

**MULTIPLE SCLEROSIS SOCIETY
OF CANADA**

**BRIEF TO THE STANDING COMMITTEE
ON FINANCE**

SEPTEMBER 2003



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The Multiple Sclerosis Society of Canada is again pleased to have this opportunity to provide input to the Standing Committee on Finance 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 Canadians who have MS; their families and caregivers; health care professionals; MS researchers and MS Society of Canada supporters.

In our submission this year the Multiple Sclerosis Society of Canada is again turning its attention to three broad themes that impact people affected by MS:

- Health Care and Health Research
- Income Security
- Charitable Giving

HEALTH CARE AND HEALTH RESEARCH

I. Health Care

In 2002, the Multiple Sclerosis Society of Canada participated in the consultation processes for both the Commission on the Future of Health Care in Canada and the study of the State of the Health Care System in Canada by the Senate Committee on Social Affairs. In both of our submissions, we focussed on the broad range of services needed for people with MS from diagnosis to management of the disease to MS research. When the reports were released later in the year, the MS Society was pleased that both reports urged significant change to Canada's health care system, and that some of these were directly addressed by the 2003 First Ministers' Accord on Health Care Renewal. We want to acknowledge the leadership of the federal and provincial health ministers in concluding the Accord and offer our support in its implementation over the coming months.

Of particular significance to people with MS were the following:

- Better access to diagnostic technology, especially MRI scanners, since early diagnosis and treatment are vital for people with MS. The MS Society was pleased that in the Health Accord, the First Ministers agreed to make significant new investments in this area.
- Drugs to treat MS are very expensive. Currently provincial and territorial drug programs provide uneven access and compensation. The MS Society welcomed the promise in the Health Accord to provide reasonable access to catastrophic drug coverage by the end of 2005/06. We urge, on behalf of people with MS waiting for drug coverage, speeding up this timetable.

At the same time, Health Canada's Therapeutic Product Directorate must do its part and have the resources available to it to carry out timely reviews to ensure that beneficial therapies are available to people who need them in a reasonable timeframe. The federal

government identified this as a priority in the Speech from the Throne, and a review of the program is now underway in which the MS Society has participated. We look forward to the results of the review and urge the government to create a more timely and more transparent process.

- One of our key recommendations to both Mr. Romanow's commission and Senator Kirby's committee was the establishment across Canada of home care for people with chronic, long-term illnesses like MS. We recognize that the Health Accord has made some important steps forward. However, extension of first dollar coverage for home care covers only short-term acute home care, including acute community, mental health, and end-of-life care. Most people with chronic illnesses will not benefit until the program is expanded, at the earliest in 2006.

The Health Accord recognizes both the costs savings of home care to government and the personal benefits to people with chronic illnesses and disabilities. Clearly, the future of Canada's health care system should include a much more central role for home care, including expanded Medicare coverage.

However, there is also much that can be done through existing programs to support a caring environment at home and to assist caregivers who are an integral part of a successful home care program. As Canada's health policy evolves, other programs which can complement and strengthen home care should be reviewed. We urge the federal and provincial governments to expand home care coverage to include chronic illness support as early as possible.

- We also draw your attention to the role of caregivers. Caregivers provide significant support for Canadians who are ill. We applaud the direction taken in the Health Accord to provide Employment Insurance and job protection to caregivers who leave jobs to care for a gravely ill or dying child, parent or spouse. We hope that this can be expanded in the same manner for caregivers of people who are severely disabled. We will address issue further in the section on Income Security.

Multiple Sclerosis Society of Canada Key Recommendations for Health Care:

- Speed up the timetable for providing access to catastrophic drug coverage;
- Ensure that Health Canada reforms the drug review process to make it more timely and transparent to stakeholders;
- Include the needs of Canadians who have chronic illnesses in future home care program agreements;
- Support the financial needs of caregivers of people who are severely disabled.

II. Health Research

People with multiple sclerosis need services and programs that address the challenges of living with a chronic disease. But they also need a robust, federally supported research program that will be an integral part of solving the MS problem. The Multiple Sclerosis Society of Canada supports its own research program which is targeted at finding the cause of MS, ways to prevent it, discover better treatments and ultimately discover the cure. But the MS Society is able to fund only a small part of the necessary research. Key to the success of health research in Canada is a well-funded and stable federal research strategy.

The creation of the Canadian Institutes of Health Research several years ago signalled that the Government of Canada recognized the importance of research to the overall future health of Canadians. We urge that this important investment continue and be expanded in the coming years to provide the needed stability for health research.

Multiple Sclerosis Society of Canada Key Recommendations for Health Research:

- Further enhance government investment in the Canadian Institutes of Health Research;
- Ensure that health research in Canada is stable and well-funded.

INCOME SECURITY

Multiple sclerosis has a profound impact on the ability to work. Most people with MS are diagnosed between ages 20 and 40 with an 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 the Canada Pension Plan (Disability) and the Disability Tax Credit.

