

# THE WAY FORWARD

Alberta's Multiple Sclerosis Partnership



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# Acknowledgments

The recommendations and activities outlined in this document reflect the hard work and dedication of many partners, who work together to improve services and supports for those living with multiple sclerosis (MS). Special thanks go to the MS Connector Services Working Group, which includes:

- MS Society of Canada (Alberta and Northwest Territories Division)
- Calgary MS Clinic
- Edmonton MS Patient Care and Research Clinic
- Red Deer MS Clinic
- University of Alberta
- University of Calgary
- Alberta Health Services
- Alberta Human Services
- Alberta Municipal Affairs

# Executive Summary

*Vision: Albertans affected by MS have access to a co-ordinated, continuous and comprehensive system of care, services and supports that empowers them to have the best quality of life possible.*

Alberta has one of the highest rates of multiple sclerosis (MS) in the world – about 340 out of every 100,000 Albertans are diagnosed with MS. Symptoms can include extreme fatigue, loss of balance, impaired speech and vision, paralysis and mental impairment. While MS raises issues similar to other chronic conditions, it also presents unique challenges because it is so unpredictable. Symptoms can come and go and vary greatly from one episode of the disease to the next, making it very difficult for people with MS to hold a job or maintain a daily routine. For the same reasons, it can be difficult to predict what supports people affected by MS will need most.

Albertans with MS identify a number of barriers to living life to its fullest including difficulty accessing the right services and supports, particularly in rural areas. Barriers extend beyond the health sector to include issues of income supports, social services, and housing.

While it is impossible to predict the progression of MS, what can be predicted is the availability of care, services and supports. *The Way Forward: Alberta's Multiple Sclerosis Partnership*<sup>1</sup> makes five recommendations that will help people with MS get the care they need, when they need it, throughout their lives:

- Provide comprehensive, integrated services;
- Co-ordinate policies for disability supports;
- Support empowerment and self-management;
- Develop education, awareness and the general capacity within our systems to support Albertans with MS; and
- Advance MS research and evaluation.

A key strength of *The Way Forward* is the commitment of all partners to work together to improve access to services and strengthen community supports. *The Way Forward* is a collaboration of the Government of Alberta, Alberta Health Services (AHS), the MS Society of Canada (Alberta and Northwest Territories) and other community partners. Partners will work together to expand knowledge of MS and address the broad range of issues related to this disease.

Work is already underway on a number of actions, including the creation of a patient navigation system and information resources for employers. Partners are also working to improve services to rural areas, incorporate research findings into evidence-based practice and support research into treatments for Albertans with MS.

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<sup>1</sup> *The Way Forward: Alberta's Multiple Sclerosis Partnership*, is referred to as "The Way Forward" throughout this document.

# Introduction

## THE BURDEN OF MS IN ALBERTA

A diagnosis of MS is life changing. It means years of living with a disease that affects the central nervous system, often resulting in extreme fatigue, loss of balance, impaired speech and vision, paralysis and mental impairment.

