

A Brain Strategy for Canada

Neurological Health Charities Canada (NHCC)

NHCC Members:

ALS Society of Canada
Alzheimer Society Canada
Brain Injury Association of Canada
Canadian Alliance of Brain Tumor Organizations
Canadian Epilepsy Alliance
Canadian Neurological Sciences Federation
Dystonia Medical Research Foundation Canada
Huntington Society of Canada
March of Dimes Canada
Multiple Sclerosis Society of Canada
Muscular Dystrophy Canada
NeuroScience Canada
Ontario Federation for Cerebral Palsy
Ontario Rett Syndrome Association
Ontario Neurotrauma Foundation
Parkinson Society Canada
Spina Bifida & Hydrocephalus Association of Ontario
Tourette Syndrome Foundation of Canada

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Executive Summary

The brain is the most vital and least-understood organ in the human body. Its tasks range from the mundane chores of keeping a living being alive and responsive to its environment – it makes sure the heart pumps, the lungs breathe, and the eyes see – to the most transcendent aspects of human capability – science, art, poetry, love, compassion. This diversity of roles confounds understanding. Quite simply, if one's brain does not work properly, every aspect of life is compromised as a result.

Neurological diseases, disorders and injuries (conditions) will become the leading cause of death and disability in Canada within the coming 20 years. Already, the impact to individuals, families and society is staggering and, while the Government of Canada has taken initial steps to fund important research in this field, a comprehensive and coordinated approach is necessary to build on current investments and to plan appropriately to meet the needs of an increasingly significant percentage of the Canadian population.

Neurological Health Charities Canada (NHCC) calls on elected representatives from all parties to work collaboratively, with each other and with the NHCC, to develop a **Brain Strategy for all Canadians** – Canadians with neurological conditions, Canadians who are involved in their care as health professionals and support program providers, researchers or as informal caregivers, and Canadians who want to learn how to keep their brain and nervous system healthy.

Members of the NHCC unanimously support seven themes within a comprehensive and coordinated national approach to address the most significant issues facing people with dementia, Parkinson's disease, multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), epilepsy, brain and spinal cord injury and other neurological conditions.

The key themes identified for a Brain Strategy for Canada include, but are not limited to:

- Research - the pressing need for accelerated and targeted investment in neuroscience research;
- Prevention – the need to learn more about primary prevention and to increase the focus of chronic disease management on secondary and tertiary prevention;
- Caregiver Support - the need to support the valuable role played by family caregivers;
- Income Security - the need to ensure that people disabled by a neurological condition are protected from poverty;
- Integrated Care & Support - the need to better coordinate care;
- Genetic Privacy - the need to protect people with neurological conditions and their families from genetic discrimination; and
- Public Awareness & Education – the need to build a better understanding of the brain and neurological conditions in the Canadian public and among front-line health professionals.

Neurological Health Charities Canada (NHCC) recommends that the Government of Canada grant \$2 million to the NHCC to fund the development of a Brain Strategy for Canada over the coming fiscal year (2010-2011).

The proposed one-year timeframe is important. Several research projects currently being funded by the Government of Canada, including the National Population Study of Neurological Conditions, will deliver results over the coming three years. Moreover, work initiated by NHCC members under each theme is already underway and needs to be aligned to a coordinated national plan. We have an ideal window of

opportunity to develop that plan now so that we are ready to act quickly to maximize current investments and initiatives as findings and opportunities emerge. To delay would be to waste precious time – time that Canadians living with neurological conditions simply do not have, time that will see more and more Canadians diagnosed, and time that the governments and policy makers will wish they had back if we fail to act now.

We applaud the Government of Canada for essential investments being made currently, including:

- funding for cross-cutting research across the neurological field (i.e. National Population Study of Neurological Conditions and the Canadian Longitudinal Study on Aging);
- several major dementia research projects (i.e. the Canadian Dementia Knowledge Translation Network and the International Collaborative Research Strategy on Alzheimer's);
- recently announced funding for an important MS study, The Epidemiology and Impact of Comorbidity on MS in Canada (ECoMS);
- and other condition-specific and broader chronic disease focused investments.