I. Canada Pension Plan (Disability)

Canada Pension Plan disability benefits [CPP(D)] are a key support for people with MS. As of December 1999, over 10,000 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.

Many of our recommendations, which we have made previously, are present as well in the excellent report *Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program*, released in June 2003 by the Standing Committee on

Human Resources Development and the Status of Persons with Disabilities. Committee members are to be commended for both the process by which this report was developed including a web-based consultation and for its well-reasoned recommendations.

As mentioned in previous submissions to the Standing Committee on Finance, people with MS are reporting better first time success in obtaining CPP(D) benefits. This is probably due to several factors including the MS Society having the opportunity to work with CPP officials to explain the complexities of multiple sclerosis and provide information to people with MS about the application process. We look forward to continuing our efforts in both of these areas.

In terms of areas of improvement re CPP(D), we will focus on the following:

Supporting people with intermittent/recurring disabilities

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. However, 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 incapacity is recurrent rather than prolonged. The differing definitions of disability demanded by federal and provincial programs also are confusing and frustrating for people.

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 more 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. The report *Listening to Canadians* made this important point, quoting a panel member of the CPP Review Tribunals who said the 4 out of 6 rule actually introduces a type of systemic discrimination against people who have episodic illnesses where there are ups and downs – which is typical of MS.

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.

Caregiver Issues

As mentioned in our comments about health care, caregivers play an important role in enabling many people with MS to remain in their homes and communities. The decision to drop out of the work force or to work fewer hours is taken to support a loved one, but it also has financial impacts – negative ones for the caregiver and positive ones for various levels of government. By providing unpaid labour, the caregiver is able to keep the disabled or chronically ill family member at home, thus saving thousands of dollars each year in hospital or long term institutional care. But the caregiver has little or no income for a significant period of time, which ultimately reduces the amount of his or her Canada Pension at retirement.

A simple solution, as is recommended in *Listening to Canadians*, would be for HRDC to provide the same drop out provisions for 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 the calculation of the caregiver's CPP benefits.

Administrative Issues

The MS Society of Canada continues to have concerns – also highlighted in *Listening to Canadians* – 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 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 and leaving people who are struggling with disabilities without a way to make ends meet.

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

- That the recommendation in *Listening to Canadians* be adopted to amend section 42 of the Canada Pension Plan relating to the terms “severe and prolonged” to take into account cyclical and degenerative physical and mental conditions;
- That there be more flexibility in the current contribution rule of 4 out of the last 6 calendar years;
- Introduce more flexible rules that would allow beneficiaries to do more part-time or occasional work without risking their eligibility for benefits;
- That the recommendation in *Listening to Canadians* be adopted to provide a dropout provision for caregivers that are the same as the child-care dropout provisions;
- That the recommendation in *Listening to Canadians* be adopted requiring applicants to identify any third party that requires them to submit an application for CPP(D);

- That HRDC and the CPP Review Tribunal continue their outreach to Canadians regarding CPP(D) and that the recommendations in *Listening to Canadians* concerning administrative improvements be followed. The MS Society will be pleased to work with the Government of Canada to produce such materials about MS and ensure they are accurate and current. We would be pleased to assist further in any way we can.

II. Disability Tax Credit

The Disability Tax Credit (DTC) provides some income security through tax relief for people with disabilities, including people with multiple sclerosis.

The MS Society of Canada is very pleased with developments initiated this year by the Ministers of Finance and National Revenue and by Canada Customs and Revenue Agency (CCRA) to resolve a number of problematic issues. The MS Society has been very active with this issue. We participated throughout the summer in a consultation by CCRA on changes to the DTC application form and have provided input to the Technical Advisory Committee on Tax Measures for Persons with Disabilities (TAC). We look forward to working with the TAC and regard its work as an excellent opportunity to substantially improve the DTC.

The MS Society has identified several areas within the DTC that should be improved for the benefit of people with multiple sclerosis.

Intermittent/recurring disability

As with CCP(D), the definition of disability in the Income Tax Act is too restrictive. Section 118.3 of the Income Tax Act says that an individual may qualify for the disability tax credit if his or her impairment is “severe and prolonged”. Section 118.4 defines ‘prolonged’ as “has lasted or can reasonably be expected to last, for a continuous period of at least 12 months”. An interpretive bulletin prepared by the Canada Customs and Revenue Agency declares “intermittent impairments are not considered prolonged.” This wording in the legislation and subsequent interpretation have the effect of barring legitimate cases from receiving the disability tax credit and easing the extra costs of having a severe disability.

The courts have recognized that impairment does not always have to be continuous or constant to qualify for the DTC. In *Albertin v. The Queen 1998*, impairment was judged to be continuous even though the individual was only impaired 50 percent of the time because the disabling impact of the impairment could recur, without warning, at any time. This court decision provides guidance to CCRA in how to deal with intermittent impairments in a fair and equitable manner.

