made in addressing income security and support issues in recent years (e.g., allowing the automatic reinstatement of CPP-D benefits in 2005 and the implementation of additional tax measures through the Disability Tax Credit), there is still a need to deliver enhanced support for people with disabilities, who are generally in the lowest income level of all Canadians. In addition, they have disability-related expenses that able-bodied members of society can avoid.

Income support continues to be the number one issue within the disability community: Lack of a secure, adequate income precludes individuals from participating and contributing fully as Canadian citizens and this in turn has profound social and health cost implications.

Income support is especially important to people living with intermittent, reoccurring disabilities like MS, because the disease often prevents individuals from participating regularly in the workforce, and also from qualifying for disability benefits because the programs in place today are tied to earning an income. The MS Society is working closely with other organizations within the Episodic Disabilities Network to tackle this issue since episodic disabilities raise particular challenges for both people affected by them and for policy makers.

With its proposed National Disability Act, the federal government has a unique opportunity to take leadership on improving access to federal disability benefits, while also realizing potential savings in administration and program costs. This would also achieve the government's objectives of ensuring that Canadians are presented with appropriate incentives to work and ensuring that government spending is sustainable.

Below, we have outlined some possibilities for both shorter-term and longer-term policy and program improvements:

### **Short-Term Policy and Program Improvements**

#### **1. Employment Insurance**

The first program that a person with MS encounters is usually Employment Insurance (EI) sickness benefits. Currently, an individual who qualified can receive up to 15 weeks of sickness benefits. This program provides vital income security for people with MS who cannot work because of an MS relapse. We suggest the program could be made more useful – and at very little extra cost – by allowing for part-time benefits coupled with part-time work for people who can manage some employment. This change would encourage an ongoing attachment to the work force, which is vital in preventing future unemployment. Administratively, a simple way of handling this would be to redefine EI sickness benefits as 75 days (instead of 15 weeks ) or 150 half days.

#### **2. Qualification Criteria for CPP(D) and Disability Tax Credit**

The current qualification criteria for CPP-D benefits require that the illness be severe (rendering the applicant incapable of regularly pursuing any substantial gainful occupation) and prolonged (long-continued and of indefinite duration). MS is permanent and often severe. As with the Disability Tax Credit, the often-fluctuating nature of MS often precludes many individuals with MS not only from participating regularly in the workforce but also from qualifying for disability benefits because their condition is recurrent rather than prolonged. We are concerned that it is too difficult for people with MS to qualify for these programs, and the evaluation tools in the current adjudication process are not effective.

We, therefore, recommend that the eligibility criteria for both the CPP(D) and Disability Tax Credit be modified to appropriately address the episodic nature of disabilities resulting from diseases like multiple sclerosis, HIV/AIDS, lupus, muscular dystrophy and mental illness.

This recommendation is supported by the 2003 report of the House of Commons Standing Committee on Human Resources and the Status of Persons with Disabilities entitled *Listening to Canadians* as well as the 2006 *Report on Mental Health: Out of the Shadows at Last* by the Senate Committee on Social Affairs, Science and Technology.

### **3. Contribution Requirements**

CPP-D benefits are based on the amount of contributions credited to an individual's CPP account as well as how long the individual contributed. The current "four out of six" contribution years rule that replaced the "five out of 10" rule has made it difficult for many people who are disabled because of MS to qualify for the program. Often people with MS will try to work part time, with a resulting drop in their contributory earnings. When they have to drop out of the workforce, they may not immediately apply for CPP-D because they hope to go back to work – once the last "MS flare up" is over. Unfortunately, that flare up is permanent. The four out of six rule introduces a type of systemic discrimination because it does not recognize the nature of episodic illnesses with ups and downs – typical of MS.

### **4. Part-Time Work**

Multiple sclerosis causes a wide variety of disabling symptoms, including severe fatigue. Many people with MS are unable to work full time. But they can manage part-time or occasional employment. Current disability benefit programs don't recognize or accommodate the needs of people with episodic disabilities for flexible work options and income support. Nor do they recognize the concept of part-time work. There is a need for an income support program that ensures that persons with episodic, recurring illnesses are able to benefit from employment when possible, without losing access to income support when unemployed and ill. Currently, in order to qualify for disability benefits, one must accept the designation of "permanently unemployable", which virtually ignores a person's work potential.