At the same time, individual neurological health charities have undertaken work that, incorporated into a pan-Canadian strategy, could extend significant benefits to the millions of Canadians who are living with a neurological condition. The NHCC is advocating for a comprehensive, strategic approach that connects this collective pool of work, builds on existing programs and infrastructure, and identifies areas for strategic investment with the following aims:

- Accelerated and targeted investment in neuroscience research;
 - transformative multi-investigator grants in brain research
 - a national program to develop technology platforms in Neuroimaging, Neurogenomics, Neuroproteomics, and Disease Models
 - a pan-Canadian training program to nurture the next generation of researchers
- Assistance to family caregivers in the valuable role they play;
 - programs to strengthen coping strategies, build caregiver competence, skills, and communications strategies for caregivers
- Protecting people disabled by neurological conditions from poverty;
 - income security measures including tax credits and changes to employment insurance
- Better integration and coordination of care, based on the principles of chronic disease management;
- Protection of people with neurological conditions and their families from genetic discrimination; and,
- Building a better understanding of the brain and neurological conditions in the Canadian public and among front-line health professionals.

The NHCC recommends that the Government of Canada commit \$2 million to fund the development of a Brain Strategy for Canada over the coming fiscal year. This process would include the development of strategic plans under each theme through broad consultation with the many stakeholders in the neurological community and across the health portfolio. These plans will be informed by existing evidence as well as evidence that emerges from research currently underway across the field.

With an established national network of stakeholders, a demonstrated track record of effectively engaging the Canadian neurological community, and excellent working relationships across the federal health portfolio, the NHCC is best positioned to undertake this work in collaboration with the Government of Canada.

A Brain Strategy for Canada – Themes:

Research

Collectively, diseases, disorders and injuries of the brain are the major health challenge of the 21st century. They most often create a lifelong burden of care, impacting the individual, their family and society. There is an urgent need for Canada to marshal its resources, including our internationally recognized competitive advantage in the neurosciences, and develop a strategic, coordinated approach to understanding and improving brain health for the benefit of Canadians and the world.

The Brain Strategy for Canada will build on major investments already being made in organizations that include Genome Canada, Canadian Foundation for Innovation, Canadian Institutes for Health Research (CHIR), and National Science and Engineering Research Council, along with the research programs operated by individual members of the NHCC. Brain research sits at the confluence of revolutions in imaging technology, genomics, proteomics, and understanding of signaling pathways. We are poised for a major leap forward in understanding and treating brain diseases and yet current funding levels for brain research are entirely inadequate to support this happening in Canada.

Canadian research is attracting worldwide attention, and we have a critical role to play in addressing the enormous burden of neurological conditions. We are a leader in neuroscience research - many important discoveries pertaining to the brain have been made by Canadians. Unfortunately, current funding does not match the capacity and additional operating dollars are required to maintain what has been created and to accelerate the pace of discovery. **Canada requires large-scale investment in a coordinated and broadly based effort that builds upon our superb brain science community, to undertake the critical research needed on the brain and to discover cures for brain disorders, diseases, and injuries.**

This research will enable Canadians to better understand how neurodegenerative disease and other neurological conditions can be prevented and treated, and translate knowledge into new and effective treatment, services and programs.

The Brain Strategy for Canada will build a network of public and private research funding bodies that will fund three areas critical to delivering on Canada's neuroscience potential. The Canadian Association for Neuroscience (CAN) has developed a framework for a coordinated national program for neuroscience, in consultation with its membership. CAN represents the largest group of Canadian scientists interested in the brain, spinal cord and nervous system.

The three research programs that make up this national approach are:

1. Transformative multi-investigator grants in brain research. The purpose is to accelerate "transformative" research from discovery to the development of new treatments and therapies for neurological and psychiatric diseases, by funding teams of investigators from various disciplines and institutions that have the best chance of producing rapid progress in understanding and treating brain diseases;
2. A coordinated national program to develop technology platforms in Neuroimaging, Neurogenomics, Neuroproteomics, and Disease Models. The Brain Strategy for Canada will enable a large-scale coordinated effort to develop and make available the technologies to enable transformative research and development of new therapies. The development of national platforms is critical for these research initiatives; and,

3. A pan-Canadian training program to nurture the next generation of researchers. To nurture and support a new generation of neuroscientists, a cadre of post-Ph.D. or M.D. fellows and research associates will require stable funding for a period of 4 years. Funding postdoctoral trainees is vital to recruiting and retaining the best young scientists in Canada.

