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Multiple Sclerosis Society of Canada
Ontario and Nunavut Division
Pre-Budget Submission

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Introduction

The MS Society of Canada, Ontario and Nunavut Division is pleased to respond to the Minister of Finance and the Standing Committee on Finance and Economic Affairs with our recommendations for advancing some of the priorities outlined in ***A Plan to Build Ontario Together***. We humbly request that, in the pre-budget consultation process undertaken by the government, our recommendations are given serious consideration.

We appreciate that it has been stated clearly that the Ford Government for the people will "help those who need it most and protect the most vulnerable in our communities". Our recommendations focus on the government's goal to **prepare people for jobs**, **build healthier and safer communities** and **make life more affordable**.

What is Multiple Sclerosis?

Multiple Sclerosis (MS) is a chronic, typically progressive disease involving the brain and spinal cord. It is a disability that has both visible and invisible symptoms and whose symptoms are often episodic, being severe at some points and not at others. The symptoms experienced include fatigue, dizziness, (muscle) weakness, vision loss and cognitive impairment. Barriers in support programs across levels of governments add immense financial and practical challenges for Ontario families who struggle to manage the realities of living with the disease.

MS has an enormous impact on all Ontarians. More than 77,000 Canadians live with the disease, a significant percentage of which reside here in Ontario. Thousands of Ontario families are affected as a result. Without the right support systems, the unpredictable nature of MS makes it particularly challenging for those living with the disease to maintain an adequate quality of life.

Why prioritize support for people affected by Multiple Sclerosis?

Canada has one of the highest rates of multiple sclerosis in the world! On average, eleven Canadians are newly diagnosed with multiple sclerosis every day! Typically, multiple sclerosis is diagnosed in people between 20-49 years of age. This means that many people living with MS are diagnosed in the prime of their lives when they are completing post-secondary education, beginning their first jobs, building their careers and starting their families.

The MS Society's Role

The MS Society of Canada focuses on ensuring that people living with MS, and their families, have the opportunity to participate fully and productively in all aspects of life.

To get there, significant provincial help is required. As part of our mandate, we connect and collaborate with federal and provincial government agencies to advocate on behalf of people living with and affected by MS on the issues and policies that impact them the most. As an organization we focus on the following

national priority areas: income and employment security, improved access and investing in health research.

People living with MS, their families and their caregivers need supportive action and investments from their government to live independently and fully participate in their communities. Ontario's budget priorities should include allocating funding dollars that help empower Ontarians living with MS so they can live with dignity, make independent decisions and have access to affordable programming, which contributes positively to their individual health, their families well being and their quality of life.

Pre-Budget Consultation Priorities

1. Income and Employment Support
2. Independent Living Programs
3. Support for Caregivers

Income and Employment Support

MS is most often diagnosed between the ages of 20 and 49, which is a crucial time in one's career and working life. As a result, a diagnosis can create a major disruption and individuals often need to be absent from work on a periodic basis due to the episodic nature of MS. Workplaces need to endeavor towards better inclusivity for staff and show a deeper understanding of the realities of colleagues with disabilities.

The MS Society believes that major investments need to be made in order to bring awareness to the episodic nature of MS and to train employers on the importance of making accommodations for individuals who want to continue to work.

We commend this government on placing a strong emphasis on employment supports to encourage and prepare people for employment faster. However, without supportive workplaces, this cannot and will not, be a reality for someone living with MS.

Some people living with MS continue to work and earn a sufficient income, which can disqualify them from eligibility for specific disability related benefits and credits. As their illness progresses, expenses related to their disease put serious strain on their finances as a larger percentage of their earnings go to health care related costs. As day-to-day expenses like housing, mobility equipment, supplies, essential services and other illness-related costs rise, household incomes are depleting quicker than ever before leaving Ontario families struggling just to get by. As a result, our organization is supportive of the Basic Income concept and would be eager to see the government take another look at implementing it in some way.

We were pleased to see Minister Smith note that "empowering people and supporting them during challenging times is a priority for our government" in a recent letter sent to us. We absolutely agree with the Minister that "the people of Ontario are the province's greatest asset, and when they succeed, our economy and province succeed". However, too many Ontarians who live with MS are being left behind because of the continuing inadequacy of disability benefits. The focus on punitive and coercive rules within the system is counterproductive and traps people in poverty instead of providing the supports they need to stabilize and move forward in their lives. Instead, the system should incentivize everyone to participate in the earned-employment market to the extent they are able by minimizing penalties against additional earned income for those in receipt of disability benefits, refundable tax credits and ODSP.

