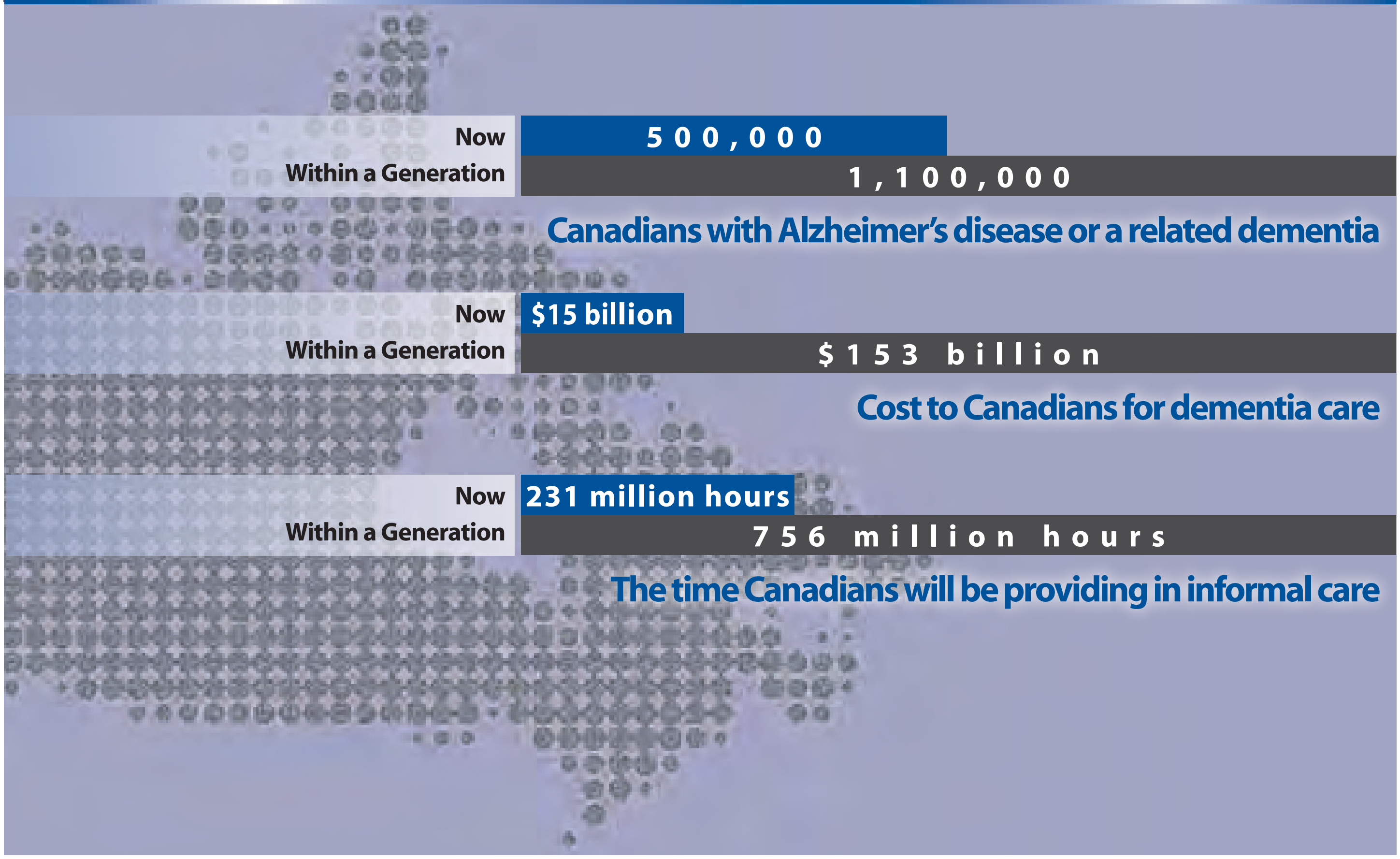
Rising Tide:
The Impact of Dementia on Canadian Society

A study commissioned by
the Alzheimer Society



Alzheimer Society

Alzheimer *Society*

The Alzheimer Society is the leading, nationwide health organization for people affected by dementia in Canada. The Society is a principal funder of Alzheimer research and training, provides enhanced care and support to people with the disease, their families and their caregivers, and is a prominent voice within all levels of government.

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Acknowledgements

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This report and the corresponding executive summary were authored by Scott Dudgeon, Chief Executive Officer of the Alzheimer Society of Canada from November 2007 until June 2009. The larger *Rising Tide* project is a culmination of hard work and dedicated support from staff within the Alzheimer Society of Canada, its board of directors, and Alzheimer Societies across Canada. The Alzheimer Society would like to say a special thank you to its subject matter experts, who are listed below, as well as the people with dementia and caregivers who have, over the years, shared their thoughts, experiences and provided guidance to the Alzheimer Society.

Unless otherwise noted, facts referred to in this document on dementia, its prevalence and the economic burden associated with it are from *Smetanin, P., Kobak, P., Briante, C., Stiff, D., Sherman, G., and Ahmad, S. Rising Tide: The Impact of Dementia in Canada 2008 to 2038*, available at www.alzheimer.ca.

Except where noted, facts about dementia, its risk factors and associated care are taken from the Alzheimer Society of Canada, as discussed by its Scientific Director, Dr. Jack Diamond, in the report *Alzheimer's Disease and Current Research*. This information can also be found at www.alzheimer.ca.

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The Alzheimer Society would like to acknowledge the generous support, ideas and advice from the following subject matter experts who assisted at various stages of the project:

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Canada's Dementia Epidemic – A Call to Action

Canada is facing a dementia epidemic and needs to take action now. Approximately 500,000 Canadians have Alzheimer's disease or a related dementia today. It is the most significant cause of disability among Canadians (65+) and it already costs Canadian society many billions of dollars each year.

For the past decade, dementia and its potential impacts on national economies have been the subject of growing interest around the globe. Forecasts show that within 20 years, worldwide prevalence will increase two-fold. There are more than 35 million people with dementia in the world at this time. It is estimated that by 2050, this number will increase to 115 million people[1]. Canada, too, can expect a several-fold increase in dementia in the coming decades.

The governments of Australia, Norway, the Netherlands, Scotland, England, France, and the European Parliament have all taken steps to study dementia and its consequences. Many have chosen to make dementia a national priority. Canada has yet to take these steps.

The Need for Current Information

The Canadian government, dementia researchers and the Alzheimer Society have been using the 1991 *Canadian Study on Health and Aging* (and the longitudinal follow-up of 1996) as the most recent basis for understanding the prevalence, incidence and economic consequences of dementia. The costs for health care, medications, diagnostic imaging and labour have all increased well beyond what was forecasted in 1991, and newer studies from other countries have shown that the true costs of dementia are markedly higher than previously projected.

Canada requires a national plan grounded in an up-to-date and comprehensive understanding of the dementia burden in Canada, in order to quantify, prepare for, and mitigate the impact of dementia. The Alzheimer Society has begun work towards such a plan.

The *Rising Tide* study was launched in 2008 in order to gain understanding of the demographic and epidemiological profile of dementia in Canada, to develop a future picture of the health and economic burden of dementia on Canadian Society, and to introduce a discussion of what can be done to reduce the impact. RiskAnalytica, a science-based risk management firm with expertise in population health analysis, was engaged by the Alzheimer Society of Canada for this research project. Specifically, the study was commissioned to generate:

- the projected prevalence of dementia in Canada by sex and age-group for a 30-year period;
- the projected economic burden of dementia in Canada for the next 30 years;
- a platform for evaluating and comparing proposed intervention strategies to mitigate the impact of dementia on Canadian society. Four intervention scenarios were generated using the platform, to illustrate its potential as an on-going evaluation tool for policy analysis and decision-making;
- a scan of the comparative health policy context to ensure that Canada's approach to dementia can capitalize on and work within the current health system.

RiskAnalytica's Life at Risk® evaluation framework is a sophisticated platform for evaluating the relative impact of strategies that may inform future policy, economic and investment decisions. It was used to generate the Dementia Base Case – an estimate of the health and economic impacts of dementia in Canada over the next 30 years, assuming no change in current policy, treatment or health interventions.

In addition, the Alzheimer Society, RiskAnalytica and a network of leading dementia subject matter experts framed and evaluated a variety of "what-if" scenarios to simulate potential interventions and the health and economic outcomes that would result from each.

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[1] *World Alzheimer Report*. Alzheimer's Disease International. September 21, 2009. http://www.alz.co.uk/research/worldreport/

Rising to the Challenge

The goal of *Rising Tide* is to generate a solid, evidence-based foundation (the Dementia Base Case) upon which policymakers can build a comprehensive national plan to prepare for and mitigate the burden of dementia on Canadian society. It is also to direct health expenditures towards activities that have the greatest potential to maximize quality of life, to support individuals and families, to leverage our scarce health human resources, and at the same time to manage growth in the rate of institutionalization and overall health costs.

Finally, *Rising Tide* demonstrates that Canadians must call on their federal, provincial and territorial governments to take action now – to rise to the challenge of the dementia epidemic by acting on the recommendations contained in this report.

A Brief Introduction to Dementia

What is Dementia?

Dementia refers to a large class of disorders characterized by the progressive deterioration of thinking ability and memory as the brain becomes damaged. Dementias are generally categorized as reversible (dementias secondary to some primary illness such as thyroid disease or kidney disease, which can be successfully treated) or irreversible. This report focuses on irreversible dementias associated with progressive neurodegenerative diseases: Alzheimer's disease, Vascular Dementia, and other dementias (specifically frontotemporal dementia, Lewy Body dementia and Creutzfeldt-Jakob disease).

Symptoms commonly include loss of memory, judgment and reasoning, and also changes in mood, behaviour and the ability to communicate. These symptoms may affect a person's ability to function at work, in social relationships, or in the usual activities of daily living.

People with dementia are not the only ones affected by the disease. Dementia places a long-term progressive burden on those who care for them. Dementia usually implies not only a long period of profound disability and suffering for the person, but also severe strain and financial burden on family and caregivers[2], health providers, the health care system, the business community, and society in general.

Alzheimer's Disease

Alzheimer's disease, the most common form of dementia[3], is a progressive, degenerative and fatal brain disease, in which cell to cell connections in the brain are lost and brain cells eventually die. It is *not* a normal part of aging.

While some debate remains, the majority of researchers believe that Alzheimer's disease occurs when the effects of many negative influences on the brain cross a certain threshold, overwhelming the brain's self-repair mechanisms. These mechanisms maintain the crucial balance between the production and elimination of the naturally occurring products of metabolism. These products are beneficial at normal levels, but become toxic at abnormally high levels. Therefore, this balance is essential to maintaining the brain's nerve cells in a healthy state.

A situation known as "oxidative stress" alters this balance and causes toxic effects on cells everywhere in the body including the brain. Many diseases, some drugs and the "internal" stress generated when a person's health and well-being are threatened can lead to 'oxidative stress.' It is believed that this, in turn, leads to the formation of plaques and tangles in the brain, which interfere with brain functions and are a characteristic of Alzheimer's disease. Therefore, oxidative stress is a key target for Alzheimer treatments, and a reason why healthy lifestyles are included in risk reduction strategies.

The vast majority of Alzheimer's disease cases are of the sporadic form (also referred to as "late onset") of the disease. However, about 5 to 7 per cent of the Alzheimer population is in the category called Familial Alzheimer's disease (FAD), in which onset typically occurs at an earlier age. The rate of decline in Alzheimer's disease is extremely variable and changes from person to person. In many instances, it may be preceded by a few years of Mild Cognitive Impairment (MCI), a condition in which true dementia is absent, but nevertheless memory and cognitive functions are detectably reduced.

Alzheimer's disease is ultimately fatal, and death usually occurs within seven to 10 years after diagnosis. The body is weakened by inactivity and muscle wasting, and a lowering of the body's immune functions makes bacterial and viral infections very common. This leads to the usual cause of death – pneumonia, hastened by the decreased ability of the affected person to cough and generally to move about normally.

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[2] *Dementia – Etiology and Epidemiology, A Systematic Review.* The Swedish Council on Technology Assessment in Health Care. Vol. 1, June 2008.

[3] Alzheimer's disease currently represents approximately 63% of all dementias included in *Rising Tide* (and will increase to 69% within 30 years).

Vascular Dementia

Vascular Dementia is the second most common form of dementia (after Alzheimer's disease)[4] . It is caused by problems in the supply of blood to the brain. There are a number of conditions that can cause or increase damage to the vascular system. These include high blood pressure, heart problems, high cholesterol and diabetes. The two main types of Vascular Dementia are stroke-related dementia and small vessel disease-related dementia. Many individuals with Alzheimer's disease also have Vascular Dementia.

Related Dementias

Other dementias include Frontotemporal Dementia (FTD, which includes Pick's Disease), dementia with Lewy bodies and Creutzfeldt-Jakob Disease (CJD). These dementias occur in combination with various chronic non-dementia conditions such as Parkinson's disease and Huntington's disease.

Risk Factors for Dementia

Risk factors contribute to the likelihood of getting a disease. They include the characteristics of a person, their lifestyle and their environment. Some risk factors can be controlled and are therefore of great interest in disease prevention and management. Other risk factors cannot be controlled. Many of the risk factors for Alzheimer's disease, such as high cholesterol levels or high blood pressure, are risk factors for many other diseases, especially cardiac diseases. Although agreement on most risk factors is well established, there are some that remain controversial.

The risk factor section below is specific to Alzheimer's disease, although some risks may also apply to other dementias

Non-Modifiable Risk Factors

- *Aging* - Aging is the most important risk factor. Despite the presence of other risk factors, the disease never sets in until some minimum adult age is reached.[5]
- *Genetic risk factors* – Aside from the mutated genes, which are heavily implicated in Familial Alzheimer's disease (FAD), genetic risk factors also play a role in the common sporadic form of Alzheimer's disease. The apoE4 gene[6] is the most important gene identified to date for the common form of the disease. However, since having a parent or sibling with Alzheimer's disease increases one's risk by two to three times[7] , other genes, not yet identified, likely also predispose individuals to Alzheimer's disease.

Modifiable Risk factors

- Type 2 (adult onset) Diabetes
- Head injury
- Strokes and 'Ministrokes' (very small haemorrhages in the brain that may only be revealed through later brain imaging)
- High cholesterol levels[8,9]

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[4] Vascular dementia accounts for approximately 20% of all dementias included in *Rising Tide*.

[5] The occurrence of dementia increases with age particularly in the elderly, over the ages of 75 and 80. Fratiglioni, L. et al. "Incidence of Dementia and Major Subtypes in Europe: A Collaborative Study of Population-Based Cohorts". *Neurology*. 54.11 (2000): 10-15.

[6] If a person's pair of apoE genes includes one of the apo4 variety (inherited from one parent), they have three times the normal risk of developing Alzheimer's disease. If they carry two apoE4 genes (one from each parent), the risk increases to ten times. However, individuals with no apoE4 genes can still get Alzheimer's disease, just as individuals with two apoE4 genes can escape it.

[7] Breitner, John C.S. "Clinical genetics and genetic counseling in Alzheimer disease" *Annals of Internal Medicine*, 1991.

[8] High levels of low-density lipoprotein (LDL) appear to significantly increase a person's risk of developing vascular dementia. "Dementia: Hope through Research". National Institute of Neurological Disorders and Stroke. 7 Aug 2009. http://www.ninds.nih.gov/disorders/dementias/detail_dementia.
htm#1367219213

[9] Longitudinal studies have established that midlife elevation of the total serum cholesterol level is associated with an increased risk of subsequent Alzheimer's disease. Patterson, Christopher et al. "General Risk Factors for Dementia: A Systematic Evidence Review". *Alzheimer's & Dementia: the Journal of the Alzheimer's Association*. 3.4 (2007): 341-347

- High blood pressure[10]
- Mild Cognitive Impairment (MCI)
- Chronic inflammatory conditions (such as certain forms of arthritis)
- A history of clinical depression[11]
- Inadequate intellectual stimulation
- Obesity

Further risk factors which have been identified, but not substantiated as well, include lack of formal education (which may be related to inadequate mental stimulation), low socio-economic status, smoking, and excessive drinking.

For a more detailed discussion of risk factors, please see *A Report on Alzheimer's Disease and Current Research* by Dr. Jack Diamond, Scientific Director, Alzheimer Society of Canada, available at www.alzheimer.ca.

