



**Partnering to strengthen Canada's future: The next step towards
implementing a national dementia strategy**

Pre-Budget Submission

August 5, 2016

Alzheimer Society of Canada 2017 Pre-Budget Submission to the Minister of Finance

Executive Summary

Dementia is a chronic, progressive health condition that causes damage to the brain. It slowly impairs memory and thinking skills, erodes independence and, eventually, takes life. There is no cure. As of yet, there is no effective way to prevent or even treat the disease. Medications may help manage the symptoms, but none can stop, slow or reverse the destruction of the brain. Today, an estimated 564,000 Canadians are living with dementia. In just 15 years, this figure is expected to rise to 937,000, an increase of 66 percent. An estimated 25,000 new dementia cases are diagnosed each year.

The Alzheimer Society of Canada is a national, not-for-profit organization dedicated to helping people with Alzheimer's disease and other dementias and their caregivers. We work closely with our provincial Alzheimer Societies to improve the quality of life and care for Canadians affected by dementia and advance the search for the causes and a cure. In fact, the Alzheimer Society Research Program (ASRP) has funded more than \$50 million in grants and awards since its inception in 1989.

There have been two significant developments in Parliament recently in support of Canadians living with dementia. First, private member's bill C-233, the *National Strategy for Alzheimer's Disease and Other Dementias Act*, passed second reading with unanimous consent on June 8 and is now before the House Health Committee for study and amendment. The parliamentary secretary to the Minister of Health announced in the House of Commons that the government will be supporting Bill C-233. In the Senate, the Committee on Social Affairs, Science and Technology is conducting a study on dementia. The committee has held public hearings and will be drafting a report. Most of the focus and testimony from the witnesses has been on a national dementia strategy for Canada.

To support implementation of a national dementia strategy and action plan for Canada, the Alzheimer Society has proposed the development of the Canadian Alzheimer's Disease and Dementia Partnership (CADDP). The CADDP is based on three strategic objectives: research, prevention and living well with dementia, as well as seven key priorities – each with a projected cost for implementation. The CADDP is based on a multiple stakeholder model and contains measurable targets for monitoring progress of each of the seven priorities. In a recent Nanos survey, 83 per cent of Canadians said they believe Canada needs a national dementia strategy.

Our proposal is a practical, scalable, results-oriented plan that would yield solutions aligned with the Government of Canada's priorities.

Budget Recommendation

The Alzheimer Society of Canada is requesting an investment of \$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 support the introduction of a comprehensive and integrated national dementia strategy.

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Background

Our elderly population is growing much faster than ever before. Last year, Statistics Canada reported that for the first time in our history, Canada has more seniors aged 65 years and older than children. Unlike many of the chronic diseases that have a major impact on our society and 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 young onset dementia can occur in people as young as in their thirties. Progression varies from person to person but can last up to 10 years and in some cases, longer. This is why Canadians live in fear of this disease. And while Alzheimer's disease and other forms of dementia can strike anyone, these conditions inflict a disproportionate burden on women. Of the current number of Canadians with dementia, 65 percent are women.

The social and economic impacts of dementia are devastating and far-reaching. It takes a tremendous toll not only on those living with the condition, but also on their families and caregivers as well as employers. According to the National Population Health Study of Neurological Conditions published by the Public Health Agency of Canada, the combined health-care system costs and out-of-pocket caregiver costs for people with dementia amounted to \$10.4 billion in 2016. By 2031, this figure is expected to increase by 60 per cent, to \$16.6 billion.¹

Generally, costs for people with dementia are estimated to be five-and-half times greater than for those who do not have the disease. Home care and long-term care are the largest contributors to direct costs. In 2011, family caregivers provided \$19.2 million unpaid hours of care. This number is projected to double by 2031.

With its stated commitment to collaborative federal leadership, the Government of Canada has an opportunity to support a significant and high-profile national health policy initiative in its mandate.

The Canadian Alzheimer's Disease and Dementia Partnership (CADDP)

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

Operating under an independent, standalone model of governance, the organization's mandate would be to lead, coordinate and facilitate a national partnership of government, industry, health providers, national health stakeholders, community groups, researchers, caregivers and persons with dementia to establish and implement an integrated, comprehensive national dementia strategy for Canada.

The national dementia strategy would be based on three strategic priorities and seven objectives, which would be assessed and measured individually against key performance indicators to gauge their success. These objectives address the intensive role of the caregiver as well as a dementia control action plan to meet the special needs of Indigenous communities. The total projected cost of this project would be \$30 million annually over five years for a total of \$150 million.

