

Foreword



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It gives us great pleasure to introduce to you the Provincial Strategy for Alzheimer Disease and Other Dementias. This report is an example of how Government and community agencies can work together to achieve our social goals. The Strategy is consistent with the Province's Strategic Social Plan and the missions of both the Department of Health and Community Services and the Alzheimer Society of Newfoundland and Labrador.

The Provincial Strategy for Alzheimer Disease Steering Committee was set up in January 2001 as a joint committee of the Department of Health and Community Services and the Alzheimer Society of Newfoundland and Labrador with a mandate to develop a Provincial Strategy and Plan of Action to address the issues associated with Alzheimer Disease and related dementias in the Province of Newfoundland and Labrador. This report represents the first phase of the Committee's work, with the next phase involving: (1) the development of a plan of action that is reflective of the current and future demographic and fiscal realities of the Province, and (2) the coordination of an implementation plan that can be used throughout the Province.

The success of this Strategy depends on the commitment of all individuals who in any way touch the lives of individuals with Alzheimer Disease or other dementias. It is through the combined efforts of both government and community agencies that we can make this a success. Consequently, we trust that this report will be beneficial to your work in this area.

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Executive Summary

Dementia refers to a group of diseases characterized by a progressive and irreversible decline of mental functions. The symptoms are loss of memory, judgement and reasoning, and changes in mood and behaviour. These symptoms may affect a person's functioning at work, in social relationships or in day-to-day activities. As the disease progresses, the individual usually becomes dependent on others to manage even the simplest of physical activities. Alzheimer Disease, the most common form of dementia, accounts for 64 percent of all dementias in Canada.

The Canadian Study on Health and Aging Working Group estimates that 364,000 Canadians over age 65 have dementias, with 238,000 of them having Alzheimer Disease, and that number is growing. An estimated 5,300 individuals in Newfoundland and Labrador are affected by dementias with 3,392 of them having Alzheimer Disease. Based on current Provincial population estimates, the number of individuals over the age of 65 with Alzheimer Disease and other dementias is expected to rise to over 10,000 by 2026.

The Canadian Study of Health and Aging also estimated that in 1994, the annual net economic cost of dementia was at least 3.9 billion dollars, which represented 5.8 percent of Canada's total health care costs. The most significant component cost was for care in long-term care institutions and for assistance with activities of daily living by professionals, family and friends in the community. These costs are predicted to escalate to over 12 billion dollars by the year 2031. The economic burden of dementia is significant not only for individuals with dementia, their families and friends, but also for society.

During the summer of 2000, the Alzheimer Society of Newfoundland and Labrador met with the then Minister of Health and Community Services, the Honourable Roger Grimes, to discuss their proposal to develop a provincial strategy and plan of action to address the issues associated with Alzheimer Disease and other dementias in the Province of Newfoundland and Labrador. The Department agreed that this was an important issue for the Province and gave its support to the initiative. In December 2000, key stakeholders were invited to participate in the development of the Strategy and the Committee, co-chaired by the Alzheimer Society of Newfoundland and Labrador and the Department of Health and Community Services. The Steering Committee commenced its work in January 2001.

The Provincial Strategy on Alzheimer Disease and Other Dementias not only supports the missions of both the Department of Health and Community Services and the Alzheimer Society of Newfoundland and Labrador but also represents a commitment to furthering the Province's Strategic Social Plan and the Principles of the National Framework on Aging. It reflects the key priorities arising from the discussions conducted by the Alzheimer Society of Newfoundland and Labrador with families, caregivers, community partners and professionals at various sessions, as well as input from the organizations represented on the Steering Committee and their networks.

Four key goals are outlined in the Strategy and the underlying objectives necessary in order to achieve these goals are explored.

GOALS

- I. Coordinated System of Care**
- II. Access to Current Information on Alzheimer Disease & Other Dementias**
- III. Support for Individuals with Alzheimer Disease & Other Dementias & Their Families/Caregivers**
- IV. Education & Skill Development**

This document is only the first step in the Province's strategic plan for Alzheimer Disease and other dementias. In the coming months, the Steering Committee, through consultation and feedback, will proceed with the next phase of the Strategy. This will involve the review of current programs and services available across the Province and the exploration of how stakeholders can work together to develop a plan of action that is reflective of the current and future demographic and fiscal realities of the Province. Once complete, the Steering Committee will continue, through their various departments and agencies, to play a coordination role in an implementation plan that can be used throughout the Province.

Background

THE ALZHEIMER SOCIETY OF NEWFOUNDLAND & LABRADOR

Vision: We ensure that the highest level of care and support is available for persons with Alzheimer Disease and their families.

