



# NEW HORIZONS IN MS CARE

Improving Access to MS  
Treatments and Medical  
Services in Northern  
Ontario Communities



## ■ EXECUTIVE SUMMARY

This paper examines multiple sclerosis (MS) care in Ontario's northern communities. Individuals affected by MS in these communities often face significant challenges in accessing the medical services they need to manage their disease, including the need to travel for diagnosis and treatment for MS, limited access to neurologists and to specialized MS clinics, access to primary care physicians, and limited knowledge of MS among primary care physicians.

The Northern Travel Grant provides some financial assistance to individuals who need to travel for care, yet the majority of people with MS who receive the grant report that they still must incur out-of-pocket expenses to receive the medical care that they need. In some instances, there are significant wait times to access specialty care and to access MRIs. MRIs aid in the diagnosis of MS and which are sometimes required for access to disease modifying therapies to treat the disease.

In this paper, the MS Society of Canada, Ontario Division, calls on the Government of Ontario to "bridge the gap" in MS care for people with MS living in northern communities. A summary of recommendations on how this can be achieved is provided below.

## ■ SUMMARY OF RECOMMENDATIONS

To improve MS care in northern communities it is recommended that:

- The Government of Ontario, North West and North East Local Health Integration Networks (LHINs) and Community Care Access Centres (CCACs) develop initiatives to improve MS care in northern Ontario through their respective chronic disease frameworks and strategies.
- The Government of Ontario, North West and North East LHINs and Ontario's MS clinics collaborate to examine ways in which primary care physicians, nurse practitioners, and family health teams can help to provide follow-up care and chronic disease management support to people with MS living in northern Ontario. This work could serve as a blueprint for LHINs across the province.
- The Government of Ontario work with neurological health charities and health care professionals to establish a Community of Practice for neurological conditions to improve knowledge exchange and translation of evidence-based best practices in diagnosing, treating, and managing neurological conditions.<sup>i</sup>
- The Government of Ontario work with the MS Society of Canada, Ontario Division, and health care professionals to establish an MS clinic in the North East LHIN, which could be supported through the Eastern Campus of the Northern Ontario School of Medicine located at Laurentian University in Sudbury.<sup>ii</sup>

- The Government of Ontario develop a more rigorous and specialized Telehealth Ontario system with staff trained to provide disease-specific health advice and support.
- The Ministry of Health and Long-Term Care recognize neurological conditions as an e-Health priority, which could allow for the development of an online disease management system similar to the e-health diabetes initiative or an online neurological “portal” such as the U.K.’s NeuroResponse system.<sup>iii</sup>
- The Ministry of Health and Long-Term Care ensure that the Northern Travel Grant reimburses the real costs of travel, including the need for overnight accommodation for people with MS who may experience fatigue and other symptoms that make travelling over many hours challenging.

## ■ INTRODUCTION

This paper explores the challenges that people living with multiple sclerosis (MS) in northern Ontario communities face in accessing medical treatment and services. Northern communities are defined by the Government of Ontario as those that are north of Parry Sound, although communities within the Parry Sound region may also experience some of the challenges identified in this paper.

Medical treatment and services are defined as those treatments and services provided by regulated (e.g. physicians, specialists, nurses, physiotherapists), and, in some instances, unregulated health care providers (e.g. personal support workers). These services may be provided in clinics, health care facilities (such as hospitals, long-term care homes, etc.), or in an individual’s home.

Although this paper focuses on people living with MS, many of the issues raised also affect individuals who live in northern Ontario communities who require medical care. This is the case for those with chronic conditions who require access to care over the long-term.

## ■ THE ISSUES

Individuals living with MS in Ontario’s northern communities often face significant challenges in accessing the medical services they need to manage their disease while remaining in their communities.

- Often, northerners with MS must travel to MS clinics in large urban centres in southern Ontario, and many incur out-of-pocket costs to do this; others simply can’t afford to make the trip.
- Like many Ontarians, some individuals with MS in northern communities also face challenges in accessing primary care physicians to help manage

their disease closer to home. Without a primary care physician, it is also extremely difficult to obtain a diagnosis of MS, as the primary care physician is most often the first entry point on the path to diagnosis.

- Regardless of where one lives, when people with MS have access to primary care physicians in their communities, these physicians are not always well-versed in the diagnosis and treatment of MS and their knowledge is limited on how best to support people living with MS.

