

Brief Submitted to the
House of Commons Standing Committee on Finance



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INTRODUCTION

Thank you, Mr. Chair and members of the Committee, for this opportunity to present the views of the Multiple Sclerosis Society of Canada. This is not our first appearance before a House of Commons Committee, nor are these our first recommendations to the Government of Canada for concerted action to work with us in finding the cure for MS and enabling people affected with MS to enhance their quality of life.

This year, however, our approach is different. Instead of advocating on behalf of a wide range of concerns, we will be focussing on income security. Income security, as you know, is the focus of this roundtable and incidentally our main priority. Along the way, we will tell you something about MS and the challenges facing people with MS, but from the vantage point of income security.

Our primary reason for focusing on income security is that adequate income defines the ability to be a full member of society. It enables participation in all manners of community activities, events and organizations. It provides the means for interaction with one's fellow Canadians and despite the myriad challenges that people with MS face every day, it provides the means for hope and the ability to improve one's own situation and that of others. Without secure income that is sufficient to support a decent quality of life, one's opportunities are diminished. When that is combined with ill health and an inability to work — as is the case for the majority of people who have lived with MS for a long time — the results are devastating.

It is important to note that these consequences affect us all. As the Government of Canada's Future Directions paper points out, the exclusion of people with MS from full participation in society and the economy means that "Canada loses the benefit of the creativity and contribution of persons with disabilities that would otherwise enrich all of our lives."

QUICK FACTS ON MS

Epidemiological studies show that Canada has one of the highest rates of MS in the world. An estimated 50,000 Canadians have this all too frequently disabling disease. Almost twice as many women as men have MS. It is usually diagnosed between the ages of 20 and 40. MS is the most common disease of the central nervous system affecting young adults in Canada.

MS attacks the protective myelin covering of the nerves, causing inflammation and often the destruction of the myelin in patches. This interrupts the normal flow of nerve impulses. The possible results include vision problems, numbness, loss of balance, extreme fatigue and even paralysis.

Spontaneous recovery from symptoms can occur and last for months or years. Unpredictable attacks occur and can cause additional symptoms. MS is often progressive. Although the cause and the cure are so far unknown, four drugs recently have been approved for the treatment of MS. They can reduce the frequency and severity of attacks. Many symptoms can be helped by other medications and therapy.

THE BURDEN OF MS

Employment Impacts

Although MS is unpredictable, most people with MS eventually are unable to work full-time; many experience total disability. In 1991, 44% of adults with disabilities (aged 15-44) were not part of the labour force. With MS, this is significantly higher. Fully 70% of people with MS are not working 5-10 years after they are diagnosed.

Recently, a study was conducted by 14 MS clinics across Canada on the costs of MS for 198 people with MS. One-third of the participants had mild MS, one-third moderate MS and one-third severe MS, based on the generally accepted Kurtzke Expanded Disability Status Scale criteria (a tool used by physicians to measure the degree of disability to a patient with MS). Despite the relatively young age of the participants (late 30s through 40s), the effect of their disease on their ability to work was dramatic.

In the mild MS group, 37% experienced a change in their employment status because of MS. As the disease progressed, an increased number became unable to work. Only 28% of those with moderate MS and 4% of those in the severe category remained fully employed. For many, the key problem is that they experience recurrent but not necessarily continuous impairment of their abilities on a long-term basis. The fluctuations inherent in the disease (individuals commonly experience periodic attacks and remissions, and the rate of progression of the disease is unpredictable) make it very difficult for people with MS to work. As one woman describes her situation:

Working regularly is difficult, if not impossible Given the unpredictable nature of the disease, along with potential daily triggers and the debilitating fatigue, the patient with MS isn't a likely candidate for regular permanent employment . . .

It is this recurrent, variable and unpredictable nature of MS attacks that is fundamental to the income security challenges faced by people with MS, because this prevents them from qualifying for disability benefits.

The Costs of MS

Investigators at the Center for Health Policy, Law and Management at Duke University have published results of a national survey of the economic costs of MS, including both the cost of medical care and the indirect costs of lost income. As the following figures indicate, MS can be a very costly illness, in terms of lost wages, the cost of health care and time spent by family members providing care. Moreover, these costs rise as the disease becomes more progressive and severe.