To provide incentives to return to the workforce, the MS Society recommends that CPP-D pay partial or reduced benefits, rather than full benefits to enable people to work part-time and still retain a portion of their benefits. In addition, we support the recommendation of the Senate's *Report on Mental Health: Out of the Shadows at Last* which called for the government to "...grant authority to the CPP to permit it to sponsor research on, and the testing of, new approaches that could target people with episodic disabilities, particularly episodic mental illness."

### **5. Harmonizing DTC and CPP-D Applications**

A significant number of Canadians qualify for both the DTC and CPP-D, however, to receive the tax credit and the disability benefit they have to fill out two lengthy applications that must be certified by health care professionals. In our view, there is no reason to make people apply twice when a single application form could be tailored to accommodate both programs. It would also have the result of bringing the DTC to the attention of CPP-D applicants and possibly give them tax savings since CPP-D is taxable. The MS Society believes harmonizing the application process would also provide significant cost savings to government.

### **6. Refundable Tax Credits**

The Disability Tax Credit is non-refundable. The current system only allows individuals who have income exceeding the personal exemption amount to access this credit or possibly to transfer it to another family member. In many cases, the tax credit is "lost" to a person who has a low income or who cannot transfer it. Given the low incomes of most people with

disabilities, making the DTC refundable would be a simple way to put more money in the hands of persons with disabilities who have disability-related expenses that able-bodied members of society can avoid.

## **7. Administrative Issues**

The MS Society of Canada continues to have concerns that some private insurance and provincial social assistance programs require people to apply first to CPP-D even though it is clear that most will not qualify under CPP-D criteria. Significant administrative costs are being transferred to CPP-D for disability assessments. The MS Society has also found that the majority of people with MS who appeal with our assistance are eventually granted benefits. This suggests that there is a flaw in the system from the beginning, making the process inefficient and wasteful of taxpayers' money. More significantly, the lengthy process unfairly leaves disabled people without a way to make ends meet.

Another challenge is the offset (also known as a clawback) by some insurance companies of the benefits that dependent children receive if a parent is a long-term disability recipient. While it is legal for insurance companies to deduct the children's benefit of \$200 a month dollar for dollar from the amount they pay to the individual, the practice is deeply discouraging to those involved, who are already living on a reduced income.

## **Longer-Term Policy and Program Improvements**

### **1. Income Security**

The Multiple Sclerosis Society of Canada urges the Government to consider an important recommendation in the 2004 *Disability Tax Fairness* report of the Technical Advisory Committee on Tax Measures for Persons with Disabilities. The report received all-party support and pointed to the need for investments in income and disability supports: "*Perhaps the most important action that the government can take to assist persons with disabilities is to invest in the supply of disability supports ... Priority should be given to expenditure programs rather than tax measures to target new funding where the need is greatest.*"

Given the complexity of the income security and supports issue, we strongly urge the Committee to recommend that the Minister of Human Resources and Social Development establish a task force to study the issue of income support for people with episodic disabilities, with consultation, within the context of the government's proposed National Disability Act.

### ***Multiple Sclerosis Society of Canada Key Recommendations for Income Security:***

- Re-define EI sickness benefits in terms of 75 days or 150 half days to allow for part-time work for individuals who can manage some employment.
- The terms "severe and prolonged" in section 42 of the Canada Pension Plan and the term "prolonged" on the Disability Tax Credit Certificate should be amended to take into account episodic and remittent mental and physical conditions.
- Develop a more flexible approach to the current contribution rule for CPP-Disability of four out of the last six calendar years.
- Make more flexible the rules regarding part-time or occasional work so CPP-Disability recipients can do more work without risking their eligibility for benefits.