These three research programs were identified as priorities based on their potential to deliver new treatments and therapies, along with opportunities for job creation and overall economic benefit to Canada.

Caregiver Support

Issues related to caregiving are common across the chronic disease spectrum however due to the lifelong, often progressive and degenerative nature of many neurological conditions, there are aspects of caregiving that are unique to this community – in particular increasing levels of dependency over time, usually upon one or several family caregivers.

The task of caregiving changes throughout the life course of most neurological conditions. Initially, when the person with the condition is still living at home, the focus for the informal caregiver may be on helping with transportation, household finance, personal care, or cooking. While the individual is receiving care from home care providers, the scope of the caregiving role broadens to include management and supervision to ensure services are delivered safely and as scheduled. Once the individual is in a nursing home, the needs change again. While support for activities of daily living is provided by the care facility, the caregiver continues to be engaged as a member of the care team to provide supportive care, including social engagement and affection.

For young people with neurological conditions, the caregiving role is further challenged by the transition to adulthood. As they naturally seek more and more independence, parents and caregivers struggle to provide the care and support required, whether at home, in a group setting or in a long-term care facility.

In a study recently released, the Alzheimer Society of Canada undertook to understand the current and projected (2008 – 2038) prevalence and impact of Alzheimer’s disease and related dementias. This study used peer-reviewed literature to understand the role of caregiving and found that the number of hours of informal care is expected to more than triple, increasing from approximately 231 million hours in 2008, to 756 million hours by the year 2038. The economic consequence of family members interrupting their careers to look after someone with dementia is enormous – a major issue of concern across the neurological conditions. Opportunity costs of Informal Caregivers will increase dramatically over the same period (defined as the wages that could have been earned by informal caregivers, were they able to participate in the labour force).

Total Unpaid Caregivers Opportunity Cost (Alzheimer’s disease & related dementia)*	
2008	\$4,995,340,836
2018	\$12,303,233,856
2028	\$26,921,613,083
2038	\$55,708,854,294

*Rising Tide: The Impact of Dementia on Canadian Society, 2010

The cumulative Opportunity Cost of informal caregiving for people with dementia, accounting for \$302 billion by 2038, represents a substantial societal burden. This burden is not unique to the families of people with dementia. People with Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis, cerebral palsy, brain tumours and other neurological conditions also receive tremendous support from family members and other informal caregivers, with a corresponding economic impact.

The Alzheimer Society study also modeled a number of scenarios designed to mitigate the identified economic consequences. One such scenario examined the impact of an informal caregiver skill-building and support program, based on research literature. Such a program could reduce the amount of caregiving time and hence the health and economic burden placed on informal caregivers. As well, it could delay admission for the person with dementia into LTC. In this scenario the intervention is applied to all informal caregivers and individuals with dementia receiving care within the model.

The reduction in caregiving time from such a program is based on a study by Graff *et al.* (2008). The study showed that informal caregiver hours could be reduced by an average of 212.3 hours over a 3 month timeframe by providing a program of occupational therapy to patients and their informal caregivers targeting improvement in:

- Informal caregiver competence, skills and communications strategies for supervision of activities of daily living, and
- Coping strategies for patient behaviours and the overall burden of care.

An informal caregiver support program has also been shown to impact patient admissions into LTC by delaying the time to admission. These effects are modeled based on a study by Mittleman *et al.* (2006). This study showed that nursing home placement could be delayed for dementia patients by a median of 557 days by providing a counselling and support intervention program for spousal caregivers in delaying the time to nursing home placement for individuals with AD.. In the short-term (10 years), a support program to provide caregiver development and support is expected to result in over 8,810 fewer Canadians over the age of 65 living with dementia in LTC (a 4.8% reduction from the base model); and a reduction in the total economic burden by over \$12.7 billion dollars (in 2008 cumulative Canadian present value terms), net of the cost of providing the intervention.. Presumably, similar effects can be achieved by supporting caregivers of individuals with other neurological conditions.

The Brain Strategy for Canada will consider how effective caregiver supports can be made available to caregivers across Canada who are dealing with family members with any of a number of neurological conditions. The Strategy will also consider the broader applicability of scenario analysis and intervention modeling.

Income Security

Within the next 20 years, neurological conditions will become the leading cause of death and disability in Canada. Diseases, disorders and injuries of the brain and spinal cord affect Canadians of all ages and backgrounds and can strike anyone at anytime. Whenever they strike, they have a profound impact on the economic well being of the person who develops the disease or experiences the injury, and on their family members and caregivers.

