

**Briefing Notes**  
for meeting with  
**Steven Fletcher M.P.**  
November 8, 2004

**Introduction**

Multiple Sclerosis (MS) is an unpredictable, at times disabling disease of the central nervous system and is the most common neurological condition affecting young adults in Canada. Typically diagnosed between the ages of 15 and 40, it affects women twice as often as men; every day three more people in Canada are diagnosed with MS. Canada has one of the highest rates of MS in the world and Manitoba has one of the highest rates in Canada, with an estimated 3500 Manitobans living with MS.

The Manitoba Division of the MS Society of Canada offers a broad range of programs and services for Manitobans affected by MS. These include provision of information, support counselling, individual and group advocacy, self-help groups, recreation and social programs, and some limited financial assistance as well as education programs both for people living with MS and for health professionals. Through our national organization, the division also contributes financially to MS research. To finance these activities, it runs several successful fundraising events each year.

**Specific Federal Issues of Concern to People Affected by MS**

***Health Care***

• **Home care**

As multiple sclerosis is a chronic and most often progressive condition, access to quality home care is essential for people living with M.S.. The vast majority of people can continue to live in the community despite increasing disability with support from home care services. These prevent reliance on expensive institutional care and allow people to continue leading independent lives. We appreciate the fact that the Manitoba home care program is currently one of the most comprehensive in the country, although we recognize that it could be further enhanced to better support people with both changing and more complex needs.

On the federal level, we are pleased with the commitment made by the federal, provincial and territorial first ministers to support the enhancement of home care services across the country. However, this commitment was specifically for short-term acute home care as well as end-of-life care. As such, the needs of people with chronic health conditions, like MS as well as other disabilities, are not being addressed. We urge that the federal and provincial governments expand home care coverage to include the needs of people who have chronic health conditions and disabilities.

• **National Pharmaceuticals Strategy**

Access to appropriate drug therapies is very important for the treatment of MS. These drugs are very expensive; currently provincial and territorial drug programs provide uneven access and reimbursement for their costs. We welcomed the first ministers' commitment in the 2003 Health Accord to provide reasonable access to catastrophic drug coverage by the end of fiscal year

2005/2006. On behalf of people with MS struggling to pay for these therapies, we urge that this timeframe for catastrophic drug coverage be accelerated.

We are pleased that the federal government has indicated a desire to streamline and speed up Health Canada's drug review process. Currently Canadians can wait several years to get access to beneficial drug therapies. However, despite the federal commitments to speed up this process, progress to date has been limited. We hope that the government will address this issue so that people can have access to drugs that are safe and effective within a reasonable timeframe.

- **Caregivers**

Caregivers play a crucial role in supporting and caring for people with MS and other chronic conditions and disabilities. The 2003 Health Accord made improvements to Employment Insurance provisions and provided job protection for caregivers who leave work to care for a gravely ill or dying child, parent or spouse. We urge that these provisions be expanded to apply to caregivers of people with chronic conditions or severe disabilities.

### ***Income Security***

MS often has a significant impact on the ability to continue working. On average, 25% of people have to stop work within five years of diagnosis, 50% within 10 years and 80% within 20 years. The two main federal programs that provide some income assistance to people with MS are Canada Pension Plan (Disability) and the Disability Tax Credit. Both are in need of improvement.

- **Canada Pension Plan (Disability)**

Many people with MS rely on CPP(D) to provide income support when they have to stop working. As of December 1999, over 10,000 of the estimated 50,000 Canadians living with MS were receiving CPP(D) benefits. In 2003, the House of Commons Standing Committee on Human Resources and the Status of Persons with Disabilities undertook a detailed examination of the program and tabled its report. This included a series of recommendations to modernize and improve the program. While the federal government did acknowledge some administrative problems with the program, it made no commitment to address the report's major recommendations and reform the program.

For their part, the MS Society and people living with MS welcomed the report and, in particular, its recommendations to:

- make the program more accessible to people with recurrent conditions like MS, by amending the terms "severe and prolonged" in section 42 of the Canada Pension Plan to take into account cyclical and degenerative mental and physical conditions;
- add flexibility to the current contribution requirement of four of the last six years, which makes it difficult for people with episodic conditions like MS to qualify;
- make it easier for CPP(D) recipients to do some part-time or occasional work, beyond the current \$3900 cutoff for allowable earnings, when they are able to do so, without risking their eligibility for benefits.

In addition, the MS Society recommends that caregivers of people with MS and other conditions be able to "drop out" their years of low or no income when they were providing care, when calculating their CPP retirement pension. This would be similar to the program's current "child rearing dropout" provision.

- **Disability Tax Credit**

The Disability Tax Credit (DTC) provides important income support through tax relief for people with disabilities, including many people with MS. In 2003, the federal government established a Technical Advisory Committee on Tax Measures for Persons with Disabilities. The MS Society and Canadians with MS have urged the committee to recommend changes to allow more people with severe disabilities from episodic diseases to be eligible for the DTC. In particular, we recommend that:

- the Income Tax Act and CRA interpretive information be amended to remove the “continuous period of at least 12 months” condition of eligibility. DTC eligibility criteria must provide enough flexibility to allow individuals with intermittent but severe disabilities to have their degree of impairment assessed.
- there be more flexibility in interpretation, more knowledge among those adjudicating applications and evaluation of daily living tests together rather than as separate and specific items. Currently, the “activities of daily living” tests are too specific and discrete to properly assess an individual’s capacity to manage daily living when dealing with a condition such as extreme fatigue – a common and often debilitating symptom of MS.
- the Income Tax Act be amended to make the DTC a refundable credit to benefit people who have severe and prolonged disabilities. As a non-refundable tax credit, the DTC reduces taxable income. As such, it does not assist those with no taxable income, as is the case for many people with disabilities, including those with MS.

We appreciate having the opportunity to meet with you and let you know something about multiple sclerosis, the Manitoba Division of the MS Society of Canada and the concerns of Manitobans living with MS. If you have any questions or want more information please do not hesitate to contact one of the following staff members:

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