



Canadian Action Plan for Brain Health: Driving research to action

Canadians Urgently Need Action on Brain Health Now

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 – whether from birth, early childhood, young adulthood, middle age or as seniors.

NHCC urges all political parties and candidates to support action on brain health now.

Recommendation #1: Create a Canadian Brain Council to lead unprecedented collaboration throughout the brain health community

Recommendation #2: Support Canadians living with brain conditions, families and caregivers

Recommendation #3: Test a new model of integrated health and support care services

Brain conditions can occur anytime during the life span

- ❖ **At birth** – Cerebral palsy, characterized by the loss or impairment of motor function, results from brain damage caused by injury or abnormal development while a child’s brain is still developing — before birth, during birth or immediately after birth. Cerebral palsy is the most common childhood disabilityⁱ;
- ❖ **Childhood** – Rett’s syndrome is a neurodevelopmental condition. It has a devastating impact: loss of spoken language, gross motor and fine motor skills and many other medical complications. There is currently no cureⁱⁱ. Brain tumours can occur at any age, but in children are a leading cause of deathⁱⁱⁱ
- ❖ **Adulthood** – Conditions such as Huntington disease and multiple sclerosis (MS) occur most frequently in midlife (from 30 to 55). In addition, dystonia, MS and other conditions such as depression and other mental illnesses are often episodic in nature, resulting in periods of disability that can vary in severity and duration, and persist for the rest of the lifespan^{iv};
- ❖ **Older adults** – Neurodegenerative conditions like Parkinson disease and various types of dementia most typically occur in adults over 60 with the incidence rising with increasing age^v. While stroke can happen at any time, it occurs more frequently in those over 65^{vi}. Stroke is the tenth leading cause of disability in Canada^{vii}.
- ❖ **Entire lifespan** – Traumatic brain injury (TBI) can occur across the entire lifespan from young children to older adults, and ranges from concussion to severe impairment. TBI occurs frequently in males between 15 and 25 years of age, often as the result of bicycle, motorcycle or motor vehicle collisions or sports-related injuries; and in older adults because of falls^{viii}.

The Costs of Inadequately Addressing Brain Health in Canada

Brain health is vital and critical to the lives of all Canadians. NHCC believes it to be a basic right that Canadians living with brain conditions have access to the best treatments, supports and research possible. One-in-three Canadians live with a brain condition. It is far too big an issue to leave unaddressed.

- ❖ Neurological and mental health disorders cost the Canadian economy \$61 billion annually^{ix} – 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^x 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^{xi};
- ❖ Between now and 2031, indirect costs due to working-age premature death and disability will increase^{xii} and total health care costs for Parkinson disease and dementia will double^{xiii}.

Build on existing evidence

Canada's investment of \$15 million in 2009 forged the way toward a better understanding of the impact of brain conditions through the Government of Canada-sponsored [National Population Health Study of Neurological Conditions](#), the most comprehensive examination of brain illnesses, disorders and injuries ever undertaken in Canada. The 2014 report, [Mapping Connections](#), provides rich new information important to improving the lives of people living with brain conditions. However, it also emphasized there is still much work to be done. The critical knowledge obtained through this research was the government's first step in assessing the scope of needed government support. Now it is time for phase two – to *provide* that support.

Critical areas that still need addressing, as identified in *Mapping Connections*:

1. Lack of information about how brain conditions affect various communities and socio-economic groups differently including:
 - ✓ Indigenous populations;
 - ✓ less prevalent brain conditions;
 - ✓ socio-economically-disadvantaged communities who have limited access to resources;
 - ✓ women who disproportionately develop certain brain conditions, or, if not affected personally, more often tend to take on the role of caregivers to those who 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). They impact every aspect of life: mobility and dexterity, impair memory and the ability to think. These conditions can make it hard to see, speak and communicate. See more at: www.mybrainmatters.ca or www.moncerveaumavie.ca.

2. Stigma which can result in inconsistency of health services, especially when individuals live with more than one condition, such as a neurological disease and a mental health condition.
3. Income insecurity – life with a brain condition often means high costs but low incomes, including for the families who provide day-to-day care.

We also know – thanks to the Government of Canada-funded [National Population Health Study of Neurological Conditions](#) – 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.^{xiv}

Across Canada, researchers, health care professionals, health charities and individuals affected by brain conditions are working to make a difference. It’s time to systematically build on their excellent work. NHCC believes the following three recommendations would make a significant difference in the lives of Canadians affected by brain conditions – individuals living with brain conditions, their families and caregivers.

Recommendation #1: Create a Canadian Brain Council to lead unprecedented collaboration throughout the brain health community

It is time for Canada to establish a Brain Council to lead unprecedented collaboration within the brain health community. We know excellent research is being done at universities and hospitals on potential treatments, better diagnoses and possible preventions. We know innovative health care services are helping people affected by brain conditions have healthier lives. What we don’t know is whether all of this knowledge and innovation is reaching the people it is intended to help.

We envision a Canadian Brain Council that would pull the brain health community together and coordinate efforts to move forward. We recommend it be comprised of Canadians living with brain conditions, families and caregivers, brain health charities, health-care professionals, social services experts, brain health researchers, the federal health portfolio, representatives of provincial and provincial governments and the pharmaceutical industry.