## ■ ABOUT MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is a complex neurological disease that attacks the brain and spinal cord, causing symptoms that are unpredictable and variable from person to person. While it is most often diagnosed in young adults, aged 15 to 40, we know that it can also affect children, some as young as two years. The impact of MS is felt by family, friends and by society as a whole. MS symptoms are varied and can affect vision, hearing, memory, balance and mobility, to name a few. Its physical, emotional, and financial effects of MS last a lifetime. Currently, there is no cure.

Canada – and Ontario - has one of the highest rates of MS in the world. There are between 55,000 – 75,000 Canadians who have been diagnosed with MS; 21,000 – 29,000 of these individuals live in Ontario.

## ■ Economic, Individual, and Societal Impact of MS

While there is not definitive data about the economic, individual and societal impact of MS, there is some information. According to one study, the estimated annual total cost of MS to Canada's economy is \$1 billion, representing a higher cost than all infectious diseases combined. During their lifetime, on average, Ontarians with MS will need \$1.6 million in care and support to manage their illness.<sup>iv</sup>

Another indication of the impact of MS can be found in hospital data. For the period 2002-2003, the number of visits by people with MS to emergency departments in Ontario was 1,519. It jumped to 1,758 for the year 2005-2006, representing a 15.7% increase. Almost 30% of people with multiple sclerosis visiting emergency departments in Ontario in 2005-06 were admitted to acute care hospitals. In 2004-05, the median length of stay in Canadian acute care hospitals for people with MS was six days, compared with four days for all patients in acute care aged 19 years and older.<sup>v</sup>

## ■ ABOUT THE MS SOCIETY OF CANADA

For over 60 years, the Multiple Sclerosis Society of Canada has provided hope and help for people with MS across Canada. **Hope** through the Society's extensive national research program; and **Help** through the delivery of services which improve the quality of life for people with MS and their families today.

The MS Society of Canada, Ontario Division, has chapters and units across the province and over 13,000 members. The division is committed to providing services and programs with an objective of enabling all those affected by multiple sclerosis to enhance their quality of life. This important work is achieved through the dedication and hard work of volunteers and staff at the chapter, unit, and division levels who are working together to end MS.

## ■ FACTS ABOUT MS IN ONTARIO'S NORTHERN COMMUNITIES

In 2002, the MS Society and Kelly & Associates undertook a needs assessment and stakeholder consultation<sup>vi</sup> study of persons with MS, their families, and their support networks in northern Ontario communities. The results of this study<sup>vii</sup> found that:

- Access to a neurologist was cited as a significant challenge for people living with MS in northern communities. Just over half (52.8%) of respondents indicated that they had access to a neurologist, leaving just under half of respondents without access to a neurologist.
- Just over half of people traveled to MS clinics in southern Ontario or elsewhere to receive specialized care. Over 75% travelled to a MS clinic by automobile and 56% of those who visited an MS clinic travelled over 500 kilometres one way to their destination.

While the cost of visiting an MS clinic varies depending on where a person lives in the north, over one-third of those who visited an MS clinic in the 2002 survey reported that, on average, it cost more than \$500 on travel and related expenses.<sup>viii</sup>

Of those respondents who travelled to MS clinics, 53% reported paying between \$300 to \$500 or more on travel than what was provided for in the Northern Travel Grant; 41% of this group reported expenses of \$500 or greater that were not covered by the Northern Travel Grant.

- Follow-up care needed to implement MS clinic recommendations was reported as a challenge, with 60% of respondents noting that follow-up care was not well met or only somewhat well met in their home communities.

The most common follow-up needs cited were: medication review, prescription and prescription renewals, medical check-up<sup>ix</sup>, physiotherapy, and a health care professional to whom questions could be directed.

Other responses mentioned included the need for blood tests, an MRI update, specialist appointments and family doctor follow-up with the MS clinic an individual visited.

- Despite 90% of respondents reporting that they had access to a primary care physician, many noted that they often had to wait weeks for an appointment. As one respondent stated: "It is a two-to-three week wait

unless you go to emergency. MS symptoms are unpredictable and can change or disappear in that time.”

Of the 10% of respondents who noted that they did not have access to a primary care physician, 40% identified a doctor shortage in their area as the reason for not having regular access to a family doctor. Other reasons given for not having regular access included:

- doctors were not accepting new patients;
- doctor had relocated to another area;
- lengthy booking times for an appointment.

In 2009, the MS Society solicited additional feedback on these issues from people affected by MS living in northern Ontario and explored possible solutions. These solutions are contained within this paper.

