

Rising Tide: The Impact of Dementia on Canadian Society

Executive Summary

A study commissioned by
the Alzheimer Society

Now
Within a Generation

500,000

1,100,000

Canadians with Alzheimer's disease or a related dementia

Now
Within a Generation

\$15 billion

\$153 billion

Cost to Canadians for dementia care

Now
Within a Generation

231 million hours

756 million hours

The time Canadians will be providing in informal care

Foreword

Alzheimer's disease and related dementias slowly destroy memory and reasoning, erode independence and, eventually, take life. Currently, there is no cure.

As the national voice for people living with dementia and their caregivers, the Alzheimer Society felt it was critical to gain a better understanding of the impact of dementia on Canadians. We therefore commissioned a two-year intensive project, *Rising Tide: The Impact of Dementia on Canadian Society*. The results point to an urgent need for immediate action by all Canadians.

The *Rising Tide* study tells us that if we do nothing, the number of Canadians with dementia in 2038 will be twice that of 2008. Over this 30-year period, the cumulative cost of dementia is projected to be \$872 billion. It tells us that if we do nothing, dementia will have a crippling effect on Canadian families, our health care system and economy.

Maintaining the status quo is not an option. We must take action today.

Recognizing the urgent need to turn the tide of dementia, this new study outlines a series of potential interventions that could help minimize the impact of these diseases. Four case simulations demonstrate how preventing or delaying dementia and supporting informal caregivers can significantly reduce the associated social and economic costs. Potential solutions all require further research to determine which are the most effective and economical interventions, but *Rising Tide* provides a strong direction.

The study also compares current policies and strategies from various regions in Canada and from around the globe, and, based on these best practices, *Rising Tide* makes a series of recommendations. These may not be the definitive answer, but can spur discussions on care, support and research needed in light of the escalating number of Canadians living with dementia.

That is the purpose of *Rising Tide*. It is the beginning of our thinking and a source of information to fuel our work. Other nations have taken proactive measures to mitigate the impact of dementia. We hope this study will help incite and guide our own federal and provincial governments in developing policies to improve the lives of people living with dementia, while ensuring the sustainability of our health care system and economy.

This study has also helped uncover new research leads. We have been able to identify gaps in primary research such as dementia prevalence in persons under the age of 65. We know that dementia affects more women than men, but don't know why. For every question the study has answered, a new one has arisen to challenge us.

We look forward to furthering this research. As a member of the Neurological Health Charities of Canada (NHCC), the Alzheimer Society is also intent on working with other neurological organizations to engage government in the issues that affect all of our populations. Together, we will strive for a strategy that can improve health care and social supports for the millions of Canadians facing these diseases.

Richard Nakoneczny

Volunteer President

Alzheimer Society of Canada

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.

Rising Tide: The Impact of Dementia on Canadian Society

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Rising Tide:

The Impact of Dementia on Canadian Society

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This document is a summary of the Rising Tide: Impact of Dementia on Canadian Society, which was based on a study conducted by RiskAnalytica, available at www.alzheimer.ca. The Rising Tide project was made possible with contributions from the Canadian Institutes of Health Research, the Public Health Agency of Canada, Health Canada, Pfizer Canada and Rx&D.

Rising Tide: The Impact of Dementia in Canada

Canada is facing a dementia epidemic and needs to take action now. Approximately 500,000 Canadians have dementia today. It is the most significant cause of disability among Canadians over the age of 65 and it already costs Canadian society many billions of dollars each year. Forecasts show that within 20 years, worldwide prevalence will increase two-fold¹. Canada too, can expect a several-fold increase in dementia in the coming decades.

The Alzheimer Society is Canada's leading voice for people with Alzheimer's disease or related dementias. We know from our involvement with people with dementia that the meagre and uneven policy response to this disease leaves an enormous gap in public health in all jurisdictions across Canada.

For the past decade, dementia and its impact on national economies have been the subject of increasing focus around the globe. The governments of many other countries have taken concrete steps to study dementia and its consequences, and many have made dementia a national priority. Canada has yet to take these steps. Canada requires a national plan, built on our growing understanding of the disease, in order to quantify, prepare for, and reduce the impact of dementia on Canadian society.

