

**on Alzheimer Disease
and related dementias**

No. 23

**The NACA Position
on Alzheimer Disease
and related dementias**

**This position was unanimously
adopted by NACA members
on July 19, 2004**

**National Advisory Council on Aging
October 2004**

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The Division of Aging and Seniors, Public Health Agency of Canada, provides operational support to the National Advisory Council on Aging.

THE NACA POSITION ON... is a series of policy papers presenting NACA's opinions and recommendations on the needs and concerns of seniors and issues related to the aging of the population.

1st printing, 2004

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Cat.: H71-2/2-23-2004

ISBN: 0-662-68395-1

What is the National Advisory Council on Aging?

The National Advisory Council on Aging (NACA) was created by Order-in-Council on May 1, 1980 to assist and advise the Minister of Health on issues related to the aging of the Canadian population and the quality of life of seniors. NACA reviews the needs and problems of seniors and recommends remedial action, liaises with other groups interested in aging, encourages public discussion and publishes and disseminates information on aging.

The Council has a maximum of 18 members from all parts of Canada. Members are appointed by Order-in-Council for two- or three-year terms and are selected for their expertise and interest in aging. They bring to Council a variety of experiences, concerns and aptitudes.

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NACA believes:

- Canada must guarantee the same rights and privileges to all its citizens, regardless of their age.
- Seniors have the right to be autonomous while benefitting from interdependence and the right to make their own decisions even if it means “living at risk.”
- Seniors must be involved in the development of policies and programs and these policies and programs must take into account their individuality and cultural diversity.
- Seniors must be assured in all regions of Canada of adequate income protection, universal access to health care, and the availability of a range of programs and services that support their autonomy.

Acknowledgements

NACA is grateful for the advice and support received from the Alzheimer Society of Canada, as well as its provincial societies, in the research and writing of this paper. The Alzheimer Society of Canada is a full partner with NACA in recommending the development and implementation of a National Strategy to address Alzheimer Disease and Related dementias.

NACA would also like to express its appreciation to the Cognitive Impairment in Aging Partnership for lending its strong support at the outset of this project and for providing expert advice as the content of the paper was developed.

The NACA Position in Brief

This report examines the many serious issues faced by those dealing with Alzheimer Disease and related dementias. The issues are examined from a variety of perspectives: those with the disease, their families and caregivers and, from a broader perspective, the Canadian public.

NACA's vision proposes a role for individuals, families, caregivers, the voluntary and private for-profit sector, and governments, in order to improve the health and quality of life of those living with dementia. The Council envisions an environment in which all sectors work together to improve the prospects of those who may be affected by dementia in the future – through improved prevention, support, treatments and eventually a cure.

In this paper, NACA will make recommendations that address the following:

- increased research, prevention and treatment;
- improved physician training and education in Alzheimer Disease and related dementias;
- assured access to treatments for all Canadians, especially pharmaceuticals;
- government funding to provide appropriate long-term care facilities, at reasonable cost, for those with dementia;
- income protection and other public policies that support caregivers;
- increased funding for home care and a wider range of appropriate housing options for those with dementia;
- ethics of dementia research and genetic testing;
- the need for the federal government to collaborate with other key partners to develop a National Strategy that designs policies and funds to diminish or eliminate the many challenges that make of Alzheimer Disease and related dementias such devastating diseases.

The NACA Position on Alzheimer Disease and related dementias

1. INTRODUCTION

In the coming decades, as Canada's population continues to age, increasing numbers of Canadians will be diagnosed with Alzheimer Disease (AD) or a related dementia (RD). Alzheimer Disease and related dementias have profound and distressing effects on millions of Canadians: those afflicted with the disease, their families and caregivers. The challenges posed by dementia to individuals, communities and Canada's health and social care systems will be enormous. Canada needs to plan now to avoid the worst consequences of these illnesses.

This document describes NACA's position on several issues associated with Alzheimer Disease and related dementias (ADRD). Specifically, the paper will:

- describe the features of Alzheimer Disease and related dementias;
- describe what current scientific research reveals about the causes, prevention and treatment of Alzheimer Disease;
- assess the adequacy of existing public policies in health and community services in addressing the care needs and improving the quality of life of Canadians affected by dementia; and
- outline the need for a National Alzheimer Strategy to address this serious disease in the context of an aging society.

1.1 Is Canada facing a looming Alzheimer Disease crisis?

Alzheimer Disease is a devastating illness. Over time, the person with the disease is robbed of his or her identity, independence and dignity. He or she eventually becomes incapable of performing the simple tasks of daily living, of remembering recent events, relating to others or controlling thoughts and emotions. For family, friends and caregivers of the person with AD, the burden can be unbearable as they try to cope with the challenges and adjust to the changes in their own lives and that of the patient as the disease progresses.

Though no longer considered a part of "normal" aging, AD is a disease that largely affects older Canadians. An estimated 420,600 Canadians over the age of 65 have AD or a related dementias.¹ This figure represents 8% of all seniors. An additional 16% of Canadians aged 65 or older exhibit less severe symptoms that are termed "mild cognitive impairment."

Because age is the highest risk factor for developing AD, the aging of the Canadian

population means that the number of people with AD will increase. By 2031, Canada's biggest demographic group – the so-called “baby-boomers” – will move into the age of highest risk for developing AD. It is estimated that by that time, the number of Canadians who will have AD or a related dementia will have more than doubled from the 2001 figure of 364,000 – to 750,000!² The majority will be older seniors: currently, one in 13 Canadians over the age of 65 has dementia while the ratio is one in three among Canadians over the age of 85.

The costs of AD are startling: economic costs alone (health care and paid/unpaid caregiving) are estimated to be \$5.5 billion per year.³ The social costs to family, caregivers and society at large (e.g., unpaid caregiving, stress, illness, depression, career interruption) are inestimable. In our aging society, these costs will rise exponentially if prevalence projections remain unchanged. Some analysts⁴ believe that over the next 25 years, AD – together with other forms of cognitive impairment – will prove to have the highest economic, social and health cost burden of all diseases in Canada.

But, how will AD affect average Canadians? In the short term, increasing numbers of “baby-boomers” will find themselves being caregivers to parents with dementia. If caregiving patterns remain constant, this burden will fall disproportionately on women. In the longer term, as the “baby boomers” enter their senior years, they themselves will be at risk for developing cognitive impairment and dementia. In addition to individual suffering, unprecedented pressures will be placed on our health and social care systems.

Canadians' general awareness of Alzheimer Disease is high, though they may lack detailed knowledge. A 2002 Ipsos-Reid poll revealed that Canadians are highly aware of AD, are often affected by it (half of those asked were either diagnosed themselves, or had a family member or friend who had been diagnosed), and are fearful of suffering from it themselves.⁵ Almost 90% , across all age groups, thought that as Canada's population ages, AD will dramatically increase health care costs. The same percentage (90%) thought that more money should be spent on AD research. A Léger and Léger poll of Canadian seniors found that dementia and cognitive decline are among their greatest fears; 75% of people over the age of 50 believe they are already suffering from some memory problems.⁶ Given Canadians' awareness and fear of AD, it is almost certain they will expect governments to take action to minimize the effects of this disease.

2. WHAT ARE ALZHEIMER DISEASE AND RELATED DEMENTIAS?

2.1 Alzheimer Disease

Alzheimer Disease is a progressive, irreversible degenerative disease of the brain resulting from certain changes to the regions of the brain responsible for memory, language, judgement, reasoning and abstract thinking. It is characterized by shrinkage of the brain due to loss of cell tissue and the presence of fibres called tangles and the accumulation of plaques. These plaques are formed in the brain by proteins that usually exist in soluble form, but for reasons unknown, aggregate and form solid deposits. The plaques and tangles, first identified by Dr. Alois Alzheimer, are now known as *indicators* of AD, though scientists are still not certain whether they are a *cause* or an *effect* of the disease.

There are two forms of AD:

- Sporadic Alzheimer Disease (90-95% of all cases); and
- Familial Autosomal Disease (FAD: 5-10%).

Sporadic AD, the most common form, typically develops in people over age 65; in fact, most cases are in individuals age 85 and older. People with sporadic AD may or may not have a history of AD in their family, but a child of a parent who has this form of AD has a higher risk of developing AD than someone with no family history of the disease.