Risk Reduction

In risk reduction, two things matter: how many risk factors a person is exposed to, and how efficiently their brain's self-healing process works. The brain's ability to withstand risk factors and to preserve and even enhance its healing capacity can be significantly helped by the adoption of a healthy lifestyle.

Healthy lifestyles enhance the production of 'growth factors' in the brain, which help brain cells maintain and make new connections. Recent discoveries suggest that healthy lifestyles may even help in the creation of new nerve cells.

Healthy lifestyles are also often effective in reducing the Alzheimer risk indirectly, by reducing specific risk factors such as stress and obesity. Appropriate treatment of medical conditions such as diabetes, high cholesterol and high blood pressure levels are also of obvious benefit. [Notably, in studies of identical twins, it was found that about 60 per cent of the overall risk factors for Alzheimer's disease comes entirely from lifestyle and not genetic susceptibility].

Strategies identified for reducing the risk of Alzheimer's disease and related dementias, or to slow the progression of these diseases once it has begun (protective factors) include:

- **Healthy diet** - A Mediterranean-style diet is associated with decreased risk of Alzheimer's disease.[12] Also important is eating anti-oxidant rich foods such as blueberries and raspberries, and dark green leafy vegetables such as spinach and collard greens. The anti-oxidants selenium and folic acid are also recommended by some. Folic acid, also known as folate, is reputed to help ward off heart disease. Moderate consumption of wine (250–500 ml/day versus a smaller or larger amount) is associated with a reduced risk of subsequent dementia, including Alzheimer's disease.[13] Similarly, certain spices used in curries, especially curcumin (found in turmeric), have been implicated in the lower than average incidence of Alzheimer's disease in curry-eating populations. Finally, there is interest in increasing the intake of omega-3 fatty acids (found especially in cold water fish, flax and walnuts) based on findings that these fatty acids were low in individuals with Alzheimer's disease, and that in some (but not all) studies, supplementing diets with them improved cognitive functioning.

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[10] Patterson, Christopher et al. "Diagnosis and Treatment of Dementia: 1. Risk Assessment and Primary Prevention of Alzheimer Disease" *Canadian Medical Association Journal*. 178.5 (2008): 548-556.

[11] A systematic evidence review concluded that depression is associated with Alzheimer's disease, however further research is required on the topic Jorm, Anthony F. "History of Depression as a Risk Factor for Dementia: an Updated Review". *Australian and New Zealand Journal of Psychiatry*. 35.6: 776-781.

[12] Scarmeas, N. et al. "Mediterranean Diet and Risk for Alzheimer's Disease". *Annals of Neurology*. 59.6 (2006): 912-921

[13] Larrieu, S. et al. "Nutritional Factors and Risk of Incident Dementia in the PAQUID Longitudinal Cohort". *Journal of Nutrition Health and Aging*. Vol. 8 (2004): 150-154.

- **Aerobic exercise** - Increased levels of physical activity have been linked to a reduced risk of subsequent dementia[14]. Even modest levels of exercise are beneficial, such as a few daily walks up and down stairs. Exercise stimulates the production in the brain of growth factors, especially one known as brain-derived neurotrophic factor (BDNF), which both promote connectivity between nerve cells and help preserve their health. Exercising also helps maintain a good blood supply and therefore oxygen supply to the brain. This is particularly important because reduced oxygen supply (hypoxia) of the brain promotes the production of the protein beta amyloid, which is associated with Alzheimer's disease.
- **An active social life** – This includes interactive and especially organized social leisure activities, for example playing cards or group theatre-going. Loneliness in individuals age 65+ has been linked to a higher risk for dementia, and clearly increased socialization is key, including things like spending time with family.
- **Intellectual activity** – This is the 'use it or lose it' principle behind such activities as doing crossword puzzles, reading or playing chess. Interestingly, in a Swedish twins study, greater participation in intellectual activities was associated with lower risk for Alzheimer's disease for women, but not for men. As with an active social life, it appears that intellectual activity establishes cognitive reserve, defined as "the brain's ability to operate effectively even when some function is disrupted or the amount of damage that the brain can sustain before changes in cognition are evident[15]."
- **Protecting your head** – Although the link between head injury and the later development of dementia is still being debated, there is clear evidence that the use of head protection (especially recreational/sporting safety helmets) reduces the risk of traumatic head injury[16].

The accepted view today is that promoting brain health through lifestyle choices is the most effective way of reducing the chances of developing Alzheimer's disease or a related dementia or slowing down the progression of these diseases in people who already have them. Adopting a lifestyle that ignores risk factors does not mean, however, that one will develop the disease, but it does increase the odds.

Care and Treatment

Appropriate care and treatment for people with dementia[17] varies greatly and is dependent on the stage of the disease, as well as how it affects each individual at any given point in time. The following illustrates a range of health interventions and other activities that are provided today at different stages.

Healthy individuals and individuals for whom a diagnosis has not been made	• The Alzheimer Society provides information on the nature of dementia, how to recognize the disease (warning signs and symptoms) and how to find help if these are present. The Society also educates the general public on risk reduction and prevention strategies.

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[14] Patterson, Christopher et al. "Diagnosis and Treatment of Dementia: 1. Risk Assessment and Primary Prevention of Alzheimer Disease. *Canadian Medical Association Journal*. 178.5 (2008): 548-556.

[15] *Can Alzheimer's Disease Be Prevented?* U.S. Department of Health and Human Services, 2009.

[16] Plassman, B.L., Havlik, R.J., Stephens, D.C., et al. "Documented Head Injury in Early Adulthood and Risk of Alzheimer's Disease and Other Dementias". *Neurology*. 55.8 (2000): 1158-1166.

[17] This report generally refers to people with dementia as *people with dementia*, unless they are being described in a clinical setting, in which case they may be referred to as *patients*. This report may also refer to *patients* when referring to a source in which that term is used. People living in care facilities are generally referred to as *residents*.

Diagnosis	• Access to diagnosis is limited by stigma and by the availability of diagnostic expertise. The Alzheimer Society works to offset the stigma associated with dementia so that individuals who need help seek it with guidance and support. • Diagnosis is typically made by the family physician or by a geriatrician, neurologist or psychiatrist, and usually includes clinical history and neuropsychological testing, with perhaps diagnostic imaging.
Disease Management	• Once a diagnosis is made, the physician may prescribe a cholinesterase inhibitor to mitigate the symptoms associated with the decline in memory, language and thinking abilities. There are, as of yet, no therapies that have been proven to slow down, stop or reverse the decline. • Other drugs may be introduced to manage co-morbid conditions or to manage the behavioural and psychological symptoms of dementia. • Individuals who have just been diagnosed with dementia may be referred to the Alzheimer Society to initiate educational and support services for the individual with dementia and their family/caregiver. • Individuals with dementia may benefit from a variety of community-based services that may be available where they live – respite care, adult day programs, early stage support groups, home help, etc. • Family caregivers may have counselling, education and support groups.
Long-Term Care	There is a variety of residential care services across the country ranging from nursing homes to dementia-specific housing. Individuals typically move into care facilities when it becomes unsafe to continue residing in their own homes and family caregivers become exhausted.
End-of-Life Care	The final stages of the disease require palliation – managing pain and providing comfort are key treatment goals. There are very few clinicians with dementia-specific palliative care experience.

While there is a broad spectrum of services appropriate to people with dementia and their caregivers at various stages of the disease, these services are maldistributed, uncoordinated and, where available, delivered with little standardization and continuity. The services are provided by too few specialized providers or by inadequately prepared generalist providers. Training of health, long-term care and continuing care providers is limited in dementia prevention, identification, diagnosis, and treatment.

The predicted surge in dementia prevalence threatens to overwhelm Canada's health care system unless specific and targeted actions are undertaken. **Canada must act.**

Why Canada Must Act

By 2038:

- 1,125,200 will have Dementia in Canada – 2.8% of the Canadian population
- The cumulative economic burden will be $872 billion
- Demand for long-term care will increase 10-fold

Alzheimer Society

The Dementia Base Case – The Growth of Dementia

Rising Tide presents comprehensive forecasts of the impact of dementia for each of the next 30 years. This impact was quantified using RiskAnalytica's Life at Risk® simulation platform, customized based on the latest dementia research. Subject matter experts worked closely with the Alzheimer Society and RiskAnalytica teams to validate data sources, the modeling strategy and results[18].

The Dementia Base Case, a forecast of the population health and economic impact of dementia on Canadian society for each of the next 30 years was generated using validated data inputs. The Base Case assumes no change in policy, no significant new scientific discovery and no intervention. The resultant profile includes measures of the population health and economic burden attributable to dementia.

By factoring in the expected population changes and evidence-based assumptions about dementia over the next three decades, a forecast of the number of new dementia cases (Incidence), deaths (Mortality), and the number of Canadians living with dementia (Prevalence) is established for each of the next 30 years.

The study then categorized those living with dementia by type and location of care that research suggests they will receive, and determined expected constraints in long-term care capacity. On this basis, a profile of care delivery was developed, i.e. a picture of how and where care will be provided to Canadians living with dementia (Health Care Utilization).

Finally, by applying assumptions for direct, indirect and opportunity costs, the total cost associated with dementia (Economic Burden) was calculated both on an annual basis in future dollars (adjusted for inflation) for 10, 20 and 30 years into the future, and on a cumulative basis for 10, 20 and 30 years (2008 present values). Together, these illustrate the Base Case Economic Burden of dementia in Canada.

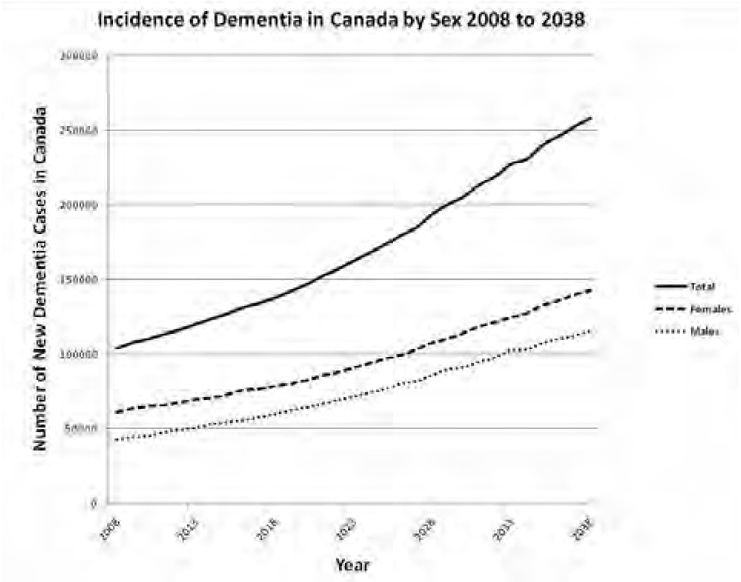
Highlights of the Base Case follow. Supporting details plus breakdowns at the provincial level are available in the document *Rising Tide: The Impact of Dementia in Canada 2008 to 2038*, which is available at www.alzheimer.ca.

Incidence: Number of New Cases of Dementia per Year

As illustrated in Exhibit 1, the number of new cases of dementia in 2038 among Canadians (65+) will be 2.5 times that of 2008.

Projected incidence: 2008 - 103,728 new dementia cases per year
2038 - 257,811 new dementia cases per year

Exhibit 1: Current and Future Dementia Incidence in Canada, Ages 65+: 2008-2038



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[18] See *Appendix* A for a more detailed explanation of the evidence-based customization process.

Alzheimer's disease accounts for roughly 50% of new dementia diagnoses each year for Canadians (65+) throughout the simulation period.

Incidence 2008-2038:

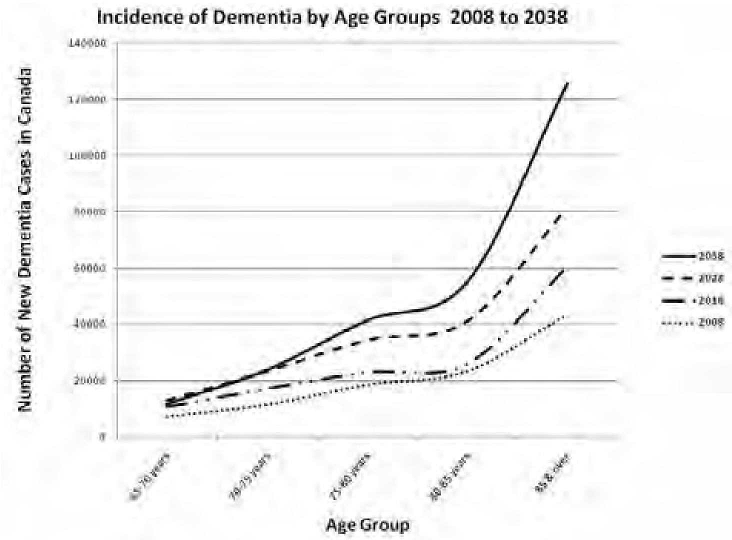
Alzheimer's disease	50-52%
Vascular Dementia	20-21%
Related dementias	28-29%

As illustrated in Exhibit 2, newly diagnosed cases will skew toward the older age groups over time. This increase in dementia incidence for older Canadians results primarily from general aging of the Canadian population.

Of this aging population:

- The proportion of men diagnosed with dementia who are over the age of 85 will increase from 33% in 2008 ➔ 43% by 2038.
- The proportion of women diagnosed with dementia who are over the age of 85 will increase from 46% in 2008 ➔ 52% by 2038.

Exhibit 2: Current and Future Dementia Incidence in Canada, Select Years, by Age Groups, 65+: 2008-2038

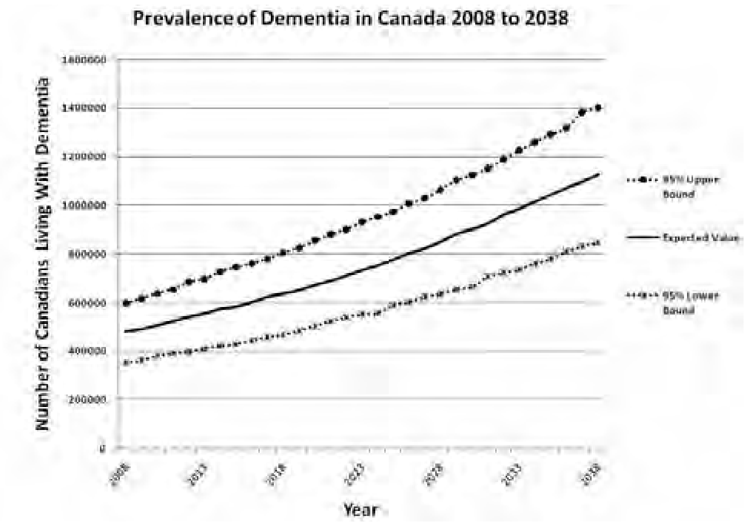


Prevalence: Number of People Living with Dementia

As illustrated in Exhibit 3, by 2038 the number of Canadians (of all ages) with dementia will increase to 2.3 times the 2008 level, i.e. to 1.1 million people, representing 2.8% of the Canadian population.

Projected prevalence: 2008 – 480,618 people, or 1.5% of the Canadian population
2038 – 1,125,184 people, or 2.8% of the Canadian population

Exhibit 3 Current and Future Dementia Prevalence in Canada, All Age Groups: 2008-2038



Note: This chart shows the expected value and the confidence intervals for prevalence estimates in select years: 2008-2038

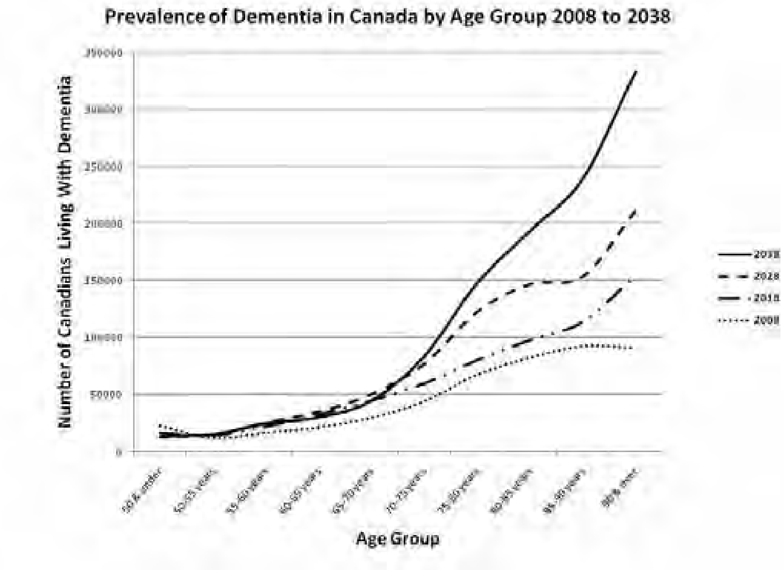
- Canadians with Alzheimer's disease or Vascular Dementia will account for the vast majority of dementia cases in Canada (approximately 83%).
    - 2008 303,878 cases (63%) Alzheimer's disease / 94,183 (19.5%) Vascular Dementia
    - 2038 770,811 cases (68.5%) Alzheimer's disease / 221,220 (19.7%) Vascular Dementia

- The prevalence of dementia is higher in females than males, with a ratio of approximately 1.36 throughout the simulation period.
    - The average female to male ratio of Alzheimer's disease prevalence is approximately 2.29
    - The average female to male ratio of Vascular Dementia prevalence is approximately 0.85

- The proportion of the Canadian population with dementia increases with age. % of Canadians with dementia:
    - 7% in 2008 ➔ 9% in 2038 of Canadians over age 60 will have dementia;
    - 49% in 2008 ➔ 50% in 2038 of Canadians over age 90 will have dementia.