The Alzheimer Society has begun work toward such a plan. In 2008, the Alzheimer Society secured public and private funds to commission the study *Rising Tide: The Impact of Dementia on Canadian Society*.

The goal of the *Rising Tide* Project is to generate a solid, evidence-based foundation upon which policymakers can build a comprehensive national plan.

This national plan would prepare for and mitigate the burden of dementia on Canadian society and direct health expenditures towards activities that have the greatest potential to maximize quality of life, support individuals and families, make best use of our scarce health human resources, and reduce institutionalization and overall health costs.

This paper summarizes the findings of the project. It describes dementia and its current and future societal impact. Specifically, it:

- describes how many people will have dementia in Canada each year over the next thirty years and projects the economic cost of these diseases for individuals and society – if nothing new is done about it;
- shows how that picture can change. The four research-based scenarios presented detail the number of cases that can be prevented and the money that can be saved if we are able to prevent dementia, delay its onset and/or better support caregivers in their role;
- describes actions taken to date, both in Canada and abroad, surveys emerging health policy options, and proposes high-priority recommendations for a pan-Canadian response to the dementia epidemic.

“The predicted surge in dementia cases will certainly overwhelm Canada’s health care system unless specific and targeted action is taken. Canada must act now.”

Richard Nakoneczny
Volunteer President
Alzheimer Society of Canada

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.

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

A Brief Introduction to 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, specifically Alzheimer's disease, Vascular Dementia, and other dementias such as Frontotemporal Dementia, Lewy body Dementia and Creutzfeldt-Jakob Disease.

Symptoms commonly include loss of short-term and long-term memory, judgment and reasoning, as well as 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.

Alzheimer's Disease

Alzheimer's disease, the most common form of dementia (approximately 63 per cent), is a progressive, degenerative and fatal brain disease. In this disease, cell to cell connections in the brain are lost and brain cells eventually die. It is *not* a normal part of aging.

Related Dementias

Vascular Dementia is the second most common form of dementia. In fact, many people with Alzheimer's disease also have Vascular Dementia, which is caused by problems in the supply of blood to the brain. Other dementias include Frontotemporal Dementia (including Pick's Disease), Lewy body Dementia, Creutzfeldt-Jakob Disease, and dementias that occur with chronic neurodegenerative conditions such as Parkinson's disease and Huntington's disease.

The Broad Impact of Dementia

Individuals with dementia² are not the only people affected by the disease. Dementia also 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 the person's family and caregivers³, as well as on health providers, the health care system, the business community, and society in general.

Risk Factors & Healthy Brain Promotion

Risk factors contribute to the likelihood of getting a disease. They include the characteristics of a person, their lifestyle and their environment. Many of the risk factors for Alzheimer's disease, such as high cholesterol levels, high blood pressure, and diabetes, are also risk factors for other diseases, especially cardiac diseases. While some risk factors can be changed, others such as genetics and aging cannot.

The accepted view today is that promoting brain health through lifestyle choices is the most effective way of reducing the risk of Alzheimer's disease and slowing down its progression. Adopting a lifestyle that ignores risk factors does not mean, however, that a person will develop the disease, but it does increase the odds of getting it.

Care & Treatment

Appropriate care and treatment for people with dementia can vary greatly and are dependent on the stage of the disease, as well as how it affects each individual at any given point in time. Available drug therapies can mitigate symptoms, but there is currently no medical treatment that can stop or reverse the disease progression, nor is there a cure or a vaccine. Education and the development of stage-specific coping skills, both for the person with dementia and their caregivers, are important aspects of effective care plans.

In Canada, services related to dementia care and available treatments are unevenly distributed and frequently lack coordination. Even where available, such treatments are often not standardized and there is little continuity of care. Health professionals receive limited training in dementia prevention, identification and diagnosis, and how to provide treatment according to "best practices."

