Written Submission for the Pre-Budget Consultations in Advance of the Upcoming Federal Budget

Framework for a National Neurological Strategy for Canada

By: Neurological Health Charities Canada

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List of Recommendations

Recommendations

Immediate

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

6. Create a working group to develop a National Neurological Strategy for Canada.
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. To do this, 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\(^1\) – 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\(^2\);
- Between now and 2031, indirect costs due to working-age premature death and disability will increase\(^3\) and total health care costs for Parkinson’s disease and dementia will double\(^4\).

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 unique responsibility and authority as a convenor 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.
Urgent Action Items and Recommendations

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;
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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.

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.

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.

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.

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 tackling them under one Strategy, there is a better chance of understanding and helping all.

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.
  o 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.
• Over the past 30 years, the number of deaths due to neurological disorders has increased by almost 40 percent worldwide.
  o 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 including developing a national strategy for neurological disorders by 2031.

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.

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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.

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## 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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<tbody>
<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>Investing in capacity building of neurological health care workforce</th>
<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 ONeurology.)
References

\(^{i}\) 2016 Report of INMHA Evaluation Panel from the CIHR Institute of Neurosciences, Mental Health and Addiction


\(^{iii}\) Mapping Connections, p. 30.

\(^{iv}\) Mapping Connections, p. 46.
