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Canadian Brain Health: Driving Research to Action



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA



Neurological Health Charities Canada

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. NHCC provides leadership in evaluating and advancing new opportunities for collaboration specific to advocacy, education and research to improve the quality of life for people affected by brain conditions.

NHCC Mission

Working together to improve the lives of people affected by brain diseases, disorders and injuries in Canada.

National Population Health Study of Neurological Conditions

The National Population Health Study of Neurological Conditions (the Study) was jointly planned and managed between 2009 and 2014 through 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 brain 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.

Thank You

NHCC received much thoughtful and generous advice from numerous individuals and organizations during the preparation of this paper. We are very grateful for that advice and counsel, which has strengthened our analyses and recommendations as to what is needed to improve the quality of life of people affected by brain conditions.

NHCC Member Organizations

ALS Canada
Alzheimer Society Canada
Alzheimer Society Ontario
Brain Injury Canada
Brain Tumour Foundation of Canada
Canadian Epilepsy Alliance
Canadian Neurological Sciences Federation
Centre for ADHD Awareness
Dystonia Medical Research Foundation Canada
Headache Network Canada
Heart & Stroke Foundation of Canada
Huntington Society of Canada

March of Dimes Canada
Mood Disorders Society of Canada
Multiple Sclerosis Society of Canada
Muscular Dystrophy Canada
Ontario Federation for Cerebral Palsy
Ontario Neurotrauma Foundation
Ontario Rett Syndrome Association
Parkinson Society Canada
Parkinson Society Ontario
Spina Bifida & Hydrocephalus Association of Ontario
The Foundation Fighting Blindness
Tourette Syndrome Foundation of Canada

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Policy Solutions: Neurological Health Charities Canada

Executive Summary

BRAIN HEALTH MATTERS

Forty-something Cherie is like so many other women, juggling the demands of work and family life. But that's only half her story. Cherie was 38 when her mother was diagnosed with Alzheimer's disease. Her mom, who loved to throw dinner parties, suddenly struggled to set the table. Seven years later, life took a new twist when her father started behaving strangely in public. He would walk up to strangers and start yelling at them for no apparent reason. It was frontal temporal dementia. The news was devastating. Watching her beloved parents slip into the clutches of dementia has been heartbreaking and frustrating.

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.

Brain health is essential to our overall health and to the sustainability of our health care system. Brain health matters.

Brain conditions affect millions of Canadians. They can affect our mobility and damage dexterity. They can impair memory and our ability to think. They can make it hard to see, speak and communicate. They can be painful and debilitating.

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 the millions of Canadians impacted by brain conditions, to our health care system and to our economy. We need to find causes. We need to find cures.

* NHCC defines caregivers as those individuals who provide unpaid care to people living with brain conditions. Most often, caregivers are family members and friends. The term, as used by NHCC, does not include individuals who are paid.

RESEARCH TO ACTION

We partnered with the Government of Canada between 2009 and 2014 to study brain health in the National Population Health Study of Neurological Conditions (the Study). In collaboration with the Canadian brain community, we completed the most comprehensive study of brain conditions ever conducted in this country. We now have a rich understanding of the scope, breadth, impact and cost of brain conditions in Canada.

The Study provides a synopsis of the social and economic impact of brain conditions on individuals, families and caregivers. It identifies policy, program and funding gaps we need to fill. It has also given us a glimpse of the consequences Canada will face between now and 2031 if we do not take action to address these gaps.

Now is the time for action.

For more information about the Study, our coalition and brain health, and to connect with NHCC member organizations, please visit www.MyBrainMatters.ca.

URGENT ACTION - THE TIME IS NOW

Unless we act now, we will see a significant increase in the number of Canadians living with brain conditions, an increase in the negative social and economic consequences associated with these conditions and an unacceptable level of new suffering in coming years.

By 2031, the overall number of Canadians living with a brain condition will increase, and more affected individuals will be living with severe disability. For example, both the number of individuals with dementia and those with Parkinson's disease are expected to nearly double, as are health care costs and caregiving demands on family and friends related to these conditions.¹ Along with physical and emotional pain, affected individuals and families will face increasing financial burdens as a result of brain conditions, and Canadian taxpayers will have to pay substantial and increasing costs for health care and other services.

It is time for action on brain health.

