

MEMBERS:

Brain Injury Canada

Brain Tumour
Foundation of Canada

Canadian Epilepsy
Alliance

Canadian Neurological
Sciences Federation

Dystonia Medical
Research Foundation
of Canada

Huntington Society
of Canada

Hydrocephalus Canada

March of Dimes Canada

Mood Disorders Society
of Canada

Ontario Federation
for Cerebral Palsy

Ontario Neurotrauma
Foundation

Ontario Rett Syndrome
Association

Parkinson Canada



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ENHANCING CANADA'S PRODUCTIVITY AND COMPETITIVENESS THROUGH ACTION ON BRAIN HEALTH

Submission to the House of Commons Standing Committee on Finance For the 2019 Pre-Budget Consultations

RECOMMENDATIONS

Recommendation 1: Develop a Canadian Action Plan for Brain Health - Build on the important data in the *Mapping Connections* report (from the study funded by the Government of Canada 2009-2013) by developing, in collaboration with Neurological Health Charities Canada, a Canadian Action Plan for Brain Health that would provide the structure for ongoing collaboration, cooperation and communication amongst individuals affected by brain conditions, health charities, researchers, policy makers and health care professionals at all levels of government. Estimated cost \$5 million over two years;

Recommendation 2: Advanced Population Research to Improve Quality of Life for People Affected by Brain Conditions - Invest \$20 million over five years to:

- (A) Fund urgently needed targeted population health research for:
 - a. dystonia
 - b. Huntington disease
 - c. hydrocephalus
 - d. muscular dystrophy
 - e. spinal cord injury
 - f. traumatic brain injury

- (B) Add these conditions to the Chronic Disease Surveillance System for ongoing surveillance;

Recommendation 3: Indigenous Rights and Inclusion - Invest \$10 million over five years into research on the impact of brain conditions on First Nations, Inuit and Métis populations specifically including the direct and indirect social impacts of these conditions on individuals living with brain conditions, caregivers, families and communities;

Recommendation 4: Improving Mental Health - Invest \$10 million over five years to develop a defined strategy to assist individuals who live with both neurological and mental health conditions to overcome structural barriers in accessing appropriate health services and obtain optimal health outcomes;

Recommendation 5: Practical Pilot Projects - In partnership with the provinces and territories, test the feasibility of adapting the proposed Expanded Chronic Care Model for Neurological Conditions in carefully selected pilot projects to assess its real-world application as an integrated care model for brain conditions. Estimated cost \$10 million over two years.

Who We Are

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent millions of Canadians living with brain diseases, disorders and injuries (brain conditions). Brain health is essential to the overall health of Canadians and their productivity, and brain conditions impact every aspect of life. They affect mobility and dexterity, while impairing memory and the ability to think. These conditions can make it hard to see, speak and communicate; and tend to be painful and debilitating. See more information at: www.mybrainmatters.ca or www.moncerveaumavie.ca.

Why Brain Health Impacts Us All

Brain conditions make it harder to work, to succeed academically 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 their emotional and mental health. Brain health matters to Canadians impacted by brain conditions, to the health care system and to the economy.

A 2007 study (*The Burden of Neurological Diseases, Disorders and Injuries in Canada*) found that 11 common brain conditions have a significant economic impact in Canada, costing an estimated \$8.8 billion per year. Indirect costs made up most of the amount, accounting for an estimated \$6.5 billion of the \$8.8 billion. Indirect costs included the dollar value of production lost due to long-term disability or premature death. In comparison, direct costs (hospital care, physician care and drugs) were an estimated \$2.3 billion.ⁱ

This information in this study was reinforced and expanded by *The National Population Health Study of Neurological Conditions in Canada* (2009-2013). The microsimulation part of the Study, projecting costs to 2031, found that total direct health care costs for Canadians with seven modelled conditions will be, depending on the condition, \$0.6 billion to \$13.3 billion greater than the health care costs of Canadians without these conditions.ⁱⁱ Indirect economic costs due to working-age disability will increase if nothing is done to change the trajectory of the number of people developing brain conditions. The total indirect economic cost, which combines working-age premature death and disability, will increase for each neurological condition and will vary between \$0.3 billion to \$8.2 billion in 2031 (depending on the condition).ⁱⁱⁱ

Why Advancing Brain Health Research is Key to Economic Prosperity: *Mapping Connections*

The Government of Canada-funded *National Population Health Study of Neurological Conditions* carried out the most comprehensive examination of neurological conditions ever conducted in Canada (2009-2013). NHCC partnered with the Public Health Agency of Canada (the lead department), Health Canada and the Canadian Institutes of Health Research to bring the study to a successful conclusion with its release in September 2014 of the report *Mapping Connections: An Understanding of Neurological Conditions in Canada*.^{iv}

While *Mapping Connections* provided rich new information about brain conditions in Canada important to improving the lives of people living with brain conditions, it also highlighted significant knowledge gaps^v including:

- how brain conditions affect various communities and socio-economic groups differently;
- inconsistency of health services;
- lack of information about how brain conditions affect Indigenous populations; and
- lack of information about less prevalent conditions.

These gaps need to be addressed to reduce the negative impacts of brain conditions on individuals, families, the health care system and society. These negative impacts were well documented in *Mapping Connections*. Having a brain condition often leads to disability, and, as noted above, affects the ability to work and contributes to families' overall financial insecurity.^{vi} Many people with brain conditions must leave their jobs prematurely. Others, particularly children who were born with or developed a brain condition shortly after birth, are not able to work at all.