## ■ ACCESSING MULTI-DISCIPLINARY TEAMS AND SPECIALIZED CARE

### **Charles' Story: Waiting it out in hospital**

*Charles had an MS relapse, an episode during which new symptoms appear or existing ones get worse. Charles required hospitalization for the duration of his relapse, which lasted two weeks. Better access to a multi-disciplinary MS team and adequate community supports to help him manage his relapse may have allowed Charles to leave the hospital sooner or may have made admission unnecessary all together.*

Due to the complexity of multiple sclerosis, people who live with the disease require multi-disciplinary care. For the most part, this care is delivered through eight MS clinics in Ontario, all of which are housed in southern Ontario, with the exception of an associate MS clinic<sup>x</sup> in Thunder Bay.<sup>xi</sup> The MS Society provides funding to all eight MS clinics in Ontario.

MS clinics are led by neurologists who have requisite training in MS and who are ideally supported by a registered nurse with certification by the International Organization of MS Nurses. These MS clinics also have access to medical and allied health professionals<sup>xii</sup> who collaborate with MS clinic staff to provide informed care for people with MS.

## ■ BRIDGING THE MS CARE GAP

Health care resources are at a premium across the province and it is not unusual for need and demand to outstrip available resources. Regardless of where they live, individuals who visit the large tertiary MS clinics located in urban centres experience limited access to these specialized clinics, and these clinics do not offer primary care.

Even people with MS who live in or near urban areas are generally seen in these clinics every 12 to 18 months, with some limited accommodation made for urgent situations. In particular, people with MS who live in northern Ontario must rely on community neurologists (when available), general practitioners and community health services for their principal MS care. Wherever possible, this care is based on specialized plans recommended by specialized MS neurologists following assessment at regularly scheduled appointments. In addition, specialists in MS clinics can be available for consultation by phone with community health care professionals to address care issues of individual patients.

**Sally's Words: There's no place like home**

*Treatments or diagnoses are extremely difficult, emotionally and physically. To have to travel on top of that is taxing not only for the individual, but for the family. And that's assuming the patient has friends and/or family to rely on. We need more services in home cities.*

However, many people cannot afford the time or the financial and physical expense of traveling to a southern Ontario clinic. A complicating factor for many is that the Northern Travel Grant is inadequate and does not cover all the expenses involved. Moreover, the physical toll that travel takes on some individuals with MS, particularly those who experience fatigue and/or chronic pain, is significant.

**■ GOING THE DISTANCE: RECOMMENDATIONS TO IMPROVE MS CARE IN NORTHERN ONTARIO**

The Government of Ontario can improve MS care in northern communities. To do so, it is important for the government, the North East and North West Local Health Integration Networks (LHINs) and Community Care Access Centres (CCACs) to view multiple sclerosis through a chronic disease lens, particularly with respect to secondary and tertiary prevention.<sup>xiii</sup>

The Multiple Sclerosis Society of Canada recommends the following initiatives to maximize the health of people with MS living in northern Ontario.

**■ Regard MS as a chronic disease in all aspects**

While currently there is not a cure for MS, there are approaches that can help slow progress of the disease and lessen its impact. These approaches can help keep people well, in their communities, and out of emergency departments. To this end:

- **The Government of Ontario, North West and North East LHINs and CCACs should develop initiatives to improve MS care in northern Ontario through their respective chronic disease frameworks and strategies.**

## ■ Continue to build MS care capacity in the north

In recent years much has been done to strengthen health care delivery in northern Ontario. New strategies such as The Northern and Rural Recruitment and Retention Initiative should help ensure that more northerners have access to primary care physicians. As well, access to magnetic resonance imaging (MRI) has improved in the North West and North East LHINs as a result of Ontario's Wait Times Strategy; however, some people in some remote northern Ontario communities still report waiting several months for an MRI. MRI assists neurologists in diagnosing MS and is sometimes required for public reimbursement of disease-modifying therapies.

The development of the Northern Ontario School of Medicine offers multiple teaching and research sites distributed across northern Ontario to help improve health service delivery capacity and knowledge in the north. Moreover, the creation of the MS clinic in Thunder Bay with assistance by the MS Society provides access to specialized MS care closer to home for people with MS in some parts of northwestern Ontario.