- Furthermore, as illustrated in Exhibit 4, prevalence of dementia in Canada will skew toward the older age groups due to general aging of the Canadian population.
    - % of individuals with dementia who are over the age of 80: 2008 ➔ 2038
        - In total: 55% ➔ 68%
        - Alzheimer's disease: 71% ➔ 78%
        - Vascular Dementia: 51% ➔ 61%

Exhibit 4 Current and Future Dementia Prevalence in Canada, Males and Females, All Age Groups: 2008- 2038



Health Care Utilization

To obtain a picture of how and where care will be provided to Canadians living with dementia, prevalence is classified into three care types:

- individuals receiving care in long-term care facilities such as nursing homes;
- individuals living at home and receiving community care;
- individuals living at home and receiving no formal care.

A Shift Towards Home/Community-Based Care

The model forecasts the demand for long-term care beds based on the projected prevalence and severity of dementia. However, availability of long-term care beds is constrained. Based on historical growth trends, the model assumes that the total number of long-term care beds in Canada will grow from approximately 280,000 beds in 2008 to 690,000 in 2038. This leaves a projected shortfall of more than 157,000 beds in 2038. The model assigns this shortfall to community care.

Exhibit 5 presents the prevalence of dementia for Canadians (65+) according to care type. Dementia prevalence increases across all care types over the 30-year simulation period. However, there is a significant shift from institutional care towards home/community-based care.

- In 2008, 55% of Canadians (65+) with dementia were living in their own homes, most with the support of some kind of community care.
- By 2038, 62% of Canadians (65+) with dementia will be living in their own homes. This represents an increase of 510,000 individuals and would substantially increase community care and caregiver burden.

Exhibit 5 Dementia Prevalence by Care Type (Ages 65+) : 2008-2038

Year	Prevalence of Dementia by Care Type in Canada (Ages 65+)					
	Long-Term Care		Community Care		No Formal Care	
	Prevalence of Dementia	Percent with Dementia	Prevalence of Dementia	Percent with Dementia	Prevalence of Dementia	Percent with Dementia
2008	183,268	45.4%	134,416	33.3%	85,938	21.3%
2018	249,268	41.8%	221,970	37.3%	124,553	20.9%
2028	335,882	39.4%	337,682	39.6%	178,747	21.0%
2038	442,682	37.6%	503,661	42.7%	232,146	19.7%

Exhibit 6 quantifies the long-term care bed shortfall:

- The long-term care bed shortfall will increase from approximately 15,400 in 2008 to 157,500 in 2038.

Exhibit 6 Supply of Long-Term Care Beds & Number of Beds Occupied by Individuals Living with Dementia (Ages 65+): 2008-2038

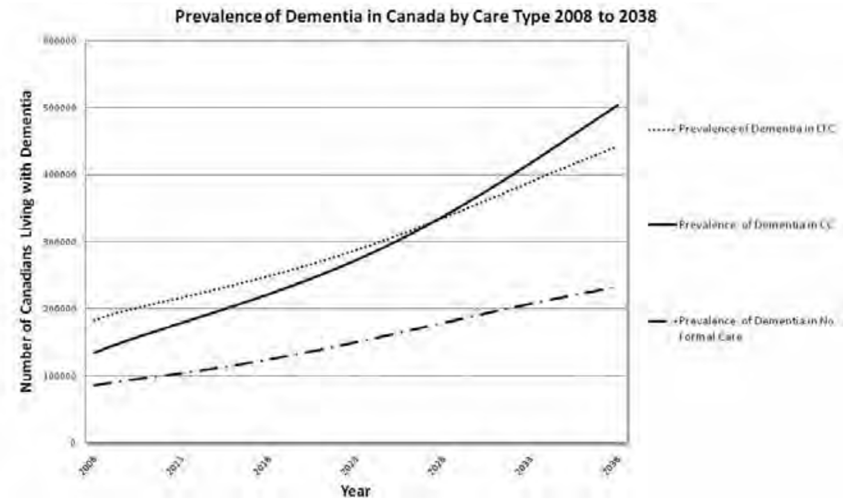
Year	Supply and Demand (by Persons with Dementia) of Long-Term Care (LTC) Beds in Canada, Ages 65+			
	Number of LTC Beds	Number of LTC Beds Occupied by People with Dementia	Prevalence of Dementia That Would Have Been in LTC	Excess Demand for LTC
2008	285,178	183,268	198,659	15,392
2018	387,880	249,268	296,473	47,204
2028	522,657	335,882	422,351	86,469
2038	688,846	442,682	600,142	157,461

Exhibit 7 illustrates the trend in the type of care utilized by Canadians (65+) living with dementia. The number of people receiving community-based care will increase at a slightly faster rate than those in long-term care due to the long-term care capacity constraints.

There is a marked shift from long-term care to community care for Canadians (65+) living with dementia:

- in community care setting receiving community care services: 33.3% in 2008 ➔ 42.7% by 2038 (or an additional 370,000 people);
- in long-term care setting: 45.4% in 2008 ➔ 37.6 % by 2038 (or an additional 260,000 people);
- in community setting (at home) receiving no formal care: 20-21% throughout the simulation period (or an additional 140,000 individuals).

Exhibit 7 Prevalence of Dementia by Care Type, (Ages 65+): 2008-2038



LTC= long term care, CC = community care

Growth in Caregiving Hours

The task of caregiving changes throughout the progression of dementia. Initially, when the person with dementia is still living at home, the focus for the informal caregiver[19] may be on helping with transportation, household finance, meals and day-to-day living activities. By the time the individual is receiving care from community service providers, the scope of the caregiving role broadens to include supervision to ensure safety. Once the individual is in a long-term care facility, the needs change again. While support for activities of daily living is provided by the care facility, the informal/family caregiver continues to be engaged as a member of the care team to provide supportive care, including social engagement and affection.

Informal Care Hours: Exhibit 8 summarizes the number of hours of work provided by unpaid caregivers for people with dementia in each of the three care types:

- By year 2038, the total number of hours of informal care will more than triple, increasing from approximately 231 million hours in 2008, to 756 million hours.
- Informal caregivers within community care settings account for the largest proportion of informal care, increasing from 60% to 69% over the 30-year simulation period.

Exhibit 8 Hours of Informal Care per Year, By Care Type: 2008-2038

Year	Hours of Informal Care Per Year By Care Type			
	Hours in Long-Term Care	Hours in Community Care	Hours in No Formal Care	Total Hours of Informal Care
2008	44,593,849	139,289,343	46,955,109	230,838,301
2018	60,653,577	230,017,730	68,053,794	358,725,101
2028	81,728,906	349,924,438	97,664,641	529,317,984
2038	107,716,208	521,920,684	126,841,507	756,478,399

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[19] The term 'informal care' is used in health services research to connote a difference between unpaid caregivers, usually family or friends, and caregiving provided by individuals who are paid for this service. The term makes no distinction beyond this.

Economic Burden of Dementia

Total Economic Burden

The Life at Risk® economic framework calculates the Total Economic Burden of dementia as the sum of direct health costs, opportunity costs (foregone wages) of unpaid informal caregivers and indirect costs. The Monetary Economic Burden reflects only actual monetary outlays and hence ignores opportunity costs.

Total Economic Burden = Direct Health Costs + Opportunity Costs of Informal Caregivers + Indirect Costs

Monetary Economic Burden = Direct Health Costs + Indirect Costs

Direct health costs are costs incurred while treating a particular disease and can accrue within or outside the formal health care system. Direct health costs pertaining to dementia within the formal health system include the cost of prescription medication, long-term care staff costs, support staff costs, long-term care administrative costs, and physician and hospital costs. Direct health costs outside the formal health care system include the cost of over-the-counter medication, long-term care accommodation and out-of-pocket expenses.

Opportunity costs of informal caregivers are the wages informal caregivers could have earned had they been able to participate in the labour force.

Indirect costs are costs that have no direct connection to dementia, but are a consequence of it. They include the loss in wages (e.g. days off or sick time) and in corporate profits that result from the reduction in labour productivity for both the individual with dementia and the provider of informal care.

Exhibit 9 presents the simulation results of the **annual Total Economic Burden** of dementia in future values. Exhibit 10 presents the **cumulative Total Economic Burden** in 2008 present values.

A breakdown of the cost components follows in Exhibits 11 – 17.

Annual Total Economic Burden

The annual Total Economic Burden, expressed in future dollars, increases substantially from approximately $15 billion in 2008 to $153 billion by year 2038.

- The Monetary Burden of dementia (direct plus indirect costs) will reach approximately $97 billion by year 2038.
- Opportunity costs of informal caregivers will add a further $56 billion to the annual Economic Burden by 2038.

Exhibit 9 Total Annual Economic Burden Attributed to Dementia, Future Values: 2008-2038

Year	Total Economic Burden of Dementia, Future Values				
	Total Direct Costs a	Total Unpaid Caregivers Opportunity Cost b	Total Indirect Costs c	Monetary Economic Burden a+c	Total Economic Burden a+b+c
2008	$8,063,733,967	$4,995,340,836	$1,864,955,665	$9,928,689,632	$14,924,030,467
2018	$19,573,547,540	$12,303,233,856	$4,845,163,396	$24,418,710,937	$36,721,944,792
2028	$43,842,755,134	$26,921,613,083	$4,380,174,051	$48,222,929,184	$75,144,542,267
2038	$92,832,808,780	$55,708,854,294	$4,097,831,931	$96,930,640,711	$152,639,495,005

Cumulative Economic Burden

The cumulative Economic Burden, expressed in 2008 dollars, will reach approximately $872 billion over the 30-year simulation period.

- Monetary Burden (direct and indirect costs) accounts for approximately $570 billion.
- The cumulative opportunity cost of informal caregivers, accounting for a further $302 billion, represents a substantial additional societal burden.

Exhibit 10 Cumulative Total Economic Burden Attributed to Dementia, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Total Economic Burden of Dementia, 2008 Present Values				
	Total Direct Costs	Total Informal Caregiver Opportunity Cost	Total Indirect Costs	Monetary Economic Burden	Total Economic Burden
2008	$8,063,733,967	$4,995,340,836	$1,864,955,665	$9,928,689,632	$14,924,030,467
2018	$119,911,702,031	$75,072,662,869	$43,703,002,416	$163,614,704,446	$238,687,367,315
2028	$270,811,509,553	$168,884,202,340	$66,957,982,212	$337,769,491,765	$506,653,694,104
2038	$489,972,224,214	$301,629,828,371	$80,615,884,427	$570,588,108,641	$872,217,937,012

The next three sections present a more in-depth look at the components of Economic Burden.

Direct Health Costs

Direct Health Costs are forecasted on the basis of (1) care type, and (2) within care type, whether care is being provided for dementia alone, or for dementia on top of a co-occurring or co-morbid health condition. In order to isolate the costs of care attributable to dementia alone, total costs of care are reported for those with a diagnosis of dementia alone upon admission, whereas only incremental costs are reported for those with dementia as a co-morbid condition.

In addition to the direct costs of Canadians living with dementia, Direct Health Costs also include the costs informal caregivers incur to treat their own negative health outcomes that often result from the stressful nature of providing support to individuals with dementia. These are referred to as Excess Health Costs.

Exhibit 11 presents the annual Direct Health Costs (expressed in future dollars) for Canadians with dementia and informal caregivers:

- Direct Health Costs for both primary dementia cases and co-morbid dementia cases will more than double every 10 years for the next 30 years across all care types.
- Excess Health Costs will increase substantially over time, to account for nearly $1 billion of Direct Health Costs by 2038.

Exhibit 11 Total and Incremental Direct Health Costs of Dementia by Care Type, Future Values: 2008-2038

Year	Direct Health Costs For Long-Term Care (LTC), Community Care (CC), No Care, and Excess Health Costs, Future Values							
	Direct Cost LTC Due to Dementia	Incremental Direct Cost LTC Due to Co-morbid Dementia	Direct Cost CC Due to Dementia	Incremental Direct Cost CC Due to Co-morbid Dementia	Direct Cost No Care Due to Dementia	Incremental Direct Cost No Care Due to Co-morbid Dementia	Excess Health Costs Associated with Caregivers	Total Direct Cost – All Methods of Care and Caregivers
2008	$3,488,976,859	$899,673,278	$899,663,518	$2,171,161,676	$148,158,636	$357,551,846	$98,548,155	$8,063,733,967
2018	$7,814,993,328	$2,015,186,959	$2,446,654,228	$5,904,520,732	$340,327,241	$821,313,134	$230,551,918	$19,573,547,540
2028	$16,589,338,377	$4,277,753,921	$5,863,632,470	$14,150,728,409	$724,283,584	$1,747,916,558	$489,101,815	$43,842,755,134
2038	$33,243,745,344	$8,572,286,535	$13,297,576,167	$32,091,095,371	$1,361,996,359	$3,286,911,426	$979,197,580	$92,832,808,780

Exhibit 12 presents cumulative Direct Health Costs:

- Cumulative Direct Health Costs through to 2038 approaches $500 billion (in 2008 dollars).

Exhibit 12 Cumulative Total and Incremental Direct Health Costs of Dementia by Care Type, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Direct Health Costs For Long-Term Care (LTC) ,Community Care (CC),No Care,and Excess Health Costs,2008 Present Values							
	Direct Cost LTC Due to Dementia	Incremental Direct Cost LTC Due to Co-morbid Dementia	Direct Cost CC Due to Dementia	Incremental Direct Cost CC Due to Co-morbid Dementia	Direct Cost No Care Due to Dementia	Incremental Direct Cost No Care Due to Co-morbid Dementia	Excess Health Costs Associated with Caregivers	Total Direct Cost – All Methods of Care and Caregivers
2008	$3,488,976,859	$899,673,278	$899,663,518	$2,171,161,676	$148,158,636	$357,551,846	$98,548,155	$8,063,733,967
2018	$49,483,790,230	$12,759,971,066	$14,355,120,812	$34,643,272,222	$2,119,405,842	$5,114,770,853	$1,435,371,005	$119,911,702,031
2028	$107,898,793,861	$27,822,959,423	$33,963,531,583	$81,964,330,756	$4,687,316,392	$11,311,919,968	$3,162,657,570	$270,811,509,553
2038	$188,201,526,525	$48,529,953,381	$64,495,526,295	$155,647,319,436	$8,077,102,509	$19,492,504,775	$5,528,291,293	$489,972,224,214

Opportunity Cost of Informal Caregivers

The simulated Opportunity Cost of informal caregivers (expressed in future dollars) is presented in Exhibit 13.This cost represents the lost wages that result from an individual's restriction from participating in the labour force because of informal care responsibilities.

- The annual Opportunity Cost of unpaid caregivers is projected to increase from approximately $5 billion dollars in 2008 to over $55 billion by the year 2038.
- Opportunity Costs associated with community care are considerably greater than those for long-term care and those associated with no formal care.The higher costs reflect both the larger role that informal caregivers play when providing care to family members with dementia in the community and the growing proportion of patients receiving community care.

