



**Finding My Place:  
Age-appropriate housing  
for younger adults with multiple sclerosis**



Multiple  
Sclerosis  
Society of  
Canada

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canadienne  
de la sclérose  
en plaques



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## Executive Summary

Although just 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. Often, this results in a significantly reduced quality of life, which can include depression and other mental health problems.

In the view of the Multiple Sclerosis Society of Canada, the appropriate solution is the availability of a continuum of appropriate housing and care. First and foremost, 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.

## Recommendations

### Home Care

- Adopt an overall home care philosophy with the goal of providing sufficient home support to individuals, who require health services or assistance with activities of daily living.
- Provide resources for an effective, high quality, equitable and accessible publicly funded home care system across the province for people with chronic, long-term diseases like MS.
- Establish standards, guidelines, benchmarks and indicators to ensure best practices in home care services.
- Ensure necessary mobility equipment and home adaptations are funded

- Develop a coordinated system of social supports including accessible transportation.

### Caregivers

- Support the critical role that family/friend caregivers play in providing home care and support services to people with MS.
- Increase the provision of services such as respite and attendant care, support, and financial assistance to support those who care for adult family members with MS.
- Develop a coordinated system to help families find necessary support and services.

### Long-Term Care

- 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. This will require an expansion of the current supply.
- Actively seek community partnerships to develop and fund age-appropriate housing for younger adults with MS and other disabilities and chronic illnesses.
- 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. 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.

## **Introduction**

This paper explores issues related to age-appropriate accommodation for younger adults with multiple sclerosis (MS) who have high care needs. Younger adults are defined as adults under the age of 65. It describes current problems and suggests some directions and models for meeting the range of needs among younger adults with MS. Even though the focus is on multiple sclerosis, many of the points raised will apply to younger adults with other disabilities or chronic diseases that require a high degree of care.

## **The Issue**

Although just 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. Often, this results in a significantly reduced quality of life, which can include depression and other mental health problems.

In the view of the Multiple Sclerosis Society of Canada, the appropriate solution is the availability of a continuum of appropriate housing and care. First and foremost, 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.

## **About the Multiple Sclerosis Society of Canada**

The mission of the Multiple Sclerosis Society of Canada is to be a leader in finding a cure for multiple sclerosis and enabling people affected by multiple sclerosis to enhance their quality of life. It is the only national voluntary organization in Canada that

supports both MS research and services for people with MS and their families. Founded in 1948, the MS Society of Canada has 28,000 members, seven regional divisions and nearly 120 chapters.

## **Facts about Multiple Sclerosis and Housing**

Multiple sclerosis is a chronic, progressive disease of the central nervous system. This unpredictable and often disabling condition affects more than 50,000 people in Canada. Because the course is commonly characterized by well-defined attacks followed by periods of recovery, people's support needs can be variable and episodic. A 2006 Canadian Institute for Health Information study found 20% of residents in Ontario hospital-based continuing care facilities were younger than 65.<sup>1</sup> The Canadian Healthcare Association reported in 2005 that in the Ontario facilities that provide complex continuing care, about 40% of residents are under 65 years old, and the number is increasing.<sup>2</sup> MS Society research has found that in 2000, 225 individuals under age 65 were living in long-term care homes, with care needs ranging from moderate to high. Most, however, fell in the higher care need categories. 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. Individuals who develop MS must cope with the wide range of symptoms and its disabling effects for the remainder of their lives, often as long as 40 years.

## **The Current Situation: Housing Options**

### ***There's no place like home***

People prefer to live in their own homes or in an environment that feels as much like a traditional home as possible. 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 stay in their homes 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 smaller group, who are more severely disabled, will need to move to a long-term care home or similar facility.

### ***Financial and social issues can affect staying at home***

Nearly 80% 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 employment and unemployment, but costs for equipment and services are substantial, and reimbursement typically does not cover the full expense. 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.

### ***Moving Forward: Home and Community-Based Approaches***

The Multiple Sclerosis Society of Canada believes that people with MS should be participating members of society, with choice and control over their lives, and with access to a range of housing and support options that meet their particular and changing needs. Ideally, individuals will be able to remain in their homes as long as possible supported by home care and other services. If remaining at home is no longer possible, there should be a system with a continuum of housing options to match diverse individual needs. This system should be grounded by an explicit philosophy and values that recognize individuals' evolving life situations and the need for age-appropriate options for younger adults with MS within long-term care settings. Provision of home care, support for caregivers and a wide range of

### **John's Story: Yearning to be in the community**

John is 29 years old and has lived for the past three years in a Kingston chronic care centre because of the disabilities caused by MS. His mother cannot provide care because of her own health problems. His father died 15 years ago. He wants desperately to leave the facility and live in the community with assistance from home care and other services. He says: "At the age of 29, I need to be out in the community, being productive and socializing, rather than sitting everyday on a chronic care floor..."

