

MEMBERS:

ALS Canada

Alzheimer Society
of Ontario

Brain Injury Canada

Brain Tumour
Foundation of Canada

Canadian Epilepsy
Alliance

Canadian Neurological
Sciences Federation

Dystonia Medical
Research Foundation
of Canada

Heart and Stroke
Foundation

Huntington Society
of Canada

March of Dimes Canada

Mood Disorders Society
of Canada

Ontario Federation
for Cerebral Palsy

Ontario Neurotrauma
Foundation

Ontario Rett Syndrome
Association

Parkinson Canada

Spina Bifida &
Hydrocephalus
Association of Ontario



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Enhancing Canada's Productivity and Competitiveness through Action on Brain Health

NHCC 2018 Pre-Budget Submission for the Standing Committee on Finance

Executive Summary

Brain health is essential to the overall health of Canadians and their productivity. Brain conditions affect millions of Canadians. They affect mobility and dexterity, impair memory and the ability to think, and make it hard to see and speak. Brain conditions make it harder to succeed academically, to continue to work and to participate in everyday activities. They can leave Canadians living with brain conditions – and their families and caregivers – isolated, stigmatized and struggling to maintain financial security and emotional and mental health. Brain health matters to the millions of Canadians impacted by brain conditions, to the health care system and to the productivity of the Canadian economy.

Between 2009-2014, Neurological Health Charities Canada (NHCC) partnered with the Government of Canada to study brain health in the National Population Health Study of Neurological Conditions (the Study). As summarized in the report *Mapping Connections: An understanding of neurological conditions in Canada* there is a rich understanding of brain conditions in Canada and what needs to be done to improve the lives of Canadians living with brain conditions and their families.

NHCC recommendations to the Government of Canada:

Recommendation 1: Work with NHCC to develop a Canadian Action Plan for Brain Health, based on the key findings of the Study as summarized in *Mapping Connections*, to improve the lives, productivity and prosperity of the millions of Canadians living with brain conditions and their families through increased brain health research and meaningful care and supports.

Recommendations 2 – 4: Work with NHCC to conduct research into three key knowledge gaps identified in *Mapping Connections*. (See below for details.)

Recommendation 5: Increase Government of Canada funding of investigator-led research with an emphasis on fundamental brain health research.

Recommendation 6: In partnership with NHCC and the provinces and territories, test the feasibility of adapting the Expanded Chronic Care Model for brain conditions in carefully selected pilot projects.

Support for others' recommendations: Adopt measures to improve income security for individuals living with brain conditions and caregivers, initiate a national pharmacare program and support an inclusive national dementia strategy. (See below for details.)

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In 2009 at age 37, Ken was on his way to work when the car he was in was hit by another vehicle. He sustained a traumatic brain injury that has left him unable to walk and return to work. After many months in hospital and rehabilitation centres, he is now in a palliative care unit at a regional hospital with nowhere else to go, despite his best efforts and those of his twin sister and mother. Everyone agrees he should not be in a long-term care home with the frail and elderly, but the nearest supportive care homes that can provide the rehabilitation services he needs have waiting lists of 10 to 20 years.

In making our recommendations to the Standing Committee on Finance, Neurological Health Charities Canada (NHCC) draws on the learnings from the National Population Health Study of Neurological Conditions (the Study), a unique partnership between NHCC, the Public Health Agency of Canada, Health Canada and the Canadian Institutes of Health Research. The Study was designed to: enhance understanding of the scope of neurological conditions in Canada and their impacts on affected individuals, families and the health care system; support the development of effective programs and services; and reduce the burden of brain conditions in Canada.

Key Findings

The Study resulted in the report *Mapping Connections: An understanding of neurological conditions in Canada*, which provides a synopsis of the social and economic impact of brain conditions on individuals, families and caregivers. The Study found neurological diseases, disorders and injuries (brain conditions) are estimated to affect almost 4 million Canadians. It also identifies crucial policy, program and funding needs to improve the lives of people affected by brain conditions.