Create care and supports that matter

- Support individuals, caregivers and families
- Harness knowledge for better care

Make research matter

- Invest in a Brain Summit to drive innovation

Canadian Brain Health: Driving Research to Action

Policy Solutions: Neurological Health Charities Canada

WE KNOW THE SOLUTIONS

Neurological Health Charities Canada (NHCC) has identified solutions that, we believe, will drive action on brain health. We bring together experts in brain health and the millions of Canadians who live with brain disorders, diseases and injuries, and their families and caregivers.

We urge all governments to recognize the needs of people affected by brain conditions as an immediate priority and to work with us to act on our proposed solutions. We look forward to working in partnership with governments, care providers, researchers, other health charities and community organizations.

Brothers Chris and Mike have witnessed life with Parkinson's 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.

NHCC recognizes there have been many significant and positive initiatives and investments by governments, brain health charities and private industry to advance brain research, treatment and health care delivery in Canada. We applaud the federal, provincial and territorial ministers of health for agreeing to work together to develop a national dementia strategy. We are also heartened by the decisions of several provincial governments to take specific action on other brain conditions.[†] All of these efforts complement NHCC's call for coordinated action on Canadian brain health.

1. CREATE CARE AND SUPPORTS THAT MATTER

The National Population Health Study of Neurological Conditions documented the health services necessary to help people living with brain conditions lead the healthiest lives possible in the settings of their choice. The Study also clearly identified the importance of non-health services in assisting people with brain conditions to live well, including supports for caregivers, education and return to work and addressing housing and transportation needs.

[†] A number of provinces have committed to funding strategic approaches to multiple sclerosis and/or brain injury including Nova Scotia, Manitoba, Saskatchewan, Alberta and British Columbia.

We believe all services that support people living with brain conditions need to be part of a proactively integrated approach to care delivery. We need to move beyond silos and, in that spirit, offer the following solutions:

Support individuals, caregivers and families
Harness knowledge for better care

1.1 Support Individuals, Caregivers and Families

Caregivers are essential to people living with brain conditions. These caregivers - family, friends and neighbours - need better support themselves.

Caregivers save health care dollars, they make lives more fulfilling, and they are often sources of great insight on therapies and care. But they also experience both financial and personal distress.

It is time for action on two important issues: caregiver support and financial security.

1. NHCC urges the Government of Canada to immediately increase support to caregivers by expanding existing programs and by investing in research on family caregiving as a foundation for future evidence-based decision making. Immediate improvements would include:
 - i. Increasing the value of the Caregiver Amount (tax credit) and the Family Caregiver Amount (tax credit) by 10 per cent in 2016 and another 10 per cent in 2018;
 - ii. Making both caregiver tax credits refundable to help families whose incomes are so low they do not benefit from the credit;
 - iii. Expanding the Employment Insurance Compassionate Care Benefit by increasing the benefit period to a minimum of 26 weeks; broadening eligibility criteria to allow for partial weeks over a longer period; extending eligibility to caregivers of people living with a serious chronic or episodic condition; and eliminating the mandatory two-week waiting period.[‡]

Life with a brain condition often means high costs but low incomes. Unfortunately, many people with brain conditions have to leave their jobs prematurely even though they would be able to work part-time or in a more flexible work environment.

They deserve better support.

[‡] NHCC acknowledges and thanks a number of organizations for taking leadership on the important issue of caregiver support, including the Canadian Caregiver Coalition, Health Charities Coalition of Canada and Canadian Consortium on Neurodegeneration in Aging.

2. NHCC urges the Government of Canada to partner with us, others in the brain and disability communities and employers to explore what barriers prevent Canadians with episodic symptoms caused by brain or other conditions from remaining in the work force and to identify potential policy solutions. We need a frank and informed discussion on what needs to be done to assist Canadians with episodic conditions and caregivers who wish to work to continue to be part of the labour force.

Background

The Study found that family and friend caregivers are an essential support system for people living with brain conditions, no matter the age or specific condition. They provide vital care but often do so without appropriate information or assistance. Caregiving can be both physically and emotionally demanding and, at times, caregivers develop high levels of stress - especially if they are providing care to individuals with cognitive impairment or behavioural issues. According to the Study, caregivers of individuals with brain conditions were twice as likely to report distress

compared with caregivers of individuals without brain conditions (28 per cent versus 13 per cent).²

Joe was born with cerebral palsy and is now 42-years-old. An active community volunteer, he lives with his mother in a condo. Joe uses a wheelchair and receives one hour of care a week from a community outreach agency. All his other daily care needs are met by his aging mother, Marianne, who is also providing caregiving support for her 90-year-old mother who has Alzheimer's disease. Marianne feels overwhelmed and exhausted, and Joe has increasing guilt about adding to her caregiving burden. He wants to move to his own apartment but the waitlist for supportive housing is at least 10 years.

