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Ms. Colleen Sonnenberg
Manager, Long-Term Care Homes Act Project
Ministry of Health and Long-Term Care
Health Program Policy & Standards Branch
Office of the Director
8th Floor Hepburn Block, 80 Grosvenor Street
Toronto, ON M7A 1R3

Dear Ms. Sonnenberg:

Thank you for the opportunity to provide feedback on draft regulations under the *Long-Term Care Homes Act, 2007*. The MS Society of Canada, Ontario Division appreciates the opportunity. Our responses are on the pages following this letter.

Multiple sclerosis is a chronic, progressive disease of the central nervous system. This unpredictable and often disabling condition affects between 22,000-27,000 people in Ontario. Because the course of the disease is commonly characterized by well-defined attacks followed by periods of recovery, people's support needs can be variable and episodic. MS is most often diagnosed in young adults – individuals who are finishing school, starting careers and beginning families.

We look forward to participating in future opportunities to help shape the development of Ontario's long-term care homes and to help improve the lives of people affected by MS who live in them.

Ms. Sonnenberg, thank you for including us in your consultation. Should you have any questions, please contact me at kim.steele@mssociety.ca or by phone at 416.922.6600 ext. 2243.

Warmest regards,

Kim Steele
Senior Coordinator, Government Relations

**MS Society of Canada Ontario Division Response:
Ministry of Health and Long-Term Care
*Long-Term Care Homes Act, proposed initial draft regulation***

Introduction

The proposed initial regulation is a positive step in improving the lives of Ontarians who live in long-term care homes. In the MS Society's previous submissions to the ministry, it has been noted that the care provided to people with multiple sclerosis (MS) who live in long-term care facilities is often felt to be inadequate and inappropriate. This is of particular concern to those individuals with MS who are younger than 65.

MS symptoms are highly unpredictable and variable from person to person. These symptoms may include: vision disturbances such as double or blurred vision; extreme fatigue; loss of balance; problems with coordination; stiffness of muscles; speech problems; bladder and bowel problems; short-term memory problems, and even partial or complete paralysis.

The proposed regulation does much to address some of the unique challenges that people with MS who live in long-term care face, but there are areas of the regulation that could be strengthened.

Long-term care homes are *homes*: people live out their *lives* in them. It is important, therefore, that people and their loved ones, who often come to visit, are made to feel *at home* in Ontario's long-term care homes. This is something to keep in mind as Ontario redevelops its long-term care homes and the regulations that support them.

Part I: Definitions

Recommendations for this section are as follows:

There is a need to define "substitute decision-maker", which is referenced throughout the proposed regulations and the *Long-Term Care Home Act* (LTCHA) but is not defined. If the definition provided in the *Health Care Consent Act* is the definition being used in the LTCHA and its regulations, this should be referenced.

Plans of Care

The MS Society strongly supports the requirement of LTC homes to create initial plans of care and comprehensive plans of care for individuals who live in LTC.

The overall spirit of the plans of care as presented is organizationally and operationally focused. While the functional aspects of this approach have merit, there is a need to also focus on client outcomes. For example, there is no mention of the objectives and outcomes of the proposed care plans vis-à-vis their perceived impact on the clients who are the beneficiaries of these plans.

Moreover, we believe that **an additional required program under the Plans of Care section - psychological well-being – should be created.** This program would assess the psychological well-being needs of individuals living in long-term care and would develop a plan to improve their psychological well-being.

Section 7 – Comprehensive Care Plans, notes:

The comprehensive plan of care would include certain assessments, such as customary routines, cognition ability, communication abilities, vision, psychological well-being, behaviour patterns, physical functioning, continence, health conditions, skin condition, activity patterns, special treatments, safety risks, cultural, spiritual, and religious preferences, dietary profile and nutritional status.

While the assessment list is thorough, the MS Society recommends that age-related needs be included as part of the assessment and, further, that age-related needs be included as a key component of comprehensive plans of care.

While we do not have statistics on the number of young adults in long-term care in Ontario, we do know from our members across the province that individuals who are under the age of 65 living in long-term care face significant challenges to their health and well-being.

We do have information on the number of young adults living in complex continuing care, which may be useful in providing some context. According to the Canadian Institute on Health Information (CIHI), in 2005–2006, just over one in six patients (17%) who received treatment in Ontario complex continuing care hospital beds was between 19 and 64 years old, and 56% (2,276 individuals) of this group had neurological conditions. Young adults with MS made up 10% (228 individuals) of the neurological group.

This is of particular concern to the MS Society because of the early age of onset for MS. An individual with MS who enters a long-term care facility designed for the frail and elderly at 35 years of age may remain there for 40 years or more. Age-inappropriate living conditions often result in anxiety, depression, and longer-term mental health issues that increase the already complex health needs of these individuals.

(Where do you think the appropriate place in this response would be to suggest the idea of age-appropriate pods, wings, etc. DG)

Section 12 – Continence care and bowel management

Overall, the direction of this section is positive. However, there is some concern with the requirement that continence products be evaluated *annually*.

It is recommended that a clause be included in Section 12 to address the need to assess some residents – particularly those affected by diseases that are progressive in nature, such as MS – more frequently than once a year.

Section 14 – Responsive behaviours

This section could be strengthened by adding the following **bolded** phrase to the final sentence:

*All approaches to care would be designed to meet the needs of residents with responsive behaviours and staff would be advised of the residents who require monitoring **and would be educated on appropriate management measures.***

Abuse and Neglect

The MS Society supports a zero tolerance policy. This section is clear, appropriate in scope and process, and absolutely necessary. However, while it deals with abuse and neglect of residents that may come at the hands of staff of long-term care homes, it does not deal with abuse and neglect that may come at the hands of volunteers, visitors, and contractual staff and consultants.

It is recommended that this section include reference to the policies and processes for dealing visitors, volunteers, contractual staff and consultants who abuse and/or neglect residents.

(Does any section deal with abuse by fellow residents? Should it be mentioned? DG)

Keeping of Waiting List

The MS Society has two recommendations with respect to the keeping of waiting lists:

- **There should be a limit of how long an individual should wait to gain access to long-term care once they have been placed on a list. Once this limit is reached, the individual should be placed *immediately* in one of his or her top five choices, with an option of exchange to a choice higher on his or her placement choices should the opportunity arise at a later date.**
- **Long-term care homes should be required to *publicly* report on the average duration of their wait list times, in a similar way in which the Ministry of Health and Long-Term reports on emergency room wait lists, wait lists for diagnostic services (e.g. MRI), etc.**

Placement into Categories on Waiting List

It is very promising that the Ministry will consider the religious, ethnic, or linguistic origins of individuals when determining the categories in which these individuals will fall into when being placed on waiting lists.

We recommend that the Ministry also consider age when categorizing individuals for placement and on waiting lists to help ensure that younger adults are placed in age-appropriate settings.

We further recommend that age considerations be incorporated as a consideration under *Section 51 – Exchange category*, which would potential benefit younger people with disabilities that are not developmental in nature.

It is encouraging that people with developmental disabilities may benefit from exchanges between appropriate facilities or group homes under the *Services and Supports to Promote Social Inclusion of Persons with Developmental Disabilities Act, 2008*. Currently, people with physical disabilities and/or diseases or conditions that are not developmental in nature do not have a similar Act from which to advocate for appropriate, socially inclusive living spaces.

Questions and comments

Thank you for the opportunity to provide feedback on the proposed initial draft regulation under the *Long-Term Care Homes Act, 2007*. Should you have any questions or comments regarding the MS Society's submission please contact Kim Steele at 416.922.6600 ext. 2243 or by email at kim.steele@mssociety.ca.