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

Multiple sclerosis (MS) impacts all Ontarians not just the people who live with MS – their family, their friends, their community, and province are all touched by this disease. The unpredictable, episodic, yet progressive nature of MS makes it particularly challenging to maintain an adequate quality of life. MS is a disability which has both visible and invisible symptoms, and barriers in government support programs add immense financial and practical challenges for Ontario families who struggle with the realities of living with MS.

Today's trying times resemble what it's like to live with MS – every single day. Every day, people with MS wake up to adversity and do everything in their power to persevere...

- The woman with progressive MS who struggles to button her shirt in the morning yet is determined to dance at her granddaughter's wedding.
- The high school athlete who ignores the tingling and numbness in his legs to rally his team to victory.
- The lawyer with blurred vision and foggy thoughts. The father struggling to say his child's name. The avid cyclist feeling her balance go.

Canada has one of the highest rates of MS in the world, Canadians know that MS can be harsh. Unfair. Overwhelming. A disease that always takes away, never gives back, and always threatens to take again. The COVID-19 pandemic is exacerbating the challenges for this vulnerable population due to the immune suppressant drugs typically used to manage their MS, the increased social isolation which puts them at greater risk for mental health issues, as well as longer term health impacts. Nevertheless, our community continues to do what we do best – remaining strong, resilient, and solution-focused. We are adapting to these challenges in real time and innovating solutions to deliver upon our mission.

Now, it's time for the provincial government to join our collective effort towards our mission of connecting and empowering the MS community to create positive change that helps realize our vision of a world free of MS. We are committed to ensuring Ontarians living with MS, and their families, can participate fully in all aspects of life. This pre-budget submission is focused providing solutions to address gaps that COVID-19 has highlighted but which have always existed; the inadequacy of the Ontario Disability Support Program (ODSP), the challenges with independent living for people living with disabilities, and the lack of support for caregivers.

Canada has one of the highest rates of MS in the world!

MS is a chronic, often disabling, disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance and mobility.

Over 77,000 Canadians live with MS. Approximately 1 in every 385 Canadians live with MS. Women are three times more likely to be diagnosed with MS than men.

MS is the most common neurological disease affecting young adults in Canada. 60% of adults diagnosed with MS are between the ages of 20 and 49 years old. On average, 11 Canadians are diagnosed with MS every day.

Income Supports

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. Knowing this, the government must take action to ensure that those who continue to work are supported in their efforts and take further action to reform the disability supports system in Ontario to ensure it truly provides people who live with a disability the opportunity to continue participating in their community

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.

Of course, all these challenges have been made even more problematic by the impacts of COVID-19 which have disproportionately affected those who live with a disability or chronic condition, women, and other vulnerable populations. Knowing that we were very pleased to see your government take action to ensure that recipients of the Canadian Emergency Response Benefit who were also on ODSP would not have that income clawed back. However, for far too many Ontarians who live with MS that change is only a temporary one and when it is reversed, they will continue to be 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:

- That no COVID-19 benefits or EI earnings brought on by COVID-19 be clawed back from ODSP recipients.
- 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.

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.

As has been made clear throughout the COVID-19 pandemic, the costs of living in Ontario are significantly more than the maximum amount ODSP provides. The CERB payments clearly recognized that it takes at least \$2,000/month to cover living expenses in our province and across the country, why then is the ODSP capped at a maximum of just over \$1,500 for an individual or just over \$1,700 for a couple?

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 at least match the amount paid out under the CERB.
- 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 at Home

People living with MS want to live independently in their own homes, 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 non-medical equipment, like shower grab bars and ramps, that enables independence and day-to-day services, such as housekeeping and snow clearing, that can help people to continue living with dignity in their own homes. This need has only become more apparent and important through the COVID-19 pandemic. People who live with MS are much more likely than most to be immune compromised or have other health factors that make them more susceptible to COVID-19 and therefore need to be isolated and at home more than average.

While each of us has learned over the last 7 months how much more housekeeping is required when being stuck inside permanently, 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. These self-directed care 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.

Unfortunately, Ontario's model of self-directed care eligibility is out of line with other provinces in Canada, representing the only province that does not allow a substitute decision maker access to this type of publicly funded program model on a care recipient's behalf. While many who live with MS are not impacted by this at first, they could be forced by the system to move away from the self-directed care model as their disease progresses and they require more assistance from a caregiver or other substitute decision maker. For people with progressive disabilities, allowing caregivers to play a role in the self-directed care model in Ontario would enable more of them to stay in their own homes and out of institutional care longer.

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 necessary changes to the Continuing Care Act, 2019 be made to include substitute decision makers and powers of attorney in the eligibility criteria of Ontario's Direct Funding program

The Assistive Devices Program (ADP) also 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. The MS Society of Canada, Ontario and Nunavut Division, would like to take this opportunity to thank the Ontario government for the work you have done to modernize and improve the ADP. The move towards digital applications and reducing wait times outlined in the **Rebuilding Main Street** plan is a welcome development and will be greatly appreciated by the MS community when fully implemented.

Unfortunately, the ADP still lacks a comprehensive list of essential equipment and prices of products on the list do not accurately reflect their cost in the real-world meaning that the 75% coverage of costs intended for the program is often not met. For example, when purchasing a power wheelchair through the ADP only 75% of the base model cost is covered which doesn't account for any additional costs for accessories, for support cushions, or for other modifications all of which are medically necessary. This situation leaves organizations like ours to cover the remaining costs just to allow someone living with MS to access their community in the same manner as someone who doesn't require an assistive device. While we have in the past been able to fill this gap, doing so will be much more challenging moving forward as a result of the financial impacts of COVID-19.

The MS Society recommends:

- Reviewing the ADP funding model to ensure that 75% of the actual cost of an individual device is being covered
- Updating the list prices of devices on current approved lists to ensure they more accurately reflect the real-world costs of the devices
- 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

Addressing the problems inherent in the ADP funding system 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.

Support for Caregivers

As the government is aware, there was a tremendous burden on the health care system with overcrowding, long wait times in hospital emergency rooms and low bed-availability even before the COVID-19 pandemic. We understand that your government has taken significant action to ensure that this situation does not reach crisis levels because of the pandemic. It also needs to be acknowledged that caregivers have played a significant role in that same work and have done so without compensation or the necessary levels of support. 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 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 period in turn reducing the burden on long-term care homes and other supportive residences.

Conclusion

The MS Society thanks the Ontario government for the important steps they have taken in recent months to ensure that people who live with MS receive the support they need in these uncertain times. From your decision not to clawback CERB from people who rely on ODSP to your recently announced improvements to the ADP you have made decisions that help the MS Community. Now, we ask the provincial government to continue this trend in light of COVID-19 and provide more supportive action and investments directed to people with MS and their caregivers. We feel this can be achieved by allocating funding dollars to the priority areas mentioned and most specifically by:

- Ensuring that no COVID-19 benefits or EI earnings brought on by COVID-19 will be clawed back from ODSP recipients.
- Increasing the income exemption amount 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 and allowing caregivers to participate in this care model.
- Redesigning the ADP funding model to better reflect real-world costs and expanding equipment options available through the program.
- 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. While COVID-19 has impacted the MS community in many ways, we know that with the support of the Ontario Government we will get through this together.

For more information, please contact:

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