

# Alzheimer Society

## **ALZHEIMER'S DISEASE: AN ECONOMIC TIME BOMB**

SPEECH DELIVERED BY  
MIMI LOWI-YOUNG, CEO  
ALZHEIMER SOCIETY OF CANADA

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Good morning, everyone.

It is a great pleasure to speak with you on such a critically important topic – and on the eve of World Alzheimer's Day.

I would like to also welcome some of my colleagues from the Alzheimer Society of Canada, the Alzheimer Society of Ontario and the Alzheimer Society of Toronto.

Before I begin, I would like to acknowledge a very special guest, who is also one of our board members – Jim Mann.

Jim, would you please stand? Jim flew in from Vancouver to be with us today.

Jim is one of the most selfless, passionate and caring people I've met in a long while. He always impresses and inspires me.

He spent 25 years with Canadian Airlines/CP Air as Director of Government Affairs. When he left the airline, he started his own management consulting firm. When he was done with that, he joined our Board.

The Alzheimer Society of Canada is really lucky to have Jim as one of our Board members.

Jim constantly reminds us why we exist and the work we must do.

That's because Jim is an expert...

He has Alzheimer's disease.

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Raise your hand if you have a partner, parent or family relative with Alzheimer's disease or dementia.

Raise your hand if you know someone who is caring for a family member or friend with dementia.

That's why I'm here today. For all of the special people in our lives touched by this disease - now and in the future.

I'd like to ask you another question. How many of you have ever joked about Alzheimer's or dementia. Be honest!

You know, you're in the grocery store and you forget what you're supposed to pick up for dinner. You say, "it must be "old-timer's disease." Or, "my grandmother is losing her mind." Or, "my uncle keeps forgetting my name; he's so demented."

That's not humour. That's fear. That's how we cope with this disease.

Dementia is probably the most feared of all chronic diseases.

Dementia takes away the memories we collect over a lifetime, memories that are the essence of who we are, how we feel and think, our desires and needs.

Dementia slowly takes away our ability to do day-to-day tasks like getting dressed or making dinner.

Eventually, dementia takes away life.

But fear hasn't stopped Jim from living his life to the fullest.

He is always in the media. He speaks regularly at public events and speaks up for the rights of Canadians with dementia.

Fear shouldn't stop us either.

Because dementia and Alzheimer's disease, the most common form of dementia, is affecting increasing numbers of Canadians and every single aspect of our society.

**747,000 Canadians** are now living with dementia. By 2031, there will be **1.4 million**.

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*That's less than 20 years away, and within our lifetime.*

And for every person with dementia, two, three or more family members are providing care.

But let me tell you more about the rising numbers.

Most of us understand dementia to be “an old person’s disease.” True, age is the biggest risk factor. After 65, the risk doubles *every five years*.

Baby boomers are entering their years of greatest risk and we’re all living longer.

But dementia is also affecting more and more Canadians in their forties and fifties, even in their thirties.

Jim is a perfect example – diagnosed at 58, in the prime of his life.

Ample evidence also shows that dementia begins decades before symptoms appear.

Think about that for a moment.

Some of us here, today, may be experiencing subtle changes in the brain that will eventually lead to dementia, and we may not even be aware of it.

Canada boasts some of the best and brightest researchers in the world who, over the last decade, have made groundbreaking discoveries and have contributed to many significant studies.

But dementia is a complex disease that continues to confound us. Its causes are not fully understood. Advances in psycho-social research have led to therapies involving music and art that greatly improve the quality of care and life for people with the disease and their families. But a cure and prevention are a long way off. Available medications may help manage the symptoms; none can stop, slow or reverse the disease process.

Let's talk about the personal impact of dementia.

It doesn't just affect the person diagnosed. It engulfs entire families.

In 2011, family caregivers in this country spent **444 million unpaid hours** providing care to someone with dementia.

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In economic terms, that's **\$11 billion in lost income** and about **230,000 lost FTEs**.

By 2040, caregivers will be spending **1.4 billion unpaid hours per year**.

**1.4 billion hours**. That's a staggering figure.

Dementia is also a progressive disease. It varies from person to person and can last eight to ten years on average.

And as many of you who raised your hands earlier already know, people with dementia will eventually require 24/7 care.

That's an incredible and gruelling responsibility for caregivers to shoulder.

Let's talk about the economic impact.

Some of you may be thinking, "well, I don't have this disease in my family, or I don't know anyone who has it, so it's not my problem."

Think again.

Dementia will have a tremendous impact on our economy *and* on our pocketbooks.

You may have heard earlier this year about a report published in the New England Journal of Medicine showing that Alzheimer's is the **"the most expensive malady in the U.S. ... exceeding that for heart disease and cancer."**

This is also what we know to be true in Canada.

By 2040, we will be spending **\$293 billion per year on dementia**.

Since 2006, our Federal Government has invested \$146 million in research through the Canadian Institutes of Health Research in Canada (CIHR).

They have committed up to \$100 million in matching funds to Brain Canada.

They have invested in various neurological and population impact studies.

\$250 million, give or take, to solve a \$293 billion per year problem?

*\$293 billion per year by 2040.*

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That's not light years away. That's around the corner.

Unless we find a cure or figure out how to prevent or reverse this disease, we and our children will be paying for dementia for a very long time.

*Dementia is a ticking time bomb.*

The number of Canadians with dementia is soaring rapidly. The impact of the disease will cut across large swaths of our population. Our economy, health and social care, our workplaces, industry, communities and families will be affected.

But Jim Mann and many others are looking to us for solutions.