Whether the condition is diagnosed in childhood, such as cerebral palsy, tourette syndrome or epilepsy; in early adulthood, such as multiple sclerosis, with most people with MS diagnosed between the ages of 15 and 40; or Parkinson's disease or Alzheimer's disease, with most people diagnosed after the age of 50; as they progress they take a toll on a person's productivity. This includes no longer being able to work – perhaps because of the disease but all-too-often because of a lack of accommodation in the workplace – or in the case of a family member having to work part-time or stop work for long periods to care for a loved one.

People affected by neurological conditions need a new plan. In the context of the Brain Strategy for Canada, the NHCC will work with the Government of Canada to develop an approach to income security for people affected by neurological conditions. Development of the strategy will involve provincial governments, persons with neurological conditions and organizations that represent them. However, we also suggest that there are some relatively easy steps that could be taken right now.

NHCC member organization, the Multiple Sclerosis Society of Canada, has suggested the following to the federal government to ease the financial burden being experienced by far too many Canadians today:

- o Allow spouses to claim the Caregiver Amount (tax credit) – not permitted currently.
- o Make Employment Insurance sickness benefits more flexible to allow people with conditions that are episodic to work part-time and receive partial benefits.
- o Make the Disability Tax Credit a refundable benefit.

The NHCC recommends that these measures serve as the first steps toward ensuring that people living with a neurological condition do not experience poverty as a consequence of their illness.

Integrated Care & Support

It can be argued that an integrated model of community care that formally aligns primary care and acute care with a network of community support services improves efficiency and effectiveness. It does this by reducing the likelihood of disconnects for populations such as people living with neurological conditions, who are reliant on a complex array of specialized medical, community and social services.

There is a considerable body of literature on the subject of integrated models of care. Anyone who has experienced a neurological condition in their family knows that it entails many visits to different settings. It doesn't help that this puzzling maze of care and treatment is usually experienced by someone dealing with a complex assortment of chronic conditions. For many, this also includes some degree of cognitive impairment.

One of the most significant concerns voiced by people who are frequent users of health services, as patients and as caregivers, is that their care is uncoordinated and it is hard to tell who is running the show. In short, the system is difficult to navigate.¹

Chronic Disease Prevention and Management

Many jurisdictions are coming to grips with the fact that their health care systems are designed for managing brief episodes of acute illness while the problems that their health systems are now primarily dealing with are chronic conditions which are not amenable to discrete episodes of acute care. For chronic conditions, the conventional approach is expensive, frustrating and time-consuming to patients, lacks continuity and does not get at root causes. As a result, many jurisdictions are turning to the chronic care model, the basic tenet of which is *productive interactions between informed, active patients and prepared, proactive practice teams*.

The Chronic Care Model, or chronic disease management, has since become a policy cornerstone in several countries and is a key policy feature in British Columbia, Alberta, and Ontario. Some of the key features of chronic disease management include:

- Case management;
- Planned visits with a focus on self-management, secondary prevention -- staying proactive;
- Multiple visit models: clinically-relevant group, self-management support training, one-on-one with specialist or primary care provider, social support;
- Team-based care, with defined roles for primary care physician, nurse, medical specialist, other care team members;
- Evidence-driven plans or protocols -- modified to meet the needs of individual patients
- Care coordinated across multiple providers and settings – specialist care and community services;
- Focus on learning and self-management; and
- Care delivery system redesign – integrating mechanisms among primary care, institutional care and community providers;

Many neurological conditions appear to be highly amenable to the core principles of chronic disease management. This approach would be an effective foundation for the kind of integrated care that is needed by people with neurological conditions.

One of the key advantages of chronic disease management and especially within the interdisciplinary collaboration that is at the heart of the model is the diversity of perspectives essential to the identification and management of comorbid conditions or complex chronic conditions. The Brain Strategy for Canada will identify how best to ensure that health and social services needed by people with neurological condition are integrated, person-centred, informed by the chronic disease prevention and management model and incorporate new knowledge about supporting navigation of the system on behalf of people whose care needs are complex.

¹ *Who is the Puzzle Maker? Patient/Caregiver Perspective on Navigating Health Services in Ontario*. The Change Foundation, June 2008. DATE OF ACCESS. http://www.changefoundation.ca/docs/ChgFdn_Puzzle_Web.pdf.

