

A Continuing Care Strategy for Albertans with Neurological Disease or Injury

A Proposal by the MS Society of Canada, Alberta Division

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VISION

The MS Society cares about lives lived, particularly lives lived in care. We envision a continuing care model responsive to the needs of all Albertans. Our vision for a compassionate, made-in-Alberta continuing care system is one that:

- Meets the needs of all clients, including those with neurological disease or injury.
- Provides quality of life in addition to basic care.
- Recognizes the client as a valued partner in decisions affecting his or her continuing care options.
- Recognizes and respects the integral role of family caregivers.

CURRENT SITUATION

Lack of choices: The continuing care system has many challenges, particularly in responding to the needs of young persons with neurological disease or injury. For young people with MS and other disabilities, there is not enough choice in continuing care: the choice to remain at home; the choice to live in a supported living environment or long-term care facility with people who have similar social and therapeutic needs; and the choice to live with dignity.¹ Complicating the picture is the plight of many caregivers who, in the absence of sufficient home care funding or respite opportunities, may be forced to consider long-term care options for family members who might otherwise remain at home. The two biggest barriers to living at home are accessible and affordable housing and a labour shortage of personal care attendants.

Pressure on the system can be relieved but it requires a willingness to move away from the status quo. It requires looking beyond the seniors population and at the second largest user of continuing care services - Albertans with neurological disease or injury.

Not just MS: Neurological disease or injury includes, for example, brain and spinal injury, muscular dystrophy and multiple sclerosis (MS). MS represents a significant percentage of all neurological disease or injury in Alberta. As of 2004, there were over 11,000 Albertans with MS.²

Who is affected: In Calgary, hundreds of people with MS receive publicly funded continuing care. Of these, the majority receive home care. A 2005 survey revealed that at least 165 individuals with MS were in a Calgary supportive living setting (e.g. group/personal care home) or a facility living setting (e.g. nursing home).³ Figures for other Alberta communities are not available, but a 2004 study indicates that 506 people with MS throughout Alberta are living in long-term care facilities.⁴ According to research, most persons affected by MS in long-term care facilities would likely be between 40-60 years of age. Most would be female and experience high levels of depression, anxiety disorders and social isolation.⁵

Many young and middle-aged people are forced into supportive or facility living settings because adequate home support is not available. The maximum monthly allowance for Home Care (no increase since 1991) is not enough to meet the high care needs of some individuals. Most people with a disabling condition like MS cannot afford to pay for private, personal care services.

¹ To witness some of these challenges, a DVD entitled "These Four Walls" is available from the MS Society. This 10-minute testimonial portrays one Albertan's experience living in long-term care.

² Alberta Health and Wellness

³ MS Society of Canada, Calgary Chapter

⁴ Alberta Health and Wellness

⁵ Several studies published from 1993-2004 by Buchanan et al.

IMPACTS ON THE COMMUNITY CARE SYSTEM

Supportive or facility living settings are largely geared to serve the needs of seniors. When young or middle-aged people with disabilities are thrust into these environments, they usually do not receive the care and support they need to stay physically, emotionally, socially and psychologically healthy, to be independent and to live a life of dignity.

Economically viable: In most cases, home care is not only better for a client's mental and physical well-being, it is usually less expensive than facility living. A 2002 study funded by Health Canada found that home care costs less than residential care at all levels of care, even when factoring in the out-of-pocket expenses of clients, family and other caregivers.⁶

The average cost for someone living in a long-term care facility in Alberta in 2001/2002 was \$4,110-\$4,350 per month.⁷ Facility fees increased by 40% in August 2003. Providing care in the home is usually a less expensive option, even if a daily care attendant is required. In 2002/2003, the average cost in Alberta of providing home care services was \$1,591 per month per person.⁸ As further evidence that facility living is poor economics, the Accessible Housing Society of Calgary estimated in 2004 that it would cost \$3,580 per month per person to house and provide personal supports to a minimum of five people with disabilities in independent living suites.

It is estimated a significant number of people under the age of 65 living in long-term care settings could live elsewhere if adequate personal and community supports were provided. This would not only help reduce the number of seniors currently on long-term care facility waiting lists, it would be more cost-effective and result in better health outcomes.