The Canadian Mental Health Commission's report of the first phase of its project "Informing the Future: Mental Health Indicators for Canada" also noted that caregivers experienced stress, with 16.5 per cent reporting very high levels of stress because of their family caregiving responsibilities.³

Needing to provide care to someone with a brain condition can make it difficult or impossible to work. For example, individuals with dementia require an average of 74 hours of care each week from family and friend caregivers.⁴ The Study also found that nearly one quarter of parents of children with brain conditions had experienced a recent pay cut or demotion because of their family caregiving responsibilities.⁵

In addition to facing the potential of low or reduced income, caregivers report significant out-of-pocket costs related to their caregiving roles.⁶ Along with the individuals directly affected by brain conditions, families and caregivers contribute to out-of-pocket expenses for vital items such as costly prescribed medications, mobility aids, in-home care and specialized transportation.

The combination of low income and high costs can result in considerable financial stress. In fact, approximately one third of families affected by a brain condition reported experiencing a recent financial crisis.⁷

Being forced to retire at age 52 because of multiple sclerosis was not the way Doug envisioned his future – not when he had a family to support. When diagnosed, he operated equipment in a manufacturing plant. Doug was able to continue in his job for a few months, but the physical and cognitive symptoms of MS took their toll. His stamina declined, and he found it difficult to focus. After a few prolonged sick leaves, he and his employer developed an accommodation plan that took him from the plant floor to the office. That strategy worked well for several years until a series of relapses caused his disease to worsen. Finally, Doug, with the support of his family, made the hard decision to leave work on permanent disability.

We applaud the Government of Canada's initiative to obtain advice through the Employer Panel for Caregivers about how employers can support employees who are caregivers. The panel report, *When Work and Caregiving Collide*, and the resulting resource toolkit are excellent steps forward in helping employers understand the complexities of caregiving and how they can assist employee caregivers to remain productive at work while carrying out their important caregiving responsibilities.⁸

Caregiving demands are escalating as the number of people living with brain conditions increases. It is vital we take immediate action to support caregivers and families. They are not only essential to the well-being of individuals with brain conditions, but also critical to the sustainability of the health care system and our economy

Depending upon the brain condition and the severity of the disability, individuals may have limited ability to work or be forced to leave their jobs prematurely. Children with brain conditions may never enter the workforce. Someone who experiences a severe brain injury at age 30 may never return to work. Individuals with brain conditions that are episodic in nature are more likely to stay employed, but over time, they too may be unable to find or keep even part-time work as a result of their symptoms.[§]

Current programs, such as Employment Insurance (EI) sickness benefits do not take into account the situation of people with symptoms that come and go over time. For example, eligibility criteria for EI sickness benefits make a gradual return to the job or intermittent work difficult, since benefits are reduced dollar for dollar by any earnings.

[§] Episodic disabilities or conditions are characterized by periods of relative good health interrupted by periods of illness or disability that can come and go in unpredictable ways. Examples of episodic conditions are multiple sclerosis, migraine, epilepsy, arthritis, HIV, diabetes and some forms of cancer and mental illness.

Current Canadian Labour Market Agreements focus on creating new jobs and promoting hiring of people with disabilities. They do not provide the services needed to help people with episodic conditions stay on the job through early support and workplace accommodations.

Supporting capable and willing people to remain in the workforce as long as possible not only helps their personal and financial well-being, it also benefits the Canadian economy. For example, total indirect economic costs related to working-age disability for Canadians with epilepsy were \$2.5 billion in 2011 and are projected to increase to \$2.8 billion in 2031⁹

We are also concerned that genetic discrimination can impact the employment prospects of people living with brain conditions. We very much appreciate the commitment in the October 2013 Speech from the Throne to end genetic discrimination by employers and insurance companies based on genetic testing. We support immediate action on this important issue since so many brain conditions have a genetic basis.**

While many challenges face people living with brain conditions, their families and caregiver, there are solutions. An essential first step in addressing these issues is to bring together the right people to discuss what policies and programs would most effectively help people with brain conditions and their caregivers to remain in the work force as long as possible.