Exhibit 13 Total and Incremental Informal Care Opportunity Costs of Dementia at Average Wages by Care Type, Future Values: 2008-2038

Year	Care Opportunity Costs of Dementia at Average Wages, Long-Term Care (LTC), Community Care (CC), and No Formal Care, Future Values						
	Cost of Informal Caregivers, LTC Due to Dementia	Incremental Cost of Informal Caregivers, LTC Due to Co-morbid Dementia	Costs of Informal Caregivers, CC Due to Dementia	Incremental Cost of Informal Caregivers, CC Due to Co-morbid Dementia	Cost of Informal Caregivers, No Care Due to Dementia	Incremental Cost of Informal Caregivers No Care Due to Co-morbid Dementia	Total Informal Caregivers Opportunity Cost
2008	$336,476,524	$628,534,364	$1,050,987,865	$1,963,233,516	$354,293,079	$661,815,489	$4,995,340,836
2018	$725,331,408	$1,354,910,916	$2,750,688,306	$5,138,254,833	$813,827,595	$1,520,220,798	$12,303,233,856
2028	$1,449,381,353	$2,707,428,073	$6,205,563,971	$11,591,923,737	$1,731,985,851	$3,235,330,099	$26,921,613,083
2038	$2,765,867,093	$5,166,608,637	$13,401,541,610	$25,033,929,072	$3,256,954,147	$6,083,953,734	$55,708,854,294

Exhibit 14 presents the 30-year cumulative Opportunity Cost of informal caregivers to Canadians with dementia.

- Cumulative Opportunity Costs through to 2038 exceeds $300 billion (in 2008 dollars).

Exhibit 14 Cumulative Total and Incremental Informal Care Opportunity Costs of Dementia By Care Type at Average Wages, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Opportunity Costs of Informal Caregivers, Long-Term Care (LTC), Community Care (CC), and No Care, At Average Wages, 2008 Present Values						
	Cost of Informal Caregivers, LTC Due to Dementia	Incremental Cost of Informal Caregivers, LTC Due to Co-morbid Dementia	Cost of Informal Caregivers, CC Due to Dementia	Incremental Cost of Informal Caregivers, CC Due to Co-morbid Dementia	Cost of Informal Caregivers, No Care Due to Dementia	Incremental Cost of Informal Caregivers, No Care Due to Co-morbid Dementia	Total Informal Caregiver Opportunity Cost
2008	$336,476,524	$628,534,364	$1,050,987,865	$1,963,233,516	$354,293,079	$661,815,489	$4,995,340,836
2018	$4,678,537,056	$8,739,454,625	$16,429,374,630	$30,689,887,115	$5,068,154,260	$9,467,255,183	$75,072,662,869
2028	$9,925,658,275	$18,541,018,076	$37,751,455,816	$70,519,295,072	$11,208,821,864	$20,937,953,236	$168,884,202,340
2038	$16,739,291,093	$31,268,807,583	$69,117,064,165	$129,109,898,864	$19,314,847,907	$36,079,918,758	$301,629,828,371

Indirect Costs

The Life at Risk® economic simulation module evaluates the indirect impact of a health condition by examining its effect on production. Dementia negatively impacts production in two ways:

- a lower productivity level for Canadians living with dementia than for otherwise healthy individuals. This reduced productivity translates into a reduction in output.;
- reduced productivity faced by employed informal caregivers due to the fatigue and stress[20] associated with providing care. This reduced productivity is also measured in terms of lost production.

Lost production is translated into lost wages and reduction in corporate profits. The sum of lost wages and reduction in corporate profits yields the Indirect Cost of disability associated with dementia and the provision of informal care[21].

Exhibit 15 presents the **lost production** attributable to dementia over the 30-year simulation period in annual future values.

- Lost production attributed to dementia was approximately $3 billion in 2008.
- Lost production attributed to dementia is estimated to rise to $6.8 billion per year by 2038.

Exhibit 15 Annual Lost Production Attributed to the Disability Due to Dementia and Informal Care, Future Values: 2008-2038

Year	Annual Lost Production from Dementia, Future Values
2008	$2,909,240,693
2018	$7,821,560,906
2028	$7,186,325,477
2038	$6,765,521,872

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[20] The 2009 *World Alzheimer Report* reference studies that estimate that 40 to 75 per cent of caregivers display very high levels of psychological morbidity as a result of their caregiving, and 15 to 32 per cent major depressive disorder. *World Alzheimer Report*. Alzheimer Disease International, 2009. http://www.alz.co.uk/research/worldreport/

[21] Also associated with losses in wages and in corporate profits is a reduction in consumption (or demand) and in government taxation revenues. However, these costs represent derivative indirect cost and, to avoid double-counting, are not included in the final determination of the Economic Burden of dementia.

Exhibit 16 shows the cumulative value of lost production expressed in 2008 dollars.

- Cumulative lost production due to dementia and informal caregiving will be approximately $130 billion over the 30-year simulation period.

Exhibit 16 Cumulative Lost Production Attributed to the Disability Due to Dementia and Informal Care, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Lost Production from Dementia, 2008 Present Values
2008	$2,909,240,693
2018	$69,463,141,959
2028	$107,348,702,524
2038	$129,846,366,889

Exhibit 17 shows the cumulative value of lost wages and lost corporate profits, which together equal total Indirect Costs expressed in present values (2008 dollars).

Exhibit 17 Cumulative Indirect Costs of Disability Due to Dementia, 2008 Present Values: 2008-2038

Years 2008 through	Cumulative Wage Impact of Dementia	Cumulative Corporate Profits Impact of Dementia	Cumulative Indirect Costs of Dementia
2008	$1,487,257,049	$377,698,616	$1,864,955,665
2018	$35,282,225,387	$8,420,777,029	$43,703,002,416
2028	$54,287,882,025	$12,670,100,186	$66,957,982,212
2038	$65,484,620,435	$15,131,263,992	$80,615,884,427

Dementia Base Case Conclusions

Since age is a primary and unchangeable risk factor for dementia, the growth of the dementia problem in Canada will gather speed as the population ages. The first of the baby boomers will enter their senior years (65+) in 2011, at which time the aging of the Canadian population and the dementia burden on Canadian society will begin to accelerate.

The Dementia Base Case shows that without intervention:

- by 2038, the rate of dementia incidence will increase to 250,000 new cases per year, 2.5 times the current level (2008). By 2038, 1.1 million Canadians will have dementia, approximately 2.8% of all Canadians and 9% of Canadians over 60;
- over the next 30 years, the excess demand for long-term care required by dementia patients will increase over 10 times the current demand (2008 values). This excess demand will cause more individuals, with higher dementia severity levels requiring more complex care, to rely on community-based care and informal care support;
- over the next 30 years, dementia will cost society over $872 billion dollars in direct health costs, unpaid caregiver opportunity costs and indirect costs associated with the provision of informal care.

The Dementia Base Case makes clear that dementia will place a tremendous strain on Canada's capacity to provide essential healthcare services and community care, as well as patient and caregiver support services, potentially overwhelming the country's health care system.

What Can Be Done

- Prevention – Increase in Physical Activity
- Prevention – A Program to Delay Dementia Onset
- Support – Caregiver Development and Support Program
- Support – System Navigator

Alzheimer Society

What Can Be Done?

Scenario Analysis

The first phase of *Rising Tide* established the Dementia Base Case: what will happen if the dementia epidemic is not addressed by any major policy change. The alarming result is intended to evoke a call-to-action, but also to provide a useful standard by which choices can be evaluated. The Scenario Analysis phase of the project shows how the Dementia Base Case can be used to identify meaningful actions – that is, *how it can be used to make a difference on Canadian society*.

Four intervention scenarios, selected by the Alzheimer Society and a panel of subject matter experts, were generated:
Intervention 1: Prevention – Increase in Physical Activity
Intervention 2: Prevention – A Program to Delay Dementia Onset
Intervention 3: Support – Caregiver Development and Support Program
Intervention 4: Support – System Navigator/Case Management

The scenarios were selected for their anticipated health and economic value, but also because evidence-based data are available to support them. **They are not meant to be the final word on what must be done, but do illustrate how policy options can be evaluated and compared in a very practical way.**

For each scenario, subject matter experts identified the relevant data and worked closely with the RiskAnalytica team to customize the Life at Risk® simulation model. As with the Dementia Base Case, subject matter experts also reviewed the simulation results for relevance and practicality. The results are expressed in "value" terms, that is in terms of how each intervention would change the health and economic burden of dementia in Canada compared to the Base Case.

Intervention Simulations

Intervention 1: Prevention – Increase in Physical Activity

The first prevention scenario examines the impact of an intervention which broadly applies evidence that increased physical activity can reduce dementia incidence. The intervention focuses on increasing physical activity by 50% for all Canadians (65+) without dementia, who are already moderately to highly active.

Prevalence data are based on the current self-reported physical activity levels from the Statistics Canada CANSIM database, and the odds ratios related to physical activity from the Canadian Study of Health and Aging (Laurin et al. 2001).

Exhibit 18 provides a summary of the value of the intervention over the next 30 years.

- A 50% increase in physical activity level for Canadians (65+) without dementia who already rate themselves as moderately to highly active was shown to significantly reduce the number of individuals diagnosed with dementia in the short and long-term. The follow-on effects of this reduction result in fewer individuals living with dementia and a reduction in the pressure on long-term care, community care and informal care. In turn, this was shown to produce significant savings in direct health costs, unpaid caregiver opportunity costs and indirect costs associated with dementia, and the provision of care by informal caregivers throughout the simulation timeframe.

Exhibit 18 Intervention 1: Prevention – Increase in Physical Activity, Impact on Dementia Burden: 2008-2038

Intervention 1: Prevention – Increase in Physical Activity
Impact on Dementia Burden
Intervention Scenario vs. Base Case

Year	Health Impact	
	Incidence	Prevalence
2018	-5,978	-32,454
2028	-8,243	-64,189
2038	-10,758	-96,412

Year	Health Care Utilization (Ages 65+)		
	Prevalence of Dementia in Long-Term Care	Prevalence of Dementia in Community Care	Prevalence of Dementia in No Formal Care
2018	-13,578	-11,698	-7,178
2028	-25,296	-25,454	-13,439
2038	-36,216	-41,556	-18,641

Years 2008 through	Economic Impact (Cumulative 2008 Present Values)				
	Total Direct Health Costs	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-$3,385,855,647	-$2,127,624,745	-$122,283,860	-$29,645,387	-$5,665,409,639
2028	-$13,686,500,180	-$8,529,091,994	-$532,274,656	-$124,825,659	-$22,872,692,489
2038	-$31,180,831,406	-$19,120,537,780	-$1,232,947,001	-$285,207,023	-$51,819,523,210

Short-Term Impact

In the short-term (10 years), a prevention program to increase levels of physical activity by 50% for Canadians (65+) without dementia who are already moderately to highly active, would result in:

- a reduction in the number of new cases of dementia of more than 5,970 (4.3% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 32,450 (-5.1%);
- over 13,570 fewer Canadians (65+) living with dementia in long-term care (-7.4%);
- over 11,690 fewer Canadians (65+) living with dementia in community care (-5.3%);
- a reduction in the cumulative Total Economic Burden of more than $5.6 billion (in 2008 dollars), (-2.4% reduction from the Base Case).

Long-Term Impact

In the long-term (30 years), a prevention program to increase levels of physical activity by 50% for Canadians (65+) without dementia who are already moderately to highly active, would result in:

- a reduction in the number of new cases of dementia of more than 10,750 (4.2% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 96,410 (-8.6%);
- over 36,210 fewer Canadians (65+) living with dementia in long-term care (-8.2%);
- over 41,550 fewer Canadians (65+) living with dementia in community care (-8.3%);
- a reduction in the cumulative Total Economic Burden of more than $51.8 billion (in 2008 dollars) (-5.9% reduction from the Base Case).

Intervention 2: Prevention – A Program to Delay Dementia Onset

The second intervention scenario examines the impact of a hypothetical prevention program which would delay the onset of dementia by approximately two years. The prevention program targets the entire dementia-free 65+ Canadian population and would combine a variety of promising, evidence-based strategies such as following a healthy diet and lifestyle.

A comprehensive study by Brookmeyer *et al.* (2007) estimates that the relative (expected) effect of such a prevention program would reduce the risk of developing dementia by 23%. This scenario assumes that the relative risk factor is equally applicable across all dementia disease types, both genders and all age groups (65+).

Exhibit 19 provides a summary of the value of the intervention over the next 30 years.

- Relative to the Base Case, delaying the onset of dementia by two years resulted in fewer individuals living with dementia and significantly reduced the constraints placed on health care resources and the health care system.
- This intervention was shown to produce significant savings in health costs, informal caregiver opportunity costs and indirect costs associated with dementia and informal care throughout the simulated timeframe.

Exhibit 19 Intervention 2: Prevention – Hypothetical Program to Delay Dementia Onset: 2008-2038

Intervention 2: Prevention –Hypothetical Program to Delay Dementia Onset
Impact on Dementia Burden:
Intervention Scenario vs. Dementia Base Case

Year	Health Impact	
	Incidence	Prevalence
2018	-25,951	-137,502
2028	-36,353	-269,736
2038	-48,409	-409,647

Year	Health Care Utilization (Ages 65+)		
	Prevalence of Dementia in Long Term Care	Prevalence of Dementia in Community Care	Prevalence of Dementia in No Formal Care
2018	-57,529	-49,748	-30,226
2028	-106,298	-106,942	-56,495
2038	-153,878	-175,868	-79,901

Years 2008 through	Economic Impact (Cumulative 2008 Present Values)				
	Total Direct Health Costs	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-$14,442,029,463	-$9,074,731,356	-$556,647,414	-$135,013,264	-$24,208,421,497
2028	-$57,808,986,147	-$36,024,947,299	-$2,329,458,341	-$546,597,397	-$96,709,989,184
2038	-$131,676,392,947	-$80,750,710,864	-$5,037,965,302	-$1,166,583,594	-$218,631,652,707

Short-term Impact

In the short-term (10 years), a program to delay dementia onset by two years would result in:

- a reduction in the number of new cases of dementia of more than 25,950 (18.9% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 137,500 (-21.6%);
- over 57,520 fewer Canadians (65+) living with dementia in long-term care (-31.4%);

- over 49,740 fewer Canadians (65+) living with dementia in community care (-22.4%);
- a cumulative reduction in the Total Economic Burden of more than $24.2 billion (in 2008 dollars) (-10.1% reduction from the Base Case).

Long-Term Impact

In the long-term (30 years), a program to delay dementia onset by two years would result in:

- a reduction in the number of new cases of dementia of more than 48,400 (-18.9% reduction from the Base Case);
- a reduction in the number of Canadians living with dementia of more than 409,640 (-36.4%);
- over 153,870 fewer Canadians (65+) living with dementia in long-term care (-34.8%);
- over 175,860 fewer Canadians (65+) living with dementia in community care (-34.9%);
- a cumulative reduction in the Total Economic Burden of more than $218.6 billion (in 2008 dollars) (-25.1% reduction from the Base Case).

Intervention 3: Support – Caregiver Development and Support Program[22]

The third intervention examines an informal caregiver skill-building and support program that reduces the amount of caregiving time and hence the health and economic burden placed on informal caregivers. The caregiver support program also aims to delay admission for the person with dementia into long-term care. The intervention is applied to all informal caregivers and individuals with dementia receiving care.

The reduction in caregiving time from such a program is based on a study by Graff *et al.* (2008). The study showed that informal caregiver hours could be reduced by an average of 212.3 hours over a three month timeframe by providing a program of occupational therapy to individuals living with dementia and their informal caregivers targeting improvement in:

- informal caregiver competence, skills and communications strategies for supervision of activities of daily living;
- coping strategies for patient behaviours and the overall burden of care.

An informal caregiver support program has also been shown to impact admissions into long-term care by delaying the time to admission. These effects are modeled based on a study by Mittleman *et al.* (2006). The study showed that admission of individuals living with dementia in long-term care facilities could be delayed by a median of 557 days by providing a counselling and support intervention program for spousal caregivers. Based on these findings, this scenario assumes that Canadians who would have been admitted to long-term care under the Dementia Base Case scenario (no intervention) will do so after a 557 day delay. It further assumes that the impact on all types of informal caregivers parallels that of the spouses in the study.

Exhibit 20 and Exhibit 21 provide a summary of the two sources of value which can be expected from this intervention over the next 30 years. Exhibit 20 focuses on the benefits of delaying institutionalization, and Exhibit 21 on the reduction in caregiving time.

- A caregiver support program that delays admission into long-term care is expected to lessen the pressures placed on long-term care resources producing significant savings in health costs. With fewer people admitted into long-term care, there will be more people residing within the community receiving community-based care and informal care. While this would shift costs to caregivers by increasing unpaid caregiver opportunity costs and indirect costs associated with dementia and informal care, the savings in direct health costs more than compensates, thus producing a significantly lower Total Economic Burden, as compared to the Base Case.
- The caregiver support program is expected to reduce economic burden for informal caregivers. As compared to the Base Case, this is expected to produce significant savings in unpaid caregiver opportunity costs as well as in indirect costs associated with informal care provision.