There are solutions, if we ensure that

- At every stage of the disease people with dementia receive appropriate care provided by skilled and well-informed, well-trained professionals, and are treated with dignity and respect
- Supports are available so people with dementia can remain in their homes longer and continue to contribute to their communities

This is only achievable if we get better at detecting this disease and intervening earlier.

We know from experience that people like Jim who receive an early diagnosis and are given access to appropriate and timely information, support and care, are able to live productively for many years.

But to do so, we need to do a better job of supporting our talented researchers so they can identify people who are at risk even before symptoms appear, improve early diagnosis, improve the quality and availability of care, primary prevention and risk factors.

So, let me be blunt. We need your help.

Alzheimer Societies in communities across Canada do important work. We hold many awareness campaigns, walks and other events each year to raise awareness and reduce stigma. We also fundraise for research. Most importantly, we provide individuals and families with compassionate care and support through many innovative programs and services.

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But we can't do it alone.

We need leaders like you to help drive change so we can contain dementia's escalating costs and provide hope and the promise of a better future for Canadians who are affected.

In 2009, the Alzheimer Society of Canada released our *Rising Tide* report, projecting the economic and social impact of dementia, to great interest in the public and in the media.

Yet, despite the evidence, our call for a national dementia strategy continues to fall on deaf ears.

These are tough economic times with governments having to make tough economic choices.

But unless we start defusing the "dementia time bomb," this disease will be the greatest threat to our economy, to our country's productivity and to our quality of life.

We must rally to ensure better integration of care and services across the health continuum.

We must offer more comprehensive care and services that offer more choice and flexibility.

We need to involve people with dementia in health planning to better understand their needs and expectations.

We must top up our investment in research to align with the economic impact of the disease.

All of these facts I've put before you today seem so overwhelming.

But we can and must take action for the sake of Jim, our parents, our relatives, our friends and colleagues, and our children.

## ***Canadians agree.***

According to a recent Nanos survey, 83 per cent of Canadians *want* a national dementia strategy. *83 per cent.*

That's a compelling number we can't ignore.

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That's why today we are calling on the Federal Government to establish the **Canadian Alzheimer's disease and dementia partnership.**

Let me explain.

We're asking government to create this arms-length, not-for-profit entity through the Public Health Agency of Canada, and to provide in its start-up phase a few million dollars, then commit to on-going funding of \$30 million each year, over five years.

This arms-length organization would facilitate the development and implementation of a fully comprehensive, coordinated and integrated national dementia strategy.

The Alzheimer Society of Canada has spent the past year consulting with many of our partners in government, in health care, research and industry on how to best tackle this disease, and leverage existing dollars and resources.

We looked at the successful model used to create the Canadian Partnership Against Cancer and the Mental Health Commission of Canada.

We're confident and optimistic that this same model we're proposing today will reap benefits for Canadians living with dementia and their families.

We're asking that this partnership engages individuals from all levels of government, policy makers, health providers, researchers and those affected by this disease, to facilitate the development and implementation of a national dementia strategy – that is efficient and cost-effective.

What do we want this strategy to achieve?

- Increase investment in research, foster greater collaboration and improve knowledge exchange and translation
- Provide a surveillance system and evidence-based information on all facets of dementia
- Enhance the competency and capacity of those delivering dementia care

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- Increase awareness of dementia's risk factors, early diagnosis and timely interventions
- Strengthen the coordination and integration of care and service delivery across the health-care continuum
- Recognize the role of family caregivers and develop supports that provide options and flexibility

And so far, our proposal has been favourably received by our allies in government, including a number of MPs.

We also have support from the Canadian Consortium on Neurodegeneration in Aging, a powerhouse of 100 plus researchers, blazing trails in dementia research today.

But that's not enough. We also need corporate Canada.

How can you contribute?

- If you have someone in your family or in your workplace affected by dementia, we need you to speak up on their behalf and on behalf of all Canadians affected
- We need influencers who have and can bend the ear of politicians and policy makers to mobilize support
- We need corporate sponsors who can raise funds for research and help broaden awareness

Each and every one of us owns dementia, and we all have a stake in this disease.

The rising numbers of people living with dementia in Canada reflect a disturbing trend around the world.

On this eve of World Alzheimer's Day, the Alzheimer's Disease International, a community of over 70 Alzheimer organizations, of which the Alzheimer Society of Canada is a co-founding member, just released its latest report on dementia's global impact and the dire need for world governments to implement plans.

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Barak Obama, Angela Merkel, David Cameron, Francois Hollande, Kevin Rudd and other western leaders have all forged ahead with their own strategic plans with significant investments in their respective countries.

Mr. Cameron, current leader of the G8, is hosting the first-ever summit on dementia in London on December 11. His country and other G8 members have pledged to find solutions to dementia.

Do we want to leave Canadians behind?

If you ask Jim, you'll get a resounding "no."

People with dementia can *and* do live well, and can continue to contribute to their communities.

A national dementia strategy can provide hundreds of thousands of Canadians with this hope, with a better and brighter future.

We need a Canadian solution. We think we have the answer in our **Canadian Alzheimer's disease and dementia partnership**.

We need to change our attitudes and behaviours towards dementia across all levels of our society.

We need to get over our fear and start having more positive conversations about this disease.

We need to act now.

When you leave here today, think about the Jim Manns and the special people in your life affected by Alzheimer's disease or dementia.

Mothers, fathers, aunts and uncles, colleagues, friends and neighbours.

We have a tremendous opportunity to make change happen.

*It is our responsibility and moral duty to make it happen.*

On behalf of the Alzheimer Society of Canada, thank you for the opportunity to speak with you today.

And we look forward to hearing and working with you.