



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

CANADIAN ACTION PLAN FOR BRAIN HEALTH: DRIVING RESEARCH TO ACTION

Brain Health Is Essential to Canada and Canadians

- The World Health Organization says neurological disorders are one of the greatest threats to public health todayⁱ.
- Brain conditions are the largest cause of disability worldwideⁱⁱ.
- One in three Canadians will be affected by a brain or nervous system illness, disorder or injury within their lifetimes.



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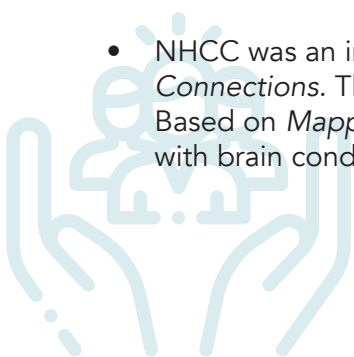
- Neurological and mental health disorders cost the Canadian economy \$61 billion annuallyⁱⁱⁱ - more than cancer and cardiovascular disease combined.
- They make it harder to work, succeed academically and participate in everyday activities, resulting in lost income, financial hardship^{iv} and lost productivity for Canada as a whole.
- Working-age Canadians with brain conditions are five times more likely to be permanently unemployed than Canadians without brain conditions^v.
- Between now and 2031, indirect costs due to working-age premature death and disability will increase^{vi} and total health care costs for Parkinson disease and dementia will double^{vii}.

The Impact Is Even More Acute Among Vulnerable Groups

- Women: Disproportionately susceptible to certain brain conditions (multiple sclerosis, dementia, stroke) and more frequently become family caregivers.
- Indigenous communities: Too little is known about how brain conditions affect Indigenous Canadians and their families or long-term social impacts. Ambiguity about which level of government is responsible complicates care provisions.
- Children and their caregivers: A quarter of parents whose children have a brain condition experience financial hardship - pay cuts, demotions or ability to work outside the home^{viii}.
- Low income Canadians: A harder impact on individuals whose incomes are already low. More than a third of adults who have a brain condition reported their families had experienced a financial crisis in the previous year^{ix}.

We've Got to Do Better

- NHCC was an integral partner in the government-sponsored study and its report, *Mapping Connections*. The Government of Canada owns the research results: It can also own the solutions. Based on *Mapping Connections* data, we are offering solutions to improve the lives of people living with brain conditions, and ultimately enhance economic productivity.



SOLUTIONS

#1: Create a “Canadian Brain Council” to pull the brain health community together, and lead unprecedented collaboration across the research community and support organizations:

- ✓ Assess progress that has been made in filling gaps identified in the seminal *Mapping Connections* report.
 - ✓ Determine the steps needed to fill those gaps including solutions for further brain condition data collection and risk factor research.
 - ✓ Assess information needs of Canadians affected by brain conditions and how brain health charities and others can better serve them.
 - ✓ Promote ongoing dialogue and collaboration between brain health researchers, industry, governments and the larger brain health community.
 - ✓ Assess awareness and education needs and foster strategies for prevention, early detection, diagnosis and treatment;
 - ✓ Examine other disability income security and support models to Canada’s needs, for example, guaranteed income models and Australia’s National Disability Insurance scheme.
- ▶ **Investment: \$3.5 million.**

#2: Support Canadians living with brain conditions, their families and caregivers. Improved financial security through:

- ✓ Increase the Caregiver Amount (tax credit) and the Family Caregiver Amount (tax credit) by 10 per cent in 2019 and another 10 per cent in 2020.
- ✓ Make both caregiver tax credits refundable to help families whose income are so low they do not benefit from the credit.
- ✓ Increase EI sickness benefits to 26 weeks with expanded flexibility for partial work and partial benefits.
- ✓ Ensure eligibility for disability tax credit and Canada Pension Plan Disability Benefits includes individuals living with brain conditions that are episodic in nature.
- ✓ Continue work to identify gaps in pharmacare coverage to ensure all Canadians living with brain conditions have access to the medications they need.

#3: Expanding the Chronic Care Model for Neurological Conditions in partnership with the provinces and territories:

- ✓ Fund a demonstration study of a proposed new model of integrated health and support care services for people living with brain conditions, families and caregivers.
 - ✓ Reduce stigma – the proposed model emphasizes caregiver support and supported transitions, acceptance and openness within health care to overcome the stigma and bias experienced by individuals who have both a neurological and mental health condition.
 - ✓ Reduce urban-rural differences in accessing health care and support services, achieving more equitable access.
 - ✓ Reduce isolation of individuals living with brain conditions and caregivers.
- ▶ **Investment: \$10 million over two years.**

THE FACES OF BRAIN CONDITIONS IN CANADA



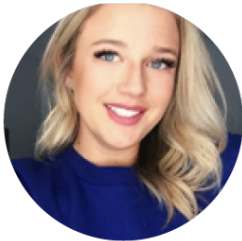
MEET SUSAN, OTTAWA

Susan has a catastrophic brain injury due to a vehicle collision. Once she was stable, she applied for the Disability Tax Credit (DTC). Despite applying three times, she has yet to successfully receive the credit.



MEET KAYLEIGH, SOUTH MOUNTAIN

Kayleigh has Rett syndrome. Seemingly healthy until she was 23-months-old, she then lost the ability to speak, to use her hands, and eventually to walk. When she turned 18, she lost access to five specialists at the children's hospital, and her family doctor lacks the specialized expertise to manage seizures, cardiac and urological issues, gastrostomy tube, osteoporosis and pain.



MEET SHAUNACY, SAUBLE BEACH

Since Shaunacy was 17 years old, she has been the primary caregiver for her mother who lives with Huntington disease. She routinely drives hours to get her mother to medical appointments. She has clocked thousands of kilometres and misses many classes to ensure her mother gets proper care.



MEET SHIRA, TORONTO

Shira was born with cerebral palsy. Attendant care support provides her daily assistance, but does not meet her needs. Shira is often overwhelmed having to search for additional funding for vital physical therapies, without which her body functions break down.



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NEUROLOGICAL HEALTH
CHARITIES CANADA

ABOUT US

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. NHCC joined the Public Health Agency of Canada, the Canadian Institutes of Health Research and Health Canada in planning and co-managing the National Population Health Study of Neurological Conditions (2009-2013). It resulted in *Mapping Connections*, the report of the most comprehensive study of neurological conditions ever undertaken in Canada.

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ⁱ Accessed at http://www.who.int/mental_health/neurology/neurodiso/en/

ⁱⁱ Global, regional, and national burden of neurological disorders during 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *The Lancet*. VOLUME 16, ISSUE 11, P877-897, NOVEMBER 01, 2017. Accessed at [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(17\)30299-5/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(17)30299-5/fulltext)

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

^{iv} 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. 24.

^v Ref – MC, p. 24

^{vi} Ref – MC – p. 30

^{vii} Ref – MC – p. 46

^{viii} Ref – MC – p. 26

^{ix} Ref – MC – p. 25.