



National Neurological Strategy for Canada – The time is now

As Canada emerges from the COVID-19 pandemic, it's time to tackle one of the most challenging but ultimately solvable health issues of the twenty-first century: the prevention, treatment and cure of neurological conditions.

It is time for unprecedented collaboration within the brain health community, building on existing national strategies and global initiatives. NHCC is ready to help lead this exciting collaborative approach.

Neurological conditions — neurological illnesses, disorders and injuries — are one of the leading causes of disability in Canada and, indeed, worldwide. One in three Canadians (more than 10 million) will have a neurological condition in their lifetime.

The Costs of Inadequately Addressing Neurological Health

Neurological health is critical to all Canadians on a personal level and impacts the Canadian economy.

- Neurological and mental health disorders cost the Canadian economy \$61 billion annuallyⁱ – more than cancer and cardiovascular disease combined;
- Working-age Canadians with neurological conditions are five times more likely to be permanently unemployed than Canadians without brain conditionsⁱⁱ;
- Between now and 2031, indirect costs due to working-age premature death and disability will increaseⁱⁱⁱ and total health care costs for Parkinson's disease and dementia will double^{iv}.

NHCC Vision for Neurological Health

- Neurological health is valued, promoted and prioritized with representation in health policies, plans and budgets;
- Neurological disorders are prevented and treated, avoiding deaths and disability, and improving quality of life through access to health care services, essential medicines and ongoing research;
- Social, economic and educational needs and freedom from stigma and discrimination are prioritized and protected for individuals living with neurological conditions and their caregivers.

Synergistic Approach to Neurological Health

The COVID-19 pandemic showed the importance of governments working together with citizens for a common goal. A **National Neurological Strategy for Canada** is an opportunity for collaboration beyond the scale of what we have ever experienced previously.

The Government of Canada has recognized that strategies are important to solving health problems, including the National Mental Health Strategy (launched 2012), the National Dementia Strategy (launched 2019), the National Autism Strategy (launched 2020). In addition, the Canadian Brain Research Strategy^v received funding in 2020 for development work.

Building on this important work and the findings in the seminal report *Mapping Connections: An understanding of neurological conditions in Canada*^{vi}, NHCC proposes the creation of a **National Neurological Strategy for Canada** to allow all Canadians to maximize brain health.

National Neurological Strategy for Canada

NHCC believes it is vital that a National Neurological Strategy for Canada be developed to tackle the knowledge gaps and needs of the millions of Canadians living with neurological disease, illness or injury.

<p>Strengthening Government of Canada leadership of neurological health</p>	<p>Investing in and improving accessibility to early diagnosis, comprehensive treatment and care</p>
<ul style="list-style-type: none"> • Supporting human rights-based laws, policies and programs for people living with neurological conditions; • Ensuring budgets are proportionate with the human and other resources needed; • Reinforcing multi-sectoral linkages for coordinated action involving all stakeholders, including people living with neurological conditions and caregivers. 	<ul style="list-style-type: none"> • Coordinating equitable access and delivery of health and social care services across the life course including transitioning from one stage of life to the next; • Making essential medicines accessible and affordable equitably across the country, including drugs for rare disorders; • Ensuring caregivers have supportive programs and financial assistance; • Supporting palliative care planning and programming.
<p>Investing in capacity building of neurological health care workforce</p>	<p>Reducing stigmatization and discrimination</p>
<ul style="list-style-type: none"> • Investing in training, support, retention and capacity-building of a non-specialist neurological health care workforce; • Investing in digital education and online learning programs to accelerate workforce training to enhance equitable access to care. 	<ul style="list-style-type: none"> • Improving public attitudes and protecting the rights of people with neurological conditions by raising awareness and promoting a better understanding of neurological conditions; • Empowering individuals from all cultures to identify their health needs, participate in the planning and delivery of services and play an active role in maintaining their own health and well-being; • Promoting neurological development and health across the life course.
<p>Strengthening health information systems</p>	<p>Fostering strategic approaches to research into neurological conditions</p>
<ul style="list-style-type: none"> • Building national capacity to collect, monitor and report on population and health care system data related to neurological conditions; • Supporting development of electronic medical records with appropriate access for individuals living with neurological conditions. 	<ul style="list-style-type: none"> • Increasing the attention given to neurological conditions in national and global research agendas, including access to clinical trials for treatments for rare disorders; • Encouraging the use of innovative technologies such as artificial intelligence and precision medicine to consolidate currently fragmented research approaches and identify new treatment options; • Supporting the Canadian Brain Research Strategy Network on a long-term basis.