Familial autosomal dominant AD, or FAD, is a rare form of the disease and makes up only 5-10% of all cases of AD.⁷ It occurs in families in which a mutated gene is passed from generation to generation. If a parent has the mutated gene, each child has a 50% chance of inheriting the gene; the presence of the gene means the individual will eventually develop the disease – usually at a younger age than the sporadic form of AD.

There is no definitive test to determine if a living person has AD. Rather, the diagnosis is made by a thorough clinical assessment that confirms symptoms and rules out other possible causes (e.g., depression, thyroid problems, medication side-effects). It can be done by a trained family physician but may require referral to a memory clinic or to specialists such as neurologists, psychiatrists, or geriatricians. A properly performed assessment can accurately confirm or rule out a diagnosis of AD 80-90% of the time. The only definitive way of diagnosing AD is to perform brain autopsy after death.

2.2 Effects of Alzheimer Disease

The progression* of AD can be broken down into three stages:⁸

- early stage: lasting 2-4 years;
- middle stage: lasting from 2-10 years; and
- late stage: lasting from 1-3 years.

Immediately preceding death, patients are mute, bedridden, and exhausted; palliative care may be required. Recent studies⁹ have indicated that the median** duration of survival after the onset of dementia is substantially shorter than was previously thought (3.1 years versus 5-9 years). Though life expectancy for those with AD can be as long as 20 years¹⁰, on average***, death occurs 8-10 years after the first symptoms of memory loss. Patients usually do not die from AD itself, but rather from secondary infections (e.g., pneumonia) that take over as the body's organs decline in function.

Though AD is by far the most common of all the dementias, several others exist, often termed "related dementias." The term dementia refers to a decline in memory and other cognitive functions sufficient to affect daily life in an alert person.¹¹ Alzheimer Disease is the most common form of dementia, representing approximately 65% of all dementias in Canada.¹²

The other major dementias include****:

- Vascular Dementia;
- Lewy body Dementia;
- Pick's Disease; and
- Creutzfeldt-Jakob Disease.

2.3 Mild cognitive impairment and its implications

Mild cognitive impairment exists when there is some decline in memory and intellectual capacity, but no dementia (e.g., behavioural problems, judgement, personality changes, etc.). It is sometimes called "Cognitive impairment, no dementia" or CIND. Those with cognitive impairment can remain relatively stable for years or they may go on to develop

* For a detailed description of the characteristics of early, middle and late stages of AD, refer to Appendix (Part II).

**Median: the median means that 50% of all those diagnosed with dementia will live longer than the median number of years; 50% will live fewer than the median number of years.

*** An individual's life expectancy after developing AD can vary significantly from the average, since the range is large (3-20 years).

****For a more detailed description of the related dementias, refer to Appendix (Part I).

dementia. Because it is a risk factor for AD, mild cognitive impairment is now an important area of dementia research.

3. CURRENT KNOWLEDGE OF CAUSES, PREVENTION AND TREATMENT

3.1 Causes of Alzheimer Disease

Though researchers have learned a great deal about AD over the last two decades, they still do not know the exact *cause(s)* of AD; nor do they know how to halt progression of the disease. Scientists suspect that in many cases, it may be a *combination* of factors that leads to AD. Rather than talk about causes of which they are unsure, researchers prefer to talk about *risk factors* – characteristics of a person or population (e.g., family history, physical health, etc.) or conditions in an environment that may be *associated* with an increased *chance* of AD. In other words, when these risk factors are present, one is more likely to develop Alzheimer. Risk factors alone, however, are not enough to cause Alzheimer Disease.

The Canadian Study on Health and Aging (CSHA-1, CSHA-2) has identified some risk factors for AD. Many other studies have validated the CSHA's findings.

3.1.1 Known risk factors to date:

- *age*: this is the single biggest risk factor for 90-95% cases of AD;
- *genetics/family history*: genetics plays a certain role in only 5-10% of AD cases; in the other 90-95% of cases, a family history of AD is a risk factor but it is neither necessary nor sufficient for AD to develop. Scientists are still exploring the role heredity plays in AD;
- *education*: individuals with less than 6 years of formal education are at a higher risk of developing AD;
- *head injury*: people who have suffered a head injury, especially with loss of consciousness, have an increased chance of developing AD;
- *strokes/depression*: strokes not only increase risk for vascular dementia but also for AD. Several studies have pointed to depression prior to diagnosis as a risk for AD;¹³
- *mild cognitive impairment (MCI)*: people with MCI have a much greater chance of developing AD. Some studies have shown that those with MCI will progress to AD at a rate of 10-15% per year; another study showed this rate to be only 5-6% per year. The subject of MCI as a risk factor – and possibilities for preventive treatment – is an area of intense research; and
- *smoking*: the evidence is mixed¹⁴; some studies have shown an increased risk for AD; others have not.

3.1.2 Other areas of research into possible risk factors

- *inflammation*: in people who have AD, there is inflammation of brain tissues, but researchers are not certain whether this is a result of the disease or a contributory factor;
- *elevated homocysteine/cholesterol/high blood pressure*: research continues to explore whether these factors, which are risk factors for vascular dementia, may also be risks for AD;
- *copper*: the theory behind exposure to copper and increased risk for AD is fairly recent but is an area of great interest; and
- *diabetes*: studies to date recognize Type II diabetes as a risk factor for AD. Research into Type I diabetes (juvenile) as a risk factor for later developing AD, is under study.

3.2 Prevention of Alzheimer Disease

Knowledge of how to prevent AD is increasing. Though more definitive research is necessary, many researchers feel that the risk of developing AD and related dementias can be reduced/delayed by certain “protective” factors:

3.2.1 *Protective factors*

- continuing number of years of formal education;
- social and intellectual exercises (reading, crossword puzzles);
- physical exercise;
- control of cholesterol/blood pressure and other vascular risk factors;
- good nutrition/exercise program;¹⁵
- avoiding brain injury (increase use of helmets in contact sports, bicycling); and
- exposure to vaccinations.¹⁶

The protective role that other agents may play (e.g., high doses of vitamins C and E, non-steroidal anti-inflammatories, ginkgo biloba, statins) requires more research before they can be advised for the general public.

3.2.2 *Mild cognitive impairment (MCI) and earlier diagnosis*

Researchers now know that the prevalence of MCI is 16.8% among Canadians age 65 and older, more than double the prevalence for all dementias combined (8%). MCI has health and quality of life implications of its own:

- those with MCI are three times more likely to be living in long-term care institutions than those with no cognitive impairments;
- people with MCI are more likely to have functional impairment;¹⁷ and
- individuals with MCI are at risk for developing dementia at a rate of 10-15% per year.¹⁸

Learning why some people with MCI go on to develop dementia while others don't could increase researchers' understanding of how and why the disease develops. If researchers can identify those with MCI who will go on to develop AD and provide early treatment, it

may be possible to at least delay, or even avoid, the onset of AD. Increasing knowledge in this area is the goal of the third phase of the CSHA.¹⁹

It is thought that significant brain cell death occurs before any clinical symptoms are noticeable. If researchers can develop means of diagnosing people with AD, earlier and with more precision (e.g., prior to significant brain damage), improved interventions may be able to halt the progression of the disease, avoiding its most severe forms.

3.3 Treatment of Alzheimer Disease

While there is no cure for Alzheimer Disease, some treatments can retard or reduce certain symptoms. Research is ongoing to find new treatments.

3.3.1 Current treatments

In Canada, there are currently three medications which help alleviate the symptoms and appear to possibly slow the neurocognitive and/or behavioural decline in some patients:

- Aricept (donepezil);
- Exelon (rivastigmine); and
- Reminyl (galantamine hydrobromide).

These three medications are useful in treating mild to moderate AD. Potential benefits from these drugs include improved cognition (memory, language and orientation) and ability to function in daily activities. Sometimes, the benefits from these medications are seen in improved behaviour rather than improved memory. This can be significant, not only for the patient, but especially for the caregiver because it is often disturbing behaviour that proves most troubling for the caregiver.

Current medications have marked limitations: they do not work for everyone; their benefits are temporary (but may be effective for considerable periods of time); and, after maximum benefits have been reached, there is a slow decline over the next year back to the condition prior to treatment. Yet, for those treated with these medications, there seems to be a slower rate of further decline after one year of treatment than in those who did not receive treatment. A new drug (memantine) to treat moderate to severe AD is being investigated in Canada. Memantine is currently in Phase 3 of clinical trials, the last stage prior to approval for use.