While the capacity for MS care is improving in Ontario's northern communities, it could be strengthened further through:

- **Collaboration between the Government of Ontario, North West and North East LHINs and Ontario's MS clinics to examine ways in which primary care physicians, nurse practitioners, and family health teams can help to provide follow-up care and chronic disease management support to people with MS living in northern Ontario.** This work could serve as a blueprint for LHINs across the province.
- **Collaboration between the Government of Ontario, neurological health charities, and health care professionals to create a Community of Practice for neurological conditions to improve knowledge exchange and translation of evidence-based best practices in diagnosing, treating, and managing neurological conditions.<sup>xiv</sup>**
- **Collaboration between the Government of Ontario, neurological health charities, and health care professionals to develop a MS clinic in the North East LHIN, which could be supported through the Eastern Campus of the Northern Ontario School of Medicine located at Laurentian University in Sudbury.**

The introduction of additional specialized MS care services in the north could facilitate improved MS care for people with MS in northern communities, who would have improved access to the care they need in a timely and manageable way. In addition, the creation of another northern MS clinic could be a valuable resource for local health care professionals in supporting their clients with MS. This in turn could help to reduce the challenges that urban MS clinics face in managing MS care across the province and could improve access to MS clinics in Ontario in general.

The ability and opportunity to participate in clinical research trials is something near and dear to the hearts of many people with MS. This is no surprise in a chronic illness with no known cure. The availability of northern clinics, staffed by qualified MS trained personnel, would help to make this a real possibility for people in the north. Currently, major clinical trials are conducted in the urban MS clinics. Clinical trials require patients to visit clinics for frequent assessments. Given the cost of travel, and the extremes of our weather, participation in clinical trials is virtually impossible for people in the north.

### ■ Use technology to leverage innovative care solutions

The Government of Ontario has launched a number of initiatives to improve patient care in recent years, such as Telehealth Ontario<sup>xv</sup> and the diabetes e-Health initiative, which provides LHINs with regional-specific diabetes information. The diabetes e-Health initiative is also developing a diabetes registry, which will help improve clinical management and patient self-management of care.<sup>xvi</sup>

Other jurisdictions are also leveraging technology to improve health care delivery. Alberta's TeleALS (Amyotrophic Lateral Sclerosis) and TeleEpilepsy programs give patients access to health care professionals to talk about disease management strategies. As well, through these programs, people in remote locations can consult physicians in different locations through video-conference or teleconference consultations.

Throughout Ontario, but particularly within the northern context, these initiatives hold great potential to help provide follow-up care and chronic disease management support to people with MS, and potentially those with other neurological conditions. These initiatives can be leveraged by:

- **The Government of Ontario developing a more rigorous and specialized Telehealth Ontario system with staff trained to provide disease-specific health advice and support.**
- **The Government of Ontario identifying neurological conditions as an e-Health priority, which could allow for the development of an online disease management system similar to the e-health diabetes initiative or an online neurological "portal" such as the U.K.'s NeuroResponse system.<sup>xvii</sup>**

### ■ Enhance the Northern Travel Grant

Timely access to health care services is a critical issue in northern Ontario. This is driven by a shortage of qualified health care professionals, particularly in specialty areas such as neurology. Despite the creation of an MS clinic in Thunder Bay, many people with MS in northern Ontario must travel to MS clinics in southern Ontario. Despite increases to the Northern Travel Grant in 2007, these individuals are often required to cover expenses out-of-pocket. To address these challenges:

- **The Ministry of Health and Long-Term Care should ensure that the Northern Travel Grant reimburses the real costs of travel, including**

the need for overnight accommodation for people with MS who may experience fatigue and other symptoms that make traveling over many hours challenging.

## ■ CONCLUSION

The MS Society of Canada believes that people with MS are entitled and should have access to excellent multi-disciplinary care from diagnosis through management of their disease, regardless of where they live. This care should be accessible close to home and these individuals should be entitled to make choices about their care and be supported in the choices they make.

The MS Society looks forward to working with the Government of Ontario and the North West and North East LHINs and CCACs to develop creative solutions to help ensure that people with MS in northern Ontario can receive the care that they need to live well in their communities.

## ■ ACKNOWLEDGEMENTS

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<sup>i</sup> Ontario has established several Communities of Practice (CoPs) in priority health care areas (Alzheimer Knowledge Exchange, Seniors Health Research Transfer Network, and Mental Health and Addictions Knowledge Exchange Network.)

<sup>ii</sup> The Northern Ontario School of Medicine has two campuses: the Eastern Campus, located in Sudbury, and the Western Campus, located in Thunder Bay. There is an Associate MS Clinic in Thunder Bay housed at the St. Joseph's Care Group.