The MS Society recommends:

- **The ODSP earning exemption be increased to $6,000 per year.**
- **The clawback rate for earnings over the exemption be reduced to 25% either through an immediate reduction or by introducing a sliding scale.**
- **The income threshold at which people are no longer eligible for ODSP be increased to reflect current realities of the cost of living in Ontario.**

Taking these measures will ensure that the social services system provides the maximum incentive for people with MS to participate in the earned-employment market to the extent they are able.

Unfortunately, the reality is that some individuals with MS who want to work, are unable to do so because of their disease. The rate of income for persons with disabilities receiving provincial support was frozen for a decade between 1993 and 2003. Following this, small, incremental increases were made each year (between 1-2 per cent). These minimal increases have not kept pace with the rate of inflation. The basic costs of living – rent, food, phone, hydro, transportation and clothing – have risen much faster than that – by 55 per cent since 1993. Disability rates, however, have only gone up a mere 20 per cent for families receiving Ontario Works and families and individuals with disabilities receiving ODSP. In effect, people living with MS have received less and less support, as costs continue to rise higher and higher.

Fixing the system will require Ontario to invest in people up front. Spending cuts for social assistance will worsen poverty, prevent the system from meeting its goals, and stop people from reaching their potential in turn hurting our economy and province. Savings will come when people are better supported, healthier and potentially able to leave the system and return to the work they never wanted to leave in the first place.

The MS Society recommends:

- **An immediate increase in social assistance rates to reflect the current cost of living in Ontario.**
- **Annual increases to ensure rates keep pace with inflation at a minimum.**

Adequate incomes allow people with MS to stabilize their lives and act as a springboard to participation in the economy and community.

Living Independently

People living with MS want the opportunity to live independently, ultimately lessening their dependence on the health care system and helping to build healthier and safer communities. This cannot be achieved without home supports such as equipment that enables independence and day-to-day services that can help people live with dignity.

Living with a disability often makes tasks such as housekeeping and snow clearing impossible. While these may seem like simple household tasks for some these activities often prove to be difficult and sometimes physically impossible for those living with a disability like MS. To maintain a decent quality of life, to stay at home and live independently, these services, or funding to pay for them, are greatly needed.

The MS Society recommends:

- **The Ontario Government invest in home retrofits and the purchase of non-medical equipment and services that will allow people with MS to stay safe, secure, and supported in their homes as long as possible.**

The value of those with disabilities being able to remain in their own homes lies both in preserving the patients' dignity and independence as well as in reducing societal costs versus alternatives like hospitals and long-term care homes.

Programs like the Direct Funding Program through the Centre for Independent Living in Toronto (CILT) allow people with MS to live independently and with dignity, giving them more control over their own health care decisions. In turn, pressure is alleviated from the health care system reducing costs and freeing up much needed spaces for those who need them. Such programs are effective in helping more people with MS live at home instead of needing supportive housing. In the past three years, Direct Funding has received an additional $5 million per year from the Ministry of Health and Long-Term Care, so that it presently serves almost 1,000 people on a budget of $45 million a year.

The MS Society recommends:

- **The Direct Funding Program be expanded by an additional $5 million investment this year, which will help increase the number of people able to participate.**

The Assistive Devices Program (ADP) allows individuals to live independently at home by providing them with accessibility equipment such as walkers, manual and power wheelchairs, power scooters and more as their disease progresses. At present, the ADP program lacks a comprehensive list of essential equipment and the waiting list to participate in the program is often far too long. The ADP paid $514 million in 2017-2018 to approximately 400,000 people. The recent Auditor General's report found that the program has enhanced service delivery since its previous audit in 2009. However, the program hasn't had a substantive update since 2001.

The MS Society recommends:

- **Additional funding for the ADP in order to shorten wait times and allow more individuals to access the program in a timely fashion.**
- **Expanding the list of approved equipment to include items such as hospital beds, shower lifts, and ceiling lifts which will give more people the opportunity to live comfortably at home**

Reducing wait times for crucial mobility devices like wheelchairs and including new devices on the ADP will enable those living with MS to contribute to their fullest extent to our economy and to ensure that they can stay in their homes as long as possible.

