

**Written Submission for the Pre-Budget
Consultations in Advance of the
Upcoming Federal Budget**

Charting the Course in a Changed World

**Submitted By: Neurological Health Charities
Canada**

August 7, 2020

Neurological Health Charities Canada

Recommendations:

- **Recommendation 1:** That the government fund basic, clinical and population health research to examine how COVID-19 impacts the central and peripheral nervous systems and what the implications could be for individuals already impacted by brain conditions.
- **Recommendation 2:** Given the fact that at least half of long-term care recipients live with a brain condition, that the government work with NHCC to test an expanded chronic care model for neurological conditions that integrates health and support care services to deliver better and more coordinated care.
- **Recommendation 3:** That the government provide sustained funding for charities and non-profit organizations, including health charities serving Canadians affected by brain conditions recognizing their vital role in providing crucial programs and filling gaps in health care services to individuals living with brain conditions, their families and caregivers.

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. Brain conditions – brain illnesses, disorders and injuries – are one of the leading causes of disability in Canada and, indeed, worldwide. One in three Canadians (10 million) will have a brain condition in their lifetime. Brain conditions affect people at all stages of the lifespan: children living with cerebral palsy, young adults with brain injuries or spinal cord injuries, women and men in mid-life with dystonia and older individuals with Parkinson's disease.

People with brain conditions – like all Canadians – have experienced many negative impacts because of the COVID-19 pandemic and the resulting necessary shutdown of much of Canadian society. However, people living with brain conditions, their families and caregivers are also experiencing the additional stress of having to live with chronic diseases and injuries including increased depression and anxiety.

They have experienced cancelled physician and hospital appointments, postponed or cancelled rehabilitation services, shortages of essential medications, suddenly scarce medical supplies such as face masks and catheters. They have faced the additional challenge of not having their usual programs and services provided by the brain health charity on which they have come to rely. While our member organizations quickly and largely successfully transitioned to delivering online services and telephone support programs, it is impossible to replace face-to-face programs and services. Our organizations have done this in the face of declining fundraising revenues and the dire necessity of having to lay off dedicated and experienced staff.

Therefore, our recommendations to the Standing Committee on Finance focus on:

- 1. Investing in basic, clinical and population health research to determine the negative impacts of COVID-19 on Canadians affected by brain conditions;**
- 2. Working with our organization to develop a model for neurological conditions that integrates health and support care services to deliver better and more coordinated care, and;**
- 3. Taking immediate action to assist brain health charities to continue to serve vulnerable Canadians affected by brain conditions.**

We believe these recommendations would help stabilize a vital part of the Canadian economy and assist recovery as Canada emerges from the COVID-19 pandemic.

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- **Recommendation 1:** That the government fund basic, clinical and population health research to examine how COVID-19 impacts the central and peripheral nervous systems and what the implications could be for individuals already impacted by brain conditions.

While initial research and treatment relating to COVID-19 focused on the respiratory system, there are an increasing number of reports in scientific journals that the virus is crossing the blood-brain barrier and causing neurological and/or psychiatric damage, resulting in symptoms of psychosis or symptoms similar to Parkinson's disease, dementia, multiple sclerosis and encephalitis. For example, two UK-based studies (one in *Brain*ⁱ and one in *The Lancet*ⁱⁱ) found both neurological and neuropsychiatric complications in people who had experienced COVID-19 infections.

The severity of the neurological/psychiatric involvement was not linked to the severity of the respiratory involvement. While these are small, early studies they do underline the need for researchers and clinicians treating patients to know how extensive neurological/psychiatric involvement might be, how to treat the brain involvement when it occurs and what recovery is in both the short and long term.

NHCC does not currently know of any reported cases of a person living with a brain condition infected by COVID-19, however, we believe the question of what might happen if a person with a brain condition becomes infected should be thoroughly examined now and proactively in the coming years. NHCC is pleased to see in the most recent CIHR COVID-19 competition there were several research projects approved that are studying aspects of brain health in the context of COVID-19 as well as a few more that are tackling the issue of needed improvements to long-term care. It is a good start but only just a start.

- **Recommendation 2:** Given the fact that at least half of long-term care recipients live with a brain condition, that the government work with NHCC to test an expanded chronic care model for neurological conditions that integrates health and support care services to deliver better and more coordinated care.

It is important to emphasize that the harmful impact of COVID-19 on nursing homes and long-term care homes was not just on the frail elderly but also on individuals with brain conditions who have no choice but to live in such homes, often because of a lack of supports in the community. University of Alberta researchers recently conducted an analysis of Alberta Health Services (AHS) data for people with neurologic conditions in the long-term care setting. They found that about 56% of people in long-term had one of 11 neurologic diagnosesⁱⁱⁱ. The Alberta analysis supports the earlier finding in the ground-breaking [National Population Health Study of Neurological Conditions](#) that half of those living in long-term care have a neurological condition.^{iv}

In an NHCC survey undertaken in June, organizations reported the pandemic has had a profound negative impact on individuals living with brain conditions both in the community and in nursing and long-term care homes. Individuals experienced increased anxiety, depression and social isolation. In some cases, individuals were afraid to have personal support workers enter their homes, while others living in nursing homes and long-term care homes were separated from family.

