

Talking Points: Priority – Make Access a Reality

LINE- Background

Make Access a Reality!

The unpredictability and episodic yet progressive nature of MS makes it particularly challenging not only in accessing the built environment, but also in accessing treatments, care, and appropriate housing.

For many individuals living with MS, disease-modifying therapies (DMTs) offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, delaying the accumulation of disability. The Conference Board of Canada report *“The Value of Specialty Medications: An Employer Perspective”* noted *“There is strong evidence to suggest that early treatment with specialty medications results in significant health benefits, including reduced disability rates and delays in the rate of disease progression.”* They found that there are societal benefits of those treated with specialty medications including reduced caregiver needs of treated dependents, and reduced use of in-patient and out-patient healthcare resources.

The needs of people with MS and their families should be at the centre of health and drug policy decisions. Their perspectives and experiences should be a top priority throughout the drug decision making processes. (i.e. Health Canada, Canadian Agency for Drugs and Technologies in Health’s (CADTH) Common Drug Review, the pan-Canadian Pharmaceutical Alliance (pCPA), and federal, provincial, and territorial drug plans). These decisions should equally take into consideration the patient voice with the clinical and cost-effectiveness considerations.

Canadians living with MS often require housing support – in home, transitional and/or long term. They should be afforded the opportunity to remain in their own homes and in the community and have care that focuses on options, diversity, and choice.

People with MS want to live at home and not be a burden on family and friends. They want to be active participants in their communities. However, we heard that accessing services to maintain this independence can be difficult. There were many barriers. Home care services and assistance with personal care vary significantly by region, have long wait times, and often limited access. For those unable to remain in their home, there are few age-appropriate long-term care facilities for people with MS and life is very difficult for those living in facilities that do not provide the mental, recreational, and social stimulation required to maintain good physical, mental, emotional, and social health.

Effective care in the home often requires housing adaptation and accessibility modification and other considerations to support independent living. Examples include, lifts, access to basements, ramps, access to house, bathroom renovations, and air conditioners. We hear from people affected by MS that there is a great need for funding to support these accessibility modifications, yet there is a lack of programs, and if there is a program (vast regional variation in current programs) the income thresholds are too low for people to access them and they don’t take into consideration the added costs of living with a disability.

We are encouraged by the Government of Canada’s commitment to introduce accessibility legislation, and by its work with the provinces and territories with their shared health priorities, and the national housing strategy. However, we want to ensure that Canadians affected by MS are represented and supported in each of these initiatives.

SINKER—Our Request:

The federal government should help *“Make Access a Reality”* by:

- ✓ **Ensuring the Accessibility Legislation** includes all Canadians with disabilities whether their disabilities are visible or invisible, and whether they are permanent or episodic (periods of wellness followed by periods of disability). The definition of disability needs to include the notion of the changing dynamic of disability including episodic, which is the case for individuals living with progressive neurological diseases like MS.
- ✓ **Ensuring timely and affordable access to all Health Canada approved treatments** for MS as early intervention is vital to avoid many of the long-term economic and personal costs that result from unnecessary irreversible disability. People living with MS and their unique perspective need to be proactively involved throughout the drug review process from Health Canada to the pan Canadian Pharmaceutical Alliance.
- ✓ **Investing in comprehensive care and appropriate housing that includes:**
 - Comprehensive home care, which focuses on the family and includes nursing and personal care, supplies (e.g. incontinence supplies) and equipment, meal preparation, home making, child care, rehabilitation, technology (home monitoring), and meaningful respite services.
 - Support for home modifications through the development of a nation-wide funding program as part of the implementation of the National Housing Strategy.
 - For those unable to remain in their home, the development of and sufficient funding for age appropriate housing, care and supports needs to be created.