

Rising Tide: **The Impact of Dementia on Canadian Society**

A study commissioned by the Alzheimer Society

What is dementia?

- Term “dementia” refers to disorders of the brain that slowly destroy memory and reasoning, erode independence and eventually, take life
- Alzheimer’s disease is the most common form, accounting for 64% of all dementias
- Other irreversible dementias include Vascular dementia, Frontotemporal dementia (including Picks disease), Lewy body disease and Creutzfeldt-Jakob (mad cow) disease

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Impact of dementia

Personal

- Long term disease burdens both person with disease and caregivers
- Causes more years with disability than any other chronic disease
- Severe financial burden for people living with disease
- Erodes health of caregivers

Systemic

- For the past decade, dementia and its impact on national economies have been the subject of increasing focus around the globe

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Dementia in Canada at a glance

- **500,000** Canadians are now living with Alzheimer's disease or a related dementia
- Within a generation (25 years), that number could reach between **1 million** and **1.3 million**
- More than **71,000** Canadians living with dementia are **under the age of 65**
- Women make up **72 per cent** of Canadians with Alzheimer's disease



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Rising Tide study: getting started

- As the voice for people living with dementia, the Alzheimer Society saw the need for better understanding of the impact of the disease on Canadians
- In 2008, the Alzheimer Society secured public and private funds and commissioned ***Rising Tide: The Impact of Dementia on Canadian Society***
- Report released January 4, 2010

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Rising Tide study: purpose

Goal

Generate a solid, evidence-based foundation upon which policymakers can build a comprehensive national plan.

What the report includes

- How many people will have dementia in Canada each year over the next 30 years
- Economic cost if nothing is done about it
- How the picture can change: four research-based scenarios show the impact of certain interventions and the cost savings that can result
- What the rest of the world is doing
- What Canada is doing
- Recommendations for a pan-Canadian response

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Rising Tide study: process

- ✓ Literature review
- ✓ Expert engagement
- ✓ Base case (prevalence, economic burden)
- ✓ Scenario analysis
- ✓ Policy review
- ✓ Recommendations
- ✓ Report

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What the report says: incidence

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.

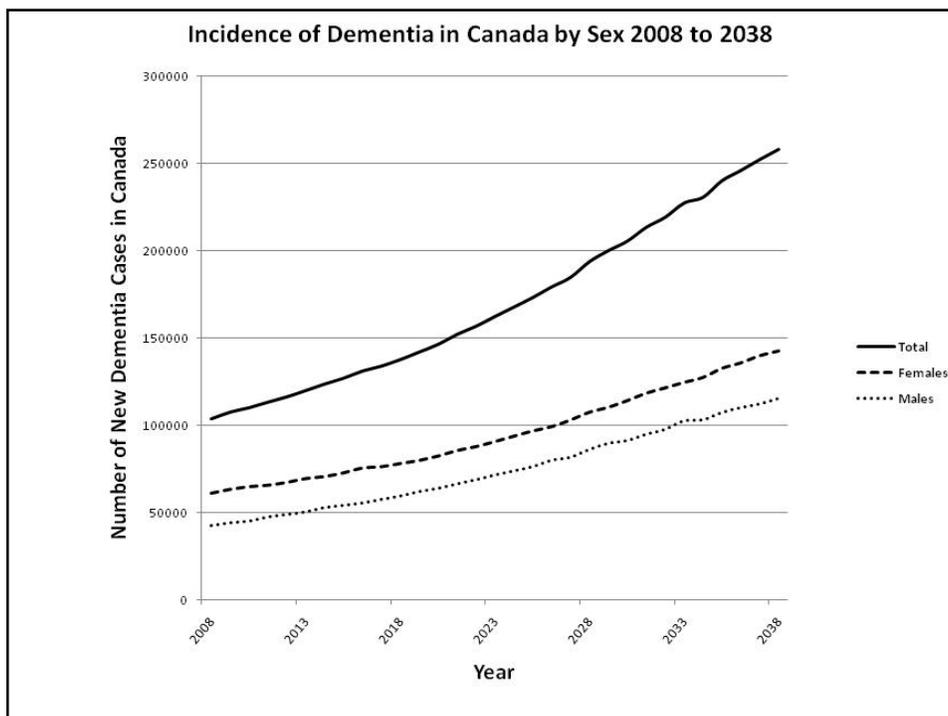
Projected incidence:

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**

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What the report says: prevalence

Prevalence: Number of People with Dementia

By 2038, the number of Canadians (of all ages) with dementia is expected to increase to 2.3 times the 2008 level.

