

**MULTIPLE SCLEROSIS SOCIETY
OF CANADA**

**BRIEF TO THE STANDING COMMITTEE
ON FINANCE**

SEPTEMBER 2002



**Multiple Sclerosis
Society of Canada**

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The Multiple Sclerosis Society of Canada is pleased to have this opportunity to provide input on issues that are of concern to people who are affected by multiple sclerosis (MS). By this we include a broad range of individuals: the estimated 50,000 people who have MS; their families and caregivers; healthcare professionals; MS researchers and MS Society of Canada supporters.

In our submission this year to the Standing Committee on Finance, the Multiple Sclerosis Society of Canada is focussing on three broad themes:

- Health and Health Research
- Income Security
- Charitable Giving

HEALTH AND HEALTH RESEARCH

The Multiple Sclerosis Society of Canada was very pleased to take part in the consultation process of the Commission on the Future of Health Care in Canada. We also provided input into the Senate Committee on Social Affairs, Science and Technology's study on the State of the Health Care System in Canada. In both of our submissions, we focussed on the broad range of services needed for people with MS from diagnosis to management to MS research, and we look forward to the release of both of these important reports in the next few months. We recognize that the decisions to be made in this area must take fiscal responsibility into consideration, but we are hopeful that through a new, mutually supportive federal-provincial dialogue, needed changes can be made.

Health Research

The MS Society is very aware that the cause, prevention and cure for multiple sclerosis will be found only through the concerted efforts of health charities, private industry and governments. Canada has a highly qualified health research community and has contributed significant new advances to a growing international body of research.

Recently, Canada increased its investment in health and medical research with the creation of the Canadian Institutes of Health Research (CIHR). The MS Society of Canada applauds this investment. We were also pleased to note targets one and two of the government's innovation strategy. We share the government's commitment to have Canada rank among the top five countries in the world in terms of research and development (R&D) performance by 2010. According to the Organization for Economic Co-operation Development (OECD), Canada currently contributes a smaller proportion of public funds for research than other G7 countries.¹

¹ Report of the Standing Senate Committee on Social Affairs, Science and Technology. Volume Two: Current Trends and Future Challenges. January 2002, p. 103.

Multiple Sclerosis Society of Canada Key Recommendations for Health Research:

- Further enhance government investment in the Canadians Institutes for Health Research
- Foster the dissemination of health research results to policy makers and health care providers to enhance evidence-based decision-making.

INCOME SECURITY

Because of the impact of multiple sclerosis on the ability to work, income security is of utmost importance to people with MS -- most of whom are diagnosed with this disease between ages 20 and 40 with the average age of diagnosis of 30. As in previous submissions, the MS Society will focus on two programs, which provide some income assistance to people with MS and our suggestions for improvement. These are Canada Pension Plan (Disability) and the Disability Tax Credit.

Canada Pension Plan (Disability)

Canada Pension Plan disability benefits [CPP(D)] are a key support for people with MS. As of December 1999, 10,027 of the 50,000 people with MS in Canada were receiving CPP disability benefits.

The Multiple Sclerosis Society of Canada has identified several areas within the CPP(D) program that should be improved for the benefit of people with multiple sclerosis and which would not place a major financial burden upon the government of Canada.

First, however, the MS Society would like to report that since last year when we had the opportunity to present before the Standing Committee on Finance, people with MS have spontaneously reported to us better first time success in obtaining CPP(D) benefits. We believe part of this may be due to our efforts in educating CPP officials about the complexities of multiple sclerosis. In November 2001, the MS Society of Canada had the opportunity to be the first health charity to present at a workshop of CPP Disability Review Tribunal members. We are grateful for this opportunity and are anxious to continue this important dialogue.

In terms of areas of improvement, we will focus on the following:

Definition of Disability

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 — i.e., long-continued and of indefinite duration. MS is permanent and often severe. The often-fluctuating nature of MS, which is characterized by periods of remission followed by unpredictable periods of worsening, frequently 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.

Contribution Requirements

CPP(D) 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.

The recent "4 out of 6" contribution years rule that replaced the "5 out of 10" contribution years rule has made it difficult for many people who are disabled because of MS to qualify for the program. In addition, the current 15 percent drop-out rule (under which 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) does not cover many young people with MS who are unable to contribute to the plan for the required 10 years.

Part-time Work

Multiple sclerosis causes a wide variety of symptoms, which are disabling including severe fatigue. Many people with MS tell us that while they aren't able to work full time, they would be able to manage part-time or occasional employment above the current \$3,900 cut off for part-time work. This would bring about the obvious advantage of increasing income as well as other benefits such as maintaining community involvement and a sense of self-worth. .

