

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

**Targeted and Appropriate Housing within the
Framework of a National Neurological Strategy
for Canada**

Submitted by: Neurological Health Charities Canada

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Recommendations

Immediate

- **Recommendation One:** That the federal government support the development and funding of programs and standards for housing for people with neurological conditions, recognizing that they have special housing needs not currently being met.
- **Recommendation Two:** That the federal government increase its investment in research into neurological conditions, recognizing that neurological conditions impose a heavy burden on Canadian health and social systems, and that the federal government support similar recommendations for increased brain and mental health research by NHCC partner organizations: the Canadian Association for Neuroscience and the Canadian Brain Research Strategy.

Longer-term

- **Recommendation Three:** That the federal government create a multi-stakeholder working group to develop a National Neurological Strategy for Canada encompassing housing, research, and other critical issues affecting people with neurological conditions.

Targeted and Appropriate Housing within the Framework of a National Neurological Strategy for Canada

Neurological Health Charities Canada (NHCC) has become increasingly concerned about the lack of adequate and appropriate housing for many Canadians living with neurological conditions. While there has been increased awareness of the need for housing by all levels of government and by the news media, most of the discussion has focused on affordable housing and not on the diverse housing needs for individuals of all ages living with neurological conditions.

When most people think about “housing”, they usually mean single-family houses, townhouses, condominiums, or apartments. In recent years, the focus has been on increasing “affordable” housing i.e., living units that cost below market prices, usually through various kinds of subsidization. Generally, not included in this conversation is the need for targeted and appropriate housing for people living with neurological conditions that can cause disabilities, both visible and invisible. Instead, they are all too often relegated to long-term care institutions, inadequate home care or dependency on stressed and overextended family members.

Recommendation One:

- That the federal government support the development and funding of programs and standards for housing for people with neurological conditions, recognizing that they have special housing needs not currently being met.

The Impact of Neurological Conditions

Neurological conditions — neurological illnesses, disorders, and injuries — are one of the leading causes of disability in Canada and worldwide. Globally, in 2016, neurological disorders were the leading cause of disability-adjusted-life years and the second leading cause of deaths.ⁱ In addition, neurological conditions occur frequently with one in three Canadians (more than 10 million) having a neurological condition in their lifetime. This has profound impact on individuals, families, and the Canadian economy.

- Neurological and mental health disorders cost the Canadian economy \$61 billion annuallyⁱⁱ – more than cancer and cardiovascular disease combined;
- Working-age Canadians with neurological conditions are five times more likely to be permanently unemployed than Canadians without neurological conditionsⁱⁱⁱ;
- Between now and 2031, indirect costs due to working-age premature death and disability will increase^{iv} and total health care costs for Parkinson’s disease and dementia will double^v.

NHCC has developed a Framework for a Neurological Strategy for Canada and urges the Government of Canada to demonstrate leadership on neurological health by working with the neurological community to develop and implement a National Neurological Strategy for Canada. While all levels of government have important roles in prioritizing and supporting neurological health, the Government of Canada has unique responsibility and authority as a convenor and leader to develop an approach that would have the greatest and most meaningful impact for Canadians affected by neurological conditions

All individuals with neurological conditions deserve to have their health prioritized by the Government of Canada through access to health care, financial supports, and, as has become increasingly more apparent, access to targeted and appropriate housing.

The Importance of Housing

In its June 2023 report to the House of Commons on its examination of the National Housing Strategy, the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities (HUMA) stated: “Across the country, too many Canadians are caught in a housing affordability crisis and are unable to access affordable and adequate housing.”^{vi} The committee also acknowledged that Canadians who have the greatest need for housing are still not well served and made a number of recommendations to address that concern.

NHCC is also concerned that access to housing is, in our view, not targeted at those who need it the most. Terms such as “affordable” and “adequate” in the context of housing neglects the needs of individuals living with neurological conditions who require both affordable housing and appropriate wrap-around services. In our view, housing for Canadians living with neurological conditions needs to be targeted and appropriate.

NHCC acknowledges that the Government of Canada has recognized there is a housing crisis and has made commitments to address some of the issues through the National Housing Strategy launched in 2017. In addition, Parliament in 2019 approved the National Housing Strategy Act, which recognizes housing as a human right and commits the Federal government to further the right to adequate housing. That Act also created the position of the Federal Housing Advocate to better address housing concerns. Finally, some of the financial pressures experienced by individuals with disabilities caused by neurological conditions may be eased by the newly approved Canada Disability Benefit although much remains unknown how that benefit will be rolled out and applied.

Unfortunately, these initiatives do not meet the current needs of many Canadians living with neurological conditions. In developing this submission, NHCC asked our member organizations how access to housing impacts the people that they represent. Here are some of their stories.

