



The Need for Age-Appropriate Long-Term Care: MS Society of Canada Views on Bill 140, Long-Term Care Homes Act, 2006

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Thank you for the opportunity to present the views of the Multiple Sclerosis Society of Canada, Ontario Division, on the proposed changes to Ontario's long-term care system. My name is John Clifford, and I am chair of the Ontario Government and Community Social Action Committee for the MS Society. With me is Deanna Groetzinger, MS Society vice-president of government relations.

The MS Society is pleased that the legislation governing Ontario's long-term care homes is being updated and consolidated through Bill 140. It is vital that our most vulnerable Ontarians receive the best care and protection possible. While many of the proposed changes are good ones, the MS Society believes there is a serious oversight within Bill 140. Namely, the proposed legislation does not contain any provisions that would facilitate the development and delivery of age-appropriate care within long-term care homes.

Why age-appropriate long-term care? Well, let me tell you about several people with MS and their experiences with the current system. Their stories, unfortunately, are repeated every day across Ontario.

There is a young man with MS who lives in Kingston. He is now 30 years old but has been living in a long-term care home for more than four years. He is severely disabled because of MS and needs considerable care. Unfortunately, his mother has her own health problems, his father is dead, and there are no other family members to assist him. He desperately wants to leave the facility and live in the community with assistance from home care and other services. He points out that even though the facility is supposed to be his home, he can't even have a nap when he needs one. MS can cause very severe fatigue but he has been told that if he lies down in the afternoon for a nap, he would have to stay in bed for the rest of the day. Clearly, a long-term care home whose primary residents are the very elderly is no place for this young man.

Even when there are community supports available, it is still hard to move out of a long-term care home as a Toronto woman knows. She was diagnosed with MS in her mid-twenties and able to manage on her own until she was about 45. In 2000, she developed a wound and had to be hospitalized. While there, she was advised by health care professionals that it would not be safe to continue to live on her own. She and her family began the process of finding a suitable place. In the meantime, she was sent from the acute care hospital to a facility for rehabilitation therapy. Frankly, this may have been a tactical mistake since she was then considered to have adequate housing. She was passed over for attendant care apartments because there were people "in more desperate need" who didn't have housing. After three years, she finally agreed to move to a long-term care home where today at the age of 50 she lives with residents who are very elderly, frail and many have dementia.

These examples provide some background to our disappointment. When reading Bill 140, we found that the needs of younger people with MS and other diseases and disabilities are not addressed in the proposed legislation.

I'll now ask Deanna to review in more detail our concerns about the proposed legislation and to provide our recommendations for improving it.

Deanna Groetzinger

Although only a minority of people younger than age 65 with MS require care in a long-term care home, it is vital for their quality of life that their housing is appropriate for their age. Too often, they are placed with much older individuals in settings designed for frail, elderly people. This can result in a significantly reduced quality of life, which can lead to depression and mental health problems.

In the view of the Multiple Sclerosis Society of Canada, the appropriate solution is to have available a continuum of appropriate housing and care. Most importantly, Ontarians who are disabled or chronically ill should have the supports they need to remain in their own homes. If, because of increased care needs, remaining at home is not possible, there should be a range of age-appropriate housing and care options.

This is not just an issue for people with MS and for the MS Society. A 2006 study by the Canadian Institute for Health Information found that 20 per cent of residents in continuing care facilities in Ontario hospitals were younger than 65. The Canadian Healthcare Association reported in 2005 that in the Ontario facilities that provide complex continuing care about 40 per cent of residents are under 65 and the number is increasing. MS Society research found in 2000 there were 225 individuals with MS living in long-term care homes, with care needs ranging from moderate to high.

Age-appropriate housing for young adults with disabilities is an issue of growing concern and is of particular significance in the case of multiple sclerosis which is diagnosed most often between the ages of 15 and 40. People who develop MS must cope with the wide range of symptoms and disabling effects of the disease for the rest of their lives.

The MS Society strongly recommends that solutions for housing and care needs not be developed in isolation. Above all, the government of Ontario should adopt an overall approach of providing sufficient home supports to individuals who require health services or assistance with activities of daily living. The philosophy of "home is best" should guide all subsequent decisions.

What this means is the development of resources for an effective, high quality, equitable and accessible, publicly-funded home care system across Ontario for

people with chronic, long-term diseases like MS. Within this approach, needed mobility equipment and home adaptations should be funded as should a coordinated system of social supports, including accessible transportation.

The MS Society was pleased to note that Monique Smith, Parliamentary Assistant to the Minister of Health and Long-Term Care, addressed this issue in her report *Commitment to Care: A Plan for Long-Term Care in Ontario*. Specifically, her report says “there may be some pressure on CCACs to place some seniors prematurely into LTC facilities because of the availability of new beds and the shortage of funding for home care...We suggest redirecting government funding into community alternatives and home care.” And later in the report, “We recommend the Ministry re-examine new bed allocations with a view to stopping the building of those not yet in the ground and redirecting this funding savings to home care...”

The MS Society shares this concern and has for some time and has developed a report about age-appropriate long-term care called *Finding My Place*. While having an adequate supply of long-term care beds is important, we fear that there is and will continue to be increased pressure on CCACs to solve their home care funding problem by persuading people to leave their homes and move into long-term care facilities. This persuasion can be very direct – imagine being told that you or your loved one can’t have home care but your care problems can be solved easily by your moving to a long-term care home – no matter if you are in your early forties and your new roommate is in her eighties.

Therefore the MS Society recommends:

- The government of Ontario proactively develop a sufficient mix of age-appropriate supportive housing, congregate care facilities and long-term care homes across the province for Ontarians who can no longer live in their own homes.
- The government of Ontario develop clear policies regarding the placement of younger adults with MS and other disabilities to ensure they receive age-appropriate care in age-appropriate settings.
- The government of Ontario ensure that age-appropriate long-term care housing options are available across Ontario so people can stay in their home communities close to family and friends.
- The government of Ontario include in the legislation a province-wide minimum staffing standard for long-term care facilities, to ensure there are sufficient staff to provide a minimum of 3.5 hours per day of nursing and personal care per resident.

- The government of Ontario ensure there are uniform provincial standards and funding assessment tools to be used by all Local Health Integration Networks in planning home care and long-term care.
- While the creation of the Office of the Long-Term Care Homes Resident and Family Adviser appears to be useful and helpful, as is the strengthening of “whistle-blower” protections, an Ombudsman for Long-Term Care position should be created or the existing Ombudsman’s responsibilities should be expanded to include long-term care.

On behalf of the MS Society of Canada, thank you for the opportunity to present today, and we look forward to your questions and comments.