The *Mapping Connections* microsimulation project found that by 2031, the overall number of Canadians living with a brain condition will increase, and more will be living with severe disability. The number of individuals with dementia and Parkinson's disease are expected to nearly double, and the number of people with brain injury are expected to increase by almost 30 percent, as are health care costs and caregiving demands and lost productivity opportunities for family and friends.ⁱ

Canadian Action Plan for Brain Health

NHCC believes a Canadian Action Plan for Brain Health is needed to bring together stakeholders in a concerted, collaborative approach to improving brain health. The Action Plan would be the focal point for solutions that build on existing knowledge and expertise and would draw upon the findings in *Mapping Connections*.

Recommendation 1

NHCC urges the Government of Canada to work with NHCC to develop a Canadian Action Plan for Brain Health, based on the key findings of the Study as summarized in *Mapping Connections*, to improve the lives,

productivity and prosperity of the millions of Canadians living with brain conditions and their families through increased brain health research and meaningful care and supports.

The following should be part of the Canadian Action Plan for Brain Health: focussed research on the causes, prevention and treatment of brain conditions; immediate action on the research gaps identified in *Mapping Connections*; test knowledge gained from the Study to advance better care for individuals affected by brain conditions right now.

Research to Fill Gaps

NHCC has identified three major research gaps from the Study. First, *Mapping Connections* did not contain robust information on some conditions for a number of reasons.ⁱⁱ Targeted studies of ALS, dystonia, Huntington's disease, muscular dystrophy, spinal cord injury and traumatic brain injury would provide the vital information needed to develop better programs and services, greater awareness and targeted research.

Second, a clear conclusion of *Mapping Connections* was that much more research needs to be done on how brain conditions affect Indigenous communities.ⁱⁱⁱ While some work is underway on mental health conditions, this is not the case in terms of neurological conditions. In addition, the one project in the Study focussing on the Indigenous experience with neurological conditions, did not include Inuit populations.

Third, *Mapping Connections* provided evidence that when individuals experience both neurological and mental health conditions, their health outcomes are more negative. Self-reported mood or anxiety disorder occurred 2.5 times more frequently in individuals with a neurological condition than in people without neurological conditions. In addition, when psychiatric diagnoses or severe behavioural disorders are concurrent with a neurological condition, access to health care services becomes much more limited.^{iv} This issue needs to be better understood and strategies put in place to combat it.

Recommendation 2

The Government of Canada, in partnership with NHCC, should carry out studies on amyotrophic lateral sclerosis (ALS), dystonia, Huntington's disease, muscular dystrophy, spinal cord injury and traumatic brain injury.

Recommendation 3

The Government of Canada, in partnership with NHCC and Indigenous communities, should conduct detailed studies of the impact of brain conditions on First Nations, Inuit and Métis populations.

Recommendation 4

The Government of Canada, in partnership with NHCC, should examine how having both neurological and mental health conditions negatively impact accessing appropriate health services and develop strategies to assist individuals and health care professionals in obtaining optimal health outcomes.

Invest in fundamental brain health research

Far too little is known about the causes, prevention and treatment of most brain conditions. Thanks to advances in research, innovative therapies are available for some brain conditions. Unfortunately, many others remain untreatable,

and their progressive course means that Canadians living with these conditions face continued deterioration, greater disability, a reduced quality of life and less ability to participate in Canadian society.

NHCC has advocated strongly for a collaborative, coordinated approach to brain health research. One of our recommendations has been for a Brain Summit to bring together leading researchers and other stakeholders to map out a coordinated approach to brain health research. We are pleased the proposed Canadian Brain Research Strategy^v aligns with our vision of a Brain Summit and are eager to be involved.

We are also encouraged by the recommendations in the recent report *Investing in Canada's Future: Strengthening the Foundations of Canadian Research*. Among other important recommendations, it calls for more collaboration both within the federal research "ecosystem" and with provincial and territorial research initiatives.^{vi} This recommendation, is very much in line with NHCC's call for greater research collaboration and coordination.