Severe Fatigue

While MS affects individuals in a myriad of different ways, virtually all people with MS experience severe and debilitating fatigue. In many cases, it is this chronic exhaustion,

and not the other physical disabilities associated with the disease that poses the biggest challenge to daily life. Fatigue is not directly measured in the ‘daily life’ tests for DTC eligibility. It is not uncommon for people living with MS to meet the discrete ‘daily living’ tests, which are highly specific and adjudicated independently of one another, and yet face severe challenges with daily living in the real world. This points to the need for flexibility in interpretation and more knowledge among those adjudicating applications.

Administrative Issues

The CCRA has the responsibility for administering the DTC. To carry out these duties effectively, CCRA staff must have access to appropriate training and resources. Staff should also be made aware of the various important court decisions (such as *Villani v. The Attorney General of Canada*) which have emphasized that benefits-conferring legislation ought to be interpreted in a broad and generous manner and that any doubt arising from the language of such legislation ought to be resolved in favour of the claimant.

DTC as a Refundable Credit

The disability tax credit is currently non-refundable. It is applied against and thus reduces taxable income. It does not assist people who do not have taxable income or dependants of individuals without taxable income. People with disabilities – including many people with MS – generally are in the lowest income levels of all Canadians. In addition, they have numerous disability-related expenses. These include canes, walkers and wheelchairs which can be claimed in part as a medical expense. They also have other more intangible expenses such as having to take expensive taxis instead of low-cost public transit, which unfortunately most people with severe mobility problems cannot use. These expenses are unavoidable and cannot be claimed as a medical expense.

Multiple Sclerosis Society of Canada Key Recommendations for the DTC:

- Amend the Income Tax Act to remove the “continuous period of at least 12 months” condition of eligibility. CCRA interpretive information should also be amended. DTC criteria must provide enough flexibility to allow individuals with intermittent but severe disability to have their degree of impairment assessed.
- The ‘activities of daily living’ tests are too specific and discrete to properly measure an individual’s capacity to manage daily living when dealing with a condition such as extreme fatigue. They should be evaluated together.
- CCRA administration must continue to train its staff and provide up-to-date training and resource materials. The MS Society would be pleased to assist with the training of CCRA staff about particular aspects of multiple sclerosis.
- Amend the Income Tax Act to make the disability tax credit a refundable credit to benefit people who have severe and prolonged disabilities.

We have provided these recommendations to the Technical Advisory Committee as well.

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 to Canadians with MS and almost \$6 million to fund 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.

A key component of MS Society fund raising is its direct mail campaign. Currently, we mail over eight million pieces of direct mail and receive more than 400,000 donations back through the mail annually. A major expense of this program is postage rates. Because Canada Post Corporation is a Crown Corporation with no government subsidies, all customers of Canada Post, including registered charities, pay commercial postage rates.

These postage fees represent as much as 43 percent of campaign expenses for registered charities. Current commercial rates are (without GST):

- Addressed Admail (sending the donation request mail out) - \$0.33 per piece (on average)
- Business Reply Mail (receiving the donation in) - \$0.60 per piece (first class rate of \$0.48 plus a handling fee of \$0.12 per piece)
- The cost of mailing donation receipts is \$0.47 (an incentive rate when mailing 5,000 pieces at a time) By law all tax receipts must be mailed first class rates.

There is precedent for assistance to identified sectors. To enhance communications from constituents, mail to Members of Parliament does not require a postage stamp. The government currently subsidizes the delivery of some magazines and newspapers to ensure that the Canadian cultural materials are available across the country.

Funds raised by registered charities through direct mail support much needed services and research for vital health issues. Direct mail revenues represent over \$12 million annually in gross revenue for the Multiple Sclerosis Society of Canada. Any postage savings would directly translate to more money going to medical research and services.

The United States Postal Service has a two-tiered postal system with approved not-for-profit organizations receiving government subsidies. The current commercial rates vs non-profit rates (in US dollars) are:

- Addressed Admail - \$0.17 (on average) - charities receive a subsidy which brings this fee to \$0.125 – 26 percent savings for the charity.
- Business Reply Mail – volume based incentive program - \$0.348 (\$0.34 plus \$0.008 handling fee for 34,000 pieces per quarter)
- Receipts are not required by law to be mailed first class, and no receipts are required for donations under \$250

As mentioned above, in the United States, charitable organizations are not required to issue receipts for income tax purposes for donations under \$250. Clearly, the Internal Revenue Service 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 registered charities.

Multiple Sclerosis Society of Canada Key Recommendations for Charitable Donations:

- Provide a subsidy to Canada Post Corporation for registered charities that utilize Address Admail and Business Reply mail services.
- Provide a subsidy to Canada Post Corporation for registered charities to assist in the mailing of donation receipts.
- 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 pleased that the government has taken important steps forward through the Health Accord to address important health care issues and 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.

The MS Society urges the government continue its leadership in addressing important income support issues through the Canada Pension Plan disability benefits and the disability tax credit. We also urge the government assist registered charities in their work of serving Canadians by directly reducing their mail-related operating overheads.

We hope that the input that we have provided will assist the Standing Committee on Finance in its deliberations. 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.¹

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