Continuum of Care
Meeting the needs of Canadians with Multiple Sclerosis
Continuum of Care: Meeting the needs of Canadians with multiple sclerosis

“The Romanow Commission and the Kirby Committee left a major gap...when they did not directly address the role of home care services for persons with... chronic health conditions... the current approach to home care is misguided and may well lead to an increasing cost spiral in health care services and, in particular, hospital services and long term care residential services,” Marcus J. Hollander.¹

“...there is growing evidence that investing in home care can save money while improving care and the quality of life for people who would otherwise be hospitalized or institutionalized in long-term care facilities,” Roy Romanow.²

People who have health problems prefer to live in the comfort of their own homes, and people with MS are no different. Fortunately, the vast majority of people with MS are able to remain safely and independently at home throughout their lives. Most remain at home with just minimal assistance and adaptations to meet their changing needs. Others, whose disease is more severe, may need home renovations and formal assistance through home care and other services. A much smaller group, who are more severely disabled, will need to move to a long-term care home or similar facility.

About Multiple Sclerosis

Multiple sclerosis is a disease of the brain and spinal cord which most often strikes between the ages of 15 and 40. The disease is often episodic in nature, especially in the first 10 to 15 years, when it is characterized by unpredictable relapses (also called attacks), followed by periods of remission. It can affect vision, coordination, balance and mobility, mood and cognition, and cause severe fatigue. Over time, the disease often becomes worse with fewer periods of remission.

Nearly 80 percent of people with MS are eventually unable to work full-time because of the severity and unpredictability of their symptoms. Not only is MS associated with under and unemployment, but costs for medications, equipment and services are substantial and reimbursement – whether from the provincial government or from private health insurance – typically does not cover the full amount. Limited housing and care choices as well as reduced income may result in younger adults with MS having to move out of their homes to care settings that are totally inappropriate.

In the view of the Multiple Sclerosis Society of Canada, the solution for people with MS and other chronic diseases and disabilities...
is equitable access to a continuum of appropriate, high quality housing and care. First and foremost, Canadians 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.

The Existing Situation

Home Care
The Canadian Home Care Association defines home care as an array of services for people of all ages, provided in the home and community setting, encompassing health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration and support for the informal (family) caregiver.³

While not included as an insured health service under the Canada Health Act, home care is recognized in the Act as an extended health services. Increasingly, provincial governments across Canada have recognized the importance of home care and began adding home care to the services they provided their citizens. Home care services range from providing health services such as wound care that previously was delivered in a hospital or doctor’s office to substituting for long-term residential care such as eating, dressing and bathing. Home care programs serve more than 1.2 million Canadians annually.⁴

For a number of years, provincial governments used home care as an extension of acute care. In the past decade this trend has accelerated. People remain in hospital for much shorter periods of time compared to 20 years ago with the result that post-operative and post-acute care are being delivered in individuals’ homes. This has saved millions on hospital costs but in many areas of the country it meant that more and more funding is going to deliver post-hospital home care instead of home care for chronic health problems. Dr. Marcus Hollander points out there is a danger in focusing exclusively on short-term home care because the definition in the minds of policy makers and the public could shift to this short-term model. “This could lead to further encroachment on home care services, and particularly home support services, for people with ongoing care needs.”⁵

Unfortunately, we have already seen this encroachment on home care services in many provinces. While short-term, post-acute home care is steadily increasing, cutbacks to long-term home care delivery are growing, and fewer people with chronic care needs are receiving the home care they need. According to the Health Charities Coalition of Canada, new home care programs, such as short-term acute care, short-term mental health and palliative care home care, are being implemented at the expense of established programs, such as chronic care services.⁶
There is considerable evidence that broadening home care funding would be cost effective. Dr. Marcus Hollander’s study, comparing home care to long-term care costs in BC in the mid to late 1990s, found annual cost to government for a person receiving home care was $9,624 compared to a cost of $25,742 for a person in a long term care facility. Home care costs were still less even when a person needed the highest level of care. Home care costs were $34,859 and long term care costs were $44,233.7

Age-Appropriate Long-Term Care

For some people with MS, the severity of the disease coupled with the lack of home care services means they must move out of their own homes. Ideally, they would move to a near-by home-like setting with other people who are in their own age range, but unfortunately, far too many younger adults with MS have to enter long-term care institutions with residents twice their age or more. The MS Society recognizes that across Canada there are some excellent housing options for younger adults who are severely disabled, but they are, unfortunately, extremely scarce. Those housing options are encouraging examples of what can and should be done.