Converted to current Canadian dollar values,¹ the average annual cost of MS in the United States exceeds \$62,000 per person with MS, with lifetime costs amounting to more than \$4 million. Of

this, lost wages average \$32,800 per person each year. Total health care costs average \$27,734, including \$11,833 of care giving provided by family members, \$2,287 in home care and personal assistance provided by paid caregivers, \$4,557 in hospital costs, and \$3,202 in physician costs. In addition to lost wages and health care, \$1,983 per person was spent on home and automobile alterations and special equipment.

For individuals with the progressive forms of MS, the costs were much higher, averaging \$90,020 per year. The total annual costs for all people with MS in the United States were estimated to be more than \$16.5 billion.

The Burden of Illness Study of Multiple Sclerosis estimated the total annual cost of MS in Canada is \$1 billion — higher than the cost of asthma (\$504 million) and all infectious diseases in Canada (\$772 million), despite their much higher incidence than MS.

CANADA PENSION PLAN (CPP)

Canada Pension Plan disability benefits are a key support for people with MS. As of December 1999, 10,027 of the approximately 50,000 people with MS were receiving CPP disability benefits.

Definition of Disability

The current qualification criteria for CPP disability benefits require that the illness be severe (rendering the applicant incapable of regularly pursuing any substantial gainful occupation) and prolonged — i.e., long-continued and of indefinite duration.

The obvious problem with these criteria is that they require the applicant's symptoms to fit into a narrowly-defined box which excludes from coverage people who have substantial, recurrent impairments, such as those caused by MS. MS is permanent and often severe although the impairment it causes may not be. The often-fluctuating nature of the illness precludes many individuals with MS not only from participating regularly in the workforce and but also from qualifying for disability benefits.

The province of Ontario has rectified this problem, which was having the same exclusionary result in their provincial social assistance programs. In 1996, the Ontario Ministry of Community and Social Services undertook a review of its social assistance program in consultation with the MS Society and other interested organizations. It examined examples of eligibility criteria for people with disabilities currently used in a number of disability income programs in other jurisdictions, including: British Columbia, Alberta, New Brunswick, New Zealand and the United States. As a result of these consultations, the Ontario government recognized explicitly cyclical or episodic disabilities such as those caused by MS in the definition of disability through the word "recurrent."

Under the Ontario Disability Support Plan Act, a person is disabled if: (i) he/she has a substantial physical or mental impairment; (ii) the impairment is continuous or recurrent and expected to last

one year or more; (iii) the impairment results in substantial restrictions in one or more activities of daily living; personal care; functioning in the community and/or functioning in the workplace.

The Ontario Human Rights Commission also adopted this approach. In March, they announced that people with fluctuating or recurrent disabilities would now be included under the definition and afforded the protections of the Ontario Human Rights Code.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend that the Government of Canada introduce a fairer definition of disability to cover individuals with a continuous or recurrent disability that is expected to last one year or more.**

Contribution Requirements

CPP disability benefits are calculated based on the amount of earnings and contributions credited to an individual's CPP account as well as how long the individual contributed. The contributory period is significant since each person's lifetime pensionable earnings are divided by the number of months in his or her contributory period to determine his or her lifetime average pensionable earnings.

Currently, under the CPP 15 percent drop-out rule, individuals who have contributed to CPP for at least 10 years are able to drop from the benefit calculation, 15 percent of the months in which they had the lowest earnings. Unfortunately, this rule excludes the many individuals with MS who are diagnosed in their late 20's and early 30's at the start of their working careers and who are unable to contribute to the plan for the required 10 years before becoming disabled.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend to the Government of Canada that the 15 percent drop out rule be extended to those who have contributed to the plan for at least five years. For young adults disabled by MS, this would provide them and their young families with a more adequate level of disability income.**

Part-Time Work

CPP disability benefits provide near-universal coverage for employees and self-employed individuals. They provide a level of protection for those who cannot afford private insurance coverage and although they are taxable, there is no income or asset testing. Despite these pluses, the "all or nothing" character of the eligibility criteria creates a version of the familiar "welfare trap." Given the recurrent or episodic nature of MS, some people with MS are able to do some work to supplement their incomes. Some private insurance carriers allow beneficiaries to work part time; however, the federal CPP program discourages part time work as it requires permission from CPP officials, people who engage in part-time work risk their continued eligibility for CPP benefits.

