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March 28, 2008

Ms. Colleen Sonnenberg
Lead, 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 regarding the development of regulations under the *Long-Term Care Homes Act, 2007*. The MS Society of Canada, Ontario Division has chosen to respond to those parts of the survey that are most relevant to our community members. 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 approximately 18,000 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 provide input in the development of the regulations under the LTCHA, including the formal process to review and comment on the proposed initial regulations.

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,

A handwritten signature in black ink, appearing to read 'Kim Steele', with a long horizontal flourish extending to the right.

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
Project Regulatory Content Development Survey**

Part II, RESIDENTS: RIGHTS, CARE AND SERVICES

Care and Services

The new Act will require the licensee to provide programs of care and services to meet the assessed needs of residents. These programs include nursing and personal support services, restorative care, recreational and social activities, dietary services and hydration, medical services, accommodation services (housekeeping, laundry and maintenance services) and an organized volunteer program. (Reference: sections 8 to 16)

1) What are the key features that should be included in each of these programs to ensure resident quality of life? Please consider what should be retained from existing programs and what improvements could be made.

The MS Society of Canada, Ontario Division supports the requirement of the licensee to provide programs of care and services to meet the assessed needs of residents.

The care provided to people with multiple sclerosis (MS) who reside in long-term care facilities is often felt to be inadequate and inappropriate. MS symptoms are highly unpredictable and variable from person to person. They 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.

Families have indicated that their loved ones with MS who reside in long-term care facilities are often put to bed at inappropriate times and are woken up when they are sleeping (which is important in dealing with extreme fatigue) to receive medications, to be brought to the toilet, changed, etc. Family members have noted that a minimal amount of care is given to their loved ones, and that they are asked to perform many care activities themselves.

Personal support workers and other health care providers are generally not trained to understand and accommodate the needs of people with MS. Staff in long-term care facilities are generally not well-educated in illness-specific support and care.

In this vein, the section on Nursing and personal support services should make mention of disease and age-appropriate training and education requirements, as well as mention of service timed to the needs of the patient. For example, people with MS whose fatigue is severe in the

afternoon should not be given a bath at that time. Improved knowledge of the disease and its symptoms, as well as requirements around timing service to the needs of the patient would help to ensure that baths are not given at times when patients need to rest to be well. Furthermore, disease specific education and training is essential for those who assess the needs of patients and those who determine individual care plans.

Another issue that people with MS who reside in long-term care homes face is obtaining access to specialized care. For example, people with MS who enter long-term care may not have access to a knowledgeable neurologist. The regulations should require long-term care homes to provide access to knowledgeable specialists.

As well, although a small minority of people younger than age 65 with MS require institutional care, it is vital for their quality of life that their housing and care are appropriate for their age. Too often, they are placed with much older individuals in settings designed for frail, elderly people that lack age-appropriate supports such as recreational and social activities, information and referral assistance, and volunteer programs. Often, this results in a significantly reduced quality of life, which can include depression and other mental health problems.

This situation is not limited to young people with MS. There are a significant number of non-seniors living in hospital-based continuing care facilities and complex continuing care facilities in Ontario:

- 20% of residents in hospital-based continuing care are under 65.¹
- 40% of residents in complex continuing care are under 65.²

The regulations should require the development of policies and practices in long-term care homes that ensure that young adults with disabilities or chronic illness can continue to live rich, meaningful lives that include peer-to-peer social interactions, flexibility for social outings, welcoming environments for loved ones, and other aspects of life that support personal well-being and fulfillment.

¹ Canadian Institute for Health Information, 2006, Facility-Based Continuing Care in Canada, 2004-2005, p. 9

² Canadian Healthcare Association Policy Brief #5, 2005. Stitching the Patchwork Quilt Together. P. 30.

24-hour Nursing Care

The new Act will continue the current requirement that at least one Registered Nurse, who is both an employee of the home and a member of the regular nursing staff of the licensee, must be on duty and present in the home at all times (that is, on a 24/7 basis). Regulations may be made requiring certain classes of homes to have more than one Registered Nurse on duty 24/7 and establishing the rules governing such a requirement. [References: subsections 8(3) and 38(2)(g)]

2) Should home size be the main factor in determining how many Registered Nurses are required to be on duty in the home at all times? Are there other factors that should be taken into account?

The range of illnesses, behaviours, and symptoms of patients should be also be taken into account, as well as the complexity of the combined care needs of patients within a given home.