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Multiple Sclerosis Society of Canada Ontario Division

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The Multiple Sclerosis Society of Canada, Ontario Division, is pleased to provide its perspective and recommendations on the 2008 Ontario Budget.

Multiple sclerosis (MS) is a disease of the brain and spinal cord. Canadians have among the highest rates of MS in the world. The causes of MS remain mysterious, and there currently is no cure. A range of disease-modifying therapies provide varying degrees of symptomatic relief, and ongoing research around the world – in which Canada is a leader – provides growing hope that a cure will be discovered.

Living with MS is often a struggle. While the disease is highly variable and unpredictable, over time, most people with MS find it difficult to maintain fulltime employment and need increased medical care and supports such as home care. Some – fortunately a relative few – will no longer be able to remain in their own homes and will have to seek institutional care.

Our approach to budgetary issues focuses on ways in which individuals and families living with MS can participate actively – economically and socially - despite the obstacles and isolation MS can create.

The first section of our submission focuses on areas that fall under the Ministry of Health and Long-Term Care. The second section deals with issues of accessibility, which may have impact on several areas of government, most notably the Ministry of Transportation and the Ministry of Community and Social Services. The final section provides a summary of our recommendations.

Health and Long-Term Care

This section of our submission calls for improved access to home care, age appropriate housing, drug therapies, assisted devices, and medical and neurological services.

Home Care

People who experience disability because of multiple sclerosis want to live in their own homes, but many require home care assistance to do so. Currently, home care support in Ontario is not adequate for many people with MS. Often, even minimal home care support can reduce emergency room visits and hospital admissions, help keep families together and prevent premature institutionalization.

There is considerable evidence that broadening home care funding is cost-effective. The alternatives to an adequate system of home care are plain: neglect or forced institutionalization. Neither is acceptable to Ontarians and clearly, neither benefits those in need.

The MS Society, Ontario Division, urges the Government of Ontario to invest in a comprehensive approach to home care for persons with disabilities and chronic illnesses as it has for seniors through the Aging at Home strategy. We believe the approach should include:

- a. Adopting an overall home care philosophy with the goal of providing sufficient home support to individuals with disabilities who require health services or assistance with activities of daily living.
- b. Funding a high quality and accessible publicly funded home care system across the province for people with chronic diseases like MS.
- c. Establishing standards, guidelines, benchmarks and indicators to ensure best practices in home care services.
- d. Ensuring that necessary mobility equipment and home adaptations are funded.
- e. Developing a coordinated system of social supports, including accessible transportation.

Age-appropriate Care and Housing

Some young adults with MS require institutional care. It is vital for their quality of life that their housing and care are appropriate for their age. However, far too many end up in long term care facilities or nursing homes that were designed for frail elderly residents and do not have the services and activities that would benefit younger disabled people. A 2006 Canadian Institute for Health Information study found that 20% of residents in Ontario hospital-based continuing care facilities were younger than 65, and the Canadian Healthcare Association reported in 2005 that approximately 40% of residents in Ontario's complex care facilities were younger than 65. This is of particular concern to the MS Society because of the early age of onset for MS.

We urge the Ontario government to take specific action to address the needs of younger adults who live with MS and other disabilities or chronic illnesses. It is unclear if the Aging at Home strategy – geared toward seniors – is also designed to address the age-appropriate needs of individuals with disabilities or chronic illnesses. We call on the province to:

- a. Increase the supply of age-appropriate housing of various housing types across the province for Ontarians who can no longer live in their own homes.
- b. Actively seek community partnerships to develop and fund age-appropriate housing for younger adults with MS and other disabilities and chronic illnesses.
- c. Develop clear policies regarding the placement of younger adults with MS and other disabilities to ensure they receive care in age-appropriate settings.

Access to New Drug Therapies

Just 12 years ago, there were no treatments for people with MS. Now, there are five – but only four are reimbursed in Ontario: Avonex™, Betaseron®, Copaxone™, and Rebif®. In 2006, Health Canada approved a new MS disease modifying medication, Tysabri®, but the Ontario Drug Program's Committee to Evaluate Drugs advised against adding it to Ontario Public Drug Programs. The result is that some Ontarians with private insurance can get access to it, but because of the cost, other Ontarians living with MS do not have access.

Ontario has not yet made the final decision as to whether this new effective therapy should be reimbursed for people with MS. We are concerned that the cost of MS drugs is being used as an excuse without sufficient attention being paid to drug effectiveness.