²This report generally refers to people with Alzheimer's disease or a related 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 name is used. People living in long-term care facilities are generally referred to as "residents"

³Dementia – Etiology and Epidemiology, A Systematic Review. The Swedish Council on Technology Assessment in Health Care. Vol. 1, June 2008

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*

Why Canada Must Act

Rising Tide presents a comprehensive forecast of the population health and economic impact of dementia, specific to Canada, for each of the next 30 years. These forecasts clearly lay out the need for a national plan.

Development of the Base Case: The Canadian Dementia Profile

The Alzheimer Society commissioned RiskAnalytica, a science-based research firm with expertise in population-based health analysis, to quantify the impact of dementia on Canadian society⁴. Using the latest dementia and health economic research and working closely with the Alzheimer Society and other experts, RiskAnalytica was able to run sophisticated simulations of the future impact of dementia.

The resulting profile forecasts, for each of the next 30 years, the number of expected:

- new dementia cases (Incidence),
- deaths (Mortality),
- people living with dementia (Prevalence),
- the Economic Burden attributable to dementia.

The forecasts assume no change in policy, no significant new scientific discovery and no new interventions, treatments or changes in care delivery.

The study categorized individuals living with dementia by type and location of care that evidence suggests they will be receiving, and determined expected constraints in long-term care capacity. Based on this, a profile of care delivery was developed, a picture of how and where care will be provided (Health Care Utilization).

Finally, by applying assumptions for direct, indirect and opportunity costs, the total cost associated with dementia (economic burden) was forecasted 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 as present values in 2008 dollars.

These projections establish the Dementia Base Case – a forecast of the population health and economic impact of dementia on Canadian society over the next 30 years.

Incidence: Number of New Cases of Dementia per year

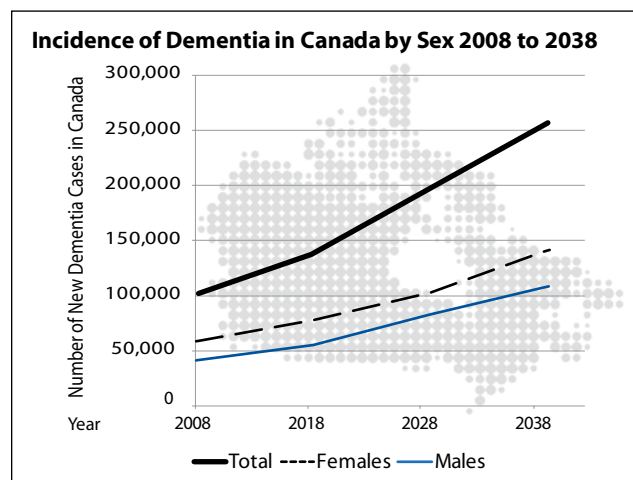
The number of new cases of dementia in 2038 among Canadians (65+), is expected to be 2.5 times that for 2008.

Projected Incidence:

2008: **103,700** new dementia cases per year
or one new case every **5 minutes**

2038: **257,800** new dementia cases per year
or one new case every **2 minutes**

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



⁴ RiskAnalytica's Life at Risk® simulation platform was customized for the *Rising Tide* study based on the latest dementia and health economic research, validated for epidemiological and economic aspects by subject matter experts and checked for data, logic and results. The simulation platform was then run to establish the Base Case.

Prevalence: Number of People with Dementia

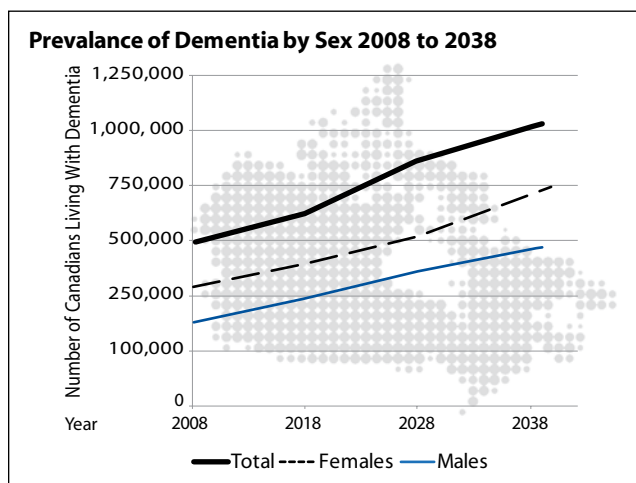
The number of Canadians (of all ages) with dementia is expected to increase to 2.3 times the current level by 2038.