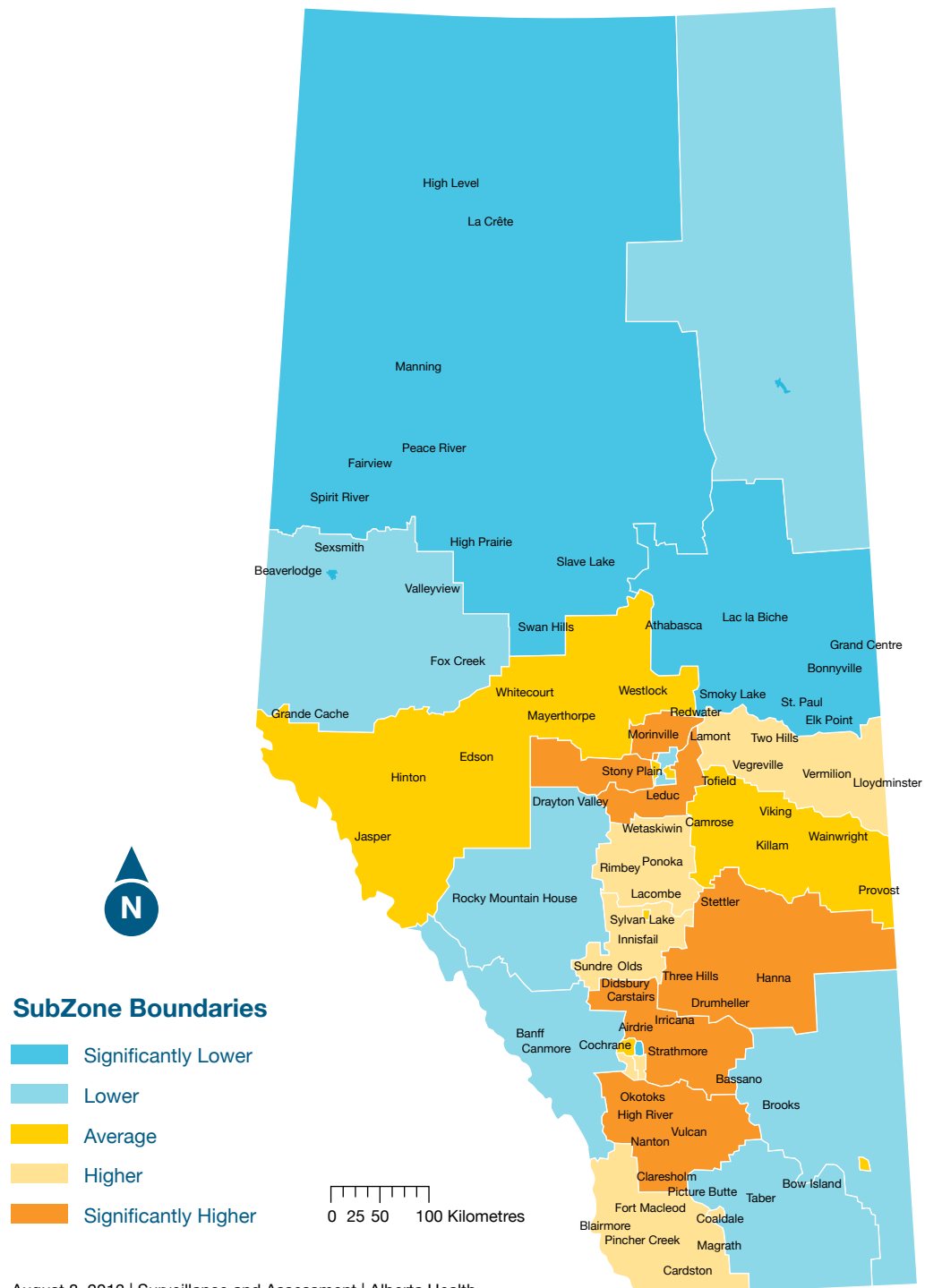
While MS raises issues similar to other chronic conditions, it presents unique challenges because of its unpredictability. Symptoms can come and go and vary greatly from one episode of the disease to the next. This can make it difficult to hold a job or maintain a daily routine. For the same reasons, it can be difficult to predict what supports will be needed over the course of the disease.

MS can be diagnosed at any time in life, from childhood to late adulthood, but for most people the first symptoms occur between the ages of 15 and 40 – the time when people are finishing school, starting careers and planning families. MS is significantly more common in women, who are over 2½ times more likely to have the disease than men.

It is well established that rates of MS are high in Canada, particularly in the Prairie Provinces and Nova Scotia. Research suggests that MS results from a complex interaction between genetics and the environment. Alberta has prevalence rates similar to those in Scandinavia and northern areas of Russia and Europe. In a study conducted by the University of Calgary, the University of Alberta and Alberta Health, it was found that people of western European descent, particularly Scandinavian, had high rates of MS while Aboriginal populations had significantly lower rates. Canada has one of the highest rates of MS in the world. According to a study conducted in 2000-01, there are 240 cases for every 100,000 Canadians. The number of people with MS in Alberta is even higher – about 340 cases for every 100,000 people.

The figure on the next page shows the geographic distribution of MS in Alberta.

Figure 1: Geographic Distribution of MS Prevalence, 2012



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## THE PARTNERSHIP

*The Way Forward* is a collaboration of the Government of Alberta, AHS, the MS Society of Canada (Alberta and Northwest Territories) and other community partners. It signifies a commitment by all agencies to expand knowledge of MS and to identify ways of addressing the broad range of issues related to this disease.

While *The Way Forward* addresses the unique needs of one vulnerable population, it is aligned with broader disease management and health policies. These include: *Alberta's Continuing Care Strategy*; *Alberta's Addiction and Mental Health Strategy*; and the *AHS Strategic Plan for Chronic Disease Management*.

Alberta is already a leader in MS research and care. *The Way Forward* builds on the province's many strengths:

- A world-class interdisciplinary care model through three specialty MS clinics in Alberta: Edmonton, Red Deer and Calgary;
- Approximately 30 specialists in MS (community neurologists) who practice in various locations throughout the province;
- A variety of MS health services and supports provided by primary care physicians and primary care networks;
- A research community that is attracting more MS researchers and leading in both quantity and innovation of MS research in Canada – due in part to funding from the Multiple Sclerosis Society of Canada, as well as the generosity of individuals and corporations in Alberta;
- An income and disability support system for people with disabilities, including people affected by MS;
- The provision of proven pharmacological treatments and a system of nursing supports; and
- An array of community-based organizations and service providers who work with people affected by MS and their families. The Multiple Sclerosis Society of Canada (Alberta and Northwest Territories Division) is the province's primary voluntary organization.