- **Brain Injury:** More than 1.5 million Canadians live with an acquired brain injury which results in cognitive, physical, emotional, and behavioural impacts. Underemployment, unemployment, and homelessness all too often follow a brain injury. The wait time for brain injury specific housing is 10 to 20 years, depending on location, and long-term care homes are default housing for many despite not being suitable because of specific emotional and behavioural needs. For those refused admission to long-term care homes, they remain in hospital for years.^{vii}
 - **Housing First Solution:** Housing is provided first followed by critical supports for physical and mental health, education, employment, substance abuse, and community connections.
- **Hydrocephalus:** An estimated 120,000 Canadians have hydrocephalus, a condition in which there is excess fluid in the brain because of a blockage.^{viii} If not treated, the condition can lead to permanent brain damage. Many young people and adults with hydrocephalus continue to live with their parents because there is not adequate supportive housing for them to live independently. As individuals age and their conditions change, an ongoing challenge is the cost of renovations to make the family home more accessible with ramps and chair lifts.
 - **Supportive Housing Solution:** Affordable housing coupled with appropriate supports would allow for independent living for many more young people living with hydrocephalus.
- **Cerebral palsy:** More than 80,000 Canadians are affected by cerebral palsy, which it is the most common physical disability in childhood.^{ix} It is characterized by a lack of muscle control due to an injury to the developing brain. Individuals with CP face significant waiting lists for housing, physical and behavioural supports and developmental services. Often, as individuals get older and their aging parents can no longer care for them, their patchwork of supports falls apart leading to a housing crisis.
 - **Wrap-around Housing Solution:** Housing is more than bricks and mortar for people living with disabilities. It is a place to live that is safe and comfortable, but it is also supports and services that allow for a truly independent life.

NHCC hopes that these stories illustrate that targeted and appropriate housing for Canadians with neurological conditions is more than just a building. It must include the services and supports that sustain their lives and protects their health and wellbeing.

Prioritizing Neurological and Mental Health Research

As noted above, neurological conditions — neurological illnesses, disorders, and injuries — are the leading cause of disability in Canada and worldwide. The range of neurological conditions is astounding with more than 400 neurological disorders. These include cerebrovascular diseases,

neurodegenerative diseases, neurodevelopmental disorders, and rare diseases. They can occur at any stage of life, from birth to older adults.

NHCC believes that collaboration in neurological and mental health research is key to making progress on preventing, treating, and ultimately curing these conditions. Right now, the vast majority of neurological conditions have no known cause, ways to prevent them, or effective treatments. Canadian brain researchers are recognized as being world leaders. It is time to provide them with the funding investment that can help bring prevention strategies and treatments to Canadians with neurological conditions.

Recommendation Two:

- That the federal government increase its investment in research into neurological conditions, recognizing that neurological conditions impose a heavy burden on Canadian health and social systems, and that the federal government support similar recommendations for increased brain and mental health research by NHCC partner organizations: the Canadian Association for Neuroscience and the Canadian Brain Research Strategy.

Longer-term

While addressing the above would make a positive difference in the lives of Canadians living with neurological conditions, their families, and caregivers, NHCC believes it is time for a more holistic and systematic approach that would have lasting impact on neurological health.

Recommendation Three:

- That the federal government create a multi-stakeholder working group to develop a National Neurological Strategy for Canada encompassing housing, research, and other critical issues affecting people with neurological conditions.,

What a National Neurological Strategy for Canada Would Accomplish

A National Neurological Strategy for Canada would address the patchwork approach to neurological health that has a profoundly negative impact on quality of life for millions of Canadians living with neurological conditions. It would be the impetus for looking at neurological health in a new way and in making neurological conditions a public health priority within Canada. It would sustainably fund neurological and brain health research that has the promise of effective prevention and treatment strategies. NHCC's vision for a National Neurological Strategy for Canada is available on its website www.mybrainmatters.ca

Mapping Connections Has Pointed the Way

It is time for Canada to build on its 2009 investment of \$15 million to better understand the impact of neurological conditions through the National Population Health Study of Neurological Conditions. Under NHCC's leadership this Study resulted in the most comprehensive examination of neurological illnesses, disorders, and injuries ever undertaken in Canada. The subsequent Study report, *Mapping Connections*, provided important new information but also emphasized there is still much work to be done.

NHCC is ready to help lead another collaborative approach, which would drive knowledge to action and result in the best quality of life for Canadians affected by neurological conditions.

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represents millions of Canadians living with neurological diseases, disorders, and injuries. NHCC focuses on neurological health as well as the intersection of neurological and mental health conditions throughout the lifetime of individuals.

References

ⁱ Global, regional, and national burden of neurological disorders, 1990-2016: a systematic analysis for the Global Burden of Disease Study. *Lancet*, Vol. 18, May 2019.

ⁱⁱ 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction

ⁱⁱⁱ Public Health Agency of Canada. *Mapping Connections: An understanding of neurological conditions in Canada*. Ottawa (ON): Public Health Agency of Canada; 2014. 98. Report No.: ISBN 978-1-100-24442-6, p. 24.

^{iv} *Mapping Connections*, p. 30.

^v *Mapping Connections*, p. 46.

^{vi} National Housing Strategy, Report of the Standing Committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities. Report 11, June 2023, p. 7. Accessed at [Committee Report No. 11 - HUMA \(44-1\) - House of Commons of Canada \(ourcommons.ca\)](#)

^{vii} Brain Injury Canada. Brain Injury and Housing. Accessed at [Brain Injury Canada - Supporting the brain injury community](#)

^{viii} Hydrocephalus Canada. Accessed at: [Home - Hydrocephalus Canada](#)

^{ix} Ontario Federation for Cerebral Palsy. Accessed at [The Ontario Federation for Cerebral Palsy \(ofcp.ca\)](#)