Projected Prevalence:

2008: 480,600 people,
or 1.5% of the Canadian population

2038: 1,125,200 people,
or 2.8% of the Canadian population

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



Health Care Utilization

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 Toward Home/Community-Based Care

The demand for long-term care (LTC) beds is based on the projected prevalence and severity of dementia. However, availability of long-term care beds is constrained. Based

on historical growth trends, the total number of long-term care beds in Canada is forecasted to 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. This shortfall is expected to be offset by a greater demand for community-based services.

The increase in Canadians (65+) living at home with dementia is expected to jump from 55% to 62%. This translates into an additional 510,000 people in this type of care by year 2038. Most will seek some type of community care, resulting in a significant shift from long-term care toward home/community-based care.

The addition of more than half a million people remaining within community and home care settings will substantially increase the burden on community-based services and caregivers.

An Increase in Informal Care

Informal care⁵ will also increase as care shifts away from care facilities. In 2008, Canadians spent approximately 231 million hours on informal care. This number is expected to more than triple by 2038, reaching 756 million hours.

Informal care delivered within community settings through community care services represents the largest proportion of informal care, and will grow from 60% to 69% of informal care by 2038.

Hours of Informal Care per Year by Type of Care 2008-2038

Year	Hours of Informal Care for Long-Term Care (LTC) , Community Care (CC), No Care			
	Informal Caregiver Hours in LTC	Informal Caregiver Hours in CC	Informal Caregiver 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

⁵ The term "informal caregiving" is used in health services research simply 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.

Why Canada Must Act

Economic Burden of Dementia

The expected Total Economic Burden of dementia is made up of direct health costs⁶, opportunity costs⁷ (foregone wages) of unpaid informal caregivers, and indirect costs⁸. The Monetary Economic Burden reflects only actual monetary outlays and hence ignores opportunity costs.

Annual Total Economic Burden

The annual Total Economic Burden is expected to increase substantially from approximately \$15 billion in 2008 to \$153 billion by the year 2038 (in future dollars).

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

Total Economic Burden =

Direct Health Costs
+ *Opportunity Costs of Informal Caregivers*
+ *Indirect Costs*

Monetary Economic Burden =

Direct Health Costs
+ *Indirect Costs*

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

Year	Annual 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

⁶ 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 health system include the cost of prescription medication, long-term care staff costs and physician and hospital costs. Direct health costs outside the health care system include the cost of over-the-counter medication, long-term care accommodation costs and out-of-pocket expenses.

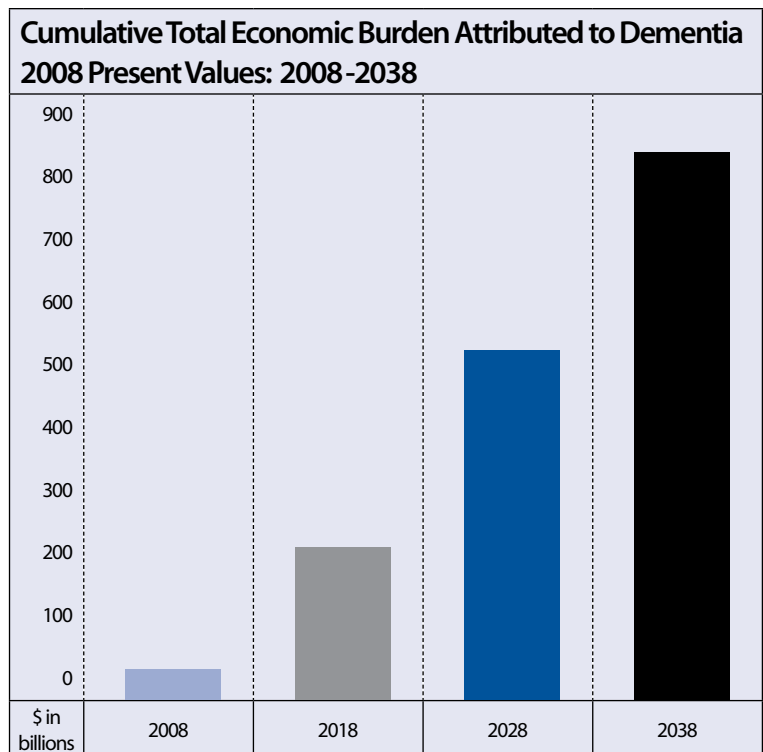
⁷ Opportunity costs of Informal Caregivers are the wages that could have been earned by informal caregivers, were they able to participate in the labour force.

