

Neurological Health Charities Canada - Policy Briefing Note

November 2011

NEUROLOGICAL HEALTH CHARITIES CANADA (NHCC) is a collective of organizations that was established in 2008 to represent people with chronic, often progressive, brain diseases, disorders and injuries in Canada. NHCC's role is to provide leadership, evaluating and advancing new opportunities for collaboration specific to advocacy, education and research projects, related to brain health.

Our collective goal is to improve the quality of life for all persons with chronic brain disease, disorders and injuries, and their caregivers, by elevating brain health to the top of government agendas and ensuring that research, prevention, treatments and supports for those living with chronic brain conditions are universally accessible and fully funded.

NHCC Members include:

ALS Society of Canada	Heart and Stroke Foundation of Canada
ALS Society of Ontario	Huntington Society of Canada
Alzheimer Society of Canada	March of Dimes Canada
Alzheimer Society of Ontario	Mood Disorders Society of Canada
Brain Injury Association of Canada	Multiple Sclerosis Society of Canada
Canadian Alliance of Brain Tumour Organizations	Muscular Dystrophy Canada
Canadian Epilepsy Alliance	Ontario Federation for Cerebral Palsy
Canadian Neurological Sciences Federation	Ontario Neurotrauma Foundation
Canadian Stroke Network	Ontario Rett Syndrome Association of Canada
Centre for ADHD Awareness Canada	Parkinson Society Canada
Dystonia Medical Research Foundation Canada	Parkinson Societies in Ontario
Foundation Fighting Blindness	Spina Bifida & Hydrocephalus Association of Ontario
Headache Network Canada	Tourette Syndrome Foundation of Canada

Executive Summary:

- The NHCC is a conduit for federal, provincial and territorial governments to reach 26 organizations representing people with chronic neurological conditions through one NGO.
- Collectively, NHCC members represent and advocate on behalf of more than 5.5 million Canadians living with a neurological condition and their families.
- Collectively, NHCC members invest approximately \$50 million per year to fund basic, clinical and psychosocial research.
- The NHCC has a proven track record for working collaboratively with both the provincial and federal levels of government, as demonstrated by the Ontario Study of Neurological Conditions and the National Population Health Study currently underway - with results expected in 2013.
- For Canada's Health Accord, the NHCC's work to date sets a platform for collective action and sheds light on the complexity of chronic disease and the many challenges faced by our citizens beyond the acute care system. The NHCC would welcome the opportunity to work together with the Canadian government to identify cost-effective opportunities and strategies to improve healthcare for Canadians living with neurological and other chronic conditions.

- **The NHCC urges the Canadian government to provide leadership in five key areas:**
 - ❖ **Creating a health care system that provides integrated care and support for both individuals with chronic, disabling conditions as well as those with acute illnesses**
 - ❖ **Providing meaningful support for caregivers in the form of a comprehensive package of education, respite, income support and mandated workplace accommodation of the episodic needs of caregivers**
 - ❖ **Establishing income security measures for individuals and families living with neurological conditions**
 - ❖ **Establishing measures to prevent genetic discrimination**
 - ❖ **Creating public awareness & providing education to build a better understanding of the brain and neurological conditions among the Canadian public and front-line health professionals**

The Importance of Brain Health

The brain is the body's most critical organ. It controls all life functions and allows us to act, move, think, feel and express both our humanity and our individuality. Quite simply, if one's brain does not work properly, every aspect of life is compromised as a result.

It is a complex organ, made up of 100 billion neurons (brain cells) – and it is the least understood. Ninety per cent of what we have learned about the brain has been in the past fifteen years, but researchers still have far to go toward fully understanding brain function.

What we do know is that 5.5 million Canadians live with a chronic neurological condition. Most of these conditions are progressive and degenerative, with no known cause or cure and while therapies exist for some conditions, in most cases, there is no way to stop or even slow the progression.

We also know that one in three Canadians will be affected by one or more of these neurological or psychiatric conditions at some point in their lives. Brain disease is not a normal part of aging; however we do see an increased incidence associated with aging. As the Canadian population ages, the impact of brain diseases, disorders and injuries will be staggering.

Neurological conditions do not discriminate; they strike men and women, young and old. The resulting burden manifests not only in the health of our citizens, but also our communities, social systems, and our economy. The enormous burden of these conditions has been seriously underestimated by traditional epidemiological and health statistical methods.

Within the next 20 years, neurological conditions will become the leading cause of death and disability in Canada. Policymakers and health care professionals are not prepared to cope with this predicted rise in brain disease, disorders and injuries. More recently, the Government of Canada has begun to address the issue of mental health, however, that is only one side of the equation. To adequately plan for the full impact of neurological and psychiatric conditions, policymakers must also acknowledge and invest in the full spectrum of brain conditions.

The NHCC Urges the Canadian Government to Provide Leadership in Five Key Areas:

1. 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

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.

¹ *Who is the Puzzle Maker? Patient/Caregiver Perspective on Navigating Health Services*

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 NHCC recommends that the Canadian government establish a health care system that provides integrated care and support for both individuals with chronic, disabling conditions as well as those with acute illness.

2. Caregiver Support

Issues related to care giving 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 care giving that are unique to this community – in particular increasing levels of dependency over time, usually upon one or several family caregivers.

The role of the caregiver changes throughout the 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 care giving 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 care giving 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 care giving 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).

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 care giving 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 care giving time and hence the health and economic burden placed on informal caregivers. As well, it could delay admission for the person with dementia into long-term care (LTC). In this scenario the intervention is applied to all informal caregivers and individuals with dementia receiving care within the model.

