

# Shaping the Health Care Provider's Approach to Supporting Persons with Neurological Conditions



## Observations from the National Population Health Study of Neurological Conditions

The health needs of individuals affected by diseases, disorders and injuries of the nervous system are often complex and extensive. Most neurological conditions are chronic and many are progressive, requiring different types of care, from different providers, at different stages of the illness. The National Population Health Study of Neurological Conditions (the Study)\* identified limitations that exist in the provision of care for individuals with neurological conditions, as well as opportunities for health care providers to better meet and manage the needs of those affected.

The information included below is intended for use by all persons providing care to individuals living with neurological conditions: specialists, general practitioners, nurses, allied health professionals, personal support workers, family and friend caregivers, and others.

### Awareness

The Study identified limited awareness of neurological conditions as a major gap in the provision of health services for individuals affected by these conditions. Enhanced awareness by care providers of certain key features can facilitate person-centred care and support an atmosphere of acceptance and openness, thereby decreasing perceptions of stigmatization and marginalization. For example:

- ❖ The needs of individuals with neurological conditions are often more complex, requiring more costly health services than those of individuals with other chronic conditions.
- ❖ When defining the care needs of individuals, disorders of function and the related spectrum of disabilities need to be considered in addition to specific diagnosis.
- ❖ The social determinants of health (e.g. education, employment, housing, transportation) must be considered in planning the care pathway for those with neurological conditions.

### Early Detection of Disease

Early detection, diagnosis, and functional assessment can lead to comprehensive management, timely referral to specialized care, and initiation of appropriate therapies to reduce the effects of impairment and disability. However, the Study found that the average time between symptom onset and diagnosis can be as long as eight years, probably because the early manifestations of some neurological conditions can be difficult to recognize and may suggest other diagnoses. Delayed diagnosis can be particularly frustrating for those in the early stages of rare conditions, whose diagnoses are largely based on clinical assessments rather than laboratory tests. In such situations, prudent care providers recommend increased monitoring and follow-up.

\* *Mapping Connections: an understanding of neurological conditions in Canada*, the report of the National Population Health Study of Neurological Conditions, is available at: [www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php](http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/index-eng.php)



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## Education and Management of Expectations

Health care providers promote empowerment of affected individuals and their families when they discuss the individual's needs, preferences and role in the management of their condition, as well as the role of the system, care providers, and society. In addition, health providers have an important role in ensuring affected individuals and families have a clear understanding of the diagnosis, the potential impacts of their condition, and what to expect regarding their care. The Study also found that individuals with neurological conditions often share many of the same functional impacts and needs, irrespective of diagnosis. Broad awareness by health providers of commonalities may support the adaptation of best practices to effectively meet the health needs of individuals with different neurological conditions.

## Coordinating Care

Care providers who are aware that individuals with neurological conditions often require support from a variety of providers can link with one another in their local communities, within and between settings, to provide coordinated care and facilitate transitions for affected individuals. Managing transitions is particularly important for childhood conditions that persist into adulthood. Networks can be leveraged by connecting affected individuals with timely referrals to the most appropriate specialists, programs, supports and facilities available.

## Important Role of Family and Friends in Providing Care

The Study documented the extent of care provided for persons with neurological conditions by family, friends, and neighbours, whose financial security, health and quality of life can be affected by their responsibilities. Effective management of individuals with neurological conditions includes attention to the health and wellbeing of family and friend caregivers, as well as their inclusion within the circle of care and team of providers.

## Cultural Sensitivity in Care Provision

The need for cultural sensitivity in providing health care for First Nations and Métis individuals living with neurological conditions was another finding of the Study. Culturally relevant approaches to health care provision are undoubtedly equally important for other cultural communities.

Regardless of the phase at which a person may find themselves along their journey with a neurological condition, it is clear that an understanding of their specific challenges and opportunities can lead to more individualized and appropriate care – care that recognizes the uniqueness of the individual and the complex nature of the management of their care.

Health providers can contact Neurological Health Charities Canada and our member organizations for more information on the Study and condition-specific resources. Individuals and families can also be referred for education and support.

Visit [www.MyBrainMatters.ca](http://www.MyBrainMatters.ca) or email [info@MyBrainMatters.ca](mailto:info@MyBrainMatters.ca)

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