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[22] Note that Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

Exhibit 20 Intervention 3: Support – Caregiver Development & Support Program, Impact on Dementia Burden: 2008-2038

Benefit 1: Impact of Delaying Admission into Long-Term Care

<table>
<tr><th colspan="6">Intervention 3: Support –Caregiver Development & Support Program
Impact on Dementia Burden: Benefit 1: Impact of Delaying Admission to Long-Term Care (LTC)
Intervention Scenario vs. Base Case</th></tr>
<tr><td rowspan="2">Year</td><td colspan="5">Health Care Utilization (Ages 65+)</td></tr>
<tr><td colspan="5">Prevalence of Dementia in Long-term Care</td></tr>
<tr><td>2018</td><td colspan="5">-8,813</td></tr>
<tr><td>2028</td><td colspan="5">-13,355</td></tr>
<tr><td>2038</td><td colspan="5">-14,270</td></tr>
<tr><td rowspan="2">Years 2008 through</td><td colspan="5">Economic Impact (Cumulative 2008 Present Values)</td></tr>
<tr><td>Total Direct Health Costs</td><td>Total Informal Caregiver Opportunity Cost</td><td>Indirect Wage Impact</td><td>Indirect Corporate Profits Impact</td><td>Total Economic Burden</td></tr>
<tr><td>2018</td><td>-$4,720,740,315</td><td>$2,241,144,070</td><td>$14,345,869</td><td>$3,533,610</td><td>-$2,461,716,766</td></tr>
<tr><td>2028</td><td>-$12,363,624,312</td><td>$5,709,864,958</td><td>$54,358,941</td><td>$12,846,813</td><td>-$6,586,553,600</td></tr>
<tr><td>2038</td><td>-$22,534,463,075</td><td>$10,072,095,845</td><td>$135,646,031</td><td>$31,457,453</td><td>-$12,295,263,746</td></tr>
</table>

Exhibit 21 Intervention 3: Support – Caregiver Development & Support Program, Impact on Dementia Burden: 2008-2038

Benefit 2: Impact of Reducing Informal Caregiving Burden

<table>
<tr><th colspan="5">Intervention 3: Support –Caregiver Development & Support Program
Impact on Dementia Burden: Benefit 2: Impact of Reducing Informal Caregiving Burden
Intervention Scenario vs. Base Case</th></tr>
<tr><td rowspan="2">Years 2008 through</td><td colspan="4">Economic Impact (Cumulative 2008 Present Values)</td></tr>
<tr><td>Total Informal Caregiver Opportunity Cost</td><td>Indirect Wage Impact</td><td>Indirect Corporate Profits Impact</td><td>Total Economic Burden</td></tr>
<tr><td>2018</td><td>-$10,231,165,526</td><td>-$39,164,418</td><td>-$9,507,720</td><td>-$10,279,837,664</td></tr>
<tr><td>2028</td><td>-$26,715,147,944</td><td>-$144,407,047</td><td>-$33,937,116</td><td>-$26,893,492,107</td></tr>
<tr><td>2038</td><td>-$50,173,500,166</td><td>-$305,146,802</td><td>-$70,732,866</td><td>-$50,549,379,834</td></tr>
</table>

Short-term Impact

In the short-term (10 years), helping caregivers develop coping skills and build competencies in their caregiving roles would result in:

- over 8,810 fewer Canadians (65+) living with dementia in long-term care (a 4.8% reduction from the Base Case);
- a reduction in the cumulative Total Economic Burden of more than $12.7 billion (in 2008 dollars); (a 5.3% reduction from the Base Case);
  - more than $ 2.4 billion (-1.0%) due to delaying institutionalization;
  - more than $10.2 billion (-4.3%) due to reducing informal caregiver burden.

Long-Term Impact

In the long-term (30 years), helping caregivers develop coping skills and build competencies in their caregiving roles would result in:

- Over 14,270 fewer Canadians (65+) living with dementia in facility-based care (a 3.2% reduction from the Base Case);
- A reduction in the cumulative Total Economic Burden of more than $62.8 billion (in 2008 dollars) (a 7.2% reduction from the Base Case);
  - More than $12.2 billion (-1.4%) due to delaying institutionalization;
  - More than $50.5 billion (-5.8%) due to reducing informal caregiver burden.

Intervention 4: Support – System Navigator/Case Management[22]

The fourth scenario examines the impact of assigning a system navigator (case manager) to each newly diagnosed person with dementia in order to provide care coordination to individuals with dementia and support to informal caregivers. The intervention is applied to all individuals with dementia and their informal caregivers.

The effects of a system navigator are estimated and modeled based on the Lewisham Case Management Scheme from a study by Challis *et al* (2002). This study showed that individuals with dementia, and their caregivers, who had received an intensive care management service that brought together secondary health care in the community and intensive care management, remained in the community longer, led to a reduced informal caregiver burden and reduced overall costs compared to individuals receiving usual care. The study concluded that a system navigator would delay long-term care admission by two years and would reduce informal caregiving hours.

Exhibits 22 and 23 provide a summary of the value of the intervention over the next 30 years. Exhibit 22 focuses on the benefits of delaying institutionalization, and Exhibit 23 on the reduction in caregiving time.

- It is anticipated that providing system navigation support would delay admission into long-term care, lessen the pressure placed on those resources, and produce significant savings in health costs. As in Intervention 3, this would result in more individuals with dementia relying on community-based care and informal care resources, and an increase in unpaid caregiver opportunity costs and indirect costs. However, as in the previous scenario, the savings in direct health costs would more than compensate, producing a significantly lower Total Economic Burden compared to the Base Case.
- It is anticipated that providing system navigation support would reduce the financial burden on informal caregivers. As compared to the Base Case, this would produce significant savings in informal caregiver opportunity costs, as well as the indirect costs associated with informal care provision throughout the simulated timeframe.

Exhibit 22 Intervention 4: Support - System Navigator, Impact on Dementia Burden: 2008-2038

Benefit 1: Impact of Delaying Admission into Long-Term Care

Intervention 4: Support –System Navigator: Impact on Dementia Burden Benefit 1: Impact of Delaying Admission into Long-Term Care Intervention Scenario vs. Base Case					
Year	Health Care Utilization (Ages 65+)				
	Prevalence of Dementia in Long-Term Care				
2018	-11,691				
2028	-17,708				
2038	-19,093				
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)				
	Total Direct Health Costs	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-$6,154,810,083	$2,921,162,482	$16,229,642	$3,991,095	-$3,213,426,864
2028	-$16,275,405,812	$7,514,362,369	$67,633,929	$15,953,949	-$8,677,455,565
2038	-$29,827,007,373	$13,326,371,848	$174,806,333	$40,490,895	-$16,285,338,297

Exhibit 23 Intervention 4: Support - System Navigator, Impact on Dementia Burden: 2008-2038

Benefit 2: Impact of Reducing Informal Caregiving Burden

Intervention 4: Support –System Navigator: Impact on Dementia Burden Benefit 2: Impact of Reducing Informal Caregiving Burden Intervention Scenario vs. Base Case				
Years 2008 through	Economic Impact (Cumulative 2008 Present Values)			
	Total Informal Caregiver Opportunity Cost	Indirect Wage Impact	Indirect Corporate Profits Impact	Total Economic Burden
2018	-$19,767,575,038	-$62,551,207	-$15,186,335	-$19,845,312,580
2028	-$51,616,180,998	-$226,717,455	-$53,295,581	-$51,896,194,034
2038	-$96,939,926,041	-$464,702,999	-$107,775,061	-$97,512,404,101

Short-term Impact

In the short-term (10 years), providing system navigation support for individuals with dementia and their caregivers would result in:

- over 11,690 fewer Canadians (65+) living with dementia in long-term care (a 6.4% reduction from the Base Case);
- a reduction in the cumulative Total Economic Burden of more than $23.0 billion (in 2008 dollars) (a 9.7% reduction from the Base Case);
  - more than $ 3.2 billion (-1.4%) due to delaying institutionalization;
  - more than $19.8 billion (-8.3%) due to reducing informal caregiver burden.

Long-Term Impact

In the long-term (30 years), providing system navigation support for individuals with dementia and their caregivers would result in:

- over 19,090 fewer Canadians (65+) living with dementia in long-term care (a 4.3% reduction from the Base Case);
- a reduction in the cumulative Total Economic Burden of more than $113.7 billion (in 2008 dollars) (a 13.0% reduction from the Base Case);
  - more than $16.2 billion (- 1.9%) due to delaying institutionalization;
  - more than $97.5 billion (-11.2%) due to reducing informal caregiver burden.

Intervention Value Comparisons

Exhibit 24 Impact of Interventions on Dementia Prevalence

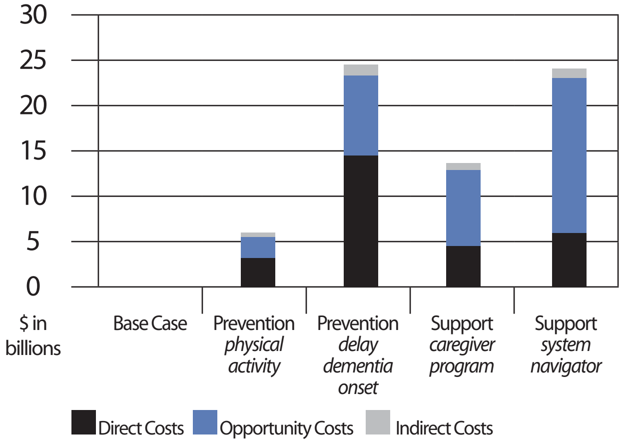
Years 2008 through	Intervention 1 Prevention: Increased Physical Activity		Intervention 2 Prevention: Hypothetical Program to Delay Dementia Onset	
	Simulated Value	% of Base Case	Simulated Value	% of Base Case
2018	-32,454	-5.1%	-137,502	-21.6%
2028	-64,189	-7.6%	-269,736	-31.8%
2038	-96,412	-8.6%	-409,647	-36.4%

Exhibit 25 Cumulative Impact of Interventions on Total Economic Burden (2008 dollars)

Years 2008 through	Intervention 1		Intervention 2 Prevention: Hypothetical Program to Delay Dementia Onset		Intervention 3 Support: Caregiver Development and Support Program		Intervention 4 Support: System Navigator	
	Simulated Value	% of Base Case	Simulated Value	% of Base Case	Simulated Value	% of Base Case	Simulated Value	% of Base Case
2018	-$ 5,665,409,639	-2.4%	-$ 24,208,421,497	-10.1%	-$12,741,554,430	-5.3%	-$ 23,058,739,444	-9.7%
2028	-$22,872,692,489	-4.5%	-$ 96,709,989,184	-19.1%	-$33,480,045,707	-6.6%	-$ 60,573,649,599	-12.0%
2038	-$51,819,523,210	-5.9%	-$218,631,652,707	-25.1%	-$62,844,643,580	-7.2%	-$113,797,742,398	-13.0%

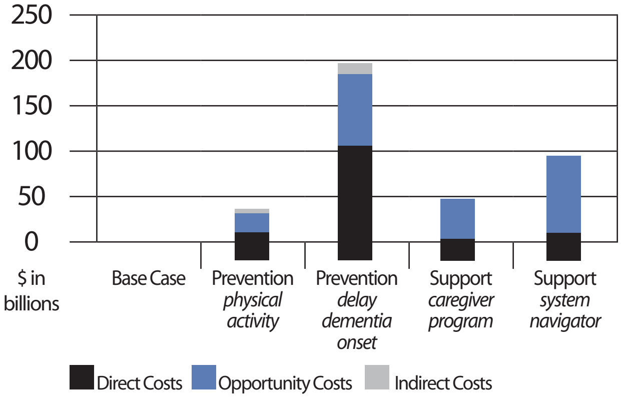
Note: Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

Exhibit 26 Cumulative 10-year Impact of Interventions on Total Economic Burden (2008 dollars)



Note: Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

Exhibit 27 Cumulative 30-year Impact of Interventions on Total Economic Burden (2008 dollars)



Note: Interventions 3 and 4 are each based on two independently-simulated scenarios: one scenario to model the impact of delaying admission to long-term care and another scenario to model the impact on caregiver burden. Showing their combined benefit assumes a zero correlation between their effects.

Scenario Analysis Conclusions

Rising Tide has looked at how dementia policy and program interventions could help to address the dementia challenge through prevention and support strategies to individuals living with dementia and their informal caregivers. The value potential of each scenario has highlighted how dementia prevention and management could reduce the health and economic burden of dementia.

The intervention scenarios demonstrate that:

- increasing by 50% the activity level of Canadians (65+) who are already active would yield a 30-year reduction in Direct Health Costs of $31 billion and a reduction in Total Economic Burden of $52 billion;
- delaying onset of dementia by two years would yield a 30-year reduction of $219 billion in Total Economic Burden, along with a reduction in prevalence of 410,000 individuals – a 36% reduction from the Base Case;
- helping caregivers develop coping skills and build competencies in their caregiving roles would yield a 30-year value of $63 billion[22];
- providing system navigation support to individuals with dementia and their caregivers would yield a 30-year value of $114 billion[22];

- the Life at Risk® platform provides a useful assessment and comparison tool for conducting evidence-based strategic options and policy analysis.

Each of the scenarios delivers considerable value, clearly indicating that an effort to devise an intervention or set of interventions warrants attention.

The two prevention strategies presented were shown to produce significant benefits from a population health perspective. These scenarios were estimated to significantly reduce the number of individuals living with dementia by 2038. With fewer Canadians living with dementia, the burden placed on health care resources across all types of care would be reduced, producing substantial savings for Canadian governments and society.

The two support interventions focused on providing help to individuals living with dementia and their informal caregivers were also shown to provide significant economic relief. The scenarios presented show substantial savings by delaying admission to long-term care facilities for individuals with dementia. Beyond the reduction in demand for long-term care resources, there are additional emotional and quality of life benefits due to the decrease in informal caregiver burden.

A Valuable Tool for Policymakers

The Dementia Base Case makes the magnitude of the population health and economic burden of dementia undeniable and reinforces the urgent need for a national dementia strategy to guide, manage and mitigate the health, economic and social impacts of dementia. These intervention scenarios clearly illustrate how the Dementia Base Case can also be used to assess and compare the relative value of alternative options.

There is a great deal of work to be done; this is only a starting point, but a crucial one. The Dementia Base Case provides policymakers and health care decision-makers with a vitally important model for gauging the impact of a comprehensive Canadian dementia strategy.

What Has Been Done

- What has been done elsewhere
- Current Approaches in Canada
- Leading Concepts and Models

Alzheimer Society

What Has Been Done

Policy Analysis

The final phase of *Rising Tide* involved looking at existing and emerging policy responses to the dementia epidemic in other countries and in different parts of Canada. A rich range of options have already been applied, which helps to broaden the understanding of what can be done. In addition, *Rising Tide* takes a brief look at two of the leading concepts and models on which many of these options are based.

The analysis concludes with recommendations for consideration. These recommendations, if adopted by policymakers and decision makers in Canada, will reduce the disease's impact on Canadian society.

What Has Been Done in Other Countries?

There are more than 35 million people living with dementia in the world at this time [23]. It is estimated that by 2050, this number will increase to 115 million people. Owing to a number of factors – ageism, stigma associated with mental disorders, the recency of treatment options – policy responses have been dismal in most countries, with however a few notable exceptions.

Australia, Norway, the Netherlands, France, and the United Kingdom have each developed specific plans or frameworks for dealing with dementia, largely directed at greater integration of health and social policies; establishing more home-based programs; adapting care facilities to better meet the needs of residents with dementia; providing education for people with dementia, their families, health professionals and the public; and investing in research. In 2008, the Council of the European Union passed a number of resolutions committing the European Parliament to support European action to combat neurodegenerative diseases, particularly Alzheimer's disease.

In March 2009, the Ontario Ministry of Health and Long-Term Care prepared a literature review looking for relevant government policies addressing neurological conditions, including Alzheimer's disease and other dementias. Of the eleven countries examined, only one – the United Kingdom (UK) with its National Service Framework (NSF) for Long-Term Conditions – has adopted an explicitly integrated framework to address all long-term neurological conditions. The report identified that "dementia is a relatively new area of policy focus and few countries have specific policies to address the disorder[24]."