Other drugs such as anti-depressants, anti-anxiety and anti-psychotics are used to treat some of the disturbing symptoms of AD but do not specifically target AD.

3.3.2 Additional treatments under investigation in Canada

A great deal of research in Canada and other countries continues to investigate the possibility of other treatments:

- vitamin E;
- omega-3 fatty acids;
- ginkgo biloba, antioxidants, caffeine, nicotine;
- non-steroidal anti-inflammatories;
- anti-cholesterol drugs (statins);
- stem cells to replace dead neurons;
- drugs to prevent plaques in brain; and
- estrogen (evidence is mixed on benefits/drawbacks).

3.3.3 Psycho-social research needed

While biomedical research (e.g., improving knowledge of risk factors, prevention and treatment/cure) is of obvious importance, so too is psycho-social research. This type of research aims to improve our knowledge and understanding about how to best maintain the quality of life for people living with dementia and those affected by it (e.g., families, caregivers). Psycho-social research focuses on increasing knowledge of caregiving techniques that provide better care to patients with AD while developing innovative ways to lessen caregivers' burden. It includes research into what programs and services (health care, housing, respite care, long-term care, etc.) are needed by those affected by AD. Psycho-social research should also investigate interventions/treatments that pharmaceutical companies are realizing are important in improving the effectiveness of pharmacological therapies.

3.3.4 Alzheimer research in Canada

For its size, Canada has made considerable contributions to Alzheimer research, both biomedical and psycho-social.* Despite this impressive record of research, Canada lags behind both its American and European counterparts in developing a coordinated national research program²⁰. The creation of the Canadian Institutes of Health Research (which includes the Institute of Aging) has been a laudable achievement, but it is not sufficient. As the Alzheimer Society of Canada states, “the CIHR has been an important component of health research in Canada. However, the incidence of Alzheimer Disease is growing at a faster rate than increases to research.”²¹

NACA RECOMMENDS THAT:

- **The federal government increase the level of research funding for basic and applied research to prevent and treat dementia.**

*See Appendix (Part III) for further information on specific research activities in Canada.

- **The federal government commit to substantial long-term funding for health promotion/disease prevention strategies that incorporate scientifically validated lifestyle and early treatment interventions – as they become available – to reduce modifiable risk factors of Alzheimer Disease and related dementias.**

4. ASSESSING ADEQUACY OF CURRENT PUBLIC POLICIES

4.1 Primary care

The most appropriate place for diagnosis and treatment of AD is at the primary care level.^{22 23} Yet, it seems that primary care physicians in Canada have inadequate training/knowledge of AD and related dementias. Consequently, those with dementia are under-diagnosed and under-treated despite the fact that current AD medications have proven moderately effective.^{24 25} It is estimated that among all those who currently have AD, only 21% are diagnosed and receive treatment; another 14% are diagnosed but do not receive treatment; and 65% remain undiagnosed. If this estimate is accurate, it represents a clear failure in translating knowledge of effective treatment into clinical practice.

Often, when a person is diagnosed with AD, he or she is not informed of the diagnosis. Sometimes, the health care professional or a family member withholds this information to “protect” the person. Yet, the person diagnosed with AD has a right to know about his/her condition. Only by knowing the diagnosis can the person learn about or make decisions regarding:

- understanding symptoms;
- treatment of symptoms;
- receiving help/support; and
- planning the future.

Early diagnosis of AD and related dementias is more important than ever. There are encouraging results in symptomatic therapy and there is hope for long term stabilization and preventive treatment.²⁶ Earlier diagnosis, together with improved treatment, has the potential to delay the onset of major AD symptoms by five years or more. This would result in a decreased prevalence of 50%, saving billions of dollars in health and social spending.²⁷

Knowledge is lacking concerning the barriers that may be preventing proper detection, diagnosis and treatment of AD at the primary care level.²⁸ Some barriers include:

- poor financial incentives (e.g., no remuneration for time spent with patient); and
- inadequate physician and caregiver knowledge of medication efficacy.

Problems at the level of primary care are compounded by the lack of coordination and accountability between various health and community services (e.g., primary care, acute care hospitals, long-term care institutions, home care, housing, social services, community

support services). This results in inadequate support in meeting the changing needs of those with dementia.

A study of dementia care networks in Ontario²⁹ showed that the three most important factors that determine satisfactory care are:

- coordination of care;
- awareness of services in the community; and
- coordination of services.

Possible solutions

Ontario's Strategy for Alzheimer Disease and Related Dementias has implemented initiatives that address some of the health care system's shortcomings in meeting AD patients' needs. To address inadequate physician knowledge of AD, the Strategy has implemented training programs for family physicians and medical students on early detection and diagnosis of AD and related dementias and on best use of local and specialized resources and advance care planning.

The Strategy includes an initiative designed to reduce the fragmentation of services for those with AD and other dementias. This initiative, called "Co-ordinated Specialized Diagnosis and Support", created local dementia networks throughout the province to help communities develop local support networks for diagnostic and treatment services for Alzheimer clients and their families. Unfortunately, one of the components of this initiative – increased specialized geriatric services – was not implemented, despite numerous recommendations by an expert panel.

NACA RECOMMENDS THAT:

- **The Canadian College of Family Physicians include content on Alzheimer Disease and related dementias in the examination process for graduating students in family medicine.**
- **Provincial governments work in collaboration with their respective Colleges of Family Physicians to develop and implement training programs for family physicians and medical students on early detection, diagnosis and treatment of ADRD.**
- **Provincial governments develop programs (e.g. dementia networks which include specialized geriatric services) to ensure that local health and social services – including charitable organizations such as the provincial Alzheimer societies – are adequately financed, integrated and available to those with dementia and their caregivers.**

4.2 Pharmaceuticals

As already mentioned, there are three drugs (Aricept, Exelon, and Reminyl) approved for the treatment of Alzheimer Disease in Canada. A fourth (memantine) may be approved soon. Current medications are moderately successful in treating the symptoms and behavioural problems experienced by Alzheimer patients. A host of other candidate medications are in various stages of investigation. It is important that Canada continue funding clinical research on new medications; but just as important, when these new, more effective drugs are developed, they should be accessible to all who need them.

Affordability and access to effective medications

Public insurance coverage by provincial drug benefit plans varies widely across Canada. The issue of prescription drug coverage affects seniors disproportionately as they use more prescription drugs – especially those that treat AD – than other population groups. Some seniors, depending on income and where they live, are still vulnerable to undue financial hardship from the high cost of purchasing necessary drugs. The federal government, in its 2003 budget, announced provisions for catastrophic drug coverage to protect Canadians in instances where they require expensive drug therapies to remain healthy (a portion of \$16B allocated over five years to specific health services).

Medications approved by Health Canada to treat Alzheimer Disease are not available in all provinces (e.g., British Columbia, Nova Scotia, New Brunswick, Prince Edward Island or Newfoundland). It is essential that as advances are made in the treatment of AD, and effective medications are approved by the federal government, all provinces make these medications available through their drug benefit plans.

NACA RECOMMENDS THAT:

- **The federal government ensure that the catastrophic drug coverage plan includes coverage of people with Alzheimer Disease and related dementias.**
- **The federal government collaborate with provincial and territorial governments, through the Common Drug Review, to make approved medications for Alzheimer Disease and related dementias accessible to all Canadians, in all provinces, by ensuring these drugs are part of provincial drug formularies and that the criteria for access are appropriate and consistent (e.g., hospital, long-term care institutions, home care).**

4.3 Long-term care institutions

The CSHA indicates that approximately 50% of those diagnosed with dementia live in the community and 50% live in institutional settings.

Though it is important that families and caregivers have access to improved home care support and housing options in the community to maximize the time that persons with AD can remain in the community (perhaps to the end), there will still be situations where

caregivers/families view long-term care placement as the most appropriate choice (e.g., late stage dementia, when symptoms of AD create a severe burden for families). Additional circumstances that make long-term care institutions more suitable include those in which social support systems for the patient (e.g., friends, family) are lacking and formal care networks such as home care or supportive housing are either unavailable or inadequate. Given the projected increase in the number of seniors with AD, it is essential that governments plan in advance to ensure an adequate supply of affordable, quality long-term care institutions. Ontario has initiated action in this area by undertaking a review of long-term care facilities across Ontario and developing a plan to ensure high quality long-term care.³⁰

Availability, affordability and quality of long-term care

Fees for long-term care residences vary widely across Canadian jurisdictions for those above the minimum provided for by public pensions. While rules and rates governing fees for long-term care vary, studies have shown they are high enough, in some jurisdictions at least, that seniors are clearly paying for medically necessary services which, had they been provided in a hospital, would have been publicly insured.³¹ In other words, the fees charged are over and above the market rates for lodging and food and are therefore subsidizing health services. The province of Nova Scotia has recently taken action to ensure that seniors are only charged market rates for room and board to eliminate the possibility that residents could be paying for medically necessary services as part of fees for lodging.