## Multiple Sclerosis Society of Canada 2007 Federal Budget Recommendations

- Grant authority to the CPP to allow for pilot projects testing new approaches that could target people with episodic disabilities.
- Work with provincial governments to stop the offsetting of CPP children's benefits.
- Harmonize the application forms for DTC and CPP-D to simplify the process for people with disabilities and to realize administrative cost savings and individual taxpayer savings.
- Move to refundable tax credits for persons with disabilities.
- Human Resources and Social Development Canada and the CPP Review Tribunal should continue their outreach to Canadians regarding CPP-D. All of the recommendations in *Listening to Canadians* concerning administrative improvements should be followed.
- Recommend that a task force be established to study the issue of income support for people with episodic disabilities with consultation, within the context of the government's proposed National Disability Act.

### Caregiver Issues

Caregivers play an important role in enabling many people with MS to remain in their homes and communities. Currently, caregivers who stop work to care for someone who is disabled are penalized: Not only do they face a loss of income when they leave the workforce, but they compromise the future level of their pension at retirement. This is unfair in view of the fact that caregivers save the government hundreds of thousands of dollars in annual costs for hospitalization or long-term institutional care by enabling disabled family members to stay at home.

To address this inequity, we recommend that CPP provide the same drop out provisions for the caregiving of family members as are given for the child-care dropout. This would exempt the low or no income period in which a caregiver is at home caring for a disabled person from being included in the calculation of their CPP retirement benefits.

In addition, the caregiver tax credit provides some welcome tax relief for a person providing in-home care for an "infirm" relative. Spouses, however, are not eligible for this small credit even though they are the usual caregivers. It should be noted that spouses often provide care out of love and compassion, not because they are required to do so. We believe that a caregiver-spouse makes an important contribution and that it ought to be recognized and rewarded through a caregiver tax credit.

Some progress was made in the 2003 Health Accord which initiated improvements to Employment Insurance provisions allowing caregivers to receive EI payments and provided job protection for individuals who leave their jobs to care for a gravely ill or dying child, parent or spouse. We suggest the government look at expanding these provisions to apply to caregivers of people who are severely disabled.

#### ***Multiple Sclerosis Society of Canada Key Recommendations for Caregivers:***

- CPP should provide dropout provisions for caregivers that are the same as the child-care dropout provisions.
- Extend the caregiver tax credit to spouses of "infirm" individuals.

- Actively pursue measures to support the financial needs of caregivers of people who are severely disabled, including extension of EI benefits.

## **HEALTH CARE AND HEALTH RESEARCH**

### **Health Care**

In September 2004, Canada's First Ministers agreed on a 10-year plan to strengthen our health care system. Providing timely access to quality care is a priority for persons with MS and their families. Following are comments and recommendations on parts of the agreement that are of particular significance to people with MS:

#### **1. Wait time reductions**

The MS Society is encouraged the government is working with the provinces to establish a Patient Wait Times Guarantee. Access to diagnostic technology, especially MRI scanners, is vital for the early diagnosis and treatment of people with MS. We are also pleased the 10-year health accord includes significant investments to reduce wait times in this area, and the federal government is providing funding that the provinces are putting to use to implement needed changes. The inclusion of strategic investments to reduce human resource shortages is also positive.

Given the significant level of federal funding going to reduce wait times, we encourage the federal government to continue take a leadership role in ensuring that Canadians have swift access to diagnostic technologies to enable better patient outcomes.

#### **2. Home care**

Access to quality home care is essential for people with MS. MS is chronic, and it is most often progressive. At some point, a significant number of people with MS will become sufficiently disabled to require home care on a long term basis. The MS Society is pleased the first ministers agreed to provide first dollar coverage for short-term acute home care, including acute community, mental health, and end-of-life care. We believe Canada's first ministers increasingly recognize home care is often more appropriate than hospital care, and that it can serve as a cost effective alternative to hospitalization. However, these measures do not address the needs of people who have chronic health problems or who are disabled.

We urge the federal and provincial governments to expand home care coverage to include chronic illness support as early as possible. We also recommend that Health Canada, working with its provincial partners, spearhead a pan-Canadian review of existing programs and services that could complement and strengthen an expanded home care strategy.