Mission: The Alzheimer Society of Newfoundland and Labrador exists to support the search for the cause and cure of Alzheimer Disease ... its diagnosis, treatment and care, to raise public awareness of the personal social impact of this disease and to promote the provision of support to families and caregivers in the Province of Newfoundland and Labrador.

The Alzheimer Society of Newfoundland and Labrador is a non-profit, charitable organization dedicated to helping those affected by Alzheimer Disease. The Society is affiliated with a National organization and consists of three Chapters and ten Family Support Groups throughout Newfoundland and Labrador. It also has established seven Resource Centres in the regions of our Province.

The Society, through its network of Chapters and Family Support Groups, is able to provide the following services to the people of our Province:

- * Information packages
- * Resource Centres in: St. John's, Gander, Corner Brook, Happy Valley-Goose Bay, Clarenville, St. Lawrence, and Grand Falls-Windsor
- * Semi-annual Newsletter
- * Educational Sessions throughout the Province
- * Alzheimer Disease: Care At Home Training Package
- * National Alzheimer Wandering Registry
- * Emergency Respite Care Programs in partnership with the Health and Community Services Boards in the St. John's, Eastern, Central and Western Regions
- * Toll Free Line
- * Family Support Groups located throughout the Province



THE DEPARTMENT OF HEALTH & COMMUNITY SERVICES

Vision: All Newfoundlanders and Labradorians will enjoy optimal health and well-being.

Mission: The Department of Health and Community Services will ensure that the people of Newfoundland and Labrador have access to services and programs enabling individuals, families and communities to achieve optimal health by maximizing an individual's health and well-being in the context of his/her life.

The Department of Health and Community Services provides a leadership role in health and community service program and policy development for the Province. This involves working in partnership with a number of key stakeholders including Health Boards, consumers, community organizations, professional associations, post-secondary educational institutions, unions, and other government departments.

The Department provides support services to four Regional Health and Community Services Boards, six Regional Institutional Boards, two Regional Integrated Boards, the St. John's Nursing Home Board, the Newfoundland and Labrador Cancer Treatment and Research Foundation, and Memorial University of Newfoundland's Medical School.

Health & Community Services Boards - responsible for the delivery of programs and services including Health Promotion, Disease Prevention, Child Welfare and Community Corrections, Family and Rehabilitative Services, Addictions, Mental Health and Continuing Care.

Institutional Boards - responsible for the delivery of acute and long term care services in hospitals, community health centres, community clinics and nursing homes.

Integrated Boards - responsible for providing a range of integrated institutional and community based services in Northern Newfoundland and Labrador.

St. John's Nursing Home Board - responsible for the six nursing homes in St. John's.

The Newfoundland Cancer Treatment & Research Foundation - provides cancer care services through the Dr. H. Bliss Murphy Center in St. John's and satellite clinics around the Province.

The Memorial University of Newfoundland Medical School - provides undergraduate, graduate and post graduate medical training as well as being responsible for continuing medical education, medical research, and contributing to the professional development of other disciplines in the health sector.



THE STRATEGY: A COLLABORATIVE PROCESS

During the summer of 2000, the Alzheimer Society of Newfoundland and Labrador met with the then Minister of Health and Community Services, the Honourable Roger Grimes, to discuss their proposal to develop a provincial strategy and plan of action to address the issues associated with Alzheimer Disease and other dementias in the Province of Newfoundland and Labrador. The Department agreed that this was an important issue for the Province and gave its support to the initiative. In December 2000, key stakeholders were invited to participate in the development of the Strategy and the Committee, co-chaired by the Alzheimer Society of Newfoundland and Labrador and the Department of Health and Community Services. The Steering Committee commenced its work in January 2001.

This Strategy not only supports the missions of both the Department of Health and Community Services and the Alzheimer Society of Newfoundland and Labrador but also represents a commitment to furthering the Province's Strategic Social Plan and the Principles of the National Framework on Aging. The Strategic Social Plan lays out three overall strategic directions that are inherent in this Strategy: (1) building on community and regional strengths, (2) integrating social and economic development, and (3) investing in people. Through the Provincial Strategy on Alzheimer Disease and Other Dementias we hope to create strategic partnerships that will further our social development and provide the much needed support to individuals, families and communities affected by Alzheimer Disease and other dementias.

The principles of the National Framework on Aging are: **dignity, independence, participation, fairness** and **security**. They guide the actions by which the vision of 'Canada, a society for all ages, promotes the well-being and contributions of older people in all aspects of life' should be achieved. These principles have also been reflected in the goals of the Provincial Strategy on Alzheimer Disease and Other Dementias.