## THE CHALLENGE

While people affected by MS already have access to a wide range of services, they still face a number of barriers to living life to its fullest:

- MS symptoms, including impaired speech and vision, paralysis and mental impairment, make it difficult to navigate all of the systems involved in MS care – health, social, disability and employment.
- It is difficult to access specialists, therapists, psychologists, and other community supports in rural areas.
- Many institutional facilities are not designed to support people with MS, particularly younger people with the disease.
- Some employers are unable or unwilling to accommodate people with the disease, often resulting in early departure from the workforce.
- Frequent remissions and relapses of the disease necessitate flexible programs for disability and income support.
- Caregivers – often family members – need more support to deal with the unpredictability of MS.





# Alberta's Vision

## VISION

Albertans affected by MS have access to a co-ordinated, continuous and comprehensive system of care, services and support that empowers them to have the best quality of life possible.

## GUIDING THEMES

### Collaboration, Person-Centred, Comprehensive

All partners share a responsibility for implementing *The Way Forward*. Partners include government ministries, the health system, the MS Society of Canada (Alberta and Northwest Territories), community organizations and individuals. People affected by MS are supported to manage their lives and their care, and to fully participate in decisions that affect their health and well-being. They will have access to comprehensive services appropriate to their needs – services which are grounded in broader government policy.

*Figure 2: Optimal Quality of Life Through Improved Chronic Disease Management*



## RECOMMENDATIONS

*The Way Forward* identifies five overarching recommendations to guide actions:

- Provide comprehensive, integrated services;
- Co-ordinate disability supports across sectors, ministries and different levels of government;
- Support empowerment and self-management;
- Develop education, awareness and the general capacity within our systems to support Albertans with MS; and
- Advance MS research and evaluation.

### Recommendation One: Provide comprehensive, integrated services.

Health care and social supports must be organized to make sure Albertans with MS get comprehensive, consistent care wherever they live. To avoid fragmented services, a navigation system will help Albertans with MS find their way around our health and social support systems and get timely access to care and social, income and housing supports.

Action underway = ➔

#### GETTING THERE:

- ➔ Develop MS clinical practice guidelines and make sure they are used consistently throughout the province.
- ➔ Provide streamlined access to evidence-based MS drug therapies for patients with Government of Alberta drug plans.
- ➔ Build on the patient navigation system currently being developed by Alberta Health and AHS so there is also information about supports beyond health care, including social, income, housing and transportation.





- ➔ Support options for people to receive services closer to home, including expansion of access to multidisciplinary care through the use of technology, and other methods to reduce the need to travel.
- ➔ Establish and improve links to MS health services between family doctors, care providers, hospitals and community supports.
- ➔ Develop infrastructure to advance supports for Albertans with MS, including an MS population database and an Internet portal to electronic patient record/personal health information.
- ➔ Establish partnerships with not-for-profits, builders and housing authorities to create affordable and specialized housing for Albertans affected by chronic disease.
- ➔ Promote awareness of health services and supports available through home care.

*A multidisciplinary team is a group of health care professionals all working together to provide health services. For the purposes of this strategy, the team extends beyond clinical interventions to include the broader community and supports from the MS Society of Canada, as well as social sector supports for housing, income and equipment.*

## Recommendation Two: Co-ordinate disability supports across sectors, ministries and different levels of government.

MS supports must be co-ordinated if they are to be responsive to the needs of patients. Furthermore, employment policies must ensure people with disabilities are not only treated fairly in the workplace, but are supported in remaining attached to the workforce, thereby improving job retention rates.

### GETTING THERE:

- ➔ Encourage fair employment practices by developing education and awareness packages for employers that discuss MS in the workplace, factoring in relapse and remission.
- ➔ Promote the use of the Alberta Supports website as a source of information about supports available to people with chronic disease.
- ➔ Consider revisions to employment and income support programs, disability tax credits and employment insurance benefits to respond to the needs of people with neurological disabilities.
- ➔ Explore ways of assisting people with MS to travel to Alberta's MS clinics.
- ➔ Work with other ministries to ensure there is age- and ability-appropriate housing for Albertans with specialized needs, including multi-use facilities and continuing care centres for young adults with disabilities.