Projected Prevalence:

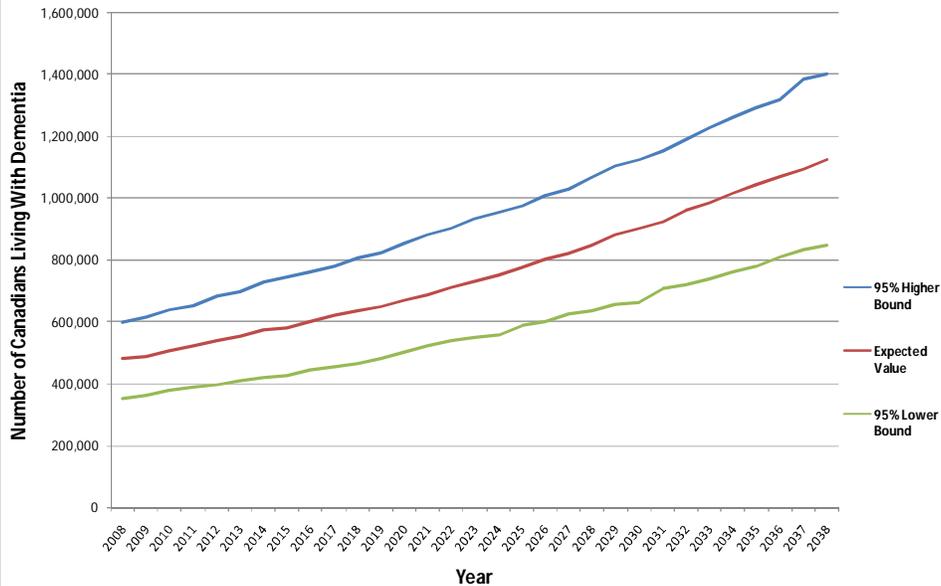
2008: 480,600 people, or **1.5% of the Canadian population**

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



Canadians with Alzheimer's disease or a related dementia

Dementia prevalence by year



The ripple effect of dementia

- Family remains the cornerstone of care, but their need for support is often overlooked
- Need for care varies by level of dementia:
 - 30% for mild dementia
 - 69% for moderate dementia
 - 88% for severe dementia
- Very high levels of psychological problems in caregivers: 40% to 75%
- Prevalence of clinical depression among caregivers: 15 to 32%
- (Note: stats from World Alzheimer's Report 2009)



What the report says: caregiving

Dementia prevalence is classified into three care types:

1. People receiving care in long-term care facilities (i.e. nursing homes)
2. People living at home and receiving community care
3. People living at home and receiving no formal care

Shift toward home/community-based care

- Number of long-term care beds expected to grow from 280K in 2008 to 690K in 2038.
- Increase in Canadians (65+) living at home with dementia is expected to jump from 55% to 62%.

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What the report says: caregiving

- As care shifts away from care facilities there will be an increase in informal care.
- The number of hours spent on informal care is expected to more than triple by 2038.

Informal Caregiver Hours, by Year, 2008-2038



Now **231 million hours**
Within a Generation

756 million hours

The time Canadians will be providing in informal care

What the report says: cost

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 is expected to increase from approximately \$15 billion in 2008 to **\$153 billion** in 2038 (future dollars).
- Monetary economic burden is expected to reach approximately **\$97 billion** by 2038.
- Opportunity costs of informal caregivers expected to add a further **\$56 billion** to the annual economic burden by 2038 .

Now **\$15 billion**
Within a Generation **\$153 billion**

Cost to Canadians for dementia care

What the report says: how to stem the tide

The report tested the impact of four potential intervention scenarios:

- ✓ Prevention: increased physical activity
- ✓ Prevention: diet and lifestyle program
- ✓ Support: caregiver training and support
- ✓ Support: system navigation

All showed potential for dramatic reductions in number of cases and or economic impact over the next 30 years.