Quality of care or patients in long-term institutions has certain characteristics, including:

- standards for staffing ratios;
- an environment that is safe and supportive;
- care plans that address/reflect dementia symptoms and behaviours;
- holistic assessments;
- registered nursing care among mix of staff services;
- access to full range of services required to maintain good physical, mental and spiritual health (e.g., dental, physiotherapies);
- medication supervision through administration and monitoring;
- therapeutic activity and sensory supervision;
- client and caregiver teaching and support;
- meaningful recreation and socialization opportunities;
- nutrition, laundry and housekeeping services;
- appropriate spiritual care;
- the involvement of family (and where possible, the person with AD) in assessments, care decisions/planning and delivery; and
- respect for the choices made by the person with AD and/or their substitute decision-maker.

There is concern among Canadians that residents in long-term care institutions are not receiving quality care. Quality of care is assured when there is adequate funding and when accountability mechanisms are in place and quality standards are enforced through

inspection and compliance activities and where the needs and preferences of the residents and family are reflected in the standards.

NACA RECOMMENDS THAT:

- **Provincial governments conduct research, collaborate with providers and offer sufficient funding to ensure there is an adequate supply of long-term care for people with ADRD who are no longer able to live in the community.**
- **Provincial governments develop appropriate legislation and create the necessary monitoring and compliance activities to ensure that all long term-care institutions, including hospitals, meet quality standards consistent with maintaining a good quality of life for residents with dementia.**
- **Provincial/territorial governments provide increased staffing ratios and provide specialized staff education and training in dementia care for long-term care facilities, including hospitals. Provincial/territorial governments should also ensure that these institutions be designed creatively to provide safe and homelike environments for people with ADRD.**

NACA REITERATES THE RECOMMENDATION (NACA Position Paper on *Enhancing the Canadian Health Care System*, 2000) THAT:

- **Funding models be reviewed to ensure that charges for room and board for residents of long-term facilities, not be set higher than current market rates in the local community for similar lodging and food service in order to eliminate the possibility of residents' room and board fees paying for publicly-insured health care services.**

4.4. Home care

Although home care has been shown to be useful in prolonging the independence and quality of life of persons with dementia, and of supporting caregivers, the CSHA reported that home care is underutilized. Only one in four people caring for a person with dementia receives formal home care services to assist in caring for a family member, even after caring for someone for five years or more. However, of those who do receive formal care, most are satisfied with the quality of care provided.³²

Uneven funding and provision of home care services across the country for people with ADRD and their caregivers means that some services for long-term chronic care conditions such as AD are either unavailable or require out-of-pocket expenses. Some additional barriers that seem to prevent caregivers of dementia patients from using home

care services include: ³³

- a reluctance to use home care until the care receiver's health is so limited that it can no longer be handled by informal care;
- a perception that caregiving is a familial responsibility;
- lack of trained personnel;
- social embarrassment felt by caregivers; and
- lack of knowledge about services and how to access them.

The 2003 Health Accord and government action

In the 2003 Accord on Health Care Renewal, First Ministers agreed to develop a national home care program to be publicly insured on a first-dollar basis for a minimum set of services in short-term acute care, including acute community mental health and end-of-life home care. While a publicly-funded home care system with this limited "basket of services" provides some benefit to those with AD and their caregivers (and is an improvement over the current situation), it falls short of the necessary range of chronic disease management home care services needed to care for people with AD in the community. Further, there is a danger that limiting coverage to post-acute care will have negative consequences for chronic home care.

It is possible that, even if home care services for chronic disease management were publicly funded, these services might prove inadequate in addressing the special needs of those with ADRD. Special training of home care personnel is required; working conditions which minimize the turnover of specially trained staff must be encouraged.

NACA RECOMMENDS THAT:

- **The federal and provincial governments collaborate to develop a common national definition of a set of home care services for individuals with chronic and long-term health problems, and that these services be fully insured as part of the *Canada Health Act*.**
- **Provincial governments provide specialized staff education and training in ADRD care for home and community care services and establish working conditions that promote continuity of staffing.**

4.5 Caregivers

The assistance provided by informal caregivers (unpaid care by family/friends) is critical in allowing those who live in the community to maximize their independence and quality of life and to delay and/or prevent moving into long-term care institutions.

The CSHA has provided much information about the situation of caregivers of persons with dementia.³⁴

4.5.1 Who are the day-to-day care providers?

Among informal caregivers, 75% are women: adult daughters comprised 29% of informal caregivers; wives represented another 29%. About 19% of informal caregivers were husbands. About one third of caregivers are employed (and are at risk of being forced to cease employment as the disease progresses); half of the caregivers in Canada are over the age of 60. Caregivers frequently have health problems of their own.

4.5.2 Use of community services by caregivers

Use of community services by caregivers of persons with dementia is surprisingly low. In fact, “having a physical disability is far more strongly predictive of service use than is dementia status.”³⁵ Sixty-nine percent of caregivers who were spouses used no services at all compared to 46% of caregivers who were sons or daughters. In most provinces, only 3-5% of caregivers used three or more services. As in the case of home care, when caregivers rely on community services, they report a high level of satisfaction.

4.5.3 Health status of caregivers

The data suggests that caregivers of those with dementia are more likely to suffer from chronic health problems and are more likely to be depressed. The risks for these physical and mental health problems are greater for informal caregivers in the community than for formal caregivers in institutions. These health problems make it more likely that informal caregivers will seek to place the person with dementia in an institution.

4.5.4 Caregiver needs

How might public policies help relieve some of the health and financial burdens incurred by caregivers? Bryan Smale and Sherry Dupuis³⁶ completed a study in which caregivers and care providers identified key areas (systemic issues, human resource issues and caregiver well-being issues) that must be improved to address the needs of those with dementia and their caregivers.

Specific strategies for change, identified by caregivers, included the provision of:

- appropriate and adequate compensation options;
- job and pension protection and caregiving leave policies in the workplace; and
- education and training opportunities on dementia and dementia care to informal caregivers.

Caregivers incur various expenses related to their caregiving. In its 2004 Budget, the federal government recognized this fact by allowing caregivers to claim a tax credit of up to \$5,000 to cover extraordinary expenses that caregivers might incur, ranging from modifying a van to additional nursing and medical equipment expenses.³⁷

The federal and provincial/territorial governments have taken additional action to support informal caregivers, including:

- in Ontario, the 2003 Budget committed to increase the tax support for family caregivers;
- the Nova Scotia 2003 Budget increased its Caregiver Tax Credit by 75%;
- Quebec has a respite care program that provides financial assistance (up to \$600) to caregivers to purchase respite services from family members or others;
- the federal 2003 Budget included a six-week employment insurance (EI) compassionate family care leave benefit to care for one's gravely ill or dying child, parent or spouse. This leave provision will include legislative changes to the Canada Labour Code to ensure job protection.

These measures are a step in the right direction, but more policies that assist caregivers are needed. For instance, the federal government provides a Caregiver Tax Credit, but to be eligible, a claimant must be related to – and live with – the person receiving care. The proposed national home care funding under the 2003 Health Reform Fund is limited to home care services for post-acute care, mental health case management and end-of-life care. None of these services are of much direct benefit to caregivers of persons with dementia.

