

**On The Path to a Cure:
From Diagnosis to Chronic Disease Management**

**Brief to the
Senate Committee on Social Affairs, Science and Technology
(Study on the State of the Health Care System in Canada)**

July 2002

The Canadian health care system is complex and diverse. Decisions or actions in one part of the system have a profound effect on other parts. Governments, communities, service providers and individual Canadians must work together as we explore avenues to renew the health care system. Together we must consider new approaches for establishing common health priorities, encouraging innovation, sharing information about best practices, coordinating research, facilitating the adoption of common standards across the health system and delivering appropriate quality care in a timely fashion to those who need it.

In reviewing the Committee's *Volume Five: Principles and Recommendations for Reform – Part I*, the Multiple Sclerosis Society of Canada was pleased to note the many views this organization shares with the Committee. Of the principles set out by the Committee there are two that have particular resonance for the MS Society: Principle 5 that speaks to the need for enhanced funding for technology and principle 17 which places the person who lives with the particular condition everyday firmly at the centre of the system. Coming from a chronic care perspective as the Society does, having the patient become the focal point at every stage of the disease is particularly important. Continuing along those lines of thought, it is important that rural citizens have the same level of access as their urban counterparts.

Multiple Sclerosis and the Multiple Sclerosis Society of Canada

The Multiple Sclerosis Society of Canada is the only national voluntary organization in Canada that supports both multiple sclerosis (MS) research and services for people with MS and their families. In addition to the national level, there are seven regional divisions and more than 120 chapters across Canada. The Society's engine is its volunteers. More than 1,500 individuals serve on the national, division and chapter boards and 13,500 individuals organize and deliver service programs, fund raising events, public awareness campaigns and social action activities. Eighty percent of the Society's net revenue goes directly to fund MS research and services for people with MS and their families while administration and fund raising costs account for just twenty percent.

Multiple Sclerosis: A Progressive, Severe and Chronic Disease

Epidemiological studies indicate that Canada has one of the highest rates of MS in the world. An estimated 50,000 Canadians have this all too frequently disabling disease. Usually diagnosed between the ages of 20 and 40, MS is the most common disease of the central nervous system affecting young adults in Canada. Periods of spontaneous recovery are interrupted by unpredictable attacks that over time result in most people with MS becoming disabled. The result: young Canadians face a progressive and unpredictable disease that cannot be prevented, and that they must live with for 40 or more years.

MS attacks the protective myelin covering of the nerves, causing inflammation and often the destruction of the myelin in patches. This interrupts the normal flow of nerve impulses. The results often include vision problems, numbness, loss of balance, extreme fatigue and even paralysis.

Although the cause and the cure are so far unknown, four drugs have recently been approved for the treatment of MS and can reduce the frequency and severity of attacks. Other medications and therapy can help many symptoms.

Most people with MS are eventually unable to work full-time and many experience total disability. In 1991, 44% of adults with disabilities (aged 15-44) were not part of the labour force. With MS, however, this is significantly higher as 70% of people with MS are not working 5-10 years after they are diagnosed.

Chronic Conditions

MS is one of many chronic conditions affecting Canadians. According to the National Population Health Survey, in 1998-99, more than half of all Canadians reported having a chronic condition. As the leading cause of disability, loss of productivity, and deterioration in the quality of life, chronic non-communicable diseases are the major health burden today in developed countries.¹

Unlike the short-term needs of the acutely ill and as outlined in the Commission's interim report, a revised health care system "must include more coherent approaches to address issues of chronic, long-term disease management."² Canadians with MS and other chronic diseases require a health care system that provides a coordinated continuum of care providing diagnostic, therapeutic, rehabilitative, supportive and maintenance services that address the health, social and personal needs of individuals with chronic conditions. Required services include prompt access to diagnostic tools, nursing, drug and physical therapy, personal care, homemaking, meal programs, friendly visiting, adult day programs, transportation, social and recreational programs.

Ensuring National Standards and Addressing Access - Rural and Remote Communities

The MS Society welcomes the Committees thematic reports and is especially interested in the Committees views and recommendations for addressing the challenges facing the rural and remote populations of Canada. The Society believes it is particularly important that the cost disparities for this population be a central consideration.

The recent First Ministers agreement on health reform reiterated support for the principles of universality, accessibility, comprehensiveness, portability, and public administration for insured hospital and medical services. To implement these principles, a long-term care delivery system must be designed to ensure that the existing disparity of services available is eliminated. The system must be flexible and have adequate resources allocated to effectively and promptly meet the changing needs of people with chronic diseases. As outlined in the Alberta Report of the premier's Advisory Council on Health Care, the answer doesn't lie in rationing health care services - Canadians should have access to the very best health care when they need it.³

¹ (Dr. David MacLean, Addressing the Burden of Chronic Disease in Canada, Brief to the Senate Committee on Social Affairs, Science and Technology, 3 April 2001, p.1.