A comparative analysis of dementia care in OECD countries was conducted in 2004[25]. The following common elements of their national dementia policies were identified:

- delaying institutionalization, enabling individuals to remain at home as long as possible;
- supporting caregivers in order to delay the move of individuals living with dementia to long-term care;
- giving individuals living with dementia as much control over their care as possible, while recognizing limitations due to cognitive impairment (e.g., in relation to having the capacity to make informed choices);
- equating service provision with need;
- promoting early diagnosis;
- co-ordinating services at the local level where possible;
- making long-term care, when required, as home-like as possible.

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[23] 2010 figures. *World Alzheimer Report*. Alzheimer's Disease International. September: 2009.

[24] *A Rapid Literature Review of Government Policies for Addressing Neurological Diseases*. Ministry of Health and Long Term Care. Toronto, ON: 2009.

[25] Moise, P., Schwarzinger, M., Um, M., and the Dementia Experts' Group. "Dementia Care in Nine OECD Countries: A Comparative Analysis." *OECD Health Working Papers*. OECD (Organization of Economic Development and Co-ordination), 2004.

A Survey of Dementia Priority Policies

The dementia-specific policies of six countries that have made dementia a health priority were reviewed by the Alzheimer Society and are summarized below. Each offers valuable lessons when considering Canada's needs.

Country	Research	Improved Care	Caregiver Support	Workforce
Australia (2006-2010)	• Collaborative research centres • Additional research funding • Prevention focus	• Primary care guidelines • Expanded psycho-geriatric consults • Early intervention • Helpline • Memory community centres	• Training • Home care support for behaviour problems	• Training
The Netherlands (2008-2011)		• Case management • Transportation to care settings • Peer support (Alzheimer café) • Helpline • Care hotels • Cluster housing with home automation • Client/person-centred policy development	• Respite care programs, temporary stays, holidays	
Norway (2006- 2015)	• Research in quality development	• Day programs • Adapted living facilities	• Partnerships with providers, families and communities	• Raising skills and knowledge • Improving collaboration among professionals • National standards to improve medical services in nursing homes
France (2008-2012)	• Partnerships/ network establishment • Additional funding	• Integrated access points • 1,000 new case managers • In-home specialist teams • Helpline	• Respite care programs • Strengthening of caregiver rights, education, support for return to work • Improving health monitoring of caregivers	• Developing skill sets in all care professionals • Developing new competencies – case managers, gerontology assistants

Scotland (2008-2011)	• Increased funding for research • Network establishment	• Early diagnosis, intervention • Post-diagnostic support • Integration of palliative care	• Information	• Developing skill sets in all care professionals • Developing new competencies – case managers, gerontology assistants
United Kingdom (2009-2014)	• Increased funding for dementia care research	• Early diagnosis and intervention • Public information to promote help-seeking • Easy access to care • Peer support • Specialist home care services • Improved care for individuals with dementia in general hospitals • Housing support • Helpline (Telecare) • Improved end-of-life care • Development of a comprehensive model of care	• Information • Carer needs assessment • Carer strategy	• Training, continuing professional development in dementia for care professionals

There are several common elements in the policies of these countries. All of these strategies are recent. Most acknowledge the importance of investing in research, supporting caregivers in their role and improving the skills of professionals who provide care to individuals with dementia. Strategies to improve the delivery of care to individuals with dementia include focusing on early diagnosis and intervention, using case management, increasing specialized home care, and making information about the disease widely available through channels such as health helplines.

A comparison of national dementia strategies also reveals some unique features such as:

- the call for a national priority in the United Kingdom with cross-government strategy development;
- the concept of Alzheimer holidays, hotels, farms in the Netherlands;
- the Dutch concept of building the national strategy on the foundation of problems identified, experienced and prioritized by individuals with dementia and their caregivers;
- the French concept of mobilizing society for the fight against dementia;
- the French goal of making dementia a European priority.

The Current Situation in Canada

At the Federal Level

The role of the Government of Canada in the provision of health services is limited to specified populations, namely: First Nations and Inuit, members of the Canadian Armed Forces, veterans, federal public servants working abroad and inmates of federal correctional facilities. Veterans Affairs Canada has received accolades from the health policy community for its Veterans Independence Program (VIP).

From a $2.9 billion annual budget of Veterans Affairs Canada, $303 million goes to the Veterans Independence Program to provide home care and support to 102,154 of Canada's 197,460 war service veterans. The average age of these veterans is 84; only 4,190 occupy long-term care beds. The Veterans Independence Program helps to keep them living independently in their own homes by paying for such services as housekeeping and grounds maintenance. The average cost per person for VIP home care is about $2,680 a year, compared with $43,000 a year for a room in an Ontario care facility or up to $1,000 a day in hospital[26].

The federal government also provides financial aid of up to $4,095 per year to caregivers who are caring for elderly parents or grandparents, or adult dependents that are dependent due to mental or physical impairment. Caregivers may also claim medical expenses of up to $10,000 per year, including respite care and attendant care.

The federal government's most significant role in dementia is the funding of dementia research, primarily through the Institute of Aging of the Canadian Institutes of Health Research (CIHR). Over the past decade, CIHR has significantly increased annual funding for dementia research from approximately $4.5 million to $20 million.

As in many countries, progress in policy development is impeded by lack of clarity as to which department is to take responsibility for dementia policy. Should it be the department responsible for seniors' issues, for chronic diseases or for mental health? As a consequence, policy for the management of dementia has been disjointed.

At the Provincial Level

Likewise, no provincial government has a department that deals strictly with dementia. Each jurisdiction has found its own way to deal with the management of dementia, whether through mental health policy, through their seniors' department, long-term care or chronic disease management.

Most provinces and territories have policies with respect to long-term care facilities, respite care and other publicly funded or administered services used by individuals living with dementia. The few dementia-specific strategies/policies that have been implemented in Canada are described below. So far, in the context of provincial dementia strategies, only Ontario has attached significant funding in support of strengthening dementia care.

British Columbia

The province of British Columbia worked with key stakeholders in 2007 to develop the BC *Dementia Service Framework*[27] to guide service delivery improvements with a view to system change. Recommendations were developed for action by the public, health service providers and decision-makers, as well as policymakers. An analysis of the current system of dementia care in BC identified seven critical gaps, including:

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[26] Steed, Judy. "Small Mercies." Toronto Star. 8 Nov 2008. http://www.thestar.com/atkinson2008/article/532165.

[27] B.C. Dementia Services Framework. British Columbia Ministry of Health (2007).
http://www.alzheimerbc.org/getdoc/1f230200-0ee6-4aef-a056-1e3b9e6d4cb7/DementiaServiceFramework_PDF.aspx

- in the health care system's capacity and ability to address the clinical and support needs of people with dementia and their families/caregivers;
- in the number of health care providers with expertise in elder and dementia care for people with dementia and their families/ caregivers;
- in the knowledge of health care providers about dementia as a chronic condition and about best practices in dementia care;
- in the policy that mitigates the impact of dementia on the people with dementia and their families/caregivers, and on the communities they live in;
- in the recognition of the role of families and caregivers as partners on the care team;
- in the capacity and ability of the acute care setting to meet the needs of people with dementia;
- in the formal integration, collaboration, and communication across care settings, between health care providers, and across health authorities.

Policy solutions recommended include:
- developing a research agenda on dementia and best practices on dementia care and services;
- developing a policy lens for the review of all policy to ensure that new policies are beneficial to individuals with dementia, including incorporating the view of dementia as a chronic condition for which chronic disease prevention and management is an appropriate framework;
- reducing stigma associated with dementia;
- improving the knowledge of health care providers about dementia;
- fostering innovation in models of service delivery.

Manitoba

In October 2002, Manitoba Health released *A Strategy for Alzheimer Disease and Related Dementias*[28] in Manitoba. The strategy was developed through an extensive consultation process co-chaired by Manitoba Health and the Alzheimer Society of Manitoba. The consultation was interdisciplinary and included representation from all Regional Health Authorities, and a variety of senior serving organizations. The goal was to provide the best possible care and support to Manitobans affected by Alzheimer's disease and related dementias and their caregivers, through the continuum of the disease. The strategy focused on the following nine areas of change:
- education for professionals, paraprofessionals, families, individuals, communities and the general public;
- guidelines for diagnosis;
- standards across all programs and services;
- family and individual support;
- comprehensive programs and services for individuals in community facilities;
- case management and interdisciplinary collaboration;
- equitable access to programs and services across Manitoba;
- human resources issues including recruitment, retention and remuneration; and
- ongoing, rigorous research and evaluation.

Saskatchewan

In 2005, the Minister of Health of Saskatchewan released *A Strategy for Alzheimer Disease and Related Dementias* in Saskatchewan, which was developed jointly with the Alzheimer Society of Saskatchewan and contains 60 recommendations focused on seven goals.

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[28] Mattus, Hope and Wendy Schettler et al. A Strategy for Alzheimer Disease in Manitoba. October, 2002:. http://www.gov.mb.ca/health/documents/alzheimer.pdf.

1. Public awareness and education.
2. Diagnosis and treatment.
3. Support for individuals and caregivers.
4. Supportive environments.
5. Programs and services.
6. Education and training.
7. Research.

Ontario

Canada's first comprehensive strategy on Alzheimer's disease and related dementias (ADRD) was initiated in Ontario in 1999, with $68.4 million invested in the strategy over the next five years[29]. The Strategy, under the auspices of the Ministry of Health and Long-Term Care and the Ontario Seniors' Secretariat, had the following goals:

- to support and improve the quality of life of individuals with ADRD and their caregivers;
- to improve treatment, care and environmental conditions of individuals with ADRD;
- to increase public awareness of dementia and the services available; and
- to develop linkages between the initiatives within the strategy.

Ten initiatives support these goals:

1. Staff education and training.
2. Physician training.
3. Increasing public awareness, information and education.
4. Planning for appropriate, safe and secure environments.
5. Respite services for caregivers.
6. Research on caregiver needs.
7. Advance directives[30] on care choices.
8. Psycho-geriatric consulting services.
9. Dementia networks, a research coalition, and specialized geriatric services.
10. Intergenerational volunteer initiative.

Since the implementation of the strategy, the Ontario government has funded the establishment of the Alzheimer Knowledge Exchange (AKE), a clearinghouse for current ADRD knowledge along with a resource for e-learning and web-based support for knowledge exchange. As well, services to individuals with dementia are being improved through the province's Aging at Home Strategy.

Quebec

The Quebec government announced that it will implement recommendations that Alzheimer's disease and related dementias be regarded as chronic conditions[31] and integrated into the ministerial action plan for 2010–2015, which identifies chronic conditions as a priority. The report also asserts that the Ministry must work with academia to develop guidelines and practice tools for the management of dementia through collaboration with the planned National Institute for Excellence in Health and Social Services (INESSS).

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[29] Ontario's Strategy for Alzheimer Disease and Related Dementias. The Queen's Printer for Ontario, 2005.
http://www.culture.gov.on.ca/seniors/english/programs/alzheimer/initiatives.shtml

[30] Advanced care directives are specific instructions, prepared in advance, intended to direct a person's medical care in the event that he/she is unable to do so in the future.

[31] Bergman, Howard. Relever le défi de la maladie d'Alzheimer et des maladies apparentées : Une vision centrée sur la personne, l'humanisme et l'excellence.

The recommendations have been made in the context of significant health system reform in Quebec, including the creation of integrated services delivered through health and social service centres (CSSS), along with family medicine groups (GMF) and clinical networks.

The plan defines seven Priority Actions and a further 24 recommendations related to dementia.

1. Raise awareness, inform and mobilize.
2. Ensure the availability of locally-responsive, personalized and coordinated services and evidence-based treatment for individuals with dementia and their caregivers.
3. In advanced stages of the disease, promote quality of life, provide access to home support.
4. Promote quality end-of-life care, in accordance with the wishes of the client and family, and characterized by dignity and comfort.
5. Provide services to family caregivers, considered partners in support.
6. Develop and support professional practice.
7. Mobilize an unprecedented research effort.

Newfoundland & Labrador

In 2001, the province of Newfoundland and Labrador, working with the Alzheimer Society of Newfoundland and Labrador, developed a *Provincial Strategy for Alzheimer Disease and other Dementias*, with four goals.

1. A coordinated system of care.
2. Access to current information on Alzheimer's disease and other dementias.
3. Support for individuals with Alzheimer's disease and other dementias, and their families/caregivers.
4. Education and skill development.

General Agreement on Key Elements

A review of dementia strategies from several countries and several Canadian provinces reveals general agreement on key elements to be factored into any comprehensive dementia strategy:

- the public needs better access to information to increase awareness, to overcome stigma, and to seek help such that early interventions can be initiated;
- people who provide care to individuals with dementia need knowledge support to ensure that dementia is recognized and that the professionals know what treatments and care strategies are appropriate for different stages in the disease.;
- caregivers need help to cope, including, reducing the financial disincentives to fulfill caregiving roles and ensuring that caregivers are supported with respite and training are critical features;
- case management and system navigation are becoming important features of dementia strategies;
- organizing services along the lines of the chronic disease prevention and management model is congruent with current policy direction in several provinces;
- continued investment in research is a common feature.

Leading Concepts and Models

Before looking at individual strategies that Canada should consider in dealing with the dementia epidemic, it is helpful to understand the leading concepts and models that are already accepted or are currently being implemented. A national policy response should work in concert with these leading concepts and models.

Integrated Models of Care

The goal of integrated models of care is to improve coordination of care for individuals who are reliant on a complex array of specialized medical, community and social services. One of the most significant concerns voiced by patients and caregivers who are frequent users of health services, is that care is uncoordinated and it can be difficult to tell who, if anyone, is in charge. In short, the system is difficult to navigate. [32]

Integrated models of care are a response to a disjointed maze of health care services. In an integrated model, health care service delivery systems are redesigned to formally align primary care and acute care with a network of community support services for improved efficiency and effectiveness.

There is a considerable body of literature on the subject of integrated models of care to draw upon. Researchers have used the experience of 250 provincial policymakers involved in redesigning health care service delivery systems to identify best practices[33], and others have created a framework [34] describing the philosophical and policy prerequisites, clinical best practices and linkage mechanisms necessary for successful care coordination across all settings.

In brief, the models of care found to be most effective at improving outcomes, client satisfaction and/or cost effectiveness tend to have the following features: [35]

- umbrella organizational structures that guide, support, maintain, and are accountable for integration, service delivery and quality and cost outcomes;
- multidisciplinary case management, a single entry point into the health care system, and packaging and coordinating services;
- organized provider networks joined together by standardized procedures, service agreements, joint training, shared information systems and even common ownership of resources;
- financial incentives to promote prevention, rehabilitation and the downward substitution of services, as well as to enable service integration and efficiency.

SIPA – An Example of Integrative Care for the Elderly

An example of an effective Canadian program of integrated care for elderly clients with disabilities is SIPA (French language acronym for Integrated System of Care for Older Persons) in Montreal. When compared against usual care, researchers found that SIPA increased accessibility for health and social home care, reduced hospital alternate level of care beds[36] by 50%, and increased caregiver satisfaction, while increasing community costs about the same amount as institutional costs were reduced. The researchers concluded that this model has the potential to reduce long-term care facility and hospital utilization without increasing cost. [37]

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[32] Who is the Puzzle Maker? *Patient/Caregiver Perspective on Navigating Health Services in Ontario.* The Change Foundation, June 2008.. http://www.changefoundation.ca/docs/ChgFdn_Puzzle_Web.pdf.

[33] MacAdam, Margaret. *Frameworks of Integrated Care for the Elderly: A Systematic Review*. Canadian Policy Research Networks, 2008. http://www.cprn.org/documents/49813_EN.pdf.

[34] Hollander, Marcus J. and Michael J. Prince. "Organizing Healthcare Delivery Systems for Persons with Ongoing Care Needs and Their Families: A Best Practices Framework." *Healthcare Quarterly*. 11.1 (2008): 45-54.

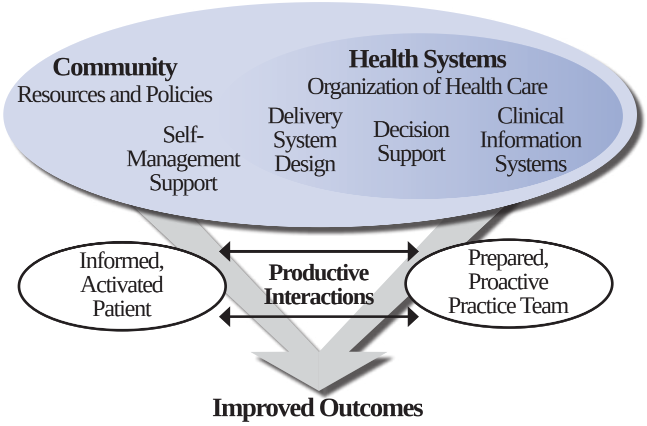
[35] MacAdam, Margaret. *Frameworks of Integrated Care for the Elderly: A Systematic Review*. Canadian Policy Research Networks, 2008. http://www.cprn.org/documents/49813_EN.pdf.