NACA RECOMMENDS THAT:

- **The federal government provide income protection of caregivers of people with dementia by amending the conditions of the Compassionate Family Care Leave Benefit to include care recipients who have chronic illnesses such as ADRD and not only those for whom death is impending.**
- **F/P/T governments expand the proposed basket of national home care services to provide for services that specifically assist caregivers, including: respite/day away programs, transportation services, support groups, counselling, and information and education programs; and that these services be provided in a way that meets the needs of caregivers (e.g., day programs that operate more than 8 hours/day).**

- **The federal government amend the qualifying conditions of the Caregiver Tax Credit to allow caregivers who are not related to – and do not reside with – the care recipient to qualify for this tax credit.**
- **The Canada Pension Plan and the Quebec Pension Plan develop “drop out” provisions for caregivers to cover periods of low or zero earnings when caregiving for those with chronic illness, including ADRD.**
- **The federal and provincial governments develop a cost-sharing program that matches the current program of Quebec, by providing up to \$600 per year to caregivers of those with chronic illness to purchase respite care from family members or others.**
- **Provincial and municipal governments collaborate with the Alzheimer Society and other voluntary sector organizations to provide education and training specific to ADRD for caregivers of people with ADRD.**

5. ETHICS

There are a number of important ethical issues related to Alzheimer Disease and related dementias. These ethical dilemmas always have implications for the person with dementia; however, they also implicate researchers, health care providers, caregivers, families and society in general. Ethical dilemmas occur when it becomes unclear what course of action to follow. These can result from inadequate information, because values are inherently in conflict with each other, or because some harm will be done regardless of the chosen course of action.³⁸

In 2003, the Alzheimer Society of Canada published *Tough Issues: Ethical Guidelines*.³⁹ This document discusses a number of ethical issues related to AD in the context of the values (respect, compassion, integrity and competency) and guiding principles established by the Society*. Some of the more important ethical issues have public policy implications in several areas.⁴⁰

5.1 Driving

A diagnosis of AD does not automatically mean the end of driving a motor vehicle. Providing the person diagnosed is capable of driving safely, he or she should be permitted to do so. Driving extends the person’s independence, freedom and mobility. However,

*For a description of the values and guiding principles related to ethics and Alzheimer Disease, refer to Appendix (Part IV).

there will come a time when the person with AD can no longer drive due to danger to himself and others. When this time comes, driving must cease immediately. How to decide when driving is no longer appropriate requires an assessment of the person's driving ability and ongoing monitoring. The decision to remove driving privileges can prove difficult for all concerned: the person with AD, caregivers and physicians. Currently, there is no nationwide standardized testing to determine when someone who has AD is unable to drive a motor vehicle safely.

5.2 Participation in research

It is important that people with AD involved in research for better treatments and a cure for dementia be capable of making informed decisions regarding their participation; if they are no longer able to give consent due to their condition, their values and wishes need to be respected by substitute decision-makers. For researchers, it is important that they abide by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Developed by the three federal government research organizations that fund research involving human subjects, this policy statement sets out standards and procedures for conducting safe and ethical research and describes the consent process.

The policies governing participation of persons with AD in research vary across provinces. Some provinces make it very difficult for those who are not capable of giving informed consent (e.g., those with mid-late stage AD) to be involved in research that may not only further researchers' knowledge of the disease but may also benefit the participant. It would be desirable, and more just for potential participants in research, if all provinces established and applied the same criteria to research participation.

In the end, it is important that as researchers work to advance our knowledge in AD, the interests of the person with AD remain paramount at all times. This requires an open dialogue and honest communication regarding the person's wishes, potential conflicts of interest (e.g., researchers' and pharmaceutical firms) and the balancing of risks and benefits.

5.3 Genetic testing

Predictive genetic testing, which can determine whether a person has a very low or very high chance of developing a certain disease, can be done in the small number of individuals who have inheritance associated with FAD. For the vast majority of people, there is no test to determine when or if they are likely to develop AD. For the few for whom predictive genetic testing is possible, the decision to test or not should be entirely personal. It is important that any genetic testing be done in a way that allows for informed consent, counselling and confidentiality.

5.4 Restraints

Restraints, in the form of a physical device, medication or modified environment, are sometimes used on people with AD. The intention is to protect the person with ADRD or others from what is viewed as disturbing behaviour related to the progression of the dementia. However, the use of restraints has consequences (loss of freedom/abilities and risk of injury); so the decision to use them should be taken only after other options have been explored. The preferred choice is not to use restraints. Often, problem-solving approaches can be developed to address the behavioural changes. These approaches are enhanced if there is a good understanding of the disease progression. They can lead to more imaginative solutions (e.g., well-designed environments, better staffing ratios that result in more appropriate care and management of the person with dementia), negating the need to use restraints. If these strategies fail, sometimes minimal restraints can be considered but should be used for a short duration only and with careful monitoring.

It is apparent that Canada lacks sufficient researchers in the area of ethics and dementia. A data search on funding grants revealed “no current students pursuing doctoral studies in this area, no grants funded, and little academic emphasis on aging, Alzheimer Disease and ethics.”⁴¹ If more research were to be carried out in Canada regarding ethics and dementia, it is likely that researchers, policy makers and practitioners would achieve greater consensus on how to make difficult day-to-day decisions with greater moral certainty and uniformity.

NACA RECOMMENDS THAT:

- **The federal government fund, through the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council, research on ethical aspects of Alzheimer Disease and related dementias.**
- **F/P/T Ministers Responsible for Seniors initiate work with appropriate stakeholders (e.g., Canadian Medical Association) in order to establish national guidelines that determine who should be making decisions regarding an ADRD person’s continued ability to drive a motor vehicle and what criteria should be applied in these decisions.**
- **The Canadian Medical Association and the Royal College of Physicians and Surgeons develop guidelines/regulations for physicians conducting genetic testing of people for AD.**
- **F/P/T Ministers of Health develop common guidelines for all jurisdictions to guide consent of those with ADRD or a cognitive impairment to participate in research.**

- **Provincial governments and provincial Alzheimer Societies collaborate with hospital, community and long-term care providers to educate health care providers and develop guidelines/regulations regarding the use of restraints on people with ADRD.**

6. HOUSING

Traditionally, people with Alzheimer Disease or other dementias were cared for in their own homes by immediate or extended family. Today, however, those with dementia have many housing options available to them and their family or caregivers. The issues regarding residing in private homes and long-term care institutions have already been addressed. Other housing options for those with dementia include:⁴²

6.1 Group homes

These are typically large single unit homes (new or converted) that house 8-10 residents. They are characterized by a family-like atmosphere and life-style. These homes have varying degrees of modification to accommodate those with dementia, are staffed with qualified personnel during the day and an on-call person during night hours. Like family homes, these residences have a living and dining room, kitchen and bedrooms. Often, there are communal activities including preparation and taking of meals, recreation and entertainment.

6.2 Assisted living

This is housing in which there is a home setting combined with support services, sometimes including health care services. Typically, assisted living accommodates 30-120 people and has the appearance of an oversized house or small apartment building. Older terms for assisted living includes “lodges”, “personal care homes” or “boarding homes”.

6.3 Supportive housing

Includes a variety of types of accommodation and a mix of on-site personnel support, homemaking services and 24-hour supervision. Supportive housing is increasingly viewed as a substitute for unnecessary institutionalization. Supportive housing is gaining attention as an attractive option for people with ADRD – especially those in the early and middle stages.

6.4 Important principles for housing people with dementia

Regardless of the type of housing option chosen, there are some important principles that must be respected if those with dementia are to occupy housing that maintains their health and adds to their quality of life to the maximum degree possible:

- *aging in place*: for a person with dementia, changing residency can be disorienting and disturbing. To minimize the disruptiveness of such a change in their environment, it is best that careful planning to ensure the necessary support services, recreational activities, etc., are in place so that a continuum of care allows for “aging in place.”
- *good management*: managing housing for those with dementia requires that certain conditions exist:
 - ▶ knowledge of the disease;
 - ▶ focus on individual dignity;
 - ▶ suitable training of staff;
 - ▶ maintaining family contact; and
 - ▶ integration of residents into community.
- *home-like atmosphere*: for the residence to feel like home, there needs to be: low-turnover of staff to allow them to get to know residents; a home-like setting; and activities of daily living intended to maximize residents’ functioning.⁴³
- *housing designed for people with dementia*: it is important that specific problems related to AD be addressed through proper physical design:⁴⁴
 - ▶ exits that are safe in an unobtrusive way;
 - ▶ hallways in which to walk and wander;
 - ▶ private rooms and small sitting areas;
 - ▶ a residential “feel”;
 - ▶ supports that enable residents to maintain their independence (e.g., handrails, non-slip flooring);
 - ▶ understandable sounds, smells, colours and views (e.g., consistent with their life experiences, backgrounds, cultures);
 - ▶ adjacent outdoor space that is secure and planned (accommodates wandering);
 - ▶ useful adaptations to the home environment (e.g., locks, safe furniture).⁴⁵