It is time for action.

1.2 Harness Knowledge for Better Care

Living with a brain condition is hard. Harder still is being frustrated that your care providers, the people you turn to for help and expertise, sometimes know very little about your condition or the most up-to-date and best practices that might make your life better.

Information is power, and it must be put in the right hands.

3. NHCC urges the Government of Canada to partner with us to pro-actively identify evidence-based best practices, standards and programs for people living with brain conditions and to develop effective ways to disseminate this information to care providers and the brain community. Building on existing tools and portals, NHCC is ready to serve as a knowledge hub and to facilitate collaboration within the brain community to support the identification, dissemination, spread and uptake of best practices across the country, recognizing the jurisdiction of provinces over health care delivery.

** NHCC acknowledges the leadership of the Canadian Coalition for Genetic Fairness, which is dedicated to establishing protections against genetic discrimination for all Canadians. A number of NHCC members are also part of the Coalition.

Background

All too often, individuals living with brain conditions face disjointed, fragmented care across multiple settings and care providers. The Study 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.¹⁰

The Study also identified a number of barriers to effective care for people with brain conditions. In some cases, family physicians were unwilling to accept them as patients because of their complex care needs. Some health service providers excluded people with brain conditions from their

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.

services if they had a co-existing psychiatric diagnosis, severe behavioural disorder or substance abuse/dependence. In addition, self-management, a key feature of chronic-disease management, is difficult to achieve when the individual has significant mental health or cognitive challenges.¹¹

Children with brain conditions face additional obstacles. They may have a crisis in care when they reach age 18 and have to move from pediatric to adult health care. A paediatric clinic setting, where the child received coordinated care from an integrated team of health professionals, is often replaced by an over-worked family physician who may have little knowledge about the child's specific brain condition. The teenager, hopefully supported by a parent or caregiver, must become an expert in his or her care and in navigating a complex system. Unfortunately, the transition is not always successful and can result in delayed and/or inappropriate care, and inferior health outcomes.

NHCC member organizations have been leaders in working with researchers and health care providers to create the programs and best practices that enable people to receive the right care from the right care providers at the right time. They work with health care leaders to deliver professional education so service providers have appropriate, up-to-date information about brain conditions.

But the creation of a program or best practice does not

mean it will be adopted or even known about by others. This is not surprising in a country as large as Canada with its complex web of jurisdictional responsibilities and informational silos. Disseminating information about an evidence-based approach or best practice, supporting adoption and uptake, and in particular, facilitating adaptation of a best practice from one brain condition to another is challenging without a deliberate plan and structure.

NHCC is ready to serve as a knowledge hub and to work with partners within the brain health community to ensure information is identified, adopted and adapted.

2. MAKE RESEARCH MATTER

We need to know more about the causes, prevention and treatment of brain conditions. We need to find cures.

Without improving our knowledge, more Canadians will be living with brain conditions, more will experience greater levels of disability, and costs for individuals, families and Canadian society will escalate.

We must tackle this now.

2.1 Invest in a Brain Summit to Drive Innovation

Stephanie has intractable epilepsy, which started when she was a toddler. Medications didn't stop her seizures, especially the "drop attacks", that would cause her to fall forcefully. Because Stephanie has global developmental delay, she requires constant supervision and help. Now older, her medical care was transferred from a specialist to a family doctor. Stephanie and her mother Barb coped reasonably well until suddenly she became unable to walk. As a result, both Stephanie and Barb are housebound with no idea what may happen next.

4. NHCC urges the Government of Canada to partner with us to convene a Brain Summit on an urgent basis. Brain Summit participants would be charged with pinpointing brain health research priorities; proposing approaches for accelerating and coordinating brain research in Canada; identifying barriers to research participation such as concerns about genetic privacy; developing recommendations for action and brain health research funding targets for the next decade. The Brain Summit would build on the important brain research initiatives already underway and address the knowledge gaps that were identified in the Study. It would bring together individuals committed to improving the lives of people with brain conditions including researchers, persons with the lived experience, public policy leaders, the private sector and health charities, and would be the catalyst for a new era for brain research in Canada.