⁸ Indirect costs are costs that have no direct connection to dementia, but are a consequence of it. They include the lost wages and corporate profits that result from the reduction in labour productivity for both the individual with dementia and the provider of informal care.

Cumulative Total Economic Burden

The cumulative Total Economic Burden is expected to reach approximately \$872 billion over the 30-year simulation period (expressed in 2008 dollars).

- The Monetary Economic 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.



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

Years 2008 through	Cumulative Total Economic Burden Attributed to 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

Why Canada Must Act

Dementia Base Case Summary

Since age is a primary and unchangeable risk factor for dementia, the growth of the dementia problem in Canada will accelerate as the population ages. The first of the boomers will enter their senior years (65+) in 2011, at which time the aging of the Canadian population will accelerate. This will place a tremendous strain on Canada's capacity to provide essential health care services and community care, as well as patient and caregiver support services, potentially overwhelming the country's health care system.

Without intervention:

- By 2038, the rate of dementia incidence for 65+ is expected to increase to 250,000 new cases per year, 2.5 times the current level (2008).
- By 2038, 1.1 million Canadians are expected to have dementia, approximately 2.8% of all Canadians.
- In the next 30 years, the excess demand for long-term care required by dementia patients will increase over 10-times the current (2008 values) demand. This excess demand is expected to cause more dementia patients with higher severity levels and requiring more complex care to rely on community-based care and informal care support.
- Over the next 30 years, dementia is expected to cost society over \$872 billion dollars (2008 present values) in direct health costs, unpaid caregiver opportunity costs and indirect costs associated with the provision of unpaid care.

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



What Can Be done

The first phase of *Rising Tide* established a Dementia Base Case: what would happen if the dementia epidemic proceeded unimpeded by any major change in policy. The second phase, or Scenario Analysis phase⁹, examined how targeted interventions could reduce the burden of dementia on Canadian society. It also validated the usefulness of the simulation platform as an assessment tool.

Four intervention scenarios were generated, each scenario representing potential dementia prevention and patient/caregiver support programs as identified and defined by the Alzheimer Society and its panel of dementia subject matter experts. These four scenarios were selected not only for the anticipated health and economic value of the interventions, but also based on the availability of evidence to support the simulations.

These scenarios are not meant to be the final word on what must be done, but are meant to illustrate how, using evidence or hypothesis, policy options can be evaluated and compared in a very practical way.

Intervention 1: Prevention – Increase in Physical Activity

The first prevention scenario examines the impact of an intervention that broadly applies evidence that increased physical activity can reduce dementia incidence. The intervention focuses on increasing physical activity by 50% for all Canadians without dementia, over the age of 65, who are already moderately to highly active. This intervention would reduce the number of people diagnosed with dementia, resulting in a reduction in the pressure on long-term care facilities, community care services and informal caregivers. This, in turn, 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.

Intervention 2: Prevention – A Program to Delay Dementia Onset

The second intervention scenario examines the impact of a hypothetical prevention program that would delay the onset of dementia by approximately two years. The prevention program targets the entire dementia-free adult Canadian population and would combine a variety of promising, evidence-based strategies such as following a healthy diet and lifestyle. Delaying the onset of dementia by two years would result in fewer people living with dementia and would significantly reduce the pressures placed on health care resources.