NACA RECOMMENDS THAT:

- **The federal government take a leadership role to increase research and knowledge about the current and future demand for community housing for people with dementia (group homes, assisted living, supportive housing, emerging models) in the context of an aging population.**
- **The federal government allocate new financial investments for all types of community housing for people with dementia by either funding individuals or housing providers, as appropriate, directly through subsidies, or indirectly through transfer payments to the provincial/territorial governments and/or municipal governments.**

- **Provincial and territorial governments ensure that local health and social services are adequately financed, integrated and available to residents in housing for people with dementia, just as they would be to any other member of the community.**
- **Provincial and territorial governments work together with municipal governments, housing providers and operators and potential/current consumers of housing for people with dementia, in order to develop the necessary consumer protection, legislation, regulation and policies appropriate to a supportive/assistive housing environment and to retirement homes.**

7. TOWARD A NATIONAL STRATEGY ON ADRD

7.1 Background

Most provinces and territories have made some progress in developing provincial strategies on Alzheimer Disease to begin coordinating public policies at the provincial/regional level. These provincial/territorial strategies have usually resulted from some form of collaboration between provincial Alzheimer societies and respective provincial governments. The comprehensiveness of these AD strategies varies widely as does their stage of implementation.* Ontario's Strategy for Alzheimer Disease and Related Dementias stands out as the most comprehensive. This five-year provincial strategy (1999-2004) included extensive involvement of the Alzheimer Society of Ontario and other key stakeholders, and included government funding of \$68.4 million. The Strategy has formally concluded and a transitional plan is being implemented.

The Strategy consisted of a 10-point action plan to assist those with ADRD and their families and caregivers:

- staff education and training;
- physician training;
- public awareness, information and education;
- planning for appropriate, safe and secure environments;
- respite care for caregivers;
- research on caregiver needs;
- advance directives on care choices;
- psychogeriatric consulting resources;
- coordinated specialized diagnosis and support; and an

* See table in Section VI of Appendix for description of provincial/territorial Alzheimer Disease strategies.

- intergenerational volunteer initiative.

During the transitional phase, work on several of the initiatives is being completed and a process has been put in place to coordinate the ongoing work, sustain the achievements of the Strategy and ensure they remain true to their original objectives, and make recommendations for the future. A Provincial Alzheimer Group has been established to provide the leadership and monitoring to the transitional phase. A Roundtable on Future Planning for People with Dementia in Ontario has also been initiated and mandated to develop a framework for planning.

In addition to involvement in provincial Alzheimer strategies, the Alzheimer Society of Canada – and its provincial and local affiliates – has done tremendous work to improve the lives of those affected by AD by increasing public awareness, providing information, providing referral to support services, developing publications and guidelines, and funding research. Other private sector organizations, both non-profit and for-profit, are involved in the development of pharmaceuticals, provision of community services, and long-term institutional care.

Alzheimer Disease and related dementias are complex problems that cannot be addressed by any single agency or sector of society. Though various sectors of Canadian society have worked to address dementia, either directly or indirectly, most of these activities have been undertaken independently. Dementia is a national challenge that does not respect jurisdictional boundaries and therefore, requires a national response.

7.2 Does Canada need a national strategy on ADRD?

7.2.1 Increasing pressure

Alzheimer Disease and related dementias have a substantial health and social impact on Canadian society. The challenge of dementia will continue to grow significantly, peaking over the next two to three decades. We have a good understanding of the current and projected prevalence, and socio-economic burden, of ADRD. The current challenges related to AD are serious, but the real ones are ahead of us. Canada has an opportunity to take collaborative, coordinated action now to prevent the worst effects of this serious disability in the decades ahead.

7.2.2 Knowledge not always applied

Biomedical and psychosocial research on AD have demonstrated ways to improve treatment and care of those affected by dementia. Yet, it is clear that research knowledge is not regularly incorporated into policy, practice, program and funding decisions. Evidence-based practices are either not widely known by policy makers or are not applied evenly in all Canadian jurisdictions. Examples include:

- earlier diagnosis and full utilization of available treatments may have the potential to delay the progression to full dementia;

- improved public policies in housing, home care, support services and caregiver support can delay or avert institutionalization and improve quality of life for people with dementia and their caregivers; and
- difficult ethical questions surrounding dementia are known but have not been addressed.

7.2.3 Models exist

Measurable progress has been made at the provincial level in developing coordinated and comprehensive ADRD strategies. But no action has been taken at the national or federal level to coordinate policies within a strategy to address dementia. There are examples of successful strategies from which all can learn, such as the one in Ontario. Also, Australia implemented a National Action Plan on Dementia Care. Canada has models of nationally integrated and coordinated strategies to address other chronic diseases (e.g., Canadian Stroke Strategy, National Diabetes Strategy) that are national in scope. These strategies have included a role for the federal government, in terms of both leadership and funding. A national strategy addressing dementia can borrow from these models.

7.2.4 Collective action needed

Stakeholders in Alzheimer Disease agree that there is need for collective action. On April 21, 2004, during the Alzheimer Society of Canada's National Alzheimer Conference, representatives from the Cognitive Impairment in Aging Partnership*, the Alzheimer Provincial Societies and the National Advisory Council on Aging met to explore the possibility and desirability of developing a national strategy on Alzheimer Disease and related dementias. It was agreed that a national strategy is needed, is feasible, and that work toward its development should commence. Further, there was consensus that in addition to addressing Alzheimer Disease and related dementias, the strategy should include mild cognitive impairment, a significant risk factor for dementia and an area of much promising research regarding early intervention.

8. A PROPOSED NATIONAL STRATEGY ON ADRD

8.1 The goals

- decrease the prevalence of ADRD;
- decrease the socio-economic burden of ADRD; and
- develop evidence-based prevention strategies, improve early diagnostics of all dementias, and improve the access to and the quality of treatment and supportive care for all Canadians affected by Alzheimer Disease and related dementias (patients, families and caregivers).

*The partnership is an initiative led by the Institute of Aging of the Canadian Institutes of Health Research, in which the Alzheimer Society of Canada is also a partner. See the Appendix (part V) for a list of the official signatories.

8.2 The means

The goals of the strategy would be achieved by translating biomedical and psychosocial research knowledge into evidence-based “best practices” in prevention, treatment and care that are consistently applied throughout Canada via an integrated and coordinated approach involving all levels of government, the health and social care systems, and the non-profit and for-profit sectors. Although coordination will occur at the national level, team leadership and implementation will occur at the provincial, regional and community levels.

The national strategy will build on successful elements of existing or future provincial strategies (i.e., elements that are suitable to all jurisdictions). The strategy will be independent of, yet compatible with, key elements of provincial strategies. There must be flexibility in having provinces continue to administer programs in ways that meet their particular needs. Development of the national strategy will involve key partners such as the Alzheimer Society of Canada and its provincial Societies and the Cognitive Impairment in Aging Partnership. Additional partners/key stakeholders will be added as necessary (e.g., federal and provincial/territorial governments).

8.3 Development and implementation

In the early stages of developing and implementing the strategy, the federal government’s role will be to act as a facilitator and catalyst, working with other partners. The federal government can carry out this role through policy development and funding consistent with the recommendations made in this report. Implementation will, for the most part, take place at the provincial and regional levels, where jurisdictional authority for delivery of many health and social programs lies.

NACA RECOMMENDS THAT:

- **The federal government, in collaboration with identified key partners (Alzheimer Society of Canada, provincial Alzheimer Societies, Cognitive Impairment in Aging Partnership, and the Institute of Aging of the Canadian Institutes of Health Research) develop a National Strategy on Alzheimer Disease and Related Dementias that sets a national vision to address dementia and that builds on successful elements of provincial strategies that will benefit all provinces.**
- **The federal government, in consultation with key partners, develop policies and programs of the Strategy by funding programs that are national in scope, and that specifically address dementia, such as increased research, pharmacare, home care, increased housing options, and support for caregivers.**

APPENDIX

I. *RELATED DEMENTIAS (RD)*

Vascular Dementia: VaD is the second most common form of dementia – after AD – accounting for 19% of all dementia cases. VaD develops suddenly after a single stroke – or series of strokes – large or small, which results in brain damage due to inadequate blood flow. Vascular Dementia affects some cognitive functions more than others (e.g., language, vision or memory). In VaD, the initial cognitive deterioration is often followed by stabilization, then followed by further deterioration. Risk factors⁴⁶ for VaD include: age (65 plus), high blood pressure, heart disease and diabetes. Medications can be used to try to minimize the risk factors and thereby avoiding or delaying the dementia. Once the dementia has developed, medications can be used to improve blood flow and therapies (e.g, physio, occupational) can benefit.