Brothers Chris and Mike have witnessed life with Parkinson disease for more than a decade, watching their father’s health decline. As young boys, Mike recalls feeling embarrassed by their father’s shuffling walk. Then they noticed he couldn’t fasten the buttons on his shirt. The Parkinson’s diagnosis came in 2006. Today, the signs of dementia affect the retired physician’s ability to communicate. Chris and Mike are not only concerned for their father’s well-being, but also worry about their mother. She is their father’s primary caregiver. She too is aging, and they know she struggles with isolation, having to stay home with their father most of the time.

It could serve as a critical knowledge hub to bring together existing resources, consider emerging trends and gap areas, and disseminate information and engage more partners in finding solutions. It would also serve as a bridge bringing together neurological and mental health sectors. The European Brain Council^{iv} provides an excellent model for how such a network could be structured, and for how it can lead to tangible results for real people.

What would this mean for Canadians?

The Canadian Brain Council would:

- ✓ Assess progress that has been made in filling gaps identified in the seminal report *Mapping Connections*;
- ✓ Determine the steps needed to fill those gaps including recommendations 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.

Susan has a catastrophic brain injury because of a vehicle collision. Once she was stable, she applied for the Disability Tax Credit (DTC). Despite applying three times, she has yet to receive the credit. Initially, she was denied the DTC because, she was told, her impairment in "performing mental functions necessary for everyday life" is not severe although CRA did not question the seriousness of her medical condition. She and her family are now working with their Member of Parliament who has guided her through a successful first stage of application. Susan is hopeful, but still worried that she might be denied the credit.

Estimated cost: \$3.5 million

Recommendation #2: Support Canadians living with brain conditions, families and caregivers

Brain conditions often lead to disability. That means leaving a job prematurely, not being able to work at all, or requiring access to mobility equipment, expensive medications, therapies, adaptations to homes or specialized transportation.

Income insecurity also affects caregivers, as documented in *Mapping Connections*. 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.

NHCC believes it is time for the next government to include Canadians affected by brain conditions in existing federal government programs, and to commit to look at disability income security models that have proven successful in other jurisdictions.

What would this mean for Canadians?

- a. Improved financial security through:
 - ✓ Increasing 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; **\$22.1 million**^{xvi}
 - ✓ Making both caregiver tax credits refundable to help families whose income are so low they do not benefit from the credit; **Information on cost not publicly available.**
 - ✓ Increasing EI sickness benefits to 26 weeks with expanded flexibility for partial work and partial benefits; **\$50 to \$100 million annually**^{xvii}
 - ✓ Ensuring eligibility for Disability Tax Credit and Canada Pension Plan Disability Benefits includes individuals living with brain conditions that are episodic in nature; **Information on cost not publicly available.**
 - ✓ Creating a National Pharmacare Program to ensure that Canadians living with brain conditions have access to the medications they need. **Up to \$20 billion**^{xviii}

At 58, Mike was a successful farmer, husband and father of four who started suddenly to behave violently and impulsively. While the diagnosis of Huntington disease brought some answers, it also caused the adult children anxiety about whether they might be at risk of developing this genetic disease. Sadly, genetic testing has found that three of the four children have the Huntington disease gene mutation and thus will develop HD. The fourth child chose not to be tested. Mike's wife Carol is now his full-time caregiver and worries she will also be the caregiver for her adult children and, perhaps, in time, her grandchildren.

Recommendation #3: Test a new model of integrated health and support care services

Individuals with brain conditions face disjointed, fragmented care across multiple settings and care providers. *Mapping Connections* documents 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.

Mapping Connections also provided substantial evidence that when individuals experience both neurological and mental health conditions, their health outcomes are more negative. When psychiatric diagnoses or severe behavioural disorders are concurrent with a neurological condition, access to health care services becomes limited^{xix}. Furthermore, individuals with neurological conditions are often denied services if they also have a mental health condition.

In some conditions, a mood or anxiety disorder occurs six times more frequently compared to people without neurological conditions.^{xx}

NHCC is looking for a commitment from political parties and candidates to work with the provinces and territories to test an Expanded Chronic Care Model for Neurological Conditions. 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.

What would this mean for Canadians?

- ✓ Reduced 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;
- ✓ Reduction in urban-rural differences in accessing health care and support services resulting in more equitable access;
- ✓ Reduced isolation of individuals living with brain conditions and caregivers.

Estimated Cost: **\$10 million over two years**

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. Caring for a child with a neurodevelopmental disorder like Rett syndrome can consume the life of the entire family. Even worse, when Kayleigh reached 18, she was discharged from five specialists at the local children's hospital and her care switched to the family doctor. He became responsible for the management of her seizures, cardiac and urological issues, gastrostomy tube, osteoporosis, pain, and so much more. Leaving the coordinated care at the children's hospital for decentralized medical care has been overwhelming for Kayleigh and her family.

Making a difference in the lives of Canadians affected by brain conditions

Canada's neurological health charities know that implementing our solutions 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 affect Indigenous peoples, women and socio-economically disadvantaged communities more profoundly. We have come together as a coalition of health charities knowing that these proposed solutions will get real results for real people. These issues cut across region, gender, age and socio-economic background. Brain conditions affect us all. Let's act now.

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Shira was born with cerebral palsy. Now 30 years old, she has a fixed government income and lives in a rent-geared-to-income apartment. Attendant care support provides her the assistance for daily needs; however, the assistance does not adequately meet those needs. As a result, Shira often feels overwhelmed and exhausted by her ongoing search for additional funding for vital physical therapies. Without those therapies, her overall body functions break down, and she ends up being hospitalized. In turn, her mental health suffers. She constantly lives in fear that she will lose her ability to live independently and will have to move to a long-term-care home. At Shira's young age this would be devastating!

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