Allowing those with disabilities to engage in part-time or occasional work without jeopardizing their CPP benefits ties in with current government priorities. As set forth in the January 2001 Speech

from the Throne, "the government will work with the provinces and territories and other partners toward a comprehensive labour-market strategy for persons with disabilities." The work disincentive effects of program criteria that class people as "employable" or "non-employable" are well studied. For people with MS, they are particularly harmful.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend to the Government of Canada the introduction of more flexible rules that would allow beneficiaries to do part-time or occasional work without risking their eligibility for benefits, in keeping with this year's Speech from the Throne.**

Appeal and application processing delays

In the past, the Multiple Sclerosis Society of Canada has criticized the backlogs in initial CPP applications and the often lengthy delays in processing appeals. Recent correspondence from the Acting Assistant Deputy Minister for Income Security Programs at the federal Department of Human Resources Development (HRDC) is encouraging. New panel members have been appointed to the Review Tribunal and the Pension Appeals Board has held "blitzes" to address the backlog of cases awaiting Leave for Appeal. The Board's membership also has been increased to 63 members. HRDC also reports that the CPP is working with the Review Tribunal and the Pension Appeals Board to update management practices and improve client communications to reduce delays.

Still, there is more to do. In its Report on Plans and Priorities for 2000-2001 (part of the annual departmental estimates process) HRDC now includes a "key result commitment" of 62 working days as the average time required to process initial CPP disability applications. We note that this is in excess of 12 weeks.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend to the Government of Canada that applications be processed within 60 calendar days of receipt, that internal reviews be completed within 60 calendar days of receipt of a request for reconsideration and that decisions of the Tribunal be rendered within 60 calendar days of an appeal hearing.**

The MS Society is also concerned about the lack of understanding that CPP officials appear to have about MS. In one case, for example, CPP staff wrote that an applicant with MS had been "cured" now that she was receiving medical treatment and was therefore found to be ineligible for benefits. Unfortunately, there is no known cure for MS. This error was not addressed until the third level of appeal. Like many people with MS, this client eventually won her appeal with the assistance of the MS Society.

Our client files reveal other such instances and lead us to conclude that CPP staff are not as knowledgeable about MS as they could be. Most recently, a CPP applicant with MS appeared before a CPP Review Tribunal hearing following Canada Pension's denial of benefits. As a result of her MS, the applicant suffers from cognitive dysfunction and extreme fatigue, both of which make it very

difficult to organize and present a case to the Tribunal. Notwithstanding that, her representative from the local MS Society of Canada chapter, who accompanied her to the hearing, was effectively barred from the hearing room until well after the applicant was forced to present her case alone, with no support whatsoever. Understandably, the applicant lost her case before the Tribunal and now has to endure the lengthy appeals process.

We have 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. The Commissioner of the Review Tribunals for Canada Pension and Old Age Security has offered to work with the MS Society to educate those working within the CPP system about MS, and we are happy to participate in this education process. This is certainly a step in the right direction, but it is only a step.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend to the Government of Canada that CPP officials be provided with information and learning materials to increase their understanding of MS and the circumstances of people with the disease. The MS Society will be pleased to work with the Government of Canada to produce such materials and ensure they are accurate and current. We would be pleased to assist further in any way we can.**

INCOME TAX CREDITS

The Disability Tax Credit and the Medical Expense Tax Credit are two principal federal tax measures that benefit people with disabilities. The disability tax credit reduces federal and provincial income tax by up to \$1020. The medical expenses tax credit provides combined federal and provincial tax relief for approximately one-quarter of eligible medical expenses.

Several years ago, these measures were expanded to provide greater support. This was encouraging, but additional changes to tax legislation would more fairly recognize the monetary costs of disability.