Pick's Disease: the exact cause of Pick's Disease (also referred to as Frontotemporal Dementia) is unknown; however, it is known that in people who have Pick's Disease, brain cells in the frontal and temporal lobes shrink or die; or, in other cases, enlarge and develop round, silver "Pick's bodies". People with Pick's dementia experience progressive particular deterioration in the areas of the brain responsible for behaviour and speech. People with Pick's dementia may become withdrawn or uninhibited or have problems with speech. Distinctive from AD, patients with Pick's often remain oriented in time and place and retain their memory, until later stages when general dementia sets in. Pick's usually strikes those aged 50-60, both men and women. Post-diagnosis, the expected lifespan is 7-8 years. There is no treatment and no way of slowing the disease's progression.⁴⁷

Lewy body Dementia: named after Dr. Levi Lewy (1912) Lewy body Dementia is a progressive dementia characterized by abnormal structures in the brain called "Lewy" bodies. Why these "Lewy" bodies – composed mainly of a protein called alpha synuclein – form is not known. Lewy body Dementia is different from AD in that only 10-15% of the neurons die or disappear; the remaining simply do not function. Accounting for 15-20% of dementias among the elderly, Lewy body Dementia is the second leading cause of dementia after AD. Similar to AD, Lewy body Dementia causes progressive memory loss; unlike AD, Lewy body Dementia usually progresses more quickly than AD and often exhibits some features of Parkinson's Disease (e.g., muscle stiffness, shaking, stooping). Currently, the cause of Lewy body Dementia is not known and researchers have not been able to determine any risk factors. There is no cure for Lewy body Dementia but some symptoms can be treated (depression, hallucinations).⁴⁸

Creutzfeldt-Jakob Disease: a form of rapid progressive dementia which results from small holes in the brain created by the loss of nerve cells and the degeneration of these cells' membranes. Early symptoms include: mood swings, lack of interest and

withdrawal. As the disease progresses, people become unsteady on their feet, experience blurred vision, slurred speech and jerky movements. Ultimately, movement and speech are lost. There are four forms of the disease: sporadic, familial, transmissible and variant (“Mad Cow” disease). There is no way to slow the disease and current medications only treat some of the symptoms. Life expectancy of someone with CJD is 6 months to several years, depending on the type developed/acquired.

II. STAGES OF ALZHEIMER DISEASE

Early stage: lasting 2-4 years: in this stage, the person is mildly forgetful, has difficulty processing new information, and has problems with concentration, communication and/or orientation. Other symptoms include mood shifts and depression. Behaviourally, the person typically becomes more passive, refrains from participating in usual activities and is restless or anxious. In day-to-day functioning, the person often has problems with completing tasks such as banking and shopping.

Middle stage: lasting from 2-10 years: in this stage, the person with AD typically experiences a further deterioration in mental abilities, moods and emotions, behaviours and in their ability to function in daily activities. For example, memory lapses increase, language difficulties become more pronounced and the patient is more forgetful about his or her own personal history. Time/place disorientation increases as does an inability to recognize friends and family. Personality changes often take place and confusion, anxiety/apprehension, suspiciousness and hostility become more prominent. Behavioural changes may include pacing and wandering, repetition, delusions, aggression, uninhibited behaviour (e.g., rudeness, sexual behaviour) and/or passiveness. During this stage, the individual with AD requires help dressing, bathing and using the toilet. Often, there will be disrupted sleep patterns, appetite fluctuations and visual/spatial problems.

Late stage: lasting from 1-3 years: mental capacities are severely compromised; there is a loss of ability to remember, communicate or function, inability to process information (e.g., read, write or speak coherently) and a severe disorientation with respect to time, place and people. A limited range of emotions may remain and effective methods of communicating are increasingly non-verbal (e.g., eye contact, crying, groaning). Sleeping becomes more frequent, the person is often unable to speak, incontinent, unable to dress or bathe and there is a likelihood of weight loss despite adequate nutrition. It should be noted that, throughout the course of AD, symptoms can vary across individuals and across stages. Not all patients experience identical symptoms at the same stage, nor will all patients necessarily pass smoothly from one stage to the next (i.e., it is possible to experience symptoms indicative of more than one stage simultaneously).

III. CANADIAN RESEARCH ACTIVITIES IN DEMENTIA

- **Canadian Study on Health and Aging (CSHA):** a population-based study carried out over the past 13 years which has received international recognition for its contributions to understanding the epidemiology of dementia, incidence/prevalence, risk factors and patterns of caregiving;
- **Canadian Institutes of Health Research - Institute of Aging:** has identified cognitive impairment as its highest research funding priority;
- **Cognitive Impairment in Aging Partnership:** composed of leading research organizations from voluntary, public and private sector that have expertise in the field of research on cognitive impairment (e.g., Health Canada, CIHR, pharmaceutical companies, Heart and Stroke Foundation, NeuroScience Canada); has led to the development of the Cognitive Impairment Network;
- **C5R Consortium:** the Consortium of Canadian Centres for Clinical Cognitive Research has carried out excellent clinical research in areas of diagnosis, and treatment outcomes;
- **University Research/Medical Schools:** the federal government provides indirect funding to university research in medicine, including Alzheimer research;
- **Alzheimer Society of Canada:** is a leading funder of both biomedical and psychosocial aspects of Alzheimer Disease providing more than \$3M in 2002 Alzheimer research; and
- **Cognitive Impairment Network:** a proposed network of expert researchers in the field of cognitive impairment in Canada. This group has applied to the Networks of Centres of Excellence for 7-year (\$35M) funding. The “ultimate goals of CI-NET are to delineate the causes of AD and other dementias, to improve the lives of individuals with dementia and those looking after them in the community, and to prevent, treat and even cure AD and dementia.”⁴⁹

IV. ETHICS AND ALZHEIMER DISEASE

(From Alzheimer Society of Canada’s *Tough Issues: Ethical Guidelines*)

Values: respect, compassion, integrity and competency

Guiding principles:

- people with Alzheimer Disease need to be told their diagnosis and made aware of available treatment options;
- people with Alzheimer Disease must have access to current information, and receive coordinated care and support from knowledgeable health care professionals;
- people with Alzheimer Disease need to participate in decision-making regarding their daily lives and future care for as long as they are able. If unable to participate, the known values and wishes of the person with Alzheimer Disease must guide all decisions.
- people with Alzheimer Disease need a safe, restraint-free living environment and protection from exploitation and abuse;
- family and friends who care for people with Alzheimer Disease need to have their

- caregiving needs assessed and provided for;
- people with Alzheimer Disease and those who care for them need to take an active role in the planning and implementation of care; and
- adequate resources must be available to provide support to people with Alzheimer Disease and their caregivers throughout the course of the disease.

V. OFFICIAL SIGNATORIES TO THE COGNITIVE IMPAIRMENT IN AGING PARTNERSHIP

Public Sector:

- Canadian Institutes of Health Research (CIHR) - Institute of Aging
- CIHR Institute of Neuroscience, Mental Health and Addiction
- Fonds de la recherche en santé du Québec
- Health Canada
- Nova Scotia Health Research Foundation
- Veterans Affairs Canada

Voluntary/Charitable/Non-Profit Sectors:

- Alzheimer Society of Canada
- Consortium of Canadian Centres for Clinical Cognitive Research
- Canadian Nurses Foundation
- Neuroscience Canada
- Heart and Stroke Foundation of Canada

Private Sector:

- Janssen-Ortho Inc.
- Pfizer Canada Inc.