² Shape the Future of Health Care. Commission on the Future of Health Care in Canada Interim Report. February 2002, p. 37.

³ A Framework for Reform. Report of the Premiers Advisory Council on Health. January 2002.

Responding to the access needs of Canadians will require a concerted and well-orchestrated effort. Many of the tools required to successfully meet this challenge already exist. Telehealth or tele-medicine provides the opportunity to meet some of these goals by providing advanced technologies to areas that would not normally have access. The expansive size of our country makes it impossible to ensure universality if we do not also ensure that there are common standards of delivery. Our health care system should not only utilize the advantages new technologies provide, but take into consideration other important factors, including the additional costs required to access them.

Costs and Disparity of Service

The total cost of illness in Canada was estimated at \$156.4 billion in 1998. Direct costs (such as hospital care, physician services and health research) amounted to \$81.8 billion, while indirect costs (such as lost productivity) accounted for \$74.6 billion. As noted by the Committee in its second report, the diagnostic categories with the highest total costs were cardiovascular and musculoskeletal diseases, cancer, injuries, respiratory diseases, diseases of the nervous system, and mental disorders.⁴

Despite significant public spending, provincial coverage for access to treatments and community support services varies widely across Canada between provinces and even within provinces. Health care resources are concentrated in urban centres while Canadians who live in rural and remote areas do not have sufficient access to family physicians and other health professionals and services.

While people in remote communities understand their location prevents immediate access to specialized physicians and facilities, they do expect reasonable arrangements for necessary medical treatment. The reality today is often quite difficult. When insured health services are not available from local providers or health care facilities, residents must travel long distances and incur additional costs for transportation, hotels and childcare. Many Canadians face significant out-of-pocket expenses for initial services leading to diagnosis, care, drugs, equipment, and supplies. A cross-Canada survey showed home care clients spending an average of \$283 a week for in-home nursing care and other home support services such as personal care, bathing and meal preparation.⁵ These out-of-pocket expenses often are aggravated by disparities in the provision of services across the country.

Recommendations:

To address the disparities in services to assist in the management of chronic diseases:

- Initiatives should continue to recruit and retain health care providers to rural areas and provide incentives for them to stay.
- Integrated networks of care must be established that can deal with the vast distances of Canadian geography.

⁴ Report of the Standing Senate Committee on Social Affairs, Science and Technology. Volume Two: Current Trends and Future Challenges. January 2002, p. 49

⁵ The Toronto Star, 27 November 1999)

- Greater use should be made of tele-medicine and other information technology-enabled technology. Tele-health and other advanced technologies are being piloted in a number of provinces and have the potential for improving access to specialized services.
- A better balance should be established between centralized and local control over service delivery and administration. The Committee’s first Principle may go a long way to ensuring that balance.
- Adequate technology and equipment ensure timely and accurate diagnosis. Once a person is diagnosed the process of managing the disease and caring for a patient can begin. People with MS require prompt access to recognized technology such as MRI scanners, proven treatments, knowledgeable health care professionals and appropriate community services to help manage their disease condition and, wherever possible, prevent development of secondary symptoms. Lack of access to MRI technology and lack of trained radiologists are particularly of concern to people with MS. National funding and minimum standards are two important elements of ensuring this happens in all parts of Canada.

Community Services, Home Care and Long-Term Care Facilities – A Patient Centred System

The Multiple Sclerosis Society of Canada strongly shares the view of the Committee that patients must at all times be at the centre of the system. In keeping with Principle 17, we look forward to reviewing your thematic report on home care in Report Six. The following outlines some of the MS Society’s concerns when looking at the variety of ways our system can ensure that the health care system is adapted to meet the needs of patients and not visa-versa.

Community-based and home care programs can replace the need for people with chronic illnesses and people with severe disabilities to stay in hospitals or move into long-term care facilities. Medicare’s ability to provide effective chronic and long-term care is evolving gradually, but needs greater support. As the Commission on the Future of Health Care in Canada (Romanow Commission) noted in its Interim Report, “Currently, there are significant variations in provincial coverage for home care services and evidence that, in some communities, the basic infrastructure to support home care is uneven or non-existent.”⁶

Between 1990 and 1998, public home care expenditures doubled. Public spending on home care expenditures, however, is a small portion of the overall provincial health care budgets which often vary by provinces.⁷ Increased resources for home care and age-appropriate long-term care facilities are critical. Greater investment is required in community-based and home care programs to eliminate the phenomenon of “bed blockers” – people with chronic illnesses who receive expensive institutional care because there are no alternatives. This will enable some reallocation of institutional funding. The reason why private spending (out-of-pocket spending

⁶ Shape the Future of Health Care. Commission on the Future of Health Care in Canada Interim Report. February 2002, p. 33.

⁷ Canadian Institute for Health Information, Health Care in Canada: A First Annual Report, Ottawa: 2000, p. 60

by individuals) is so high is that the current system under funds community-based and home care programs. This penalizes individuals and families in need and provides an incentive to hospitals to keep people with chronic illnesses in institutional beds.