Intervention 3: Support – Caregiver Development and Support Program

The third scenario examines the impact of an informal caregiver skill-building and support program. In this scenario, the intervention is applied to all informal caregivers and individuals with dementia receiving care within the model. Such a program could reduce the amount of caregiving time provided by informal caregivers, and hence the health and economic burden placed on them. As well, it could delay admission for the person with dementia into a long-term care facility.

Intervention 4: Support – System Navigator

The fourth scenario examines the impact of assigning a system navigator (case manager) to each newly diagnosed dementia patient to provide care coordination to people with dementia and caregiver support to informal caregivers. In this scenario, the intervention is targeted to all people with dementia and their informal caregivers. It is anticipated that providing a system navigator would both reduce caregiving time and delay admission into a long-term care facility, thereby lessening the pressure placed on long-term care resources and producing significant savings in health costs.

⁹ In the Scenario Analysis phase, the RiskAnalytica's Life at Risk® platform was used to assess the results of targeted interventions and to validate the platform as an assessment tool. Subject matter experts worked to identify relevant literature and data to drive adjustments to the Life at Risk® model for each intervention.

Intervention Value Comparisons

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 in Total Economic Burden of \$219 billion, along with 410,000 fewer prevalent cases, i.e. a 36% reduction from the Dementia Base Case;
- helping caregivers develop coping skills and build competencies in their caregiving roles would yield a 30-year value of \$63 billion;
- providing system navigation support for people with dementia and their caregiver would yield a 30-year value of \$114 billion;
- the Life at Risk® platform provides a useful assessment and comparison tool for conducting evidence-based strategic options and policy analysis.

Impact of Intervention 1 and 2 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%

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

Years 2008 through	Intervention 1 Prevention: Increased Physical Activity		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: Intervention 3 and 4 in the chart above are based on two scenarios that were simulated independently. Showing their combined benefit assumes a zero correlation between their effects.

What Can Be done

Each of the four scenarios delivers considerable value.

Prevention strategies, such as increasing physical activity levels or a program to delay disease onset, were shown to produce significant benefits from a population health perspective. These scenarios were estimated to significantly reduce the expected number of people 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.

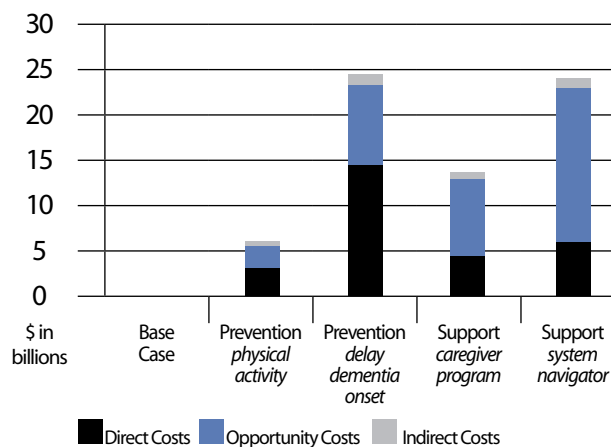
Support programs for patients and their informal caregivers were also shown to provide a significant reduction in the economic burden related to dementia by delaying admissions to care facilities. Beyond the reduction in demand placed on long-term care resources, there are additional emotional and quality of life benefits, as well as economic benefits due to the decrease in informal caregiver burden.

Clearly, efforts to devise an intervention or a set of interventions with the goal of substantially delaying onset of dementia warrant attention.

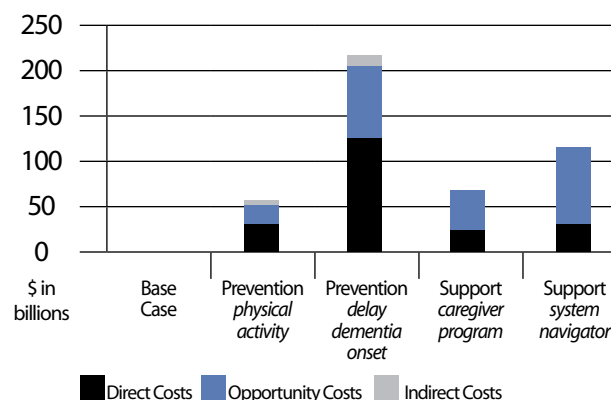
A clear understanding of the dementia burden in Canada makes the magnitude of the associated population health and economic burden undeniable and reinforces the urgent need for a national strategy to guide, manage and mitigate the health, economic and social impacts of dementia.