Appeal and Application Processing Delays

In the past, the Multiple Sclerosis Society of Canada has criticized the backlogs in initial CPP(D) applications and the often lengthy delays in processing appeals. As mentioned above, the application and appeals processes seem to be improving although we continue to monitor them through our members. In addition, we will continue to seek opportunities to provide information about MS to Human Resources Development Canada officials and to the CPP Review Tribunal members to assist them to do the best job possible.

The MS Society of Canada, as well as other organizations, is concerned 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. It appears to us that significant administrative costs are being transferred to CPP(D) for disability assessments.

The MS Society has 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 and leaving people who are struggling with disabilities without a way to make ends meet.

The Multiple Sclerosis Society of Canada is aware that the Sub-committee on the Status of Persons with Disabilities has launched a study of the Canada Pension Plan (Disability) and looks forward to providing input from people with MS.

Multiple Sclerosis Society of Canada Key Recommendations for CPP(D)

- 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 **severe** continuous **or recurrent** disability that is expected to last one year or more.
- 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.
- 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 more part-time or occasional work without risking their eligibility for benefits.
- 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 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.

Disability Tax Credit

As with the Canada Pension Plan (Disability), the Disability Tax Credit (DTC) provides some small amount of income security through tax relief for people with disabilities including people with multiple sclerosis. As members of this Committee are no doubt aware, Canada Customs and Revenue Agency (CCRA) undertook a massive mailing to more than 100,000 Canadians in 2001 demanding that they reapply for the DTC. As a result, numerous people with disabilities, especially people with unpredictable and recurrent conditions such as MS, are no longer eligible for the disability tax credit. Officials at CCRA have indicated that they are acting on the intentions of the Department of Finance, we therefore would like to bring our concerns to your attention.

The MS Society has been very active with this issue: we have made a submission before the Sub-Committee on the Status of Persons with Disabilities; we have provided

information to all Members of Parliament about our concerns in conjunction with a coalition of other health and disability organizations and have continued to dialogue with CCRA officials about DTC concerns.

We cannot believe it was the intention of Members of Parliament who approved the language in the Income Tax Act to exclude from receiving the DTC, a person with MS who might be able to struggle to walk 50 metres on level ground on one of her “good” days, but ordinarily cannot climb stairs unsupported or walk a block in less than 30 minutes.

The courts have also recognized that an impairment does not always have to be continuous or constant to qualify for the DTC. In *Albertin v. The Queen 1998*, an impairment was judged to be continuous even though the individual was only impaired 50 per cent of the time because the disabling impact of the impairment could recur, without warning, at any time.

The Multiple Sclerosis Society of Canada fully supports the recommendations put forward by the Sub-Committee on the Status of Persons with Disabilities in its report, *Getting it Right for Canadians: The Disability Tax Credit* tabled in the House of Commons on March 21, 2002. We look forward to the response from CCRA expected shortly. We understand, as well, that changes to the T2201 form are being considered. We look forward to seeing these changes but must stress that any revisions should be focussed on making the process fairer and more transparent to Canadians who have multiple sclerosis.

Multiple Sclerosis Society of Canada Key Recommendations for the DTC:

- The Multiple Sclerosis Society of Canada urges the Committee to recommend to the Government revision of the DTC criteria to include individuals with a **severe** and **prolonged** physical or mental impairment that is continuous, progressive, episodic or recurrent.
- The MS Society of Canada urges that *Getting it Right for Canadians: The Disability Tax Credit* be used as a basis for reform of the DTC.

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 \$8 million in service programs and \$6 million for MS research. More than 80 percent 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 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.

Another suggestion we would like to put forward 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.

Multiple Sclerosis Society of Canada Key Recommendations for Charitable Donations:

- 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.
- 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 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.

In addition, 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. The MS Society applauds this role and urges the government continue its leadership this fall with the tabling of reports by the Commission on the Future of Health Care in Canada and the Senate Committee on Social Affairs, Science and Technology.

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 three reasons: (i) health and health research are vital concerns of people with a chronic, as yet, incurable disease; (ii) 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 (iii) 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 while at the same time we are conscious of the need for fiscal responsibility.

We thank the Committee for its 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 20 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. 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 that totals \$6 million.

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

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.²

² Report of the Standing Senate Committee on Social Affairs, Science and Technology. Volume Two: Current Trends and Future Challenges. January 2002, p. 49