(Adapted from a proposed global multi-sectoral approach by ONEurology.)

Neurological health is a global concern

The United Nations and the World Health Organization have recognized that brain health – both neurological and mental health – is a pressing issue that all countries must address. Currently:

- Only 24 percent of countries worldwide have stand-alone neurological health policies. Canada is not among them, despite being a high-income country.
 - According to the *WHO Atlas Country Resources for Neurological Disorders, 2017*, most of the countries without stand-alone neurological health policies are low- or middle-income countries^{vii}.
- Over the past 30 years, the number of deaths due to neurological disorders has increased by almost 40 percent worldwide^{viii}.
 - Researchers attribute this increase to population growth, ageing populations and the lack of available treatments for neurological conditions.
- In 2018, the United Nations identified neurology as a priority area resulting in WHO creating a dedicated Brain Health Unit.
- At the 2020 World Health Assembly, countries around the world unanimously approved a resolution to develop a 10-year Intersectoral Global Action Plan on epilepsy and other neurological disorders. Canada spoke in favour of the resolution.

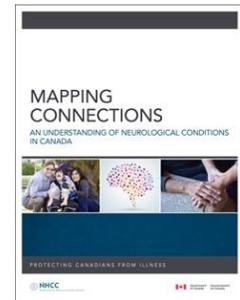
In brain research, Canadian scientists, including Canadian Association for Neuroscience^{ix} members, are represented by the Canadian Brain Research Strategy (CBRS) in joining researchers from nations around the world to form the International Brain Initiative^x. Its goal is to move neuroscience forward by increasing collaboration and knowledge sharing, leveraging talent and reducing duplication of efforts.

- A number of regions including the European Union, the United States and Japan are already funding large-scale brain research initiatives. As yet, Canada is not.
- NHCC is a key partner organization of CBRS ensuring that the voices of people with experience are represented in the creation of a Canadian research strategy.

Mapping Connections has pointed the way

Canada's investment of \$15 million in 2009 forged the way toward a better understanding of the impact of brain conditions through the National Population Health Study of Neurological Conditions, the most

comprehensive examination of neurological illnesses, disorders and injuries ever undertaken in Canada. The subsequent study report, *Mapping Connections*, provided important new information but also emphasized there is still much work to be done.



Knowledge gaps that need addressing include:

- 1 Gaps in the knowledge of the impacts** about how neurological conditions affect various communities and socio-economic groups differently:
 - a. Children affected by a neurological condition, and those living with an affected parent or sibling;
 - b. Women who disproportionately develop certain neurological conditions, or, if not affected personally, more often tend to take on the role of caregivers to those who are affected;
 - c. Individuals in Indigenous populations (First Nations, Inuit and Metis).
- 2 Gaps in knowledge of health services use and availability of services for:**
 - a. Individuals who experience mental health issues as part of their neurological condition including the important issues of stigma and access to services;
 - b. Individuals who have cognitive decline resulting from a neurological disease or injury;
 - c. Caregivers of individuals with neurological conditions along the life course.
- 3 Gaps in knowledge about the risk factors** for the development and progression of neurological conditions:
 - a. Individuals with less-prevalent neurological conditions (rare disorders) such as Huntington disease and Rett syndrome;
 - b. Extent of neurological conditions among children (cerebral palsy, epilepsy, multiple sclerosis, brain injury and stroke), and the persistence of these conditions into adulthood.
- 4 Gaps in knowledge about the risk factors** for the development and progression of neurological conditions:
 - a. Risk factors for the progression of neurological conditions;

- b. Relative and population-attributable risk of modifiable risk factors for the onset of neurological conditions.

The complete list of knowledge gaps is available at [NHCC Mapping Connections: Gaps Identified](#). The results of an NHCC-led assessment of progress made on knowledge gaps are available at [Mapping Connections Assessment Report 2018](#).