In those cases where long-term care is the only option, residents require age-appropriate care. There needs to be adequate staffing levels, flexibility with schedules to accommodate a more mobile lifestyle, access to therapeutic services and age-appropriate activities.

PRINCIPLES DRIVING THIS PROPOSAL

1. **Aging in place:** That given the proper family support, many individuals with high care needs could remain at home rather than be in an institution. Major barriers include: limited suitable housing; limited caregiver support; and the inability to recruit, train and adequately pay personal care attendants.
2. **Balance:** That home care could be a more viable option if the investment in home care, supportive living and facility living were more balanced.
3. **Dignity:** That young and middle-aged adults not be placed in facilities designed and programmed to serve seniors but in programs designed to accommodate the needs of younger persons.
4. **Inclusion:** That problems and issues associated with continuing care for people with MS extend to others with neurological diseases or injuries.
5. **Leadership:** That government has indicated a strong desire to improve continuing care through recent *Health Policy Framework* and the *Achieving Excellence in Continuing Care* reports.
6. **Partnerships:** That non-profit groups with community resources like the MS Society can be more fully utilized to improve continuing care, in partnership with government.
7. **Client-centred care:** That individuals be recognized as partners in all decisions affecting their continuing care.

⁶ *The Third Way: A Framework for Organizing Health Related Services for Individuals with Ongoing Care Needs and their Families*. Drs. M Hollander and Michael Prince

⁷ Alberta Health and Wellness

⁸ Ibid

THE PROPOSAL

The MS Society is prepared to contribute a leadership role in assisting the Office of Disability Issues (ODI) to develop a provincial Continuing Care Strategy for Albertans with Neurological Disease or Injury. The Strategy would focus on addressing needs of greatest concern and developing solutions that would result in both short and long-term benefits.

The MS Society has invited other community organizations with similar interests to participate in the development of such a Strategy. It is expected that ODI would provide the project management and create an advisory committee of these interested stakeholders. The continuing care project team would consult with health authorities, service providers, community organizations, housing developers, and users of the system to gauge support for the Strategy and a proposed operational framework. Partners would be expected to help implement the Strategy within their own populations, program sets and spheres of influence.

The Strategy requires a business case to validate the need, to provide a common base of understanding, to identify priority areas, and to outline an operational framework. Supplemental research and in-depth discussions with key stakeholders is needed to develop the business case.

Provincial multi-stakeholder initiative: To support the proposal, the MS Society has approached community organizations with an interest in continuing care to participate in the advisory committee once established. Some of these organizations include: Canadian Paraplegic Association (Alberta), Muscular Dystrophy, Dickensfield Extended Care Centre, Good Samaritan Society, Alberta Committee for Citizens with Disabilities, Calgary MS Clinic, ALS, Cerebral Palsy, Parkinson's, Bethany Care Centre, and other stakeholders. There is an eagerness to proceed with a Strategy that focuses on people with neurological disease or injury. Stakeholders have indicated a willingness to share their knowledge and expertise. Some have agreed in principle to be development partners. Inter-ministerial cooperation will be crucial to the success of this initiative.

EXPECTED OUTCOMES

It is expected that a Continuing Care Strategy for Albertans with Neurological Disease or Injury would result in a more client-centred approach, where the focus is on fulfilling individual needs – not just maintaining the status quo. The Alberta Government's passage of the *Family Support for Children with Disabilities Act* in 2004 indicates there is a strong willingness to move in this direction.

On a practical level, implementation of a Continuing Care Strategy would enable the MS Society and its partners to increase essential, non-medical supports already offered by non-profit groups. These include services such as visitation, client/family/staff education, peer/family support, fitness and wellness, social involvement, and coping skills. These services and others enhance the home and facility care provided by nurses and professional staff. On a broader scale, the Continuing Care Strategy can serve as an effective community supports model.

An effective Continuing Care Strategy would enable us to reach all Albertans with MS and other neurological diseases or injuries. We believe it would relieve some pressure on supportive living and long-term care facilities and result in healthier outcomes for a significant number of Albertans.