Intervention Value Comparisons

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



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



What Has Been Done

- What has been done elsewhere
- Current approaches in Canada
- Leading concepts and models



What Has Been Done

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. It also examined leading health system thinking: integrated community care and chronic disease prevention and management. The analysis concludes with recommendations for consideration.

These recommendations, if adopted by policymakers and decision-makers in Canada, will reduce the impact of dementia on Canadian society.

What Has Been Done Elsewhere

Australia, Norway, the Netherlands, France, Scotland and the United Kingdom have recently developed specific plans or frameworks for dealing with dementia. These plans are largely directed at:

- increasing the integration of health and social policies;
- establishing more home-based programming;
- adapting care facilities to better meet the needs of residents with dementia;
- providing education programs for people with dementia, their families, health professionals and the public;
- investing in research.

Strategies adopted to improve the delivery of care to people with dementia include focusing on early diagnosis and intervention, using case management, increasing specialized home care and making information about dementia widely available.

Current Approaches in Canada

In Canada, the response to the dementia epidemic through health and social policies is inconsistent. In the absence of a national policy or plan, each jurisdiction has found its own way to deal with the impact of dementia. However, few jurisdictions have funded dementia-specific health services.

- British Columbia has a *Dementia Service Framework* to guide service provision and policy development.
- Manitoba has a *Strategy for Alzheimer Disease and Related Dementias*.
- Saskatchewan has a *Strategy for Alzheimer Disease and Related Dementias* that makes 60 recommendations focusing on seven goals.
- Ontario's *Strategy for Alzheimer Disease and Related Dementias* was backed up with investments in education, public awareness, respite services and psycho-geriatric consulting resources.
- The Quebec government will be implementing recommendations that Alzheimer's disease and related dementias be regarded as a chronic condition and be integrated into the ministerial action plan for chronic diseases, following the recent release of a report entitled *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 also address seven priority areas including awareness, care coordination, case management, services for caregivers and investing in research.
- Newfoundland and Labrador has a *Provincial Strategy for Alzheimer Disease and other Dementias*.

A review of dementia strategies from several countries and several Canadian provinces reveals general agreement on the following 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 so that early interventions can be initiated;
- people who provide care to individuals with dementia need information and awareness programs 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 their caregiving roles and ensuring that they are supported with respite and training;
- case management and system navigation are 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 required.

Leading Concepts and Models

In developing a national dementia policy or framework, Canada can benefit greatly from considering policy alternatives in light of such leading concepts and models:

- **an integrated model of community care** that formally aligns primary care and acute care with a network of community support services;
- **chronic disease prevention and management**, with its focus on beneficial interactions between informed, active patients and prepared, proactive practice teams.

How We Can Make a Difference

- Recommendations for a National Dementia Strategy



How We Can Make A Difference

Canadians need a pan-Canadian response to the dementia epidemic that improves care at every stage of dementia. *Rising Tide* demonstrates that actions of the highest priority must include steps to prevent dementia, delay its onset, improve care and look after the needs of caregivers. The study features a variety of policy options, each of which will help reduce the impact of dementia on Canadian society.

Recommendations for a National Dementia Strategy

The following five components of a comprehensive National Dementia Strategy are essential for ensuring sustainable success:

1. Accelerated investment in all areas of dementia research, including Biomedical, Clinical, Quality of Life, Health Services and Knowledge Translation;
2. Clear recognition of the important role played by informal caregivers by providing information and education, supporting their roles as care partners and providing financial support;
3. 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. Strengthening 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;
 - 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 on our economy, our health care system, and the lives of millions of Canadians, **inaction is not an option**. Canadians must prevail on their respective provincial, territorial and federal governments to develop a pan-Canadian response to the dementia epidemic.

If we 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.



Alzheimer *Society*

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