Under-funding of community based and home care programs puts additional demands upon health charities and related voluntary organizations. The MS Society of Canada's mission is to support equally MS research to find the prevention, treatment and cure of this often disabling disease and service programs to assist people with MS and their families. If governments fail to do their part, there will be added pressure on organizations like the MS Society to fund home care, possibly to the detriment of finally ending this devastating disease.

According to the 1998/99 National Population Health Survey, publicly funded home care use increased with age, disability and diminished income. Indeed, 37 per cent of people aged 85 and over received publicly funded care and people in the lowest two income brackets were much more likely to receive care than those in the highest income bracket.⁸ Several current trends and factors will place more reliance upon community services including:

- Shorter hospital stays
- Greater reliance on outpatient procedures
- Reductions in the number of hospital beds
- Rapid increases in the numbers of people aged 65 and over and increasing life expectancy
- Increasing pressures on informal caregivers

Enabling people to receive more treatment at home will improve quality of care, relieve pressures on hospitals and continuing care institutions, and result in significant savings for individuals and taxpayer-funded health services. On the whole, home care is much cheaper than delivering long-term care services in an institutional setting.

Recommendation:

Governments should work together to develop a more coherent and consistent national home care strategy funded under Medicare.

A comprehensive home care program:

- Allows the health care system as a whole to operate more cost-efficiently.
- Reduces pressure on acute care beds and emergency rooms by providing medical interventions in alternate settings and using hospital resources only when needed
- Reduces the demand for institutional long-term care beds, while enabling disabled and/or aging Canadians to maintain their independence and dignity in their own homes and communities.
- Helps support family caregivers and sustain their commitment.

⁸ Canadian Institute for Health Information, Health Care in Canada: A First Annual Report, Ottawa: 2000, p.58.

Long Term Care Facilities

Given the young age of many Canadians diagnosed with chronic diseases, at some point in the lives of a minority of people with MS the need arises for age-appropriate long-term care facilities and/or assisted living facilities. Today, all-too-often, younger men and women who are severely disabled because of MS and other chronic diseases are placed in long term care facilities that are largely inhabited by the frail elderly, a group with which those who are younger have little in common. The needs of younger Canadians with long-term chronic diseases and who are severely disabled must be met.

Recommendation:

- A range of long-term and/or assisted-living facilities must be available to meet the differing and changing needs of younger Canadians with chronic diseases who have high care needs.

New Therapies

Thorough and timely review of new therapies to treat chronic diseases such as MS and provide relief of MS-related symptoms is essential. Current federal and provincial government planning for a national drug formulary should include legislated time frames for approval of new therapies. Health Canada should systematically implement post-approval surveillance of drug safety and side effects.

In January 2002, Health Canada took an important step in this direction by introducing conditional Notices of Compliance for new drug therapies. Health Canada continues to review additional post-approval surveillance mechanisms.

Recommendations:

- A national drug formulary should include legislated time frames for the approval of new therapies.
- Health Canada should systematically implement post-approval surveillance of drug safety and side effects.

Fostering Research

In keeping with the Committee's views expressed in Chapter 5 of Report 5, the Society believes that while knowledge is in itself of great value, its overall impact, its real benefit, is maximized when that new knowledge is translated into social and health benefits. The knowledge gained by health research leads to improved diagnosis and treatment, enhanced prevention, targeted treatment and better quality of life and health outcomes for all Canadians. Canada has a highly qualified health research community and has contributed significant new advances to a growing international body of research.

Recently, Canada increased its investment in health and medical research with the creation of the Canadian Institutes of Health Research (CIHR). Designed to integrate and coordinate health and medical research, CIHR provides an important opportunity to capitalize on existing research

strengths, improve disease management and health outcomes, and maintain a competitive advantage in an international, knowledge-based economy.

Despite recent CIHR funding increases, according to the Organization for Economic Co-operation Development (OECD), Canada still contributes a smaller proportion of public funds for research than other G7 countries.⁹

Recommendations:

The federal government should continue to take steps to ensure Canada is a leading centre for health and medical research, by:

- Continuing to support the development of multi-disciplinary, integrated, provincial centres of excellence in health research.
- Promoting public/private partnerships for expanding research support.
- Supporting commercialization of new products and services developed through health and medical research.
- Further enhancing government investment in the Canadian Institutes for Health Research to reach the stated funding goal of \$1 billion annually.
- Fostering the dissemination of health research results to policy makers and health care providers to enhance evidence-based decision-making.

Conclusion:

The MS Society of Canada strongly supports maintaining the five core principles of Medicare. We believe that Medicare should be renewed and made sustainable by better addressing issues of chronic disease management in Canada, improving access to quality community and institutional-based services and ensuring that consumers have greater participation in and control over the services they receive.

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⁹ Report of the Standing Senate Committee on Social Affairs, Science and Technology. Volume Two: Current Trends and Future Challenges. January 2002, p. 103.