[36] The concept of "alternate level of care" (ALC) is a key hospital utilization and health system performance indicator. An ALC bed represents a bed occupied by a patient whose acute care is complete, but the patient has not been transferred to a more appropriate level of care, whether at home (with or without home care) or in a long-term care facility.

[37] Beland, Francois, Howard Bergman and Paule Lebel, et al. "A System of Integrated Care for Older Persons with Disabilties in Canada: Results from a Randomized Controlled Trial." *Journal of Gerontology.* 61A.4 (2006): 367-373.

Chronic Disease Prevention and Management

The Chronic Care Model



The basic tenet of the chronic disease prevention and management concept is productive interactions between informed active patients and prepared, proactive practice teams. It is patient-centred and designed specifically to improve care for individuals with chronic conditions.

Conventional health care systems were designed to manage short episodes of acute care and simply do not respond well to the challenges of chronic care. In coping with chronic conditions, the acute care model is expensive, fails to get at root causes of illness or disease, lacks continuity and is frustrating and expensive for patients. Therefore, as many jurisdictions struggle to deal with rising incidence of chronic conditions, they are turning to the chronic care model.

Since its development in the early 1990's, the Chronic Care Model [38] (also known as the "chronic disease model" or "Wagner model") has become a policy cornerstone in several countries and is a key policy feature in British Columbia, Alberta, and Ontario.

The Chronic Care Model emphasizes case management, defined roles for all team members, and coordination of care across multiple health providers and health settings. It includes planned visits with health care team members so that patients remain engaged in learning and managing their health/disease. As an integrated model of care, it requires a redesign of care delivery systems for seamless information sharing and case management.

The Chronic Care Model makes better use of our already scarce health human resources as the use of allied health professionals, such as dieticians, nurses, etc., and redistributes resources to the most appropriate and cost-effective providers. As well, the length and number of emergency or acute care occurrences are reduced.

Dementia and the Chronic Care Model

Dementia appears to be highly suitable to the core principles of chronic disease management. With earlier diagnoses, individuals with dementia and their families are in a good position to take on the task of self-management – learning about the disease, risk mitigation opportunities, intervention choices, and coping mechanisms.

In addition to the concept of self-management, roles are identified for family physicians, specialized experts (psychiatrists, geriatricians, neurologists, neuropsychologists), community resources providers (Alzheimer Society staff and volunteers) and family/informal caregivers – each plays an interdependent role, but all are working together. Since the Chronic Care Model uses the patient's unique situation as the starting point and marshals the resources needed to create and implement a care plan, co-morbid conditions would also be identified and incorporated into the team care approach.

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[38] Developed by Ed Wagner at the MacColl Institute for Health Care Improvement.

How We Can Make a Difference

- Recommendations for a National Dementia Strategy

Alzheimer Society

How We Can Make a Difference

Canadians need a pan-Canadian response to the dementia epidemic that improves care at every stage. Other countries have risen to the challenge. Canada must do the same. To date, the record of tackling this challenge in Canada has been uneven: some provinces are without any dementia-specific policies, others have policies that have not been implemented. The few provinces that have made earnest efforts are still largely unprepared for the impending societal impact of dementia.

Clearly, something must be done.

There were more than 480,000 Canadians with dementia in 2008. This number will grow by 32% to 635,000 within 10 years, and by 77% to about 850,000 in a mere 20 years. Canadians are supporting their family members who have dementia through 230,000,000 hours of unpaid caregiving. By 2038, those caregiving hours will balloon to 756,000,000.

The current Economic Burden of $15 billion per year will grow to $153 billion per year (in future values) by 2038, if nothing is done to change the trajectory.

If dementia were stopped now, and all the money that would have been spent on it was put aside, including the income that caregivers forego to look after their family members, by 2038 it would equal $872 billion (in 2008 dollars).

We must take action now. A pan-Canadian response is imperative if we are to meet this critical societal challenge.

Despite the lack of a national plan, Canada has valuable experience on which to build. A pan-Canadian response can and should leverage the experience of provinces that have put measures in place (Ontario), provinces with imaginative new ideas (Quebec), as well as the experience from other jurisdictions facing similar challenges. Canada's national dementia strategy must be developed in partnership with the Alzheimer Society, Canada's research community and federal/provincial/territorial governments.

Improved Care at Every Stage of the Dementia Care Continuum

Before we look at the recommendations, it should be noted that improved care at every stage of dementia is an achievable goal. From risk reduction for healthy individuals to end-of-life care, promising options exist. The chart highlights these options by stage[39] – a useful consideration when aiming for a comprehensive dementia strategy. The options can be assessed in detail using research evidence and the Life at Risk® platform to compare their health and economic impacts, relative to cost of implementation.

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[39] Early in the project, a broad cross-section of experts was asked for advice in defining the dementia experience from beginning to end. The Dementia Care Continuum, used for this discussion and mapped in Appendix D is the product of this discussion

Care Continuum	Policy Option
Healthy individuals & individuals for whom a diagnosis has not been made	• Promote brain health and encourage healthy lifestyle choices for risk reduction; • Make individuals aware of the impact of lifestyle choices on their cognition: healthy individuals as well as individuals with dementia; • Target research into prevention; • Ensure that health professionals are aware of risk factors and protective factors and can use this knowledge as the basis of advice to their patients.
Referral	• Governments need to work with universities and professional associations and colleges to ensure an adequate supply of geriatricians, geriatric psychiatrists, neurologists, neuropsychologists and other professionals necessary for the diagnosis, treatment and care of people with dementia; • Governments must work with universities and professional associations and colleges to ensure minimum competence in the diagnosis and treatment of dementia among primary care professionals.
Diagnosis	• Reduce stigma, so worried individuals will seek help; • Create opportunities for cognitive screening for MCI and dementia diagnosis for all at-risk Canadians (65+); • Ensure Canadians have access to quick, convenient, dignified diagnosis; • Support diagnostic education for primary care providers; • Improve access to specialized geriatric and neurological expertise to primary care providers through collaborative practices; • Ensure that diagnosis is conveyed in a sensitive, helpful way and that it is followed by treatment, care and access to information; • Provide support programs so all individuals newly diagnosed have proactive access to reliable services, including support and education; • Support research investigating the role of biomarkers and advanced imaging in the diagnosis of dementia.
Co-morbid Conditions	• Promote chronic disease management approaches such as multidisciplinary teams, use of registries, protocols, and guidelines for patient/caregiver self-management, so that dementia is identified and treated in the context of the many chronic conditions to which Canadians (65+) are prone; • Promote screening for depression in patients who have dementia, and for their caregivers; • Target research into the interplay between cognitive and other chronic conditions.
Disease Management	• Promote early detection and intervention; • Promote models of care that integrate primary care, hospital services, long-term care services and facilities, and community care; • Support case management, system navigation; • Ensure equitable access to appropriate medication; • Support research into new approaches to treatment and care.

Caregiver Support	- Monitor the health of caregivers; - Provide training and education for caregivers through the Alzheimer Society and/or regional health authorities; - Reduce the financial hardship associated with caregiving; - Create opportunities for respite, peer support.
Long-Term Care	- Ensure that long-term care is funded at a level that permits the availability of staff trained in understanding dementia, skilled in the management of the psychiatric and behavioural symptoms of dementia, and deployed to ensure that residents have days filled with social interaction, physical activity and nutritious meals; - Create national person-centred standards for care facilities; - Research the role of built space in enhancing the lives of residents with dementia.
End-of-Life Care	- Ensure that staff of hospitals, long-term care facilities, and home care and community agencies have access to palliative care support, including the management of pain in verbally non-communicative patients; - Promote advance directives.

Recommendations for Moving Forward

A Canadian dementia strategy must be comprehensive in scope and designed to reduce the impact of dementia on Canadian families, businesses, communities and governments. Jurisdictional dovetailing is key as each element in a program is dependent on the other elements.

While not wanting to limit the potential scope of a national strategy, the following is offered as a starting point of discussion as key features of a Pan-Canadian Response to the Dementia Epidemic.

1. Increasing the investment in dementia research.

2. Providing support for informal caregivers.

3. Emphasizing prevention and early intervention.

4. Building an integrated system of care.

5. Strengthening and supplementing the dementia workforce.

#1 Increase the Investment in Dementia Research

A comprehensive strategy must include an accelerated investment in dementia research. Most of what we know about dementia care and treatment has been learned as a result of recent research investments. Research is paramount to managing the impending dementia epidemic.

Canadian Expertise

Canada has some of the best dementia researchers at work in the world today. The accomplishments of these scientists and others are all the more notable when considering the modest investment made in dementia research. Canadian Institutes for Health Research (CIHR) is currently spending about $21 million per year on dementia research (80% biomedical, 15% clinical) and the Alzheimer Society spends an additional $3 million (approximately half for biomedical and half for "quality of life"). Canada's strengths in Alzheimer's disease research, described by CIHR's CEO Alain Beaudet, includes "genetics, the biological basis of neurodegenerative processes, brain imaging, animal model development, early diagnostic tools, publicly and privately funded clinical trials, and long-term/end-of-life care[40]." It is imperative that we leverage Canada's dementia expertise to the fullest.

International Partnerships

CIHR has recently developed a dementia focus – the International Collaborative Research Strategy for Alzheimer's Disease (ICRSAD), which is becoming a productive international partnership. This should be encouraged and supported with new investment. International partnerships are particularly beneficial for prevention research because partnerships can pool larger study populations. To adequately understand the complex interplay of risk and protective factors, and to understand the role that prevention strategies may play in delaying onset of dementia or in preventing it outright, large cohort studies are essential.

Prevention

Current efforts to find a cure are focused on individuals who have been identified as having dementia. Individuals with sufficient symptoms of dementia to warrant a diagnosis are already experiencing significant brain cell death. Real progress towards conquering dementia will be made when individuals most at risk can be identified and prevention interventions are initiated before symptoms show up. This will entail significant investment in research into biomarkers, advanced diagnostic imaging, as well as the cohort and prevention studies mentioned above.

Psychosocial Research – Improving Quality of Life

Important research is also being done in the psychosocial field, emphasizing the importance of the quality of life for a person with dementia as well as their family caregivers. Quality of life research spans a wide array of topics ranging from: enhancing memory, cognitive abilities, language, and daily living activities; examining the impact of family caregivers; and supporting and enabling individuals with dementia. Further research is focused on quality of life at different stages of the disease and care levels, such as: meeting care needs at the community level, improving quality of care at the institutional level, and shifting to a person-centred care model in long-term care facilities.

In order to maintain Canada's leadership role in dementia research, to reap the commercial benefits of discovery and improve the quality of life of Canadians, Canada needs to dramatically increase funding it makes available to its dementia scientists.

In response to the dementia epidemic Canada must, as a minimum, triple dementia research spending.

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[40] Alain Beaudet, in Global Research in Alzheimer's Disease, Canadian Institutes of Health Research, 2009

#2 Provide Support for Informal Caregivers

Support for caregivers, and clear recognition of the important role they play as care partners, is an essential component of any comprehensive strategy to deal with dementia. Compared with other chronic conditions, the demands of dementia on caregivers are particularly severe. An Ontario Home Care study reported that those providing informal care to persons with dementia are likely to spend 75% more time caregiving than those providing care to individuals with other conditions.[41]

However, caregivers report that they find the work rewarding and that, given the choice, they would want to continue doing it for as long as possible. Caregiving by family members helps keep families intact. As well, family caregivers are better able to recognize changes in symptoms and escalate attention as required.

Nevertheless, the task of caregiving can be unrelenting. When the role becomes unbearable, there are two frequent consequences: (1) the person with dementia moves to a long-term care facility; and (2) the caregiver's health is diminished and the individual requires health services themselves .[42] The job is hard – physically, emotionally, and financially. Caregiver stress has been shown to be a significant predictor of early institutionalization for the person with dementia. [43]

There is also growing international recognition that informal caregivers will be in short supply in the near future. [44] The shift in population growth to the very elderly means that spouses will be less able to perform caregiving duties. Younger family members will be less available as women's participation in the workforce continues to grow, and families are both smaller and more likely to live geographically apart. Finally, changing family norms are resulting in reluctance among younger people to look after frail elderly family members.

As a consequence, it is incumbent on governments to demonstrate that the work of caregivers is valued and that society makes it easier to continue providing care – through caregiver information and training, meaningful respite care and other programs that can support them in their roles as care partners, including financial support.

The pan-Canadian response to the dementia epidemic must provide meaningful support to caregivers.

#3 Emphasize Prevention & Early Intervention

The scenario analysis demonstrates that a central feature of a pan-Canadian response to the dementia epidemic needs to be a focus on maintenance of brain health, prevention of dementia, delay of onset and early intervention. This is an area of exciting promise as there is new research evidence into the role of risk factors and protective factors. Epidemiological studies and animal models have demonstrated a link between a number of factors and reduced risk for dementia.

Rising Tide examined the impact of two prevention strategies in the Scenario Analysis: one that increased physical exercise of healthy Canadians (65+); the other a hypothetical prevention program that delayed dementia onset by 2 years. Both were shown to have significant impacts.

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[41] A profile of Ontario's Home Care clients with Alzheimer's Disease or Other Dementias. University of Waterloo, Ideas for Health, and the Alzheimer Society of Ontario.. 29 Sept 2008. http://alzheimerontario.org/local/files/Web%20site/Public%20Policy/Profile-of- Home-Care-Clients-April-2007.pdf

[42] World Alzheimer Report, Alzheimer Disease International, 2009.

[43] Fisher, L and M.A. Lieberman. "A Longitudinal Study of Predictors of Nursing Home Placement for Patients with Dementia: The Contribution of Family Characteristics". Gerontologist. 39.6 (1999): 677-686.

[44] Moise, P., Schwarzinger, M., Um, M., and the Dementia Experts' Group. "Dementia Care in Nine OECD Countries: A Comparative Analysis". OECD Health Working Papers. OECD, 2004.

It isn't known whether the 2-year delay in onset would come from regular use of statins, anti-inflammatory agents, exercise or improvements in diet. What is clear is that the case for doing further research and applying the risk reduction knowledge already available is beyond a doubt.

In addition, greater emphasis on early intervention is needed. Undetected dementia places older adults at risk for delirium, motor vehicle accidents, medication errors, and financial difficulties.[45] Early detection also offers opportunities for early treatment, more self-management, greater education and support, all of which can improve quality of life for those directly involved while reducing the heavy societal costs associated with institutionalization.

A pan-Canadian response to the dementia epidemic must focus on maintenance of brain health, prevention of dementia, delay of onset and early intervention.

#4 Build an Integrated System of Care

As a leading health policy concept specifically suited to the impending dementia epidemic, Canada's National Dementia Strategy must establish integrated models of care as a priority across all jurisdictions. Only then will there be real improvement in care for Canadians who need complex arrays of specialized medical, community and social services, including individuals with dementia.

Health care service delivery systems must be redesigned to formally align primary care and acute care with a network of community support services. Integrative models of care, as a focus of our national strategy, would facilitate the use of research to reduce or delay incidence, to help caregivers perform their role, and to organize services in the community in order to reduce long-term care facility utilization.

Governments across Canada should seed innovation in integrated systems of community care, such as the SIPA initiative mentioned earlier. Hallmarks of a national integrated system of care strategy would include:

- consistency with the care coordination best practices described by Hollander and Prince(2001;2008);
- clearly defined community-specific relationships among home care, community services including the Alzheimer Society, hospital services, primary care, residential care, hospice and specialized geriatric services, with well-defined roles for each, yet with common philosophies of care, protocols, and guidelines;
- case management to ensure that the various integrated pieces are well-coordinated from the individual's perspective;
- a focus on prevention;
- facilitating early intervention;
- building a chronic disease prevention and management framework;
- mandating dementia-friendly residential care.

The pan-Canadian dementia strategy must foster greater integration of care and increased use of accepted frameworks or "best practices" in chronic disease prevention and management, community support and community care coordination.