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Strategic Objective: Research

Priority 1: Accelerate investment in all areas of dementia research, including bio-medical, clinical, social, health services and policy. Projected cost: \$40 million over five years

Priority 2: Develop evidence-based practice standards of care in chronic disease prevention and management. Projected cost: \$10 million over five years

By co-ordinating dementia research investments nationally and internationally, research efforts toward finding a cure and improving quality of life for persons with dementia will be maximized. Canadians will also have access to the same standard of care, regardless of where they live.

Strategic Objective: Prevention

Priority 3: Provide a surveillance system to inform health policy and service planning, foster evidence-based strategies for prevention and management and support research. Projected cost: \$30 million over five years

Priority 4: Promote broader public awareness of Alzheimer's disease and other dementias and combat stigma. Projected cost: \$25 million over five years

Early interventions will support the ability of Canadians to plan for their future, including providing for social, health and end-of-life care. Physicians will be better able to screen and detect dementia earlier in the disease process. Canadians will be better informed about the disease and what they can do to support someone in their community or workplace that has dementia. This increased awareness will reduce stigma for those living with dementia.

Strategic Objective: Living Well With Dementia

Priority 5: Recognize and support the important role played by informal caregivers by providing access to financial benefits through the tax system. Projected cost: \$20 million over five years

Priority 6: Strengthen the dementia workforce and promote an emphasis on prevention, early detection and early intervention. Projected cost: \$5 million over five years

Priority 7: Ensure that persons with dementia, including First Nations, Inuit and Métis are involved in all aspects of the Partnership. Projected cost: \$20 million over five years

Caregivers who must leave paid employment or curtail self-employed work in order to provide care will be able to access job protection provisions and income support.

Physicians and professional care providers will also be able to detect symptoms at an early stage, to make an earlier diagnosis and will have access to resources, dementia-specific education materials and training opportunities. As a result, Canadians will experience person-centered dementia care that is respectful and responsive to their needs.

A special challenge will be to ensure that Indigenous people in remote communities have access to early diagnosis, good information and care support in culturally sensitive ways.

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Alignment with Government Priorities

The objectives and priorities of the CADDP would support the government's work in several key areas:

Science and Innovation

The Alzheimer Society of Canada supports the government's commitment to science and innovation and is delighted that action is being taken to consult on new ideas and approaches. This country has access to some of the best research minds in the world and we need to be doing more to take advantage of that, particularly when it comes to Alzheimer's and dementia research.

Countries like the United States and the United Kingdom have recently made moves towards significant investments in this area. A bill before the Senate in the U.S. proposes to lift funding for research on Alzheimer's and dementia to \$1.4 billion. In the U.K., the government has doubled funding in Alzheimer's research to £66 million (approximately C\$113 million) since 2010.

In contrast, Canada spent \$52 million on research into all neurodegenerative diseases in the 2012/13 fiscal year.

As noted, there is currently no cure and no medicines that significantly treat dementia. Canada has an opportunity to position itself as a leader in this area while also working to improve the lives of people diagnosed with Alzheimer's and their caregivers. Making the investment to create a hub of dementia-related research in Canada will attract investment and world-class researchers, create jobs and increase our economic competitiveness globally.

Ensuring Canada does not lag behind its international partners

According to Alzheimer's Disease International, 24 countries worldwide have developed and funded comprehensive national Alzheimer plans, including Australia, Japan, Norway, The Netherlands, France, United Kingdom, Luxembourg and Switzerland. **Canada is one of only two G7 nations without a national dementia strategy in place.**

In October 2015, Canada was a signatory to the Pan American Health Organization's (PAHO) Regional Plan of Action on Dementia, which obliges countries to develop national action plans. More than simply abiding by this commitment, Canada should be taking action to become a leader and innovator in its implementation.

Conclusion

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

Across the country, families and friends of these individuals are looking to the federal government to take the lead and support a national dementia strategy to address this condition.

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The Alzheimer Society of Canada is respectfully requesting an investment of \$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 strategy that will bring Canada to the forefront in addressing this disease.

We look forward to working with the Government of Canada on this timely and critical policy initiative.

For more information:

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Reference

¹Public Health Agency of Canada. Mapping Connections: An Understanding of Neurological Conditions in Canada – The National Population Health Study of Neurological Conditions, September 2014, Ottawa.