Moving forward on neurological health

It is time for unprecedented collaboration and to build on existing national strategies and global initiatives. NHCC is ready to help lead this exciting collaborative approach which would drive knowledge to action and result in the best quality of life for Canadians affected by neurological conditions. It is critical that governments work collaboratively with stakeholders by developing a **National Neurological Strategy for Canada**.

Neurological conditions can occur across the life course

There are hundreds of neurological conditions, some that affect hundreds of thousands of individuals in Canada, and some that affect just a few. All can be devastating to individuals' quality of life and their families and caregivers. Many share similar risk factors and outcomes.

- **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 disability^{xi};

- **Childhood** – Rett 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 cure^{xii}. While brain tumours can occur at any age, in children they are a leading cause of death^{xiii};
- **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^{xiv};
- **Older adults** – Neurodegenerative conditions like Parkinson's disease and various types of dementia most typically occur in adults over 60, with the incidence rising with increasing age^{xv}. While stroke can happen at any time, it occurs more frequently in those over 65^{xvi}. Stroke is the tenth leading cause of disability in Canada^{xvii}.
- **Entire lifespan** – Epilepsy and traumatic brain injury (TBI) can occur across the entire lifespan from young children to older adults, all genders and all ethnicities. Epilepsy is the most common, chronic brain disease with seizures being an important symptom. It can be a consequence of other brain conditions. Traumatic brain injury 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^{xviii}.

References

- ⁱ 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction
- 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. 24.
- ⁱⁱⁱ Mapping Connections, p. 30.
- ^{iv} Mapping Connections, p. 46.
- ^v The Canadian Brain Research Strategy is a pan-Canadian grassroots endeavour of research leaders which aims to link brain research initiatives and projects, public and private funders, and patient organizations in a uniquely collaborative effort that will push the frontiers of brain science. It coordinates Canada's participation in the International Brain Initiative. Accessed at <https://canadianbrain.ca/>
- ^{vi} From 2009-2013, NHCC, with the Government of Canada, helped lead the most comprehensive study of neurological conditions ever undertaken in Canada. The study resulted in *Mapping Connections: An understanding of neurological conditions in Canada*, which provided a vital base of information for all to use to help improve the lives of Canadians living with brain conditions, their families and caregivers.
- ^{vii} Atlas: country resources for neurological disorders – 2nd ed. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.
- ^{viii} Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016 *Lancet Neurol* 2019; 18: 459–80 Published Online March 14, 2019 doi: 10.1016/S1474-4422(18)30499-X.
- ^{ix} The Canadian Association for Neuroscience (CAN) is the largest association of neuroscientists in Canada. CAN is composed of over one thousand researchers, who work at academic institutions across the country. They share the common goal of ensuring neuroscience remains one of the greatest research and innovation strengths of Canada. See more at <https://can-acn.org>
- ^x The International Brain Initiative (IBI) has been established to coordinate efforts across existing and emerging national and regional brain initiatives. Accessed at <https://www.internationalbraininitiative.org/>
- ^{xi} Accessed at <https://www.ofcp.ca/about-cerebral-palsy>
- ^{xii} Accessed at <https://www.rett.ca/rett-syndromertt/what-is-rett-syndrome/>
- ^{xiii} Accessed at <https://www.braintumour.ca/2494/brain-tumour-facts>
- ^{xiv} Accessed at <http://episodicdisabilities.ca/home.php>
- ^{xv} Licher S, Darweesh SKL, Wolters FJ, et al Lifetime risk of common neurological diseases in the elderly population *J Neurol Neurosurg Psychiatry* Published Online First: 02 October 2018. doi: 10.1136/jnnp-2018-318650: <https://jnnp.bmj.com/content/early/2018/08/26/jnnp-2018-318650>
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- ^{xvii} Lang JJ et al. Global Burden of Disease Study trends for Canada from 1990 to 2016. *CMAJ* November 05, 2018 190 (44) E1296-E1304, Accessed at <http://www.cmaj.ca/content/190/44/E1296>
- ^{xviii} Chan V, Zagorski B, Parsons D and Colantonio A. Older adults with acquired brain injury: a population-based study. *BMC Geriatr.* 2013; 13: 97. Published online 2013 Sep 23. doi: 10.1186/1471-2318-13-97.