It is noteworthy that this Strategy has evolved not only as a collaborative effort of the organizations represented on the Steering Committee, but also from research and consultations conducted by the Alzheimer Society that lead to their draft proposal.

The following agencies were represented on the Steering Committee:

- * Alzheimer Society of Newfoundland and Labrador
- * Department of Health and Community Services
- * Health and Community Services Regional Boards
- * Health Canada - Atlantic Region
- * Human Resources Development Canada
- * Institutional Health Boards
- * Newfoundland and Labrador Housing Corporation
- * Seniors Resource Centre
- * St. John's Nursing Home Board

Alzheimer Disease & its Impacts on Society

ALZHEIMER DISEASE & OTHER DEMENTIAS

Dementia refers to a group of diseases characterized by a progressive and irreversible decline of mental functions. The symptoms are loss of memory, judgement and reasoning, and changes in mood and behaviour. These symptoms may affect a person's functioning at work, in social relationships or in day-to-day activities. As the disease progresses, the individual usually becomes dependent on others to manage even the simplest of physical activities.

Alzheimer Disease, the most common form of dementia, accounts for 64 percent of all dementias in Canada. The features of Alzheimer Disease include a gradual onset and continuing decline of memory, as well as changes in judgement or reasoning, and inability to perform familiar tasks. Sometimes a person may have symptoms such as sudden onset of memory loss, early behaviour problems, or difficulties with speech and movement.

These symptoms may suggest a dementia other than Alzheimer Disease: Creutzfeldt-Jakob Disease, Lewy body Dementia, Pick's Disease or Vascular Dementia.

Alzheimer Disease is a progressive degenerative disease of the brain and was first described by the German neuropathologist, Alois Alzheimer in 1906. The Canadian Study on Health and Aging Working Group estimates that 364,000 Canadians over age 65 have dementias, with 238,000 of them having Alzheimer Disease, and that number is growing. The incidence of the disease increases with advancing age, but there is no evidence that it is caused by the aging process. The initial symptoms include memory loss and confusion. It attacks both men and women, with those over age 65 being the most vulnerable to the disease. There is no known cause of, or cure for, Alzheimer Disease. However, there are now medications that treat some of the symptoms.

OUR CHANGING DEMOGRAPHICS

Canadians aged 65 and over form the fastest growing segment of the population, expected to triple to 7.8 million by the year 2031. As the aging population grows, so will the importance of dementia as a cause of disability and death. Due to declining birth rates and youth out-migration patterns, the population of Newfoundland and Labrador is one of the fastest aging in the country. Over the last two census periods the population of seniors has increased significantly, with this increase being most notable in the over 75 age cohort. While the population is aging more rapidly, seniors are also experiencing

better health and living longer. As of the 1996 census, 10.7 percent of the population (60,010 people) was age 65 or over and 4.6 percent (25,552 people) was age 75 or over. By the year 2026, it is projected that almost one quarter of the total population (approximately 132,000 people) will be over age 65, with more than 10 percent of the population (approximately 55,000 people) being over age 75. The average life expectancy (at birth) by 2026 is expected to be 77.6 years for males and 82.9 years for females (Source: Economics & Statistics Branch, Department of Finance, January 2000 revised projections).

The Canadian Health and Aging Study Working Group estimates that 364,000 Canadians over age 65 have Alzheimer Disease or other dementias. While the disease mostly affects those over the age of 65, it can and does affect people in their forties and fifties. A demographic shift is occurring in Canada. As the 'baby boom' generation ages, the prevalence of Alzheimer Disease will increase dramatically. By the year 2031, it is estimated that over 3/4 million Canadians will be affected by Alzheimer Disease and other dementias. This figure does not include the countless family members who must cope with the effects of the disease. An estimated 5,300 individuals in Newfoundland and Labrador are affected by dementias with 3,392 of them having Alzheimer Disease. Based on current Provincial population estimates, the number of individuals over the age of 65 with Alzheimer Disease and other dementias is expected to rise to over 10,000 by 2026.

FINANCIAL & SOCIAL CHALLENGES

The Canadian Study of Health and Aging estimated that in 1994, the annual net economic cost of dementia was at least 3.9 billion dollars, which represented 5.8 percent of Canada's total health care costs. The most significant component cost was for care in long-term care institutions and for assistance with activities of daily living by professionals, family and friends in the community. These costs are predicted to escalate to over 12 billion dollars by the year 2031. The economic burden of dementia is significant not only for individuals with dementia, their families and friends, but also for society.

