

**MULTIPLE SCLEROSIS SOCIETY  
OF CANADA**

**BRIEF TO THE SUB-COMMITTEE ON THE STATUS OF PERSONS  
WITH DISABILITIES**

**MULTIPLE SCLEROSIS AND CPP(D) ISSUES**

**FEBRUARY 2003**

## **Introduction**

The Multiple Sclerosis Society of Canada welcomes the opportunity to provide input to the Sub-Committee on the Status of Persons with Disabilities of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities.

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. An estimated 50,000 people in Canada have MS.

### **Canada Pension Plan (Disability)**

Canada Pension Plan disability benefits CPP(D) are a key support for people with MS. MS is a chronic disease of the central nervous system that unfortunately often leads to severe disability. As of December 1999, 10,027 people with MS in Canada were receiving CPP disability benefits.

### **Multiple Sclerosis and Unemployment**

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.

According to a major study of the cost of MS in Canada, the time to employment change occurs quite soon after diagnosis and escalates with increasing disability: 25% of people with MS have a significant change in employment within five years following diagnosis; 50% within 10 years following diagnosis; and 80% within 20 years following diagnosis.<sup>1</sup>

Viewed in terms of severity of disability, even in people who are still able to walk, almost 50% are unemployed. A major contributing factor for unemployment in MS is the impact of fatigue. This is an all-pervasive, overwhelming fatigue that is quite different from feeling tired because of physical exertion. It is thought by physicians to be connected to the location of MS plaques within the central nervous system and is the most common symptom in MS, reported by more than 80% of those who have the disease.

How does having MS then lead to unemployment? Dr. Luanne Metz, director of the MS Clinic, Foothills Hospital, Calgary, has identified these significant factors:

- Physical and/or cognitive inability to carry out the tasks of the job;
- Inability to complete the job at an acceptable rate and capacity (fatigue is often a factor);
- Insufficient stamina to continuously, reliably complete the job (fatigue is a major factor);
- Frequent disease activity, illness related to MS or need for treatment may lead to too many sick days to allow employability.

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<sup>1</sup> Burden of Illness of Multiple Sclerosis: Part 1: Cost of Illness, *Can. J. Neurol.Sci.*, 1998: 25: 23-30

Here are several examples of how MS fatigue negatively impacts a person's ability to work:

*A Winnipeg woman has been unable to work for several years. She now receives CPP(D) but only after going through several appeals. One of her primary disabling symptoms is fatigue. She must sleep at least 12 hours a night. If she has to go to an appointment or social event, she must sleep 16 hours the night before and following the appointment go straight home to rest again. Outwardly, she has no visible disability.*

*A Kirkland, Quebec man had to stop work after continually falling asleep at work. He said this would happen initially when he was working on the computer or reading contracts. At the end of his employment, the waves of fatigue resulting in him falling asleep would occur even at meetings with others: "My life became work and sleep. I had no energy to do anything else...In the last month or two there were nights when I went to bed without supper because I had no energy to reheat food in the microwave or answer the door if I ordered something."*

## **Addressing the Problem**

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.

## **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. Changing the definition of disability to include conditions that are severe prolonged or recurrent would be fairer to people who have diseases, like MS, that can be cyclical and unpredictable.

## **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, as mentioned. 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. Allowing more flexibility for part-time and occasional work has the obvious advantage of keeping someone in the workforce and still assisting them with CPP(D) benefits.

### **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. 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. It appears that within the appeals process, people have an opportunity to provide more detailed information to the medical adjudicator. This suggests 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 recommends:**

- A new, fairer definition of disability be developed to cover individuals with a **severe prolonged or recurrent** disability that is expected to last one year or more;
- 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;
- **More flexible rules** be adopted that allow beneficiaries to do more part-time or occasional work without risking their eligibility for benefits;
- That **fixed timelines for application, review and appeal** be implemented. Applications should be processed within 60 calendar days of receipt, internal reviews completed within 60 calendar days of receipt of a request for reconsideration and decisions of the Tribunal should be rendered within 60 calendar days of an appeal hearing; Attention should be paid as well to the unnecessarily long time it takes to receive a Review Tribunal Hearing date – in several cases this has stretched to more than six months.
- 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 have already begun this process with several CPP regional offices and hope to continue this collaborative effort.

## **CONCLUSION**

The Multiple Sclerosis Society of Canada is pleased that the Sub-Committee is undertaking this study. Secure, adequate income support 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. It is important that CPP(D), a key component of this support, be as effective and fair as possible.

We would also like to congratulate the Sub-Committee for establishing its website and encouraging Canadians to participate directly through the online poll and e-consultation. This approach should allow people from across Canada to play a role in the Sub-Committee's work and provide some important perspectives to Sub-committee members.

We thank the Sub-Committee for its time and consideration.

### **For more information:**

Deanna Groetzinger  
Vice-President, Communications  
Multiple Sclerosis Society of Canada  
250 Bloor St. E., Suite 1000  
Toronto ON M4W 3P9  
416 967-3007  
[deanna.Groetzinger@mssociety.ca](mailto:deanna.Groetzinger@mssociety.ca)  
[www.mssociety.ca](http://www.mssociety.ca)

## APPENDIX

### **MORE 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 a national office, 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, education 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 more than \$5.1 million.

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>2</sup>

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