- Supportive/assisted living
  Supportive/assisted living can be provided through collective housing, with the addition of services such as meals, housekeeping, and round-the-clock personal care and health services.

Personal Story: From home to institution

At 43 with primary-progressive MS, Katie lives in a long-term care facility because her care needs are too high for home care and supportive living. Until three years ago, she was living independently in her own barrier-free condo when she was told advised her care needs exceeded what home care could provide.

Katie moved to a supportive living arrangement and while it was not her own home, it did provide her the opportunity to stay in the community while receiving necessary health services and supports. This was all shattered a few years later when Katie was placed in a long term care facility for seniors. She was told this was a temporary placement but soon found out that she was not allowed to return to the community (home or supportive living) because she exceeded the level of care that home care was able to provide.

Katie has since been moved to another facility that has a younger population but she continues to face challenges receiving adequate care. The facility is not equipped to deal with individuals who are busy and engaged in employment, volunteering, social and recreation programs outside of the institution.8
• **Congregate care homes**
  Congregate care homes provide housing and care to small groups of people in home-like settings in the community.

• **Age-appropriate services in long-term care homes**
  Some institutions have adopted innovative approaches to meet the needs of younger clientele. These include designating a floor or wing for young adults with MS and/or other chronic diseases, providing training about the diseases to facility staff, and combining independent living arrangements with group activities delivered in an age-appropriate manner.

**What Is Being Done**

Over the past decade, there has been agreement by the federal, provincial and territorial (FPT) governments that home care is a health care priority. Following the release in 2002 of two extensive examinations of Canada’s health care system by Roy Romanow and Michael Kirby, the FPT first ministers agreed to provide first-dollar coverage of short-term acute home care and end-of-life care. They also agreed by 2006 the services could include nursing/professional services, pharmaceutical and medical equipment/supplies, support or essential personal care needs and assessment of client needs and case management.

**Personal Story: Situation not “desperate” enough**

Even when age-appropriate facilities are available, Diane’s story illustrates how hard it is to move out of a long-term care home where residents are mostly elderly and frail. Diane was diagnosed with MS in her mid-twenties. She was able to manage in her own apartment until late 2000 when she was 45. She developed a wound that required her to be hospitalized. While in hospital, she was advised by doctors and other health care professionals she should not return to her own apartment because of her health issues. She and her family began the process of finding a suitable place for her to live. In the meantime, she was sent from the acute care hospital to the neurology floor of a rehabilitation hospital.

In retrospective, this move may have been a poor decision since once there, she was considered to have adequate housing. Places in facilities with attendant care apartments went to people “in more desperate need”. After three years of constant but unsuccessful attempts by herself, her family and social workers, she agreed that moving to a long-term care facility was the only way she would ever leave hospital. Today at the age of 50, she lives in an institution whose residents except for her are geriatric, frail and many have dementia.⁹
Moving ahead on home care and age-appropriate long-term care

Formally recognizing the benefits of home care was an excellent step forward, but more needs to be done to meet the needs of Canadians with MS and others with chronic illnesses and disabilities. The Multiple Sclerosis Society of Canada looks to leadership from all levels of government so there is a true continuum of care.

Recommendations for Action

- The federal, provincial and territorial governments work together to develop and fund a comprehensive home care strategy to result in the inclusion of home care within the Canadian health care system, recognizing and respecting jurisdictional differences and responsibilities.

- The federal, provincial and territorial governments work together to develop and promote national standards for home care with agreement on core services including case management, professional services, palliative care services, personal care services, pharmaceuticals and equipment and supplies.

- The federal, provincial and territorial governments recognize and support the critical role that unpaid caregivers such as spouses, other family members and friends play in providing home care and support services to people with MS and other chronic illnesses and disabilities.

- The federal, provincial and territorial governments work together to develop and promote age-appropriate supportive housing, congregate care and long-term care homes for people who can no longer live in their own homes.

The Multiple Sclerosis Society of Canada welcomes the opportunity to provide insights and expertise in the development of home care and age-appropriate care policies and programs.
References


3. Canadian Home Care Association website: [www.cdnhomecare.ca](http://www.cdnhomecare.ca)

4. Canadian Home Care Association website: [www.cdnhomecare.ca](http://www.cdnhomecare.ca)


8. Katie is a member of the Multiple Sclerosis Society of Canada.

9. Diane is a pseudonym. Her sister provided her story.

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