Framework for a National Neurological Strategy for Canada

As Canada emerges from the COVID-19 pandemic, it is 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 and resolve.

Neurological Health Charities Canada (NHCC) is seeking to collaborate with the federal government in building a National Neurological Strategy for Canada.

The Impact of Neurological Conditions

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

- Neurological and mental health disorders cost the Canadian economy $61 billion annually — 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 conditions;
- Between now and 2031, indirect costs due to working-age premature death and disability will increase and total health care costs for Parkinson’s disease and dementia will double.

NHCC believes that it is time for the Government of Canada to demonstrate leadership on neurological health by working with the neurological community to develop and implement a National Neurological Strategy for Canada. NHCC recognizes that the federal government has already undertaken several national strategies on brain conditions including a National Mental Health Strategy, a National Dementia Strategy, a National Autism Strategy, and a National Concussion Strategy.

While these strategies provide important, concrete steps in support of some aspects of brain health, they do not address all neurological conditions, resulting in individuals with some neurological conditions getting the support they need while others are ignored. All individuals with neurological conditions deserve to have their health prioritized by the Government of Canada through appropriate accessible health care and financial supports.

Building a successful National Neurological Strategy for Canada

While all levels of government have important roles in prioritizing and supporting neurological health, the Government of Canada has a unique responsibility and authority as a convener and leader. NHCC is proposing a multi-faceted approach to addressing neurological health to make the greatest and most meaningful impact for Canadians affected by neurological conditions.

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represents millions of Canadians living with neurological diseases, disorders and injuries. NHCC focuses on neurological health as well as the intersection of neurological and mental health conditions throughout the lifetime of individuals.
Urgent Action Items

NHCC recognizes that the Government has made commitments to address long-overlooked and pressing issues: the development of national Pharmacare, standards for long-term care, support for the health care workforce and mental health research funding. NHCC asks that the Government of Canada work with the neurological community to ensure that the unique needs of Canadians affected by neurological conditions are proactively addressed.

1. Accelerate the development of the Canada Pharmacare Act to ensure individuals living with neurological conditions have access to affordable medications, including conditions that are rare, no matter where they live in Canada;

2. Address the needs of Canadians affected by neurological conditions including those with episodic disabilities in the development of disability benefit support programs;

3. Recognize that institutional long-term care is not appropriate for most Canadians living with neurological conditions and, instead, work with the neurological community to develop evidence-based program models and national standards for community-based home care including appropriate housing and integrated supports;

4. Fund capacity building of the health-care workforce to ensure that individuals living with neurological conditions have access to the appropriate continuum of health care no matter where they live;

5. Fund research that investigates the intersection of mental health aspects of neurological conditions.

Long-term

While addressing the above would make a positive difference in the lives of Canadians living with neurological conditions, their families and caregivers, NHCC believes it is time for a more holistic and systematic approach that would have lasting impact on neurological health.

It is time for the Government of Canada to work with NHCC and other stakeholders to create a National Neurological Strategy for Canada.

What a National Neurological Strategy for Canada Would Accomplish

NHCC believes that a National Neurological Strategy for Canada would finally address the patchwork approach to neurological health that has a profoundly negative impact on quality of life for millions of Canadians living with neurological conditions. It would be the impetus for looking at neurological health in a new way and in making neurological conditions a public health priority within Canada. The implementation of a Neurological Health Strategy for Canada would result in a society where:

- 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 seamless access to health care services from childhood to adulthood, 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.
Moving Forward

NHCC realizes that the Government of Canada is not solely responsible for realizing this vision of neurological health. Instead, NHCC proposes that the Government of Canada work with us to convene provincial and territorial governments and the neurological community to co-create a National Neurological Strategy for Canada. The COVID-19 pandemic showed the critical importance of governments working together with citizens toward a common goal. A National Neurological Strategy for Canada is an opportunity for collaboration beyond the scale of what we have ever experienced previously.

Recommendation: NHCC recommends that the Government of Canada demonstrate national leadership on neurological health by creating a working group to develop a National Neurological Strategy for Canada.

Mapping Connections has Pointed the Way

It is time for Canada to build on its 2009 investment of $15 million to better understand 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.

**Mapping Connections identified knowledge gaps that need addressing:**

1. Gaps in the knowledge of how neurological conditions impact various communities and socio-economic groups differently including:
   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, who more often take on the role of caregivers to those with neurological conditions;
   c. Individuals in Indigenous populations (First Nations, Inuit and Metis).

2. Gaps in knowledge of the use and availability of health services use for:
   a. Individuals who experience mental health issues as part of their neurological condition, such as dystonia, resulting in stigma and lack of 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 including:
   a. Individuals with less-prevalent neurological conditions (rare disorders) such as Huntington disease and Rett syndrome;
   b. The extent of neurological conditions among children (brain injury, brain tumours, cerebral palsy, epilepsy, hydrocephalus, and spina bifida), and the persistence of these conditions into adulthood.