Genetic Fairness

Many neurological conditions have a genetic basis and at this point, there is no protection from the discrimination that arises from the identification of a genetic risk of developing these conditions. Canada needs a genetic non-discrimination plan to ensure that genetic data is used properly, without fear of repercussion. This strategy must prevent insurers and employers from inducing applicants to take genetic tests, and from receiving genetic information or family histories, for the purposes of assessing the liability of the applicant, based on imputed or perceived disability.

Many Canadians who are at risk of genetic discrimination will count on the Brain Strategy for Canada to build on the Private Member's Motion M-444, which reads:

“That, in the opinion of the House, the government should develop and implement anti-discrimination protections with respect to genetic information, including, but not limited to, information gathered through genetic testing and family history, that include:

A. effective enforcement mechanisms;

B. a standing body mandated to document cases, evaluate the effectiveness of anti-discrimination protections, and make recommendations to the government about the uses of genetic information and direct-to-consumer testing;

C. a public awareness campaign to focus attention on the issue of genetic discrimination and its link to genetic testing and research.”

Public Awareness and Education

The brain is the most vital and least-understood organ in the human body. Its task range from the mundane chores of keeping a living being alive and responsive to its environment – it makes sure the heart pumps, the lungs breathe, and the eyes see – to the most transcendent aspects of human capability – science, art, poetry, love, compassion. This diversity of roles confounds understanding.

Some Canadians have thought the advent of a Mental Health Commission of Canada would be helpful to Canadians concerned about neurological conditions however the Commission's mandate excludes such conditions as Parkinson's disease, multiple sclerosis, amyotrophic lateral sclerosis and other neurological conditions. Many Canadians would assume that Alzheimer's disease and related dementias, which affects 500,000 Canadians and costs Canadian society \$15 billion per year, would be a matter of great concern to policymakers, yet there is no evidence to support this assumption. Policymakers need a framework for guiding their response to the impact of neurological conditions on Canadian families and businesses. The Brain Strategy for Canada will provide such a framework.

A robust public awareness and education plan will help policymakers situate brain health in the broader context of healthy living and will situate neurological conditions in the context of emerging approaches to the prevention and management of chronic conditions. It will also situate neurological conditions in a resource allocation context appropriate to the scale of their aggregate health impact.

The most pressing case for addressing the public's lack of understanding of the role of the brain and of neurological conditions relates to access to care. As with mental health problems, too few Canadians have sufficient understanding of the problems they are experiencing to seek the help they need. Too few Canadians get the kind of diagnostic, treatment and support they are seeking because front-line providers have an inadequate understanding of the brain, central nervous system, and the conditions to which they

are prone. In both cases, people with neurological conditions and people with a responsibility to care for them, stigma and misunderstanding create a huge barrier to effective treatment.

NHCC will work closely with the Mental Health Commission of Canada (MHCC), the mental health community, and, especially, Canadians living with neurological conditions to understand the aims, methods and success factors of the recently launched MHCC anti-stigma campaign with a view to defining the scope of a parallel anti-stigma public awareness campaign under the auspices of the Brain Strategy for Canada. The brain, along with the central nervous system and the conditions to which they are vulnerable, constitute the proverbial elephant described by many blind men. If we focus on cognition, we miss neuromuscular issues, if we focus on the role of aging in brain pathology, we miss the neurological conditions of childhood. The Brain Awareness program will help Canadians understand the breadth of issues pertinent to the brain. The program will raise awareness and understanding about the brain and nervous system as one system, with mechanisms common across neurological and psychiatric conditions.

Conclusion

NHCC is looking forward to engaging the Government of Canada and the Subcommittee on Neurological Disease of the Standing Committee on Health in robust dialogue about ensuring that Canadians with neurological conditions can count on the establishment of a Brain Strategy for Canada that incorporates:

- Research - the pressing need for accelerated and targeted investment in neuroscience research;
- Caregiver Support - the need to support the valuable role played by family caregivers;
- Income Security - the need to ensure that people disabled by a neurological condition are protected from poverty;
- Prevention - the need to learn more about primary prevention and to increase the focus of chronic disease management on secondary and tertiary prevention;
- Integrated Care & Support - the need to better coordinate care;
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