For many who live with MS the ability to live independently or not isn't entirely about their own capacity. Instead they face challenges in the built environment that can render them unable to live independently or to participate in their communities and our economy to the extent that they are able. This part of the MS Community and many more people along with them are closely watching the commitment spelled out in the AODA to a fully accessible province by 2025. Unfortunately, what they've seen so far doesn't look promising. As the Honourable David Onley noted in the introduction to his 2019 Review of the AODA "Every day, in every community in Ontario, people with disabilities encounter formidable barriers to participation in the vast opportunities this province affords its residents – its able-bodied residents… For most disabled persons, Ontario is not a place of opportunity but one of countless, dispiriting, soul-crushing barriers." In order for the province to meet its commitments to be fully accessible by 2025 much more needs to be done.

The MS Society recommends:

- **The Government recommit to implementing the AODA and ensuring our province is fully accessible by 2025.**
- **Making appointments to the Accessibility Advisory Council and restarting the work of the Standards Development Committees to address accessibility challenges in the built environment.**

Reducing barriers in the built environment and fully implementing the AODA will allow more people living with MS to live independently for longer and to participate more fully in their communities and our economy.

Support for Caregivers

As the government has indicated, there is a tremendous burden on the health care system with over-crowding, long wait times in hospital emergency rooms and low bed-availability. Undoubtedly, family caregivers are bearing a large part of that burden right now and the MS Society believes one way to help build healthier and safer communities is to ensure that they are supported. Family caregivers play an important role that often requires them to take extended leaves from their jobs, making the need for enhanced financial supports essential. Providing more initiatives for people who act as caregivers including counselling, staff support and further training will help increase the capacities of caregivers and their families.

In some cases, caregivers are forced to leave their current employment in order to provide care to their family members or loved ones with MS. This can place a significant strain on household incomes and when combined with the additional expenses experienced by people as an outcome of their disability, can drive families into poverty. In fact, according to the Ontario Caregiver Organization's Spotlight on Ontario's Caregivers Report for 2019, more than 30% of caregivers in Ontario faced financial hardship as a result of the impact that expenses related to caregiving had on their family's budget.

In Ontario, individuals can take unpaid leave, but paid caregiver leave is only found under Federal Compassionate Care Benefits (CCB) and caregivers are not eligible unless the person they are caring for is near death.

The new Ontario Caregiver Tax Credit is a welcome addition to caregiver supports. However, it is non-refundable and thus, does not benefit low-income caregivers. Even for those who qualify, the maximum annual tax savings is just $306. Other provinces provide more substantial financial support to recognize the individual sacrifice and societal benefits caregivers provide. For example, primary caregivers in Manitoba are eligible for a $1,400 **refundable**, non-income tested tax credit to recognize their efforts and cover expenses such as shopping, transport, outings and respite.

The ideal alternative is to provide monthly direct financial support via a caregiver allowance, like in Australia and many European countries. In Canada, Nova Scotia has demonstrated that this approach best serves both caregivers and the public.

The Nova Scotia Caregiver Benefit program provides a caregiver with up to $400 per month, tax free (subject to income limits.) According to preliminary evaluation of the Caregiver Benefit Program in Nova Scotia, the caregiver benefit reduced the probability that individuals would be admitted to long-term care by 56 per cent, resulting in savings to the government health and social system of $50,000 per person, per year.

The MS Society recommends:

- **The Ontario Government follow suit with other Canadian jurisdictions by providing a caregiver allowance like in Nova Scotia, or a refundable credit like in Manitoba.**

This assistance has been shown to greatly contribute to the ability of caregivers to provide care at home and maintain that over a longer time period in turn reducing the burden on long-term care homes and other supportive residences.

Conclusion

The MS Society implores the provincial government to provide more supportive action and investments directed to people with MS and their caregivers for them to live independently and fully participate in their communities. We feel this can be achieved by allocating funding dollars to the priority areas mentioned and most specifically by:

- Increasing the income exemption amount, increasing the eligibility threshold, and reducing the clawback rate for ODSP.
- Increasing social assistance rates immediately and ensuring they keep pace with inflation moving forward.
- Investing financial resources in home retrofit programs and non-medical equipment to allow people to stay in their homes.
- Investing an additional $5 million into the Direct Funding Program.
- Redesigning and increasing the efficiency of the ADP and expanding equipment options.
- Recommitting to full implementation of the AODA by 2025 beginning by making appointments to the Accessibility Advisory Council and restarting the Standards Development Committees.
- Providing further financial and respite supports for caregivers as demonstrated in other provinces like Manitoba and Nova Scotia.

It is our hope that the Ontario government will enhance contributions to the abovementioned priorities recognizing that strategic investments in these areas will empower individuals with MS to gain greater independence and enjoy a much-improved quality of life.

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