He points out that although the institution is supposed to be his home, he can't even take a nap when he needs to: "Having MS, I am sometimes very fatigued in the middle of the day and wish to lie down for a nap. Recently... I was told by staff that if I lay down for a nap, I would have to stay in bed for the rest of the day."

John has tried to find a more age-appropriate housing option in the community, but with no success despite the fact that staff at the chronic care centre agree that it is no place for a 29-year-old man.<sup>3</sup>

long-term care housing alternatives are the keys to this continuum of care.

#### ***1. Home care is essential***

Care at home – this simple phrase sums up the desired outcome for individuals who, because of disability for chronic illness, need some assistance to live independently and successfully in their own homes. Coupled with appropriate mobility and other aids and home adaptations, even minimal home care

support can prevent premature removal of people with MS from their homes and keep families intact. “Over the last couple of years, the MS continued to worsen. Linda became increasingly confined to her home and the wheelchair. But then, the daily angels began to appear. Through a home care program, a steady stream of loving and caring individuals arrived at the door to help make Linda’s life comfortable and fulfilling.”<sup>4</sup>

Adequate and effective home care services are an urgent need. While Ontario home care services provide excellent, time-limited care for people leaving acute care hospitals, this is not the case for individuals who need home care because of chronic illness or disability. 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 that the 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.<sup>5</sup>

In other parts of Canada, this approach is being followed. The overall philosophy and approach in Manitoba is that home care will be provided to all individuals, regardless of age, who require health services or assistance with activities of daily living. This has resulted in people with severe disabilities being able to stay in their own homes.

## **Recommendations**

**The MS Society believes government should:**

- Adopt an overall home care philosophy with the goal of providing sufficient home support to individuals, who require health services or assistance with activities of daily living.
- Provide resources for an effective, high quality,

### **Susan’s Story: Trapped with residents twice her age**

Susan is a single, 43 year old woman who feels trapped because of where she has to live. She has lived in a Sudbury long-term care facility for two years. Her roommate is over 90 years old. They get along well, but Susan is often bored because not only her roommate but most other residents are well over 70. Trips outside the facility are possible but have to be booked two days in advance. Trips on weekends are not allowed. This creates a problem for her in visiting family and friends in her hometown, which is a small community outside of Sudbury. Often, her computer is her only contact with the outside world.<sup>6</sup>

equitable and accessible publicly funded home care system across the province for people with chronic, long-term diseases like MS.

- Establish standards, guidelines, benchmarks and indicators to ensure best practices in home care services.
- Ensure necessary mobility equipment and home adaptations are funded
- Develop a coordinated system of social supports including accessible transportation.

### **2. Family caregiver issues must be addressed**

An individual’s well being is inextricably linked with that of his/her caregivers, whose needs should also be recognized. While it is rewarding to provide care to someone you love, it can still be an unrelenting, exhausting commitment, too often unrecognized and unsupported. A number of studies, including one undertaken recently by the MS Society of Canada,

have found the stress of caregiving impacts the caregiver's own health and adds additional costs to the health care system.<sup>8</sup> Caregivers need to be backed up by a strong, integrated network of community-based services and programs.

## **Recommendations**

### **The MS Society believes government should:**

- Support the critical role that family/friend caregivers play in providing home care and support services to people with MS.
- Increase the provision of services such as respite and attendant care, support, and financial assistance to support those who care for adult family members with MS.
- Develop a coordinated system to help families find necessary support and services.

### **3. Providing housing alternatives**

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 the move would be to a near-by home-like setting with other people who are in their own age range.

The MS Society recognizes that Ontario has some excellent housing options for younger adults who are severely disabled, but unfortunately, they are very limited, compared to the demand. However, their existence is encouraging as examples of what can and should be done. Equally excellent housing options have been developed in other provinces as well.

#### **A. Supportive/ assisted living housing**

Supportive/ assisted living is provided through collective housing, with the addition of services

### **Diane's 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 Toronto complex care hospital for rehabilitation therapy.

In retrospective, this move may have been a poor decision since once at the hospital, 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.<sup>7</sup>

such as meals, housekeeping, and round-the-clock personal care and health services. The Ontario Ministry of Health and Long-Term Care funds 24-hour support care in a variety of settings although there are currently long waiting lists for relatively few spaces. Some examples of supportive/ assisted living housing are:

• *St. Lawrence Street Supportive Housing, Toronto*  
Funded through a community/government/donor partnership, two specially designed four-bedroom apartments were developed for residents who might otherwise live in a hospital or chronic care facility. Ontario March of Dimes (OMOD) provides 24-hour on-site attendant care services

• *Jean and Howard Caine Apartments, Oakville*  
This building, developed by OMOD, has 59 units. It houses over 50 people with physical disabilities, offering attendant care services to 24 apartments, while the remaining units are occupied by a mix of adults with disabilities and persons without disabilities.