We call on the Government of Ontario to cover the full cost of new effective drug therapies approved by Health Canada which offer significant relief to people with MS.

Specialized Treatment for Spasticity

In some cases, people with MS who are severely disabled need access to specialized medical devices, such as implantable pumps to deliver medication that can control painful muscle spasms. At this point, the only program for people with MS is the London Health Sciences Centre.

We understand that an expert committee within the Ministry of Health and Long-Term Care is examining this issue. In the meantime, nobody disputes the need for a province-wide strategy for providing neuromodulation services.

We call on the government to act now on such a strategy to ensure that these individuals receive the services they require.

Services for Northern and Rural Residents

Timely access to health care services is a critical issue in rural areas and northern Ontario where there is often a shortage of qualified health care professionals, especially in specialty areas such as neurology. People in northern Ontario often have to travel to medical centres in southern Ontario for services and, because the Northern Travel Grant is woefully inadequate, bear much of the travel costs themselves, despite the increases announced in July of 2007.

In the short- to medium-term, there is little alternative for people in the north to travel to southern centres for specialized treatment. We call on the government to increase reimbursement under the Northern Travel Grant, to reflect the real costs of travel where it is necessary.

Assistive Devices

The Ontario Assistive Devices Program (ADP) provides assistance to people with disabilities who require mobility equipment such as wheelchairs, walkers and a variety of technological aids to remain independent. People with MS tell us that because the cost of the devices has risen they are required to pay increasingly more out of their own pockets – often from inadequate disability pensions.

The MS Society, Ontario Division, calls on the Ontario government to increase funding for the Assistive Devices Program to keep up with changes in the prices of assistive devices.

Accessibility

The Government of Ontario has taken great steps to improve accessibility for people with disabilities. Despite the progress that has been made, people with disabilities still face significant barriers.

Transportation

Ontario is slowly developing more accessible transportation, but public transportation for people with disabilities is currently not available in many parts of the province, especially in smaller communities. The proposed Transportation Standard is a positive step forward, but considerable modification is required to make it truly workable and enforceable.

For example, the timelines for most standards should be shortened considerably and can be done for the most part without adding to the cost of operating the system. There is no reason why bus, streetcar and subway operators cannot now announce each stop. As well, affixing a sign with the universal symbol of access to accessible vehicles could be accomplished in weeks, rather than the three years specified in the standard.

Investments must be made to purchase accessible transportation infrastructure. Transit providers may also require support to develop the policies, practices, and human resource training needed to support accessible public transit systems.

We encourage the Government of Ontario to implement strategies to ensure the development of accessible public transportation systems across the province through its support of municipal and regional transit projects, including those that are part of MoveOntario 2020.

Employment

MS Society research has found that, over time, fewer than 30% of people with MS remain in the work force. While some people cannot work because they are severely disabled, others have told us that they would have been able to stay employed if more workplace accommodation had been available. This approach does not bode well for the economic well-being of people with MS and their families, or for the province.

We urge the Government of Ontario to expedite the work of the Employment Accessibility Standards Development Committee so that people living with MS and other disabilities or chronic diseases can have the same access to the employment as other Ontarians and maintain their workforce attachment as long as their situation permits.

Summary of Recommendations

In summary, the MS Society, Ontario Division, recommends that the Government of Ontario:

- Invest in a comprehensive approach to home care for persons with disabilities or chronic illnesses as it has for seniors through the Aging at Home strategy.
- Increase the supply of and access to age-appropriate housing of various housing types across the province.
- Cover the full cost of new effective drug therapies approved by Health Canada which offer significant relief to people with MS.
- Expand access to specialized medical devices and treatments for pain and spasticity, such as neuromodulation, to ensure that these services and treatments can be more easily obtained by people with MS who live throughout the province.
- Increase reimbursement under the Northern Travel Grant, to reflect the real costs of travel where it is necessary.
- Increase funding for the Assistive Devices Program to keep up with changes in the prices of assistive devices.
- Implement strategies to ensure the development of accessible public transportation systems across the province through its support of municipal and regional transit projects, including those that are part of MoveOntario 2020.
- Expedite the work of the Employment Accessibility Standards Development Committee so that people living with MS and other disabilities or chronic diseases can have the same access to the employment as other Ontarians and maintain their workforce attachment as long as their situation permits.

Thank you for your time and interest. We will be pleased to answer any questions.

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