COVID-19 has had an inordinately negative impact on Canadians living with brain conditions and their caregivers as shown by two NHCC surveys (one undertaken in April and the second in early June). Prior to the pandemic, the report, [Mapping Connections](#), from the [National Population Health Study of Neurological Conditions](#) documents that Canadians with brain conditions face disjointed, fragmented care across multiple settings and care providers resulting in sub-standard care.

NHCC has repeatedly urged the government to continue its investment in brain health which began in 2009 with the funding of the study. It is even more imperative now that this work continue.

NHCC respectfully asks for a commitment from the Government of Canada to work with NHCC, in coordination with the provinces and territories, to test an **Expanded Chronic Care Model for Neurological Conditions**. A project in the National Population Health Study of Neurological Conditions provided a model emphasizing caregiver support and supported transitions,

acceptance and openness to overcome stigma associated with brain conditions, and ensuring increased knowledge of brain conditions reaches across all services and programs – not just health care.

- **Recommendation 3:** That the government provide sustained funding for charities and non-profit organizations, including health charities serving Canadians affected by brain conditions recognizing their vital role in providing crucial programs and filling gaps in health care services to individuals living with brain conditions, their families and caregivers.

NHCC's undertook two surveys of member organizations to determine the impact of the COVID-19 pandemic and resulting lockdown on individuals affected by brain conditions and on organizations themselves. Member organizations reported regarding their clients:

- **92% reported client's appointments with doctors were cancelled;**
- **92% reported client's procedures at hospitals were cancelled;**
- **91% reported clients had a lack of access to rehabilitation services;**
- **50% reported clients were not able to access emergency services;**
- **45% reported clients lacked access to social workers and psychologists; and**
- **33% reported clients lacked access to medical supplies.**

NHCC member organizations stepped in by organizing virtual services and programs whenever possible (webinars, telephone support) and providing direct funding. The length of client support calls in one organization increased from 15 minutes to one hour since the organization was the only accessible support available. Bev Heim-Myers, Interim CEO of the Huntington Society of Canada responded to the June survey saying, "COVID-19 has created angst and volatility in families that were already at risk...and a low priority in the system...the added burden is put on the shoulders of [our organization]."

NHCC organizations unhesitatingly undertook this important work despite most experiencing drastic reductions in revenue. More than 90% of survey respondents said their revenues have been impacted negatively by COVID-19 and the subsequent lockdown. Significantly reduced fundraising revenues have led to lay offs of dedicated and experienced staff, cancelled or reduced program services and decreased health research funding. A few examples: Parkinson Canada had to lay off 30 per cent of its total staff while Heart and Stroke cut 45 per cent of its workforce.^v A few organizations have been able to recall some staff, thanks in part, to the wage subsidy program. Others have found the emergency relief programs overly complicated to access^{vi} and in the case of the rent subsidy program, in the hands of landlords who were not eager to participate.

NHCC fully supports Imagine Canada's call for a **Sector Resilience Grant Program** stabilization program for all eligible organizations that would provide grants to cover core operating costs to allow organizations to respond to rising community needs and costs. This support is needed quickly to offset the collapse of revenue sources such as donations and earned income that are used to support operations outside of wages that are not addressed by the wage subsidy. We believe this support would strengthen the sector for the longer term and improve resiliency in the face of COVID-19. NHCC would not be eligible for this support since we are not a charity but a coalition. Instead, we are requesting support for our member

organizations and the hundreds of other charities and non-profits that are serving vulnerable Canadians every single day across Canada.

In conclusion

COVID-19 has had a profound impact on Canadians and the Canadian economy: It has highlighted problems of access to health care, especially for vulnerable communities; and it has highlighted issues of income inequality. Going forward, we can choose to attempt to return to “normal”, or as a society, we can take this opportunity to make the urgent changes that will improve life for all Canadians.

NHCC has made three specific recommendations, which we hope would help stabilize a vital part of the Canadian economy and assist recovery as Canada emerges from the COVID-19 pandemic. In addition, we strongly urge the government to become more collaborative and work more closely with health charities to improve healthcare and programs for vulnerable Canadians. NHCC is willing and able to bring the expertise of Canadians with the lived experience to the table, and we look forward to the opportunity to work together in the near future.

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References

ⁱ Paterson, RW et al. The emerging spectrum of COVID-19 neurology: clinical, radiological and laboratory findings, *Brain*, July 8 2020.

ⁱⁱ Varatharaj, A et al. Neurological and neuropsychiatric complications of COVID-19 in 153 patients: a UK-wide surveillance study, *The Lancet*, June 25, 2020.

ⁱⁱⁱ Ho, Chester et al. Unpublished preliminary analysis using Alberta Health Services administrative data, 2020.

^{iv} Public Health Agency of Canada. Mapping Connections: An understanding of neurological conditions in Canada. Ottawa (ON): Public Health Agency of Canada; 2014.

^v The Toronto Star. <https://www.thestar.com/news/gta/2020/04/17/not-for-profit-sector-turn-to-staff-cuts-amid-slump-in-revenue.html>

^{vi} Association of Fundraising Professionals. Coronavirus Response Survey-Canada Findings: <https://afpglobal.org/sites/default/files/attachments/resource/AFPCOVIDSurveyFindingsCanadainfographic.pdf>