• *Disabled Persons Community Resources, Ottawa*  
DPCR serves 54 clients in four buildings; three are standard apartment buildings, with an average of 16 clients in self-contained units. The fourth is a group home for younger people. All provide housekeeping, meals and 24-hour attendant care services.

• *Cheshire Homes, London*  
Cheshire London operates four supportive housing programs for disabled adults. One is a group home setting and the others are self-contained units in apartment buildings. Attendant care services are available 24-hours a day.

### **B. Congregate care homes**

Congregate care homes provide housing and care to small groups of people in home-like settings in the community.

• *Standing Oaks, Sarnia*  
Ontario March of Dimes partnered with a community group to obtain a grant from the Ministry of Health

and Long-Term Care for construction of a congregate care home for medically fragile people. The result, Standing Oaks, is a single-storey dwelling built to serve six individuals with severe disabilities.

• *Ulysse Gauthier residence, Granby, Quebec*  
An alternative to hospitalization, this residence stems from a partnership between the hospital, CLSC (community health centre), and the MS Society of Canada, and houses eight adults, five of whom have MS. Its focus is on responding to the individual's physical, psychological, and social needs.

### **C. 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 in-

dependent living arrangements with group activities delivered in an age-appropriate manner.

• *Castleview Wychwood Towers, Toronto*  
This long-term care home, mainly for seniors, has a 19-bed younger adult unit. Many residents of this special unit have neurodegenerative diseases or MS or have experienced a stroke.

These examples illustrate viable solutions that already exist and which should be expanded. Younger adults with MS and other disabilities and chronic disease should not have to live in facilities with frail elderly individuals with whom they have little in common. What is needed is the will to ensure that age-appropriate long-term care is a priority throughout Ontario. Unfortunately, obstacles still remain. In June 2005, the MS Society was disappointed to learn that a 90-bed facility in Hamilton

**“Some institutions have adopted innovative approaches to meet the needs of younger clientele.”**

for younger adults who are disabled was not going ahead as previously promised by the Government of Ontario and hospital officials in Hamilton. Instead, the current residents of Hamilton Health Sciences Chedoke Continuing Care Centre were to be dispersed to other facilities with no regard as to whether the placements were age appropriate. This should not be happening in Ontario.

## Recommendations

### The MS Society believes government should:

- 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. This will require an expansion of the current supply.
- Actively seek community partnerships to develop and fund age-appropriate housing for younger adults with MS and other disabilities and chronic illnesses.
- 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. 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.

## Conclusion

The Multiple Sclerosis Society of Canada believes that people with MS should be participating members of society, with choices and control over their lives. This includes access to a range of housing and support options that meet their particular and changing needs. Ontario has a long-standing tradition of providing appropriate health care services in a variety of settings to serve its diverse population. The Multiple Sclerosis Society of Canada calls on the Government of Ontario to take

action on this issue of ensuring that younger adults with MS and other chronic health needs receive the care they need. In the view of the Multiple Sclerosis Society of Canada, the appropriate solution is the availability of a continuum of appropriate housing and care, described in this paper. The MS Society looks forward to working with the Ministry of Health and Long-Term Care and regional health officials to move this vision forward.

## References

- <sup>1</sup> CIHI, 2006, Facility-Based Continuing Care in Canada, 2004-2005, p.9
- <sup>2</sup> Canadian Healthcare Association Policy Brief # 5, 2005. Stitching the Patchwork Quilt Together. p. 30
- <sup>3</sup> John is a pseudonym. The information is taken from a letter John sent to the Ontario Ministry of Health, other officials and the MS Society of Canada.
- <sup>4</sup> Globe and Mail Oct. 7, 2005 p. 20 "Lives Lived"
- <sup>5</sup> Hollander Analytical Services Ltd., 2003 (updated 2004) Unfinished Business: The case for chronic home care services, a policy paper.
- <sup>6</sup> Susan is a pseudonym. Her story is from an MS Society survey of its chapters in Ontario about age-appropriate housing issue.
- <sup>7</sup> Diane is a pseudonym. Her sister provided her story.
- <sup>8</sup> The Family Caregiver Pilot Project (2000-2003) and The Caring Balance Pilot Project (2003-2005); Multiple Sclerosis Society of Canada.

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