



Partnering to strengthen Canada's future: A national dementia plan

**Submission by Mimi Lowi-Young
Chief Executive Officer
Alzheimer Society of Canada**

Submitted August 6th 2014

Alzheimer Society of Canada 2015 Pre-Budget Submission to the Standing Committee on Finance

Executive Summary

Dementia is a devastating disease. It slowly destroys memory and reasoning, erodes independence and, eventually, takes life. The Alzheimer Society of Canada is eager to partner with the federal government to help achieve a national dementia plan for Canada that will provide support for people with dementia and curb the rising human and financial costs of this disease.

According to Alzheimer Society projections, 747,000 Canadians are living with Alzheimer's disease and other dementias. However, this number will increase to 1.4 million by 2031. We are conscious of the need for common strategies, many of which are being proposed by like-minded organizations such as the Neurological Health Charities Canada (NHCC), the Health Charities Coalition of Canada (HCCC) and the Canadian Caregivers Coalition (CCC) and will have a positive impact on people living with dementia. Through our alliances across the health sector, the Alzheimer Society supports these proposals, many of which are aligned with our budget submission.

Alzheimer's disease is the leading form of dementia, representing over two thirds of dementia cases in Canada today. Alzheimer's and most dementias cannot be prevented once they begin their destructive course. Medications may help manage the symptoms, but none can stop, slow or reverse the destruction of the brain.

The Alzheimer Society of Canada is a national, non-profit organization dedicated to providing help for people with Alzheimer's disease and other dementias as well as their caregivers. We work closely with our provincial Societies to improve the quality of life for Canadians affected by dementia and advance the search for the cause and cure. In fact, the Alzheimer Society Research Program (ASRP) has funded more than \$40 million in grants and awards since its inception in 1989.

The Alzheimer Society is grateful for the ongoing engagement and cooperation from the Government of Canada, including their commitment to renew and increase research investments for dementia and other neurological diseases. But the health and prosperity of our country demand we do more. Unless we intervene, the annual economic costs of dementia are projected to increase from \$33 billion today, to \$293 billion by 2040.

How then do we respond to this overwhelming threat to Canada's health and economy? How do we address the rising tide of economic and social costs? We have a solution: By bringing together a partnership of dementia experts, government officials, health-care providers, researchers and Canadians impacted by the disease to establish and implement an integrated, comprehensive national dementia plan.

Our proposal is a practical, scalable, results-oriented plan which would yield solutions aligned with government priorities.

The Alzheimer Society of Canada is requesting \$30 million per year over five years, for a total of \$150 million, to create and fund a Canadian Alzheimer's disease and Dementia Partnership (CADDP) to spearhead a national dementia plan. This represents just \$1 per Canadian per year for a disease that is already costing our economy over \$1000 per person per year.

Background

As baby-boomers across the country continue to age, Canada is facing the stark reality that the number of Canadians with Alzheimer's disease and other dementias will double in the next 16 years. Unlike many of the chronic diseases that take a major toll on our society and our economy, Alzheimer's disease is not preventable, it remains incurable and its causes are unknown. At the present time, medications can help manage the symptoms but none can stop, slow or reverse the progression.

Age remains the biggest risk factor for dementia. After 65, the risk doubles every five years. But dementia also occurs in people in their forties and fifties. Progression varies from person to person but can last anywhere from eight to 10 years and in some cases, longer. This is why Canadians live in fear of this disease.

And while Alzheimer's and other dementias can strike anyone, women are most specifically impacted. They account for 72 per cent of Canadians with Alzheimer's and are twice as likely as men to develop dementia. They are also twice as likely as men to be a primary caregiver to someone with the disease.

In 2011, Canadians spent 444 million unpaid hours providing care to family members living with dementia. This amounts to an estimated \$11 billion in lost income and the equivalent of 227,760 full-time jobs. By 2040, these families will be devoting a staggering 1.2 billion unpaid hours per year to support a family member with dementia.

However, these numbers don't just affect caregivers, they affect us all. Currently, the costs of dementia in Canada total \$33 billion per year, according to recent research by the Alzheimer Society and the Mental Health Commission. This amount is expected to rise to more than \$293 billion per year by 2040.

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.

The Canadian Alzheimer's Disease and Dementia Partnership

The Alzheimer Society of Canada is proposing a truly national solution to curb the personal, societal and economic toll of Alzheimer's disease and other dementias.

The Society is requesting \$30 million per year over five years, for a total of \$150 million, to create and fund a Canadian Alzheimer's disease and Dementia Partnership (CADDP). This represents just \$1 per Canadian per year for a disease that is already costing our economy over \$1000 per person per year.

The organization's mandate would be to lead, coordinate and facilitate a national partnership of dementia experts, governments, researchers, health-care providers, people living with dementia and their families in the development and implementation of an integrated, comprehensive national dementia plan in Canada.

The plan would be based on eight key strategic objectives which would be assessed and measured individually using key performance indicators to gauge their success.