Background

We are proud of our participation in the National Population Health Study of Neurological Conditions - the most comprehensive study of brain conditions ever conducted in this country. The Study gave us crucial information that we can now use to improve the quality of life for people

living with brain conditions. It also pointed out serious gaps in knowledge that additional research must fill as soon as possible.^{††}

Why the urgency? Consider this: Brain conditions are both costly to affected individuals and their

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 immediate answers about his behaviour, it also made his four adult children anxious about whether they too might be at risk of developing this genetic disease that combines symptoms similar to Alzheimer's, Parkinson's and schizophrenia all in one disease. Sadly, genetic testing has found that three of his four children have the Huntington disease gene mutation, meaning they will all develop the disease. The fourth child chose not to be tested for fear of genetic discrimination. 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.

families, and to Canada as a whole. The Study found that by 2031, depending on the condition, total direct health care costs related to certain brain conditions will be up to \$13.3 billion greater than health care costs of Canadians without these specific conditions. This number does not include indirect costs resulting from a reduced ability to participate in the work force or out-of-pocket costs incurred by individuals with brain conditions and their families.¹²

If innovations in care, prevention and treatment can be found - if cures can be found - a substantial amount of these costs could be directed to address other important personal and societal needs.

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.

We recognize that the Government of Canada, provincial and territorial governments, industry, individual foundations and health charities have already made considerable investments in brain health research. We thank the Government of Canada for its leadership in this area and for partnering with the brain community.

However, there is an urgent and accelerating need for Canada to marshal its resources, including our

^{††} As reported in *Mapping Connections*, the National Population Health Study found a number of research gaps that should be investigated further. Priority examples are: 1. brain conditions with an early life onset (i.e., pre-natal, birth, infancy or childhood); 2. specific brain conditions not included in or under-represented in the Study (e.g., vision, dystonia and ALS); 3. brain conditions occurring within populations not usually included in national surveys (First Nations, Inuit and Métis); and 4. the relationship between mental health and brain conditions across the life course of people living with brain conditions.

internationally recognized competitive advantage in the neurosciences, to develop a carefully considered and coordinated approach to understanding and improving brain health for the benefit of Canada and the world. The Canadian Consortium on Neurodegeneration in Aging as well as the National Dementia Research and Prevention Plan demonstrate the Government of Canada's ability to lead action in specific areas of brain research. NHCC applauds these initiatives as a model for a larger accelerated and coordinated approach to addressing brain conditions across the life course.

We believe the innovations and cross-cutting solutions that would flow from a more comprehensive approach to brain research would be improved quality of life for people affected by brain conditions, reduced duplication and improved value for each investment, and a positive impact on the overall sustainability of our health system.

There is great potential for a major leap forward in the understanding of and treatment of brain conditions, but we are concerned that current funding levels for brain research are not adequate.

In our view, Canada requires large-scale investment in a coordinated and broad-based approach that builds upon our brain science community's well-recognized capacity to undertake the critical research required to develop desperately needed therapies as well as other initiatives to greatly improve overall quality of life for people living with brain conditions.

We believe that the way to kick start this effort is to bring together key leaders in the brain community, including individuals with the lived experience of brain conditions, to develop a brain research plan for the coming decade.

NHCC is ready and eager to work with the Government of Canada and other partners to develop the brain health research solution and to help lead the brain research plan once it is launched.

IN CONCLUSION

It is time to put research to action for individuals like Ken, Joe, Doug, Kayleigh, Stephanie and Mike, whose lives have been turned upside down by a brain condition, and who are challenged to live well and participate to their full potential in our society. It is time to make the essential policy and program changes for caregivers like Cherie, Chris and Mike's mom, Marianne, Barb and Carol, who struggle with their own well-being as they support their loved ones. They need help now.

The National Population Health Study of Neurological Conditions has pointed the way. It is time for action on brain health.

ENDNOTES

¹ 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.

² *Mapping Connections*; p. 28.

³ *Informing the Future*, accessed online at: <http://www.mentalhealthcommission.ca/English/informing-future-mental-health-indicators-canada>

⁴ *Mapping Connections*; p. 47.

⁵ *Mapping Connections*; p. 26.

⁶ *Mapping Connections*; p. 48.

⁷ *Mapping Connections*; p. 25.

⁸ *When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers*, accessed online at: <http://www.esdc.gc.ca/eng/seniors/cecp/index.shtml>

⁹ *Mapping Connections*; p. 30.

¹⁰ *Mapping Connections*; p. 40.

¹¹ *Mapping Connections*; p. 41.

¹² *Mapping Connections*; p. 46.