VI. SUMMARY* OF PROVINCIAL STRATEGIES AS OF JULY 2004

Province	Provincial Strategy	Developed by:	Funder	Stage of Development	Important Highlights of Strategy:
Alberta and the NWT	Alberta Health and Wellness released: <i>"Strategic Directions in Health Aging and Continuing Care in Alberta for Alzheimer Disease and other dementias."</i> as a reference tool to be used by the Regional Health Authorities in their planning cycle.	This document was developed in a consultative manner that included the Alzheimer Society, Regional Health Authorities, family caregivers, physicians, public and private facilities and Alberta Health and Wellness.	The government did not attach any resources to the document nor was it sent forward as a standard for minimum requirements in local health authorities.	Since release of the document (2002) the government has taken pieces and begun the work of developing the tools to meet the objectives. 2 projects currently underway re: the education and training objective 1. Palliser Health Authority pilot project is intended for front line staff in LTC. 2. project targeted at colleges and university programs.	Six themes with proposed strategies for achieving the desired outcomes: 1. Public Awareness 2. Education and training 3. Support for informal caregivers 4. Service delivery across the continuum of care 5. Supportive environments 6. Ethical issues.
British Columbia	Former Strategies for End of Life, Diabetes, & Mental have all been shelved. Government has included Dementia on the Chronic Disease Management program. (1 of the top 10 chronic diseases).	ASBC supports the British Columbia Medical Association recommendations that the government develop a collaborative plan for dementia care (includes a recommendation that ASBC be funded for education and support.)		Beginning Stages Working on a Path for Chronic Disease Management Note: Access to drug is a separate issue.	ASBC is focusing on the following 3 issues and not a formal "strategy." 1. The need for Pharmacare to provide coverage for the Health-Canada approved Alzheimer medications; 2. Identifying dementia as part of B.C.'s Chronic Disease Management program (done); and 3. Improving coordination of services at the community level and enhancing community support programs.
Manitoba	Pending <i>Manitoba Strategy for Alzheimer Disease and Related Disorders.</i>	Over four years ago, Minister of Health directed the Department of Health to develop an Alzheimer Strategy to prepare for the future care of a growing number of Manitobans affected.		November 2002, a <i>Manitoba Strategy for Alzheimer Disease and Related Disorders</i> was submitted to the Minister of Health. April 2003, government accepted the Strategy in principle and commitment was	1. Education (both public and professionals) 2. Guidelines for Diagnosis 3. Standards (person centered approach to care) 4. Family and Individual Support (flexible support options) 5. Programs and Services (more responsive facility and community based

VI. SUMMARY* OF PROVINCIAL STRATEGIES AS OF JULY 2004

Province	Provincial Strategy	Developed by:	Funder	Stage of Development	Important Highlights of Strategy:
				<p>made to establish a Stakeholder Advisory Committee in early summer 2003 to develop a plan of action. To date, no further action has been taken by the Government of Manitoba</p> <p>Recent regional action to restrict coverage for cognitive enhancers seen as contrary to Strategy</p>	<p>programs)</p> <ol style="list-style-type: none"> 6. Case Management and Collaboration (improves access to services and expertise) 7. Equitable Access 8. Human and Financial Concerns (sufficient number and mix of health care providers and care options) 9. Research and Evaluation (work towards establishing and maintaining best practices)
Nfld and Labrador	<i>Provincial Strategy for Alzheimer Disease and other Dementias.</i>	<p>The Alzheimer Society (AS) has partnered with the Department of Health and Community Services in developing a Strategy.</p> <p>Steering Committee is co-chaired by the AS and the Department of Health and Community Services</p>	Work to date funded by government.	<p>The Strategy document is the first phase of the Committee's work with the next phase involving: i) The development of a plan of action; ii) The coordination of an implementation plan that can be used throughout the Province</p> <p>The Steering Committee will play a coordination role. Government announced a plan to develop a new seniors' drug subsidy program and announced that cognitive enhancers will be added to provincial formulary. Action pending.</p>	<p>Goals of the Strategy:</p> <ol style="list-style-type: none"> 1. Coordinated System of Care 2. Access to Current Information on Alzheimer Disease & Other Dementias 3. Support for Individuals with AD & other Dementias & their families/caregivers 4. Education & Skill Development
New Brunswick	<i>"A Strategic Framework for Supporting Persons Affected by Alzheimer and related diseases in New Brunswick". 1997</i>	Community partners, caregivers, professionals and Alzheimer Society representatives from the eastern provinces (NS, PEI, NF, QUE, NB) meet to review and make final	Work to date funded by Department of Health and Community Services and ASNB	Framework developed from 1994 to 1996, and presented to Minister of Health in 1997. 2000 - establishment of a joint ASNB & Government Working Group - group identified long & short-term priorities for implementation - which were presented in June 2001.	Action Plan to be developed for two identified short-term priorities: <ol style="list-style-type: none"> 1. Education and 2. Respite

VI. SUMMARY* OF PROVINCIAL STRATEGIES AS OF JULY 2004

Province	Provincial Strategy	Developed by:	Funder	Stage of Development	Important Highlights of Strategy:
		recommendations to the framework.		January 2003 - a joint ASNB and Government Education Working Group to develop an action plan for the education of health care workers in New Brunswick. Plan to be presented to government in September 2004.	
Nova Scotia	No formal Strategy as of yet	Two representative action committees established to address specific objectives under the <i>Initiatives for Action</i> project.	Co-sponsored by Nova Scotia Department of Health and Alzheimer Society of Nova Scotia (Together, the two are contributing more than \$300,000 to <i>Initiatives for Action</i>)	"Alzheimer Strategy for Nova Scotia: A planning Framework of Services for people affected by Alzheimer Disease" submitted in 1998. Initiatives for Action announced in 2000. 2001: Inventory completed of Dementia Education programs Discussions with the Department of Health recently resumed.	May 2002 Physician Needs Assessment in Alzheimer Disease and other Dementias June 2002 Report by the Action Committee on Physician Diagnosis and Treatment June 2002 Report by the Action Committee on Education of Health Professionals
Ontario	Completed 5-year Strategy <i>Ontario's Strategy for Alzheimer Disease and Related Dementias 1999</i>	Collaboration of Ontario Provincial Government (Ministry of Health and Long term care and Ontario Seniors Secretariat) with extensive consultation with relevant stakeholders.	Ontario Government	Strategy completed. Ongoing initiatives for the transitional period include: · The <i>Ontario College of Family Physicians</i> continues to co-ordinate work related to physician education. · The <i>Ontario Community Support Association</i> is co-coordinating work on staff education. · A <i>Provincial Alzheimer Group</i> was established: - to provide co-ordination of the components continuing	Strategy Initiatives: 1. Staff Education and Training 2. Physician Education 3. Increase in Public Awareness, Information & Education 4. Planning for Appropriate, Safe and Secure Environments 5. Respite Services for Caregivers 6. Research on Caregiver Needs 7. Advance Directives on Care Choices 8. Psychogeriatric Consulting Resources 9. Coordinated Specialized Diagnosis and Support · Dementia networks · Research coalition

VI. SUMMARY* OF PROVINCIAL STRATEGIES AS OF JULY 2004

Province	Provincial Strategy	Developed by:	Funder	Stage of Development	Important Highlights of Strategy:
				forward, focusing on improving service and making life more meaningful for those experiencing ADRD; - to promote systemic change to support the needs of the growing population affected by ADRD; - to foster & support linkages and identify opportunities for development of services, education, research and supportive public policy	<ul style="list-style-type: none"> · Specialized geriatric services 10. Intergenerational Volunteer Initiative. See www.alzheimerontario.org for more information
Prince Edward Island	In the development stage. Discussions have resumed with the Provincial Government				
Quebec	Ministry of Health and Social Services (MSSS) Action Plan for Alzheimer Disease (Provincial Strategy).	Ministry of Health and Social Services (MSSS)			Objectives of the Ministry of Health and Social Services (MSSS) action plan for Alzheimer Disease (Provincial Strategy). 1. Public education 2. Improved diagnosis 3. Accessible support and services 4. Supports to acquire quality services adapted to their needs. 5. Increase research of types.
Saskatchewan	Under development	Alberta Alzheimer Society and stakeholders		Focus Groups completed and working committees identified around each theme from the focus groups Draft recommendations to be completed by May 28 th to be distributed to committee members and stakeholders by June 29 th	Focus group themes 1. Public Awareness/Public Education 2. Quality Dementia Care 3. Diagnosis/Prevention/Treatment 4. Support for Caregivers 5. Supportive Housing/ Independent Living 6. Service Delivery Across the Continuum: Continuity of Services/Navigating the Health Care System/Services in the Community 7. Education and Training

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