Intervention 1: Prevention – increased physical activity

Increasing physical activity by 50% for all Canadians without dementia, over the age of 65, who are already active

- Would reduce the number of people diagnosed with dementia, resulting in reduced pressure on long-term care facilities, community care services and informal caregivers
- Would yield a 30-year reduction in Direct Health Costs of \$31 billion and a reduction in Total Economic Burden of \$52 billion

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Intervention 2: Prevention – diet and lifestyle program

Hypothetical diet and lifestyle program to delay onset of dementia by two years for entire dementia-free adult Canadian population

- Would result in fewer people living with dementia and would significantly reduce the pressures placed on health care resources
- Would yield a 30-year \$219 billion reduction in Total Economic Burden, along with 410,000 fewer prevalent cases, a 36% reduction from the Dementia Base Model

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Intervention value comparisons

Impact of interventions 1 and 2 on dementia prevalence

Years 2008 through	Intervention 1 Prevention: Increased physical activity		Intervention 2 Prevention: Diet and lifestyle 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%

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Intervention 3: Support – Caregiver development and support

Skill-building and support program for all informal caregivers and individuals with dementia receiving care

- ↓ Reducing the amount of caregiving time provided by informal caregivers could
 - reduce the health and economic burden placed on them
 - delay admission for the person with dementia into a care facility
- Helping caregivers develop coping skills and build competencies in their caregiving roles would yield a 30-year value of \$63 billion

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Intervention 4: Support – System navigator

System navigator (case manager) for newly diagnosed dementia patients to provide care coordination and caregiver support

- System navigator would
 - ↓ reduce caregiving time and delay admission into a care facility
 - ↓ reduce the pressure on long term care resources with significant savings in health cost
- Providing system navigation support for people with dementia and their caregiver would yield a 30-year value of \$114 billion

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Impact of interventions on cost (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%

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Around the world...

Other countries have developed **frameworks** for dealing with dementia that focus on:

- ✓ integration of health and social policies
- ✓ more home-based programming; adapting care facilities
- ✓ education programs
- ✓ investing in research

Strategies adopted to improve the delivery of care to people with dementia focus on

- ✓ early diagnosis
- ✓ intervention
- ✓ case management
- ✓ specialized home care
- ✓ making information about dementia widely available

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Leading concepts and models

A national policy response should work in concert with these leading concepts and models:

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

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How we can make a difference

Rising Tide makes five recommendations for a comprehensive National Dementia Strategy:

1. Accelerated investment in all areas of dementia research
2. Clear recognition of the role of informal caregivers
3. Increased recognition of the importance of prevention and early intervention
4. Greater integration of care and increased use of chronic disease prevention and management
5. Strengthening Canada's dementia workforce

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The Time to Act is Now!

What the Alzheimer Society will do 2010-2011

- ✓ Public education: *Rising Tide* release – year long, multi-faceted communication platform
- ✓ Funding for research
- ✓ Policy discussions with federal and provincial governments – ongoing
- ✓ Keep in touch with best practices in care
- ✓ Host Alzheimer Disease International conference in Toronto – March 2011

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The Time to Act is Now!

What YOU can do

- Speak to your government representatives
- Share your story
- Tweet a tribute to someone who has been affected by Alzheimer's
- Take charge of your brain health
- Donate
- Volunteer with your local Alzheimer Society

Visit www.alzheimer.ca for more information and a copy of the Rising Tide report

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BC Dementia Service Framework

- 2006 BC *Dementia Service Framework*
- 130 evidence-based recommendations that provide system-wide direction

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Seven critical gaps in dementia care:

- System capacity and ability
- Expertise of health care providers in elder and dementia care
- Knowledge about dementia and best practices
- Policy
- Recognition of the role of families and caregivers
- Capacity and ability of the acute care setting
- Integration, collaboration, communication across care settings

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\$1 M Grant to Improve Dementia Care in BC

- Province-wide **Web** resource.
- **Multi-cultural** outreach and education
- Dementia **education framework**
- A dementia **policy lens**
- Better **support for caregivers**
Early Intervention and Referral
- **E-learning**

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Maintaining The Momentum

- Early intervention
- Support for the family caregiver
- Education for the family & professional caregiver