Recommendation 5

The Government of Canada should Increase funding of investigator-led research with an emphasis on fundamental brain health research.

Harness Knowledge for Better Care

All too often, individuals living with brain conditions face disjointed, fragmented care across multiple settings and care providers. *Mapping Connections* documented a lack of knowledge or awareness of brain conditions among health service providers and limited availability and/or accessibility of necessary services, particularly for people living in rural areas. In addition, more health services are available for people with common brain conditions than for those with rare conditions, resulting in inequitable access.^{vii}

NHCC believes one of the projects in the Study would be an excellent starting point for improved health care for people living with brain conditions and their families and caregivers. A team led by Dr. Susan Jaglal propose changes to the existing chronic care model to make it more effective for people with brain conditions, including more emphasis on caregiver support and supported transitions, acceptance and openness to overcome the stigma associated with brain conditions, and ensuring increased knowledge of brain conditions across all services and program, not just health care.^{viii}

Recommendation 6

The Government of Canada should, in partnership with NHCC and the provinces and territories, test the feasibility of adapting the Expanded Chronic Care Model for brain conditions in carefully selected pilot projects.

Immediate Support for Individuals, Families and Caregivers

Life with a brain condition often means high costs but low incomes.^{ix} Many people with brain conditions must leave their jobs prematurely. Caregivers also experience job loss and reduced work hours.^{xi} This means fewer people contributing to the economy and paying taxes. Life with a brain conditions also brings added costs for medications, some of which are only partly covered by private or public drug plans, mobility equipment, adaptations to homes and specialized transportation.^{xii}

NHCC recognizes and applauds the excellent work underway by our member organizations and by other coalitions in advocating for better income security, caregiver supports, national pharmacare and a national dementia strategy. We are pleased to add our voice to these important issues (*more information available at www.mybrainmatters.ca*)

Estimated Cost of NHCC Recommendations

NHCC estimates the cost of implementing the recommendations as follows:

Recommendation 1:	\$5 million over two years
Recommendations 2 – 4:	\$40 million over five years
Recommendation 5:	Not costed since this has been addressed by Canada’s Fundamental Science Review
Recommendation 6:	\$10 million over two years
Total	\$55 million over two to five years

Who we are

Neurological Health Charities Canada (NHCC) is the voice of Canadians living with brain conditions through a coalition of nearly 20 organizations that represent people with diseases, disorders and injuries of the brain, spinal cord and peripheral nervous system.

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Endnotes

ⁱ Public Health Agency of Canada. *Mapping Connections: An understanding of neurological conditions in Canada*. Ottawa (ON): Public Health Agency of Canada; 2014. 98 p. Report No.: ISBN 978-1-100-24442-6, p. 6. Report of the National Population Health Study of Neurological Conditions, conducted in partnership with Neurological Health Charities Canada.

ⁱⁱ *Mapping Connections*, pp. 69-70.

ⁱⁱⁱ *Mapping Connections*, p. 31.

^{iv} *Mapping Connections*, p. 41.

^v Canadian Brain Research Strategy, accessed at: <https://www.canadianbrain.ca>

^{vi} Canada’s Fundamental Science Review. *Investing in Canada’s Future: Strengthening the Foundation’s of Canadian Research*. p. xxviii. Accessed at: [http://www.sciencereview.ca/eic/site/059.nsf/vwapj/ScienceReview_April2017.pdf/\\$file/ScienceReview_April2017.pdf](http://www.sciencereview.ca/eic/site/059.nsf/vwapj/ScienceReview_April2017.pdf/$file/ScienceReview_April2017.pdf)

^{vii} *Mapping Connections*, p. 40.

^{viii} Jaglal et al. *Development of a Chronic Care Model for Neurological Conditions*, p. 10. Accessed at:

<https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-409>

^{ix} *Mapping Connections*, p. 24.

^x *Mapping Connections*, p. 25.

^{xi} *Mapping Connections*, p. 26.

^{xii} *Mapping Connections*, pp. 38-39.