Income insecurity also affects caregivers. Nearly a quarter of parents whose children have a brain condition reported financial problems such as pay cuts, demotions and/or the ability to work outside the home.^{vii} For both people living with brain conditions and caregivers, this means fewer people are contributing to the economy.

For many Canadians living with brain conditions, insufficient access to mobility equipment, adaptations to homes, or specialized transportation is costly and ultimately becomes a barrier to workforce participation.^{viii}

The Brain Health Action Plan: Recommendations Explained

Recommendation 1 asks the Government of Canada to recognize that **brain health is a major health issue** for Canadians and that brain health be incorporated into government policy. By applying a brain health “lens,” steps can be taken to alleviate the negative social and economic impacts brain conditions have on traditionally vulnerable communities including:

- **Indigenous populations;**
- **socio-economically-disadvantaged communities who have limited access to resources** and;
- **women who disproportionately develop certain brain conditions and, if not affected personally, take on the role of family caregivers.**

NHCC recommends the Government of Canada work with our coalition to build on the excellent framework that *Mapping Connections* has provided. A **Canadian Action Plan for Brain Health** is needed to provide a knowledge hub for ongoing collaboration, cooperation and communication among individuals affected by brain conditions, health charities, researchers, policy makers and health care professionals at all levels of government.

Focusing on disseminating knowledge about brain research, best practices, awareness building and stigma reduction, the Action Plan would build a virtual and accessible online platform to promote dialogue between individuals affected by brain conditions, community and health service providers, scientists, researchers, clinicians, industry and thought leaders.

Recommendation 2 calls for funding of **targeted population health research into over-looked brain conditions**: *Mapping Connections* did not contain robust information on some conditions, because of technical reasons and/or because some conditions are less prevalent.^{ix}

Targeted studies on dystonia, Huntington disease, hydrocephalus, muscular dystrophy, spinal cord injury and traumatic brain injury would overcome these issues and provide the vital information needed to develop better programs and services, greater awareness and targeted research. When future studies are completed, these conditions should be added to the Canadian Chronic Disease Surveillance System for ongoing analysis.

Recommendation 3 urges that research be carried out on the **impact of brain conditions on First Nations, Inuit and Métis populations**: a clear conclusion of *Mapping Connections* was that much more research needs to be done on how brain conditions affect Indigenous communities.^x

While some work is underway on **mental health conditions, this is not the case in terms of neurological conditions for Indigenous communities**. In addition, the only project in the Study focusing on the Indigenous experience with neurological conditions, **did not include Inuit populations**.

Recommendation 4 asks the Government of Canada to **develop a strategy to assist individuals who live with both neurological and mental health conditions**: *Mapping Connections* provided solid 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 some conditions, a mood or anxiety disorder occurred six times more frequently compared to people without neurological conditions.**^{xi} In addition, when psychiatric diagnoses or severe behavioural disorders are concurrent with a neurological condition, access to health care services becomes much more limited.^{xii} This issue needs to be better understood and strategies put in place to combat it.

Recommendation 5 calls for the Government of Canada to **test the proposed Expanded Chronic Care Model for Neurological Conditions**: One of the outcomes of the study was the development of a better model to provide care for people living with brain conditions and their families and caregivers. The proposed model emphasizes 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 programs, not just health care.^{xiii}

NHCC recommends the Government of Canada, in partnership with the provinces and territories, test the feasibility of adapting the proposed Expanded Chronic Care Model for Neurological Conditions in carefully selected pilot projects to assess its real-world application as an integrated care model for brain conditions.

Thinking Forward: Brain Conditions Continue to Impact Millions of Canadians

NHCC strongly believes that implementing the recommendations set forth herein will improve the lives, productivity and prosperity of the millions of Canadians living with brain conditions and their families. Brain conditions impact every demographic and every region in Canada, and specifically affect Indigenous peoples, women and socio-economically disadvantaged communities more profoundly.

Unemployment among Canadians living with brain conditions is 12 times higher than the general population, and by 2031, the number of Canadians with brain conditions will increase, with the number of people with Alzheimer’s disease and other dementias, Parkinson’s disease and traumatic brain injury is expected to double.

Supporting Canadians with brain conditions is not solely about improving health and social policy, it is vital to the future of our economy. We look forward to working with the Government of Canada and other important partners to establish a Canadian Action Plan for Brain Health.

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Estimated Cost of NHCC Recommendations

Recommendation 1:	\$5 million over five years
Recommendation 2:	\$20 million over five years
Recommendation 3:	\$10 million over five years
Recommendation 4:	\$10 million over five years
Recommendation 5:	\$10 million over two years
Total	\$55 million over two to five years

End Notes

ⁱ Canadian Institute for Health Information, *The Burden of Neurological Diseases, Disorders and Injuries in Canada* (Ottawa: CIHI, 2007).

ⁱⁱ 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, p. 47. http://www.mybrainmatters.ca/wp-content/uploads/Mapping_Connections.pdf

ⁱⁱⁱ *Mapping Connections*, p. 30.

^{iv} *Mapping Connections*.

^v *Mapping Connections*, pp. 31-32, 48-49, 69-70, 74.

^{vi} *Mapping Connections*, p. 25.

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

^{viii} Mitra et al. *Extra costs of living with a disability: A review and agenda for research*. Accessed at <https://www.sciencedirect.com/science/article/pii/S193665741730078X>

^{ix} *Mapping Connections*, pp. 69-70.

^x *Mapping Connections*, p. 31.

^{xi} *Mapping Connections*, p. 17.

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

^{xiii} 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>