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[45] Sternberg, S.A., Wolfson, C., & Baumgarten, M. "Undetected Dementia in Community-Dwelling Older Individuals: The Canadian Study of Health and Aging". Journal of the American Geriatrics Society. Vol. 48 (2000): 1430-1434.

#5 Strengthen and Supplement the Dementia Workforce

Canada must ensure basic dementia skills among primary care providers, emergency department staff, care facility nurses, assisted living personal support workers, and all others employed in care settings that are likely to serve individuals with dementia. Individuals concerned about their brain health are sometimes hesitant to seek help. When they do, it is imperative that health professionals can recognize the warning signs, make a diagnosis and provide treatment and support.

These care providers need to be supported with the expertise of geriatricians, neurologists, psychiatrists, nurses, and other professionals with specialized knowledge of dementia and its treatment. Government will need to work with universities and the professional colleges that regulate these professionals to improve the supply of these scarce skills.

In the meantime, strategies that will make the best use of our limited specialized resources through a collaborative team approach need to be employed. Nurses, pharmacists and other health professionals are both expanding their scopes of practice and developing interdisciplinary team skills. The voluntary sector is already providing useful knowledge and supports to Canadians living with dementia and their caregivers. These initiatives should be fostered.

Standardized evidence-driven care plans and protocols for dementia prevention, diagnosis, disease management and end-of-life care, as a common basis for training entire care teams, are needed – from primary care to specialized care, from patient self-management to caregiver support, for the formal health system to the voluntary sector, and across all health disciplines.

Canada needs to ensure that the dementia epidemic is met with an appropriate supply of dementia specialists and well-trained generalists working collaboratively. These scarce resources must be supplemented by a well-resourced voluntary sector, with a nationally available support program as a priority.

Conclusion

Rising Tide, through the analysis of available data, has provided Canada with important information about the impact of dementia on Canadian society and what can be done to change the trajectory of this impact – whether measured in individuals acquiring the disease, the hours spent by their caregivers, the cost of providing health services or the economic impact of interrupting a career to look after somebody at home.

It is the fervent hope of the Alzheimer Society that these ideas will foster further discussion and analysis, and find their way into policies that create real change. This study and report can also serve as a prototype for how other neurological conditions and chronic conditions might be addressed.

The Government of Canada has demonstrated sensitivity to the issues raised in this report by (1) funding in part the study that serves as the foundation for this report; and (2) committing in June 2009, $15 million over four years to fund a population study to help Canada better understand neurological conditions and their impact on Canada. The latter is a unique partnership between the government and Neurological Health Charities of Canada (NHCC), including the Alzheimer Society, which will help us learn about the relationships among the neurological conditions. It is a step forward.

However, it is clear from this current analysis that Canada must take immediate steps to both prevent or delay onset of dementia, and better serve Canadians who develop one kind of dementia or another. Accordingly, Canadians are urged to prevail on the federal government and their respective provincial or territorial governments to develop a pan-Canadian response to the dementia epidemic, the hallmark of the response to include:

1. An accelerated investment into all areas of dementia research including Biomedical, Clinical, Quality of Life, Health Services and Knowledge Translation;
2. A clear recognition of the important role played by informal caregivers – by providing information and education, support in their roles as care partners including financial support;
3. An increased recognition of the importance of prevention and early intervention for these diseases, for both health care professionals as well as the general public;
4. Greater integration of care and increased use of accepted frameworks or "best practices" in chronic disease prevention and management, community support and community care coordination;
5. A strengthening of Canada's dementia workforce by:
    a. increasing the availability of specialists including geriatricians, neurologists, psychiatrists and advanced practice nurses with specialized knowledge of dementia;
    b. improving the diagnostic and treatment capabilities of all frontline professionals;
    c. making the best use of general and specialized resources through inter-professional collaboration;
    d. supporting patient self-management and caregiver participation in care coordination; and
    e. leveraging the capabilities of the voluntary sector through investment and training.

Now that we have a clear sense of the scale and impact of the dementia epidemic in Canada, inaction is not an option. Our economy, our health care system, the lives of millions of Canadians will be affected.

We must put our minds to it and implement the recommendations described above. Canada *can* meet the challenge of the dementia epidemic. **The time to act is now.**

Appendix A: Adapting *Life at Risk®* for Rising Tide

Rising Tide used RiskAnalytica's Life at Risk® simulation platform to model the impact of dementia on the Canadian population for the next 30 years: 2008-2038. The platform is customizable to suit the needs of the particular problem at hand, in this case, forecasting the health and economic impacts of dementia, using data imported from primary and/or secondary sources.

Within the Life at Risk® platform, the possible future health states of a population along with the associated economic burden are simulated by incorporating the relationships between different populations, the natural history of the disease, socio-economic risk factors, epidemiology, and economic impacts.

- Within the model, individuals are divided into independent population groups called cells, based on their individual characteristics (age, gender, health state, etc.). Individuals move from one cell to another according to specified rules based upon epidemiological research findings. The model generates ***incidence*** (new dementia cases in a year) and ***prevalence*** (number of individuals living with dementia) data over time as individuals move from cell to cell.
- The population's movement is further modeled through various disease states, providing a profile of ***health care utilization*** over time by individuals with dementia. Individuals with dementia are grouped according to the type of care they receive, whether as residents in care facilities (**Long Term Care** or LTC), at home receiving **Community Care** (CC) or at home but receiving ***no formal care***.
- The economic model considers the costs associated with each disease state and care type. It also considers the effects of dementia with respect to workplace productivity both for employed individuals with dementia and for their unpaid informal caregivers[46]. The decrease in labour hours and the resultant decrease in production are translated and added into the ***Total Economic Burden***.

The quality of demographic, epidemiological and treatment/care data are critical drivers of quality in the model's results, and appropriate selection of data and rules at the outset is paramount. Accordingly, a literature review and data scan was completed to identify the state of research and knowledge in the fields of dementia epidemiology, prevention, treatment, and care management. Data was collected across a wide spectrum of indicators: incidence, prevalence, mortality, survival, life expectancy, risk factors, direct and indirect health costs, and hospital and care facility utilization. A list of sources is summarized in Appendix B.

Subject matter experts in Dementia, Epidemiology and Health Economics were consulted widely to review the data collected in the environmental scan. Several teleconferences were held with subject experts from the Universities of Toronto, Ottawa, McMaster, McGill, and Waterloo to review preliminary findings, to identify alternative data sources, and to comment on the epidemiological implications of various (national and international) data sources within the Canadian context. Advice gained through these consultations led to the identification of evidence-based empirical models and data for use by the platform that was acceptable to subject experts. A summary of Key Life at Risk® data and assumptions are included in Appendix C.

A panel of 30 of Canada's leading dementia experts – epidemiologists, neurologists, geriatric psychiatrists, geriatricians, psychologists, nurses and social workers, Alzheimer Society professional staff, long term care leaders, and other leading experts – came together to develop a ***Dementia Continuum Map***, included in Appendix D, which depicts the range of dementia experiences, including the identification of risk factors, screening, early detection, treatment, disease management, counselling, care and caregiver support. The Map was developed in order to (1) clarify the paths of individuals through the dementia disease process, (2) identify the drivers of health and economic burden and thus to aid in defining data requirements for the Model, and (3) identify leverage points in the dementia disease management process which may become foci for improvement and hence candidates for policy and intervention development.

Using the map, the panel identified a number of key intervention opportunities to inform *Rising Tide's* subsequent selection of intervention scenarios for simulation. A list of subject matter experts consulted for Data & Model Validation and Dementia Continuum Mapping can be found at the beginning of this paper.

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[46] The term 'informal caregiver' is used in this report to refer to those (usually family members) who support individuals with dementia, but who are not providing care in the formal capacity of health professionals.

Appendix B: Sources

1. Alzheimer's Australia (2005). Dementia estimates and projections: Australian states and territories. Reported by Access Economics PTY Limited for Alzheimer's Australia.

2. Alzheimer's Disease Facts and Figures, 2007. Alzheimer's Association.

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Appendix C: Key Life at Risk® Data and Assumptions[47]

Demographic Data

- All population demographics were obtained from Statistics Canada's CANSIM database.

Epidemiological Data

- Health states of the population were generated using the demographic model by assuming static historical incidence, mortality rates and prevalence proportions.
- Dementia prevalence and the prevalence of major subtypes (Alzheimer's disease and Vascular Dementia) was estimated from a combination of data from the 1991 Canadian Study of Health and Aging (CSHA) and European data from the EURODEM studies provided in Berr et al. (2005).
- Dementia incidence rates and the rates of major subtypes (Alzheimer's disease and Vascular Dementia) were estimated from the 1996 CSHA follow-up study.
- Mortality was estimated using data from the CSHA (Wolfson et al. 2001)

Health Care Utilization and Costs

- The proportions of individuals residing in long-term care, as well as those residing in their home and receiving care in their communities, in Ontario, are reported in Tranmer *et al.* (2003). The historical proportion of those residing in long-term care and community care with dementia was assumed to apply to the future dementia prevalence simulations.
- A further division of dementia patients into those with co-morbid conditions, as well as those suffering from dementia alone, was adopted from Wodchis *et al.* (2008). The study indicated that in Ontario, for the year 2007/08, nearly 18% of residents admitted to long-term care directly following an acute care hospitalization had Alzheimer's disease or a related dementia as the principle diagnosis on their acute care discharge record. In this context, the model assumed that 18% of all dementia patients residing in long-term care were admitted into long-term care with dementia as their primary diagnosis. Wodchis *et al.* (2008) further estimated that the cost per resident per day for individuals living with dementia is approximately 1.06 times the average cost of long-term care. The same assumption used for prevalence in long-term care due to dementia (18%) is assumed for Community Care and No Formal Care.
- Statistics Canada Table 107-5509119 provides the number of long-term care beds, of which 64.3% were occupied by individuals with dementia in 2000.
- Long-term care bed utilization is constrained by the supply of beds.
- The supply of beds is determined from a log function of dementia prevalence and long-term care beds as determined from history (1991 to 2006).
- The demand for beds is determined by holding constant the proportions of individuals with dementia in long-term care by age and gender from Tranmer *et al.* (2003).
- The actual number of individuals with dementia occupying a bed is determined by holding the dementia occupancy rate of 64.3% for long-term care beds constant.
- As of 2000, there has been a difference between the demand for beds and the supply of beds for individuals with dementia.
- It is assumed that individuals with dementia in long-term care in Ontario are representative of the dementia population in Canada.

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[47] Smetanin, P., Kobak, P.,, Briante, C., Stiff, D., Sherman, G., and Ahmad, S. Rising Tide: the Impact of Dementia in Canada 2008 to 2038, available at www.alzheimer.ca <http://www.alzheimer.ca/>

Economic Model Assumptions

- Disability (in the economic model) is assumed to correspond to one's reduction in productivity in the workplace. The reduction is computed with respect to the production capacity of a healthy (no disability due to any disease) individual within the workplace.
- The disability associated with dementia is computed among the employed population only.
- The disability associated with dementia is computed from Statistics Canada Labour Force Survey and the Statistics Canada Participation and Activity Limitation Survey (PALS 2001) disability study.
- Unpaid caregivers exhibit the same employment rates as the general Canadian population.
- The number of hours which an employed unpaid caregiver devotes for the provision of care to an individual with dementia is directly proportional to the amount of time lost within their workplace.
- The amount of time lost at work is proportional to the loss of productivity. As a result, the amount of time which is spent on caregiving is indistinguishable from an economic disability.
- Costs are calculated within the economic model in future dollars. However, for analysis and comparison purposes, cumulative costs are presented as present values adjusted to 2008 dollars at ten year intervals.

Direct Health Costs Due to Dementia

- It is assumed that the costs of long-term care for individuals with dementia is 1.06 times the average cost of long-term care per Wodchis *et al*. (2008).
- It is assumed that there are no direct health care costs for individuals living with dementia that are not using formal care services.
- These costs were simulated, adjusting for inflation over time.

Direct Health Costs Due to Co-Morbid Dementia

- The incremental long-term care direct health care costs due to dementia as a co-morbid condition is 6%.
- The incremental community care direct health care costs due to dementia as a co-morbid condition is of 52.9% as taken from Shapiro and Tate (1997), and using incremental average costs of home care for dementia.
- It is assumed that there are no direct health care costs for individuals living with dementia that are not using formal care services.

Out-of-Pocket Expenses for Individuals with Dementia Not Receiving Formal Care

Not receiving formal care for dementia

- It is assumed that this is equal to out-of-pocket expenses when in community care due to dementia.

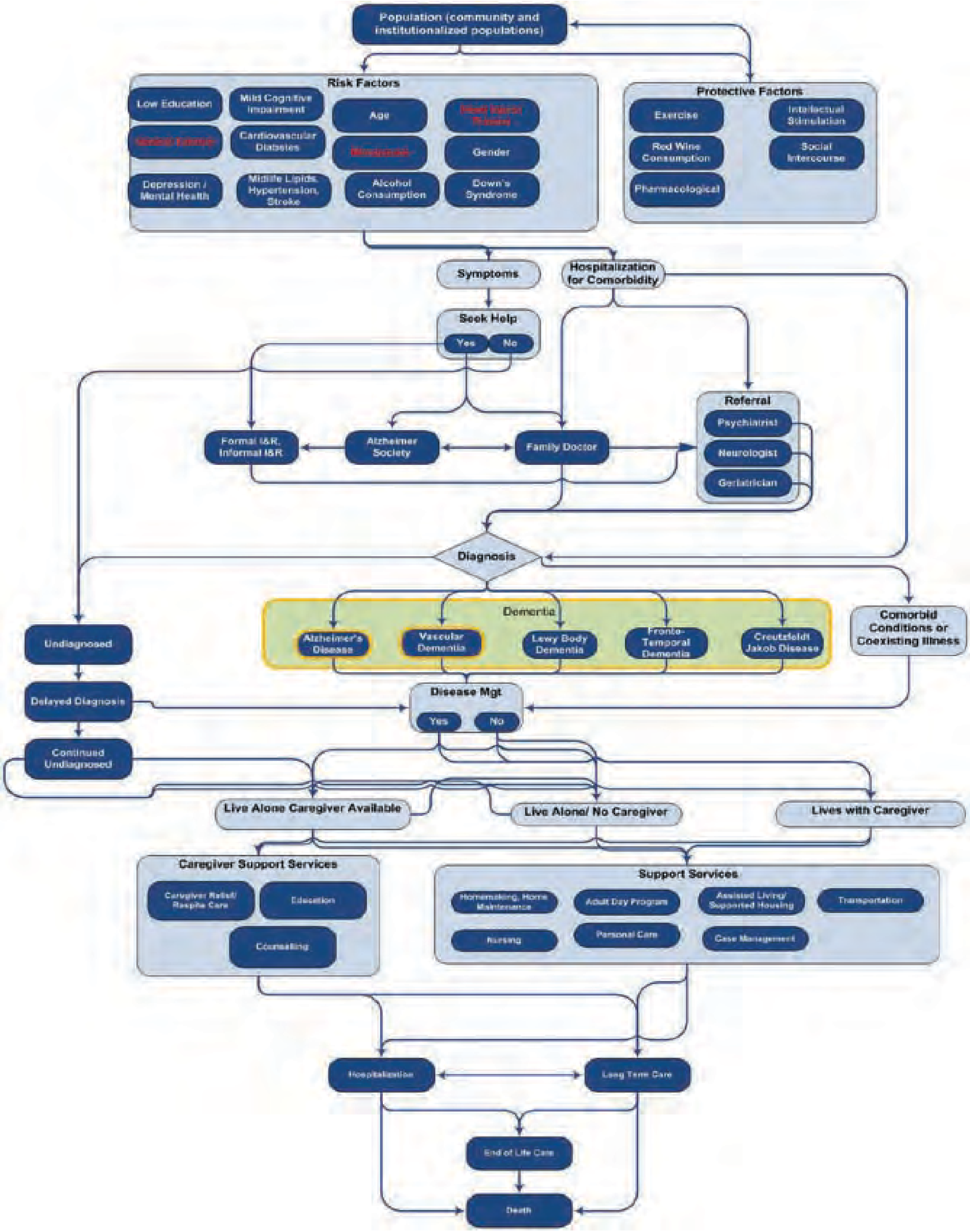
Not receiving formal care for co-morbid dementia

- It is assumed that this is equal to out-of-pocket expenses when in community care due to co-morbid dementia.

Informal Caregivers

Informal caregiver hours and costs across each care type/setting were calculated as costs directly due to dementia and costs due to dementia as a co-morbid condition.

Appendix D: Dementia Continuum Map



Alzheimer Society

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