The health of caregivers is a major consideration with Alzheimer Disease and other dementias, as the majority of individuals with dementias are cared for in the community. Without strong and outreaching support programs, there is a great potential for caregivers to become ill. When caregivers become ill, the health care system absorbs the cost related to yet another illness, the breakdown of home care and the resulting placement of the person with a dementia in a long-term care facility.













Vision & Guiding Principles

THE VISION

The citizens of Newfoundland and Labrador share a common vision for the humane care of individuals with Alzheimer Disease or other dementias and their families/caregivers. This vision is founded on certain fundamental principles, which should guide the development and implementation of a strategy on Alzheimer Disease and other dementias.

FUNDAMENTAL PRINCIPLES

As outlined in this report, the Steering Committee has established the following principles to guide the Strategy on Alzheimer Disease and Other Dementias:

-  Respect for basic human rights - independence, privacy, dignity, self-determination.
-  People have the right to information and to make choices for themselves.
-  Because competence is lost gradually with the disease progression, the right of the individual with Alzheimer Disease or other dementia to make decisions and choices within their ability must be maintained.
-  Support for family caregivers is equally as important as caring for the individual with Alzheimer Disease or other dementia.
-  Dementia is a unique illness that requires specialized responses from the entire community.
-  Care should be client-centred, timely, accessible, appropriate, flexible, holistic, based on the individual's needs and delivered by competent personnel.
-  Service delivery systems should be easy to access and understand.
-  Service options need to be available in a sufficient amount to meet the needs.
-  Supports for the individual with Alzheimer Disease or other dementia should begin from the moment warning signs send them to obtain a diagnosis.
-  Restraints, either physical or chemical should only be used in extreme circumstances, not as a matter of regular treatment.
-  Newfoundlanders and Labradorians should have access to consistent levels of humane and competent care throughout the Province.
-  Alzheimer Disease and dementia crosses all cultures; therefore, the needs of all ethnic communities must be addressed.

Goals & Objectives

This document reflects the key priorities arising from the discussions conducted by the Alzheimer Society of Newfoundland and Labrador with families, caregivers, community partners and professionals at various sessions, as well as input from the organizations represented on the Steering Committee and their networks. It outlines the foundation for successfully fulfilling the Alzheimer Society's mission of alleviating the physical and social consequences of Alzheimer Disease and the mission of the Department of Health and Community Services to ensure access to services and programs enabling optimal health by maximizing an individual's health and well-being in the context of his/her life.

GOALS

- I. Coordinated System of Care
- II. Access to Current Information on Alzheimer Disease & Other Dementias
- III. Support for Individuals with Alzheimer Disease & Other Dementias & Their Families/Caregivers
- IV. Education & Skill Development

This document is only the first step in the Province's strategic plan for Alzheimer Disease and other dementias. In the coming months, the Steering Committee, through consultation and feedback, will proceed with the next phase of the Strategy. This will involve the review of current programs and services available across the Province and the exploration of how we can work together to develop a plan of action that is reflective of the current and future demographic and fiscal realities of the Province. Once complete, the Steering Committee will continue, through their various departments and agencies, to play a coordination role in an implementation plan that can be used throughout the Province.

I. Coordinated System of Care

Individuals with Alzheimer Disease and other dementias and their families/caregivers have multiple needs and therefore, many agencies and programs are required to meet these needs. A coordinated system of care, focused on individual needs, will be necessary in order to achieve a seamless continuum of care. This continuum of care must be based on the unique needs of those with Alzheimer Disease and other dementias and must be integrated into the current and future health and community services delivery system.

Objectives:

- ✿ A coordinated system of care that responds to the wide range of service needs across the full continuum of care.
- ✿ Services that are client-focused, based on individual care plans, developed with the individual needing care and/or their family/caregivers. The process must reflect individual choice and need, and support individuals and their families/caregivers to access optimal community resources throughout the disease process.
- ✿ The establishment of long-term care guidelines that recognize the special characteristics of individuals with Alzheimer Disease and other dementias and their families/caregivers and responds to the wide range of service needs across the full continuum of care.
- ✿ Government and community agencies need to work together to explore new concepts for the provision and delivery of cost effective, efficient and creative approaches to care for individuals with Alzheimer Disease and other dementias and their families/caregivers.

II. Access to Current Information on Alzheimer Disease & Other Dementias

To respond appropriately to Alzheimer Disease and other dementias it is important that the most up-to-date information is available to the public. Through the Alzheimer Society's national organization and local initiatives, up-to-date information on Alzheimer Disease and other dementias is regularly maintained through their Resource Centres in the various Regions. However, it is increasingly important that this information be shared with all key segments of the population, such as teachers, bankers, police, public service officials and community leaders. Such awareness generates a more sensitive environment for the individual and families coping with Alzheimer Disease and other dementias and can facilitate supportive intervention and earlier diagnosis.