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Objective 1: Research

To accelerate investment in all areas of dementia research, including bio-medical, clinical, quality-of-life, health services and knowledge translation. Outcomes will include increasing bench-to-bedside research/early-stage clinical trials, increasing volunteer participation in trials and making more knowledge translation tools available to the public.

Objective 2: Surveillance System

Assemble a working group of provincial and territorial partners to develop a national population-based risk reduction and dementia screening mechanism including agreed-upon prevention and performance targets.

Objective 3: Public Awareness

Create a multi-platform awareness campaign based on the UK Dementia Friends model.

Dementia Friends will:

- Give Canadians a better understanding of dementia.
- Partner with the private sector to deliver Dementia Friends training to employees.
- Offer Dementia Friends programs through local and regional Alzheimer Societies across Canada.

Objective 4: Caregiver Support

In partnership with the Alzheimer Society and using the Alzheimer Society's support and education programs such as First Link®, increase support for early intervention services designed to connect individuals and families affected by dementia with services and support as soon as possible after diagnosis.

Objective 5: Dementia Workforce

Work with interdisciplinary health professional organizations to develop dementia specific education materials for physicians, nurses, and other health-care providers. Training will also be provided to a new multi-disciplinary workforce that includes allied health professionals across the continuum of care.

Objective 6: Prevention and Early Diagnosis

In partnership with the Heart and Stroke Foundation, the Canadian Diabetes Association and the YMCA, the Alzheimer Society proposes that the Partnership collaborate on a single comprehensive program that will significantly reduce the incidence of dementia. Building on existing events such as the Alzheimer Society's "Walk for Memories," this Partnership would also include establishing an annual national walking week and a comprehensive public awareness campaign focusing on prevention and early diagnosis.

Objective 7: Best Practices

Assemble a working group of provincial and territorial partners to identify best practices for disease prevention and management. This working group will provide recommendations to federal and provincial Ministers of Health to improve the coordination of federal and provincial programs that benefit dementia-related care, support services and research.

Objective 8: Enhance Quality of Life

The partnership would assemble a working group of provincial and territorial partners, stakeholders, caregivers and persons with dementia to support the development and enhance existing provincial dementia plans. The CADDP would also work with and for First Nations, Inuit and Métis to improve access to early diagnosis tools and caregiver support programs that respect cultural sensitivities.

Alignment with Government Priorities

An investment of \$30 million per year over five years for a total of \$150 million by the Government of Canada in the Canadian Alzheimer Disease and Dementia Partnership would meet current and future government needs including:

Balancing the federal budget to ensure fiscal responsibility and economic growth.

Creating and implementing an integrated, comprehensive and national dementia plan in Canada will not only improve individual lives, but also, by aligning and coordinating programs already in place, generate significant savings for the Government of Canada. In addition, by enabling more Canadians to contribute to the workforce, our proposal would spur greater economic activity.

Supporting families and helping vulnerable Canadians by focusing on health, education and training.

One of the key objectives of the our proposal would be to increase support for early intervention services designed to connect individuals and families affected by dementia with services and community based support systems as soon as possible after diagnosis. It would also advance greater integration of care and increase use of best practices in chronic disease prevention and management.

Maximizing the number and types of jobs for Canadians.

People diagnosed with dementia in the prime of their working years as well as the caregivers who are providing their care, are often forced to abandon their careers, which deals a tremendous economic blow to the bottom line of Canadian businesses. At the same time as it limits our nation's productivity, the economic toll dementia exacts on our public health system is enormous.

With improved supports, education and research into medications to better treat those living with dementia as proposed by the Plan, the burden on family caregivers will gradually ease. This will allow them to make greater contributions in the workplace, earn higher wages and generate greater economic activity.

Conclusion

Three out of four Canadians know someone who is affected by Alzheimer's or another dementia. This staggering number brings home the reality of just how pervasive this disease is. It cuts across demographics like gender, socio-economic status and religion and yet we still don't know how to prevent it or even how to treat it.

Across the country families and friends of these individuals are waiting for their federal government to take the lead and lay out a national plan to address this disease.

The Government of Canada has taken some important steps in the fight against dementia and to bring our country into a leadership position on research, knowledge, prevention and treatment of this disease. The highlighting of dementia in the government's last Speech from the Throne as well as investments in research at CIHR has demonstrated an acknowledgement of the need to address this issue.

If Canada is to continue down a path of economic growth and prosperity, it is clear that we need to address the issue of our aging population head-on. Much is being done to ensure our next generation of workers is well-trained and ready to face the future, but we cannot forget about those who will also need our care.

Once again, the Alzheimer Society of Canada is respectfully requesting \$30 million per year over five years, for a total of \$150 million, to create and fund a Canadian Alzheimer's disease and Dementia Partnership (CADDP) to spearhead a national dementia plan that will bring Canada to the forefront in addressing this disease.

We look forward to working with the Government of Canada on this important initiative.