#### **3. National pharmaceutical strategy**

Drugs to treat MS are expensive – up to \$25,000 a year to prevent new MS attacks. Currently provincial and territorial drug programs provide uneven access and compensation. Right now, people with MS in Newfoundland have no provincial government help in covering the cost of needed drug therapy, while individuals living in Nova Scotia or Quebec or Alberta pay just a small portion of the total cost. In the 2003 Health Accord, first ministers agreed to provide reasonable access to catastrophic drug coverage by the end of fiscal 2005/06.

## Multiple Sclerosis Society of Canada 2007 Federal Budget Recommendations

Unfortunately, we are still some distance from a national pharmaceutical strategy. The report by the Ministerial National Pharmaceuticals Strategy Task Force in July provides some evidence of progress, but no solid plan. The MS Society urges that a program to cover catastrophic drug costs be implemented as soon as possible.

Improvement was promised as well to the drug approvals process for breakthrough drugs. We urge that Health Canada's Therapeutic Product Directorate be provided with the resources necessary for timely reviews in a transparent manner to ensure that beneficial therapies are available to people who need them in a reasonable timeframe.

### ***Multiple Sclerosis Society of Canada Key Recommendations for Health Care:***

- Expand the home care program agreements to address the needs of people who are chronically ill and/or disabled.
- Work with provincial governments to provide access to catastrophic drug coverage across Canada as soon as possible.
- Immediately implement improvements to Health Canada's drug review process to make it more timely and transparent to stakeholders

## **Health Research**

The Finance Committee has asked for recommendations on program spending measures that will help ensure the health of Canadian citizens for their own benefit as well as for their employers: The Multiple Sclerosis Society of Canada believes that investments in health research and innovation are investments in the economic health of Canada and its citizens. They are a vital part of a strategy to reduce health care costs and to produce a healthier population because they foster the discovery of therapies and treatments that can keep people active in the workforce and in their homes raising their families.

Budget constraints recently led the Canadian Institutes of Health Research (CIHR) to impose a 21.5% cut in the budgets of funded researchers. This is of great concern to the MS Society. CIHR is the bedrock upon which all other health research in Canada is built.

The Multiple Sclerosis Society of Canada itself is part of the overall Canadian health research effort. We support our own large research program which is targeted at finding the cause of MS, ways to prevent it, discover better treatments and ultimately discover the cure. Key to the success of MS Society funded health research is an overall publicly supported research strategy that is well-funded and operates with stable and predictable funding levels – which a well-funded CIHR would provide.

Going forward, we urge the government recognize the importance of stable and predictable funding levels for CIHR, and that it also put a priority on developing a long-term, integrated strategy with input from other funding partners for the support of health research in Canada.

### ***Multiple Sclerosis Society of Canada Key Recommendations for Health Research:***

- The federal government further enhance government investment in the Canadian Institutes of Health Research through increased multi-year funding commitments to provide opportunities for stability and planned growth.

## **CHARITABLE SECTOR ISSUES**

The MS Society of Canada applauds the elimination of the capital gains tax on donations of publicly-listed securities to charities in the 2006 budget. We believe more could be done to build on this excellent initiative.

Canada's charitable and voluntary sector is a major contributor to enhancing productivity growth in Canada. The voluntary sector is large; it has an estimated \$112 billion in annual revenues, with \$109 billion in assets. The MS Society is a significant health charity within the sector. Annually, the MS Society raises more than 97% of its funds from the Canadian public with very little reliance on government or foundation funding. In 2005, the Society was proud to provide more than \$9 million in service programs and more than \$6 million for MS research. More than 80% of MS Society revenues are from individual donors.

The charitable sector could be even more productive. In 2005, the MS Society sent 1.13 million tax receipts for amounts less than \$250 to donors across the country by first class mail, as required by law. If we were not required to send tax receipts, we could have directed the \$750,000, which went to postage and supplies directly related to tax receipting, to MS research and services for people with MS and their families.