As is true under the Canada Pension Plan, the definition of disability for determining eligibility for the disability tax credit does not take account of the situation of people with MS, i.e., that their disability is substantial and recurrent. The current requirement is that claimants have a disability that is prolonged (continuous or expected to last for at least 12 months) and severe. These requirements exclude many people whose MS is in the early stages.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend to the Government revision of the criteria to ensure that individuals with a substantial physical or mental impairment that is continuous *or recurrent* and expected to last one year or more qualify for the Disability Tax Credit.**

Both federal tax credits are non-refundable, i.e., they are not applied against (and thus reduce) taxable income. This means they do not apply to those who do not have taxable income or are dependants of individuals without taxable income. Because they are non-refundable, these tax

credits exclude many people with MS who can no longer work or who have no taxable income. Many people with MS have considerable disability-related expenses that they could claim if they had taxable income. Because individuals without taxable income generally are at the low end of the income scale, they perceive this exclusion as unjust.

Both tax credit measures fail to offset significant disability-related costs and expenses. Given that the costs of their disability effectively excludes their ability to participate fully as citizens, we urge the Committee to recommend a single refundable tax credit, that would replace the disability tax credit and the medical expense tax credit and provide a greater level of support than is currently available for low-income beneficiaries.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend to the Government the creation of a new refundable Disability Expense Tax Credit to replace the Disability Tax Credit and the Medical Expenses Tax Credit and to provide a 29 per cent tax credit, as opposed to the current 17 per cent, for low-income beneficiaries.**

CHARITABLE DONATIONS

The MS Society receives almost no funding from the federal government and very limited support from provincial governments (for special, designated services). Nonetheless, the Society is proud to provide \$7.8 million in service programs and \$4.9 million for MS research. Roughly 90 per cent of MS Society revenues are from donations by Canadians. The vast majority of our donations are between \$25 and \$50.

Currently, the tax treatment of charitable donations provides limited incentive for charitable donations by individuals with modest incomes. Increasing the income tax benefit for individual charitable donations would benefit recipient charities and would recognize charitable giving is a feature of Canadian life that should be both celebrated and supported.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend that the Government enhance tax incentives for charitable donations for Canadians whose total donations are \$3,000 a year or less.**

Another suggestion is that the Government of Canada consider adopting the donation tax receipt model used by US Internal Revenue Service. In the United States, charitable organizations are not required to issue receipts for income tax purposes for donations under \$250. Clearly, the IRS has determined that fraud relating to claimed donations of less than the threshold amount is well below the cost of tracking these smaller donations. At the same time, this saves an enormous burden to time and expense for charitable organizations.

- **The Multiple Sclerosis Society of Canada urges the Committee to recommend that the Government consider exempting charitable organizations from the requirement of issuing receipts for income tax purposes for donations of less than \$250.**

CONCLUSION

The Multiple Sclerosis Society of Canada is pleased that the current government has taken important steps forward on the funding of health research through the establishment of the Canadian Institutes of Health Research. The success of its fiscal strategies has created opportunities for the government to take a leadership role in many areas.

The government has recognized both the need and the unique role it plays in enhancing the quality of life for people and families affected by MS. As the 1999 Speech From The Throne pointed out:

Strong communities depend on the participation of all of their members. To this end, the Government will pursue its efforts with other governments, the private and voluntary sectors, and all citizens to build communities in which Canadians with disabilities are fully included . . .

The income security issues we have raised with you today do not represent all the concerns or needs of people with MS. We have focused on these issues for two reasons: (i) secure and adequate income is the foundation for the ability of people with MS to fully exercise their rights as Canadian citizens, and to be part of mainstream Canadian economic and social life; and (ii) the recent successes of the federal government's fiscal policies have created new and important opportunities for it to lead in the fairer treatment of people with disabilities.

We thank the Committee for its time and consideration. We would be pleased to answer any questions and at any time to provide additional information about multiple sclerosis and the work of the MS Society and its volunteers.

Note

1. The Duke University study reports costs in 1994 US dollars. These have been escalated by 31% to reflect changes in US disposable income from 1994 – 1999 (source: statistical tables, US 2001 Budget). An exchange differential of \$Can = \$US 0.70 also has been applied.