Objectives:

Government and community agencies need to partner to:

- ✿ identify the information needs of individuals with Alzheimer Disease and other dementias, their families/caregivers, professionals, researchers, decision makers, employers, and the general public;
- ✿ develop relevant information products;
- ✿ ensure Province-wide distribution of these products; and
- ✿ ensure that this information is accessible to those who need it.

III. Support for Individuals with Alzheimer Disease & Other Dementias & Their Families/Caregivers

Additional measures are needed to support individuals with Alzheimer Disease and other dementias and their families in their caregiving roles. Access to support services can alleviate some of the emotional strain of caregiving and can enable families to provide care at home for longer periods of time, which will ultimately reduce costs of long-term care while supporting families and communities.

Objectives:

- ✿ Development of innovative, responsive and flexible support programs for individuals with Alzheimer Disease and other dementias and their families/caregivers in all areas of the Province.
- ✿ Refinement of eligibility criteria for programs and services that are client-focused, based on impairment of function dependencies and primary caregivers' ability to cope, rather than on diagnosis or the age of the individual.
- ✿ Examination of innovative housing options to accommodate individuals and families coping with the changing consequences of Alzheimer Disease and other dementias.
- ✿ Incorporation of the Alzheimer Society of Canada's Guidelines for Care into the philosophy of care and therapeutic programming.
- ✿ Implementation of mechanisms to ensure that those in need of support are aware of the programs and services available and have access to them.

IV. Education & Skill Development

The provision of care for individuals with Alzheimer Disease and other dementias is a specialty area requiring distinct knowledge and expertise. It is important that all formal and informal caregivers receive training on how to care for someone with Alzheimer Disease and other dementias due to the many different behaviors of the disease.

Objectives:

- ✿ Incorporation of content relevant to Alzheimer Disease and other dementias into core curricula for all health care professionals.
- ✿ Development of Provincial training programs for support workers, such as home support workers and personal care attendants.
- ✿ Review of Provincial training requirements for support workers.
- ✿ Availability of continuing educational programs for formal and informal caregivers.
- ✿ Special efforts in public education and awareness to ensure community support and early diagnosis.

Issues & Challenges

The Provincial Strategy on Alzheimer Disease and Other Dementias is meant to play an integral role in the development of policies, programs and services that affect the lives of those touched by Alzheimer Disease and other dementias in any way. While it is recognized that the issues and challenges may be varied, it is the intent that by working together we can effect some real, meaningful change.

The issues and challenges which will be faced by the Steering Committee and our community partners in creating an achievable plan of action include:

- ✿ The demographic impact of an aging population leads to an increase in the prevalence of Alzheimer Disease and other dementias, which ultimately increases the demand for services.
- ✿ Partnerships and linkages in the community need to be fostered and strengthened.
- ✿ Services need to be coordinated to offer a comprehensive level of care for those affected by Alzheimer Disease and other dementias.
- ✿ Awareness and educational opportunities of Alzheimer Disease and other dementias needs to be increased amongst health professionals.
- ✿ Innovative and accessible supports and programs are required to respond to the needs of a client centered system of care.
- ✿ Advances are necessary in the area of diagnosis and ongoing assessment.
- ✿ High costs associated with dissemination of information throughout the Province.
- ✿ Much of the legislation dealing with long term care and neglected adults is outdated and will be revisited over the next couple of years.
- ✿ Evolving treatments present a constant challenge and dilemma.
- ✿ One of the most significant challenges to gaining access to services is the vast geography of the Province and the existence of hundreds of isolated communities with small populations.

A Coordinated Plan for Action...

The goals and objectives outlined in this report are only the first step in the strategic planning process. The Steering Committee's work has just begun and the Committee will now begin work on the development of concrete proposals and an implementation framework related to the enclosed recommendations.

The success of this Strategy does not lie on any one department or agency but rather, depends on the commitment of all individuals who in any way touch the lives of individuals with Alzheimer Disease and other dementias. It is through the combined efforts of both government and community agencies that we can make this a success and create a plan that is reflective of the current and future demographic and fiscal realities of the Province.

We invite your comments on the Strategy and welcome your valuable input into the next phase of the process. Please let us know how you, or your organization, may become involved.

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This document is also available on the Internet at
<http://www.gov.nf.ca> under 'Publications'.

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