The MS Society suggests the government consider assistance to the charitable sector in two ways. First, remove the requirement that tax receipts be sent by first class mail. This would in itself result in considerable savings for charities. Second, we recommend removing the requirement of issuing income tax receipts for donations of less than \$250, unless specifically requested by the donor, with donors being able to claim their credit on the basis of a cancelled cheque or credit card receipt. This recommendation has been endorsed by the Senate Standing Committee on Banking, Trade and Commerce in its December 2004 report on charitable giving in Canada. In the United States, charitable organizations are not required to issue receipts for income tax purposes for donations under \$250.

### ***Multiple Sclerosis Society of Canada Key Recommendations for Charitable Donations:***

- Remove the requirement that tax receipts be sent by first-class mail (which would provide a 40 percent savings in mailing costs.)
- Exempt registered charities from the requirement of issuing receipts for income tax purposes for donations of less than \$250.

## **CONCLUSION**

The Multiple Sclerosis Society of Canada is encouraged that the issues of Canadians with disabilities are a priority for the government as it begins mapping out a new National Disability Act and we will look forward to being part of this important work.

We hope our suggestions in all three major areas that are priorities for people living with MS will be helpful. We thank the members of the Finance Committee for their time and consideration.

## **APPENDIX**

### **BACKGROUND ABOUT MULTIPLE SCLEROSIS AND THE MULTIPLE SCLEROSIS SOCIETY OF CANADA**

Multiple sclerosis is a disease that touches people across a wide spectrum in this country since studies indicate that Canada has one of the highest rates of MS in the world. Usually diagnosed between the ages of 15 and 40, MS is the most common disease of the central nervous system affecting young adults in Canada. Periods of spontaneous recovery are interrupted by unpredictable attacks that over time result in most people with MS becoming disabled. The result: young Canadians face a progressive and unpredictable disease that cannot be prevented, and that they must live with for 40 or more years.

The MS Society of Canada is the only national voluntary organization in Canada that supports both multiple sclerosis (MS) research and services for people with MS and their families. In addition to the national organization, there are seven regional divisions and more than 120 chapters across Canada. The Society's engine is its volunteers. More than 1,500 individuals serve on the national, division and chapter boards and 13,500 individuals organize and deliver service programs, fund raising events, public awareness campaigns and social action activities. More than 100,000 Canadians participate in one of the Society's fund raising events. Eighty percent of the Society's net revenue goes directly to fund MS research and services for people with MS and their families while administration and fund raising costs account for just twenty percent.

The Multiple Sclerosis Society of Canada is a major funder of MS research in Canada. The MS Society was founded in 1948 and less than a year later was able to provide its first research grant of \$10,000 to the Montreal Neurological Institute. Today, the MS Society supports a research program of \$6 to \$7 million annually. In addition, its related MS Scientific Research Foundation funds large cooperative multi-disciplinary research projects. Together they are the largest funders of MS research in Canada.

While MS is unpredictable, most people with MS are eventually unable to work full-time and many experience total disability. In 1991, 44 percent of adults with disabilities (aged 15-44) were not part of the labour force. With MS, however, this is significantly higher. Nearly 80 percent of people with multiple sclerosis are eventually unable to work full time because of the severity and unpredictability of their MS symptoms. The change in work force attachment comes fairly soon after diagnosis: 25 percent have a change in their employment status within five years of diagnosis; 50 percent within 10 years and 80 percent within 20 years.

The total cost of illness in Canada was estimated at \$156.4 billion in 1998. Direct costs (such as hospital care, physician services and health research) amounted to \$81.8 billion, while indirect costs (such as lost productivity) accounted for \$74.6 billion. The diagnostic categories with the highest total costs were cardiovascular and musculoskeletal diseases, cancer, injuries, respiratory diseases, diseases of the nervous system, and mental disorders.<sup>1</sup>

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<sup>1</sup> Report of the Standing Senate Committee on Social Affairs, Science and Technology. Volume Two: Current Trends and Future Challenges. January 2002, p. 49