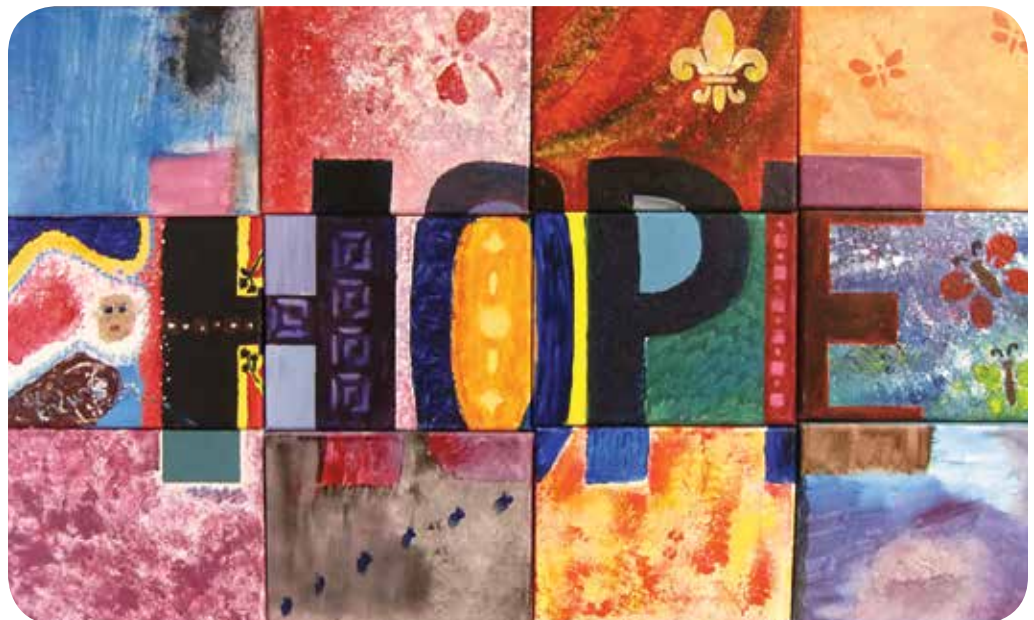


### Recommendation Three: Support empowerment and self-management.

Standard, well-defined mechanisms must enable people with MS to participate in their communities and to make informed decisions about the treatment and management of their disease.

#### GETTING THERE:

- ➔ Develop information about MS care, resources and services to be made available across the province to Albertans with MS and their caregivers.
- ➞ Through education and other supports, help people with MS develop skills to manage their own care.
- ➞ Expand on 'Group Visit' programs for select groups of patients such as young moms and teachers to increase the skills needed for self-management.
- ➔ Involve people with MS and their caregivers in treatments related to care, caregiver education, and respite services.
- ➔ Identify and address barriers to self-management.



**Recommendation Four: Develop education, awareness and the general capacity within our systems to support Albertans with MS.**

Public education and awareness can generate changes that positively affect people living with MS. For example, the MS Society's 'MS Active Now!' program increases awareness of the benefits of physical activity, so fitness and health professionals can design programs for persons with MS. Furthermore, specific information on adaptations and equipment for employers may increase their openness to accommodating people with disabilities in the workplace.

**GETTING THERE:**

- ➔ Target education and awareness to priority groups, such as employers, and staff of continuing care facilities.
- ➔ Extend education to a broader range of health care and service providers, and explore new approaches to share knowledge, including knowledge related to MS and mental health issues.
- ➔ Support knowledge transfer activities through web-based educational programs, conferences and training centres.
- ➔ Develop a module for an educational resource centre targeting tools for the public, service providers and employers.





## Recommendation Five: Advance MS research and evaluation.

Alberta is recognized as a national and international leader in research and will continue to lead improvements in the treatment and understanding of MS.

### GETTING THERE:

- ➔ Increase knowledge about specific clinical treatments, such as impacts of Chronic Cerebrospinal Venous Insufficiency (CCSVI) therapy, and follow-up with people who have undergone the procedure internationally.
- ➔ Increase research capacity in the province.
- ➔ Implement mechanisms to translate research into practice.
- ➔ Continue to build evidence and evaluate models of care, such as Early Contact programs, to support early diagnosis and self-management.
- ➔ Allocate funds to advance MS research in the province.

## Conclusion

Implementation of *The Way Forward* will take collaboration and commitment from all stakeholders, including MS patients and their families. Work is already underway to improve services to rural areas, incorporate research findings into practice, develop information resources for employers, and support research into treatments for Albertans with MS.

Ultimately, *The Way Forward* will help achieve better outcomes for people with MS. They will benefit from a broad system of support that includes not just family and friends, but also health care providers, community supports and specialized services. Most importantly, people with MS will be empowered to be active participants in decision-making and the management of their disease.

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