The reduction in care giving 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 NHCC recommends that the Canadian government provides meaningful support for caregivers in the form of a comprehensive package of education, respite, income support and mandated workplace accommodation of the episodic needs of caregivers.

3. 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 any time. Whenever they strike, they have a profound impact on the economic wellbeing 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 the disease progresses it takes 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. The NHCC would appreciate the opportunity to 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:

- Make Employment Insurance sickness benefits more flexible to allow people with conditions that are episodic to work part-time and receive partial benefits.
- Make the Disability Tax Credit a refundable benefit.

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

4. 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.

It is a well-established principal that individuals shall not be discriminated against based on their disability; yet outdated laws still enable insurance companies to discriminate based on perceived disability, or the prospect of future disability. Cases of genetic discrimination have been documented in Canada and they will continue to grow. It occurs when people are treated unfairly because of actual or perceived genetic differences, e.g., “bad genes”, “genetic underclass”. It may mean being rejected for employment, a lower level of employment or loss of access to insurance based on the notion that the individual may be disabled in future. Predictive, diagnostic information can be obtained through tests administered by trained medical personnel or through commercial tests available to the public or by asking for family histories.

Yet insurance law permits insurers to require health information and to use it without transparency to determine eligibility, set premiums and manage their risks. Insurers ask applicants to divulge personal health information, including genetic data, and family histories and to consent to have this information verified. This unfairly puts consumers under duress, because they are denied needed coverage if they fail to do so. Consumers must also agree to have their personal health information, including genetic data, shared with other insurers through the Medical Information Bureau; effectively closing off an individual’s insurance options and threatening privacy rights.

Failure to disclose this information can mean that the insurance policy will be deemed null and void or even fraudulent. For example, in a 1990 court case, the heirs of an asymptomatic individual, at time of his application for life insurance, were denied benefits when the man died - even though the cause of death was not related to his genetic mutation.

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.

Of the G8 Countries, Canada is the only country that does not have a genetic fairness policy in place whether through legislation or a voluntary moratorium by the insurance industry.

The NHCC recommends that the Canadian government establish measures to protect all citizens from genetic discrimination.

5. Public Awareness and Education

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. Stigma and misunderstandings create huge barriers to effective treatment for both people with neurological conditions and people with a responsibility to care for them.

NHCC would work closely with the Mental Health Commission of Canada, the mental health community, and, especially, Canadians living with neurological conditions to understand the aims, methods and success factors of the recently launched anti-stigma campaign with a view to defining the scope of a parallel anti-stigma public awareness campaign. 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. A 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.

The NHCC recommends that the Canadian government create public awareness campaigns & provide education programs to build a better understanding of the brain and neurological conditions among the Canadian public and front-line health professionals.

The NHCC's Proven Record for Working Collaboratively with Government

National Level - National Population Health Study

In 2009, the Honourable Leona Aglukkaq, Minister of Health, announced the government's commitment to a 4-year \$15 million National Population Health Study to fill in gaps in knowledge about the state of neurological conditions in Canada. The Study, managed by both NHCC and the Public Health Agency of Canada, will provide new information to improve knowledge about the impact of current and projected neurological diseases over the next twenty years. The funding serves to support three national surveys, thirteen Pan Canadian Research Studies, a Micro-Simulation Project before concluding with a Synthesis Process to be submitted as a formal report of recommendations to the Minister of Health. Concluding in 2013, this study is the first of its kind in Canada where it will provide key information to improve current knowledge on neurological conditions.

Provincial Level - The Ontario Neurological Study

The Ontario members of the Neurological Health Charities Canada (NHCC) partnered with the Ontario Ministry of Health to develop recommendations that would inform improvements for Ontario citizens living with a brain disorder or injury. The Ontario study goals were:

- To create a roadmap aimed at reducing the impact of disability for Ontarians living with neurological conditions and their care partners.
- To identify ways to improve services and supports for individuals with neurological conditions and their care partners through strategic investments that build on existing programs and services and leverage linkages with identified government priority activities.

The work of the NHCC Ontario committee involved a literature review, a review of the burden of Neurological conditions in Ontario, a significant stakeholder consultation involving over 350 participants and the committee's work through a long range scenario planning process involving both a scenario development and an environmental (PESTEL) analysis. The outcome of this work culminated in a report entitled *Wired for Success: Towards an Ontario Brain Strategy*.

The long range scenario planning process used by the Ontario committee identified a number of themes that can be viewed as catalysts for change. These themes were set in a context of a broad array of neurological stakeholders that represent both the cognitive and physical disability communities. The chronicity of these conditions and the corresponding burden are the common factors that unite the communities around a common purpose. The notion of personalized support and participation, and supporting caregivers were areas of common interest and importance. The opportunities to harness knowledge, mobilize technology, design the built environment and integrate systems were also seen as dominant themes. It was further recognized that shifting the culture, engaging the private sector and utilizing funds were key themes to be addressed.

The report identified as well a number of policy implications and opportunities that included:

- Engaging Family Health teams in Neurological Care and connecting specialized care
- Creating choice and system navigation
- Strengthening community support
- Enhancing social inclusion- income, employment, education, housing and social connections and participation
- Fostering technology and research
- Building a neuro partnership

Conclusion

The consultation that continues to support NHCC's work validates the needs identified by our community. The Ontario work linked to the National Population Health Study, where the burden of neurological disease and disorder is being articulated, creates an important starting point in identifying opportunities and strategies to improve health care for Canadians with neurological conditions.

For policy makers charged with providing recommendations on Canada's Health Accord, NHCC's work to date sets a platform for collective action that can be addressed at both the provincial and federal levels by offering cost effective solutions and strong returns on investment. More importantly, these results have and will shed light on the complexity of chronic disease and the many challenges faced by our citizens beyond the acute care system.

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