<sup>iii</sup> NeuroResponse is an online platform that is currently focused on enhancing access to prompt and appropriate MS care and advice. Expansion of the platform to other neurological conditions is being explored. NeuroResponse consists of three components: NeuroDirect, a telephone triage/advice line service staffed by MS nurses; NeuroMail, an email advice service that General Practitioners can use to contact a consultant neurologist; NeuroView – video clinic linking to an expert neurology team with the patient and local clinical view.

<sup>iv</sup> Canadian Institute for Health Information. *The Burden of Neurological Diseases, Disorders and Injuries in Canada*. Ottawa, 2007.

<sup>v</sup> Ibid.

<sup>vi</sup> Kelly & Associates. *Needs Assessment and Stakeholder Consultation for Northern Care Task Force Initiative*. MS Society of Canada, Ontario Division. Toronto, 2002.

<sup>vii</sup> The Kelly & Associates study involved interviews, survey work, and focus groups. With respect to the survey work, 927 people affected by MS received surveys, and 327 (35.3%) of these individuals responded.

<sup>viii</sup> When the survey was conducted, individuals who qualified for the Northern Travel Grant received 34.25 cents/km; as of July 1, 2007 this was increased to 41 cents/km. As of October 1, 2007, recipients are also entitled to a \$100 accommodation allowance provided they are required to travel at least 200km one-way.

<sup>ix</sup> The medical check-up referred to is a consultation. In preparation for a consultation, primary care physicians receive a summary note from the MS specialist outlining the patient's visit to the MS Clinic. This summary note, called a consultation note, includes any recommendations for follow-up, changes to meds, etc.

<sup>x</sup> The MS Society provides funding to MS clinics across Ontario. The Society distinguishes between affiliated MS Clinics and associated MS Clinics. Affiliated clinics are those that provide patient services (including diagnosis and treatment), education, and research of patients with MS, while associated clinics are those that provide patient services and education. Both affiliated and associated clinics are lead by a neurologist with requisite training in MS, and ideally have a registered nurse on staff with certification by the International Organization of MS Nurses, and access to medical allied health professionals.

<sup>xi</sup> The Thunder Bay MS clinic is located at St. Joseph's Hospital and serves northwestern Ontario, including the Kenora District, Rainy River District, and the Thunder Bay District. The Thunder Bay clinic is staffed by three neurologists who provide diagnostic services and MS care, including determination of the most appropriate rehabilitative assessment and care of their patients, as well as education of their patients, caregivers and of health care professionals. The MS Society provides funding support to the Thunder Bay MS clinic.

<sup>xii</sup> These medical or allied health professionals possess skills in, but not limited to, neurology, psychiatry, clinical genetics and/or physical medicine and rehabilitation, nursing, urology, ophthalmology, social work, neuropsychology, physiotherapy and occupational therapy.

<sup>xiii</sup> Primary prevention refers to the prevention of disease or injury in individuals. Secondary prevention focuses on early diagnosis, use of referral services, and rapid initiation of treatment to stop the progress of disease process where possible and avoid unnecessary complications. Tertiary prevention deals with the rehabilitation and return of a patient to maximum function with a minimum risk of recurrence of physical or mental disorder.

<sup>xiv</sup> Ontario has established several Communities of Practice (CoPs) in priority health care areas (Alzheimer Knowledge Exchange, Seniors Health Research Transfer Network, and Mental Health and Addictions Knowledge Exchange Network.)

<sup>xv</sup> The implementation of Telehealth Ontario, offers expanded access to health care information using registered nurses who provide, confidential health advice or general health information 24 hours a day.

<sup>xvi</sup> The registry will track test dates and provide lab results and give health care providers and patients reminders, alerts, and reports on established health indicators. Through integration with other systems such as the Ontario Laboratories Information System, the Diabetes Registry will continually identify new patients with diabetes and will consolidate and update information on critical diabetes indicators.

<sup>xvii</sup> NeuroResponse is an online platform that is currently focused on enhancing access to prompt and appropriate MS care and advice. Expansion of the platform to other neurological conditions is being explored. NeuroResponse consists of three components: NeuroDirect, a telephone triage/advice line service staffed by MS nurses; NeuroMail, an email advice service that General Practitioners can use to contact a consultant neurologist; NeuroView – video clinic linking to an expert neurology team with the patient and local clinical view.