4. Gaps in knowledge about the risk factors for the development and progression of neurological conditions including:
   a. Risk factors for the progression of neurological conditions;
   b. Potentially 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](#).
Neurological Health is a Global Concern

There are more than 400 neurological disorders. These include cerebrovascular diseases, neurodegenerative diseases, neurodevelopmental disorders and rare diseases. By prioritizing tackling them under one Strategy, there is a better chance of understanding all and helping all.\textsuperscript{v}

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 \textit{WHO Atlas Country Resources for Neurological Disorders, 2017}, most of the countries without stand-alone neurological health policies are low or middle-income countries\textsuperscript{vi}.

- Over the past 30 years, the number of deaths due to neurological disorders has increased by almost 40 percent worldwide\textsuperscript{vii}.
  - 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.

- In May 2022, the seventy-fifth World Health Assembly unanimously adopted the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. The Plan will address the worldwide challenges and gaps in providing care and services for people with epilepsy and other neurological disorders and ensure a comprehensive, coordinated response.
  - Canada supported the Plan, and is well positioned to move forward on key Plan actions: developing a national strategy for neurological disorders by 2031; activating a public awareness campaign for neurological disorders by 2031; and providing essential medications and basic technology required to manage neurological disorders by 2031.

NHCC Partnering with the Canadian Brain Research Strategy

NHCC recognizes the vital importance of collaboration in neurological research and is actively involved as a partner organization in the development of the Canadian Brain Research Strategy\textsuperscript{viii} (CBRS) \textsuperscript{viii} NHCC brings expertise in ensuring that the voices of people with lived experience are represented in the creation of this approach to brain research, which has as its goal increased collaboration and knowledge sharing on an international level.

A number of regions including the European Union, the United States and Japan are already funding large-scale brain research initiatives. As of yet, Canada has not. Canadian scientists, including Canadian Association for Neuroscience\textsuperscript{ix} members, are represented by the Canadian Brain Research Strategy in joining researchers from nations around the world to form the International Brain Initiative and in working to involve Canada more directly.

Moving Forward on Neurological Health

It is time to build on existing national strategies and global initiatives. NHCC is ready to help lead this unprecedented 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.
### 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.

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<tr>
<th>Strengthening Government of Canada leadership of neurological health</th>
<th>Investing in and improving accessibility to early diagnosis, comprehensive treatment and care</th>
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<tr>
<td>• Supporting human rights-based laws, policies and programs for people living with neurological conditions;</td>
<td>• Working with provinces and territories to lead the coordination of equitable access and delivery of health and social care services across the life course including: transitioning from one stage of life to the next, palliative care and mental health;</td>
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<td>• Ensuring budgets are proportionate with the human and other resources needed to maximize neurological health;</td>
<td>• Making essential medicines accessible and affordable equitably across the country, including drugs for rare disorders;</td>
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<td>• Adopting global neurological health initiatives including the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders.</td>
<td>• Expanding caregiver supportive programs and financial assistance.</td>
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<th>Reducing stigmatization and discrimination</th>
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<td>• Investing in training, support, retention and capacity-building of the neurological health care workforce;</td>
<td>• Improving public attitudes and protecting the rights of people with neurological conditions by raising awareness and promoting a better understanding of neurological conditions;</td>
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<td>• Investing in digital education and online learning programs to accelerate workforce training to enhance equitable access to care.</td>
<td>• 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;</td>
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<td>• Promoting neurological development and health across the life course including mental health aspects.</td>
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<th>Strengthening health information systems</th>
<th>Fostering strategic approaches to research into neurological conditions</th>
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<td>• Building national capacity to collect, monitor and report on population and health care system data related to neurological conditions;</td>
<td>• Increasing the attention given to neurological conditions in national and global research agendas, including access to clinical trials for treatments for rare disorders;</td>
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<td>• Supporting development of electronic medical records with appropriate access for individuals living with neurological conditions.</td>
<td>• Encouraging the use of innovative technologies such as artificial intelligence and precision medicine to consolidate currently fragmented research approaches and identify new treatment options;</td>
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<td>• Supporting the development of the Canadian Brain Research Strategy Network on a long-term basis.</td>
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(Adapted from a proposed global multi-sectoral approach by ONEneurology.)
Appendix One

Neurological Conditions 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;  

- **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. While brain tumours can occur at any age, in children they are a leading cause of death;  

- **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;  

- **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. While stroke can happen at any time, it occurs more frequently in those over 65. Stroke is the tenth leading cause of disability in Canada.  

- **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.
Appendix Two

Examples of Individuals Affected by Brain Conditions Who Need Help Now

- Joe was born with cerebral palsy and is now 42-years-old. 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. He wants to move to his own apartment but the waitlist for supportive housing is at least 10 years.

- 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.

- 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.

- 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.
References

1 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction
4 Mapping Connections, p. 46.
5 The OneNeurology initiative aims to unite and strengthen neurology-related groups to stimulate collaborative advocacy, action and accountability for the prevention, treatment and management of neurological disorders worldwide. https://OneNeurology.net
8 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/
9 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 Accessed at https://www.ofcp.ca/about-cerebral-palsy
xii Accessed at https://www.brain tumour.ca/2494/brain-tumour-facts

Contact: Deanna Groetzinger, Manager, Neurological Health Charities Canada deanna.groetzinger@mybrainmatters.ca | www.mybrainmatters.ca