



The time is now:
*Fully funding Canada's first
national dementia strategy*

Pre-Budget Submission
House of Commons Standing Committee on Finance
August 3, 2018

Recommendation:

That the Government of Canada provide \$150 million, over five years, to fully fund a robust, world-class national strategy for Alzheimer's disease and other dementias.

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Executive summary

The Alzheimer Society of Canada is pleased to submit this brief in advance of the 2019 federal Budget, addressing the consequences of dementia on Canada’s competitiveness.

Today, more than half a million Canadians are living with dementia. In less than 15 years, 937,000 Canadians will be living with dementia, an increase of 66 per cent.

The scale of dementia and its impact on Canada’s productivity and economy is staggering. In 2011, Canadians provided 444 million unpaid hours caring for people with dementia – or an equivalent of more than 200,000 full-time jobs. This number is projected to more than double in the next two decades. The cost of dementia, \$10.4 billion in 2016, is also projected to double by 2031.

Women are disproportionately affected by dementia. Not only do they represent 65 per cent of Canadians living with dementia who are 65 and older, women also make up a majority of caregivers in Canada. Women are also more likely to spend more than 20 hours a week caring for a family member, often impacting their careers and mental health, with depression and exhaustion frequently reported.

Canada has taken some important steps to address dementia, now the seventh-leading cause of death according to Statistics Canada. The 2018 federal Budget included a five-year, \$20 million investment in dementia, the first time that dementia has been included as a distinct item in a federal Budget. This is a welcome starting point and provides a strong foundation upon which to build.

In an historic achievement, Canada has also committed to developing a national dementia strategy, joining 32 other countries worldwide. National strategies are in place in Canada for other health conditions, including cancer and mental health.

Canada, with its first-ever national dementia strategy, stands ready to usher in a new era of dementia research, awareness, care and support. This can only be realized, however, if sufficient funding is allocated to ensure the effective implementation of a national dementia strategy. The experience of other countries shows that strategies need dedicated, sustained public funding to be successful.

“Women are disproportionately affected, making up two-thirds of [seniors with dementia]. Many women also take on the caregiving responsibilities for family members living with dementia.”
-Budget 2018

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Funding for Canada’s national strategy should also be separate from larger envelopes. As the WHO observed in a study released this year, “earmarked funding is pivotal to ensuring follow-through for implementation and avoiding the diversion



*“Canadians affected by dementia are **looking to Parliament** to fully fund a national dementia strategy.”*

of funds away from other areas of the national/subnational health care budget.” Funding should be sustainable and reliable, rather than on a project-by-project basis.

We applaud the Government of Canada’s initial commitment of \$20 million in community-based projects that address some of the challenges of

dementia. Canadians affected by dementia are looking to Parliament to take the next step, and fully fund a national dementia strategy.

To realize a fully-funded, robust, world-class dementia strategy, **the Alzheimer Society of Canada recommends an investment of \$150 million over five years.**

About the Alzheimer Society

The Alzheimer Society is Canada’s leading nationwide health charity for people living with Alzheimer’s disease and other dementias. Active in communities across Canada, the Society:

- Offers information, support and education programs for people with dementia, their families and their caregivers.
- Funds biomedical and quality of life research to find disease-altering drugs and a cure, as well as improve the quality of care and life for people with dementia.
- Promotes public education and awareness of Alzheimer’s disease and other dementias, including brain health, to ensure people know where to turn for help.
- Influences policy and decision-making to address the needs of people with dementia and caregivers.

Background

On June 22, 2017, the *National Strategy for Alzheimer’s Disease and Other Dementias Act*, received Royal Assent and became law. Canada will become the 32nd country with a national dementia strategy, when the final strategy is launched in 2019.

For over ten years, the Alzheimer Society has been calling for such a strategy. In November 2016, the Senate Committee on Social Affairs, Science and Technology

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echoed those calls, endorsing a fully-funded national dementia strategy. The Senate Committee supported the Alzheimer Society, recommending “at least” \$150 million in federal funding over five years, a recommendation we are submitting to the Commons Standing Committee on Finance for inclusion in the 2019 federal Budget.

Since passage of the *Act*, considerable progress has been made:

- The Minister of Health has appointed a Ministerial Advisory Board on Dementia.
- The Public Health Agency of Canada hosted a National Dementia Conference, “Inspiring and Informing a National Dementia Strategy for Canada.”
- The 2018 federal Budget included \$20 million in new funding for dementia care and support, over five years.

Our recommendation for immediate investment is supported by health-care professionals and advocacy groups across the country. HEAL – Organizations for Health Action, a coalition of 41 national health-care associations and charities – has recommended that “the federal government focus on seniors’ care by investing \$150 million [...] to support the delivery of a national dementia strategy.”

In June 2018, Federal-Provincial-Territorial (FPT) Ministers of Health met in Winnipeg, where they received an update on progress towards a national dementia strategy. Ministers also considered key outcomes from the National Dementia Conference, one of which was the importance of funding a national dementia strategy.

Breakdown of costs associated with a fully-funded national dementia strategy

Strategic objective	2019	2020	2021	2022	2023
Dementia research \$40 million	\$5 million	\$5 million	\$10 million	\$10 million	\$10 million
Surveillance system \$15 million	\$5 million	\$5 million	\$5 million		
Public awareness \$25 million	\$5 million	\$5 million	\$5 million	\$5 million	\$5 million
Early detection \$15 million		\$5 million	\$5 million	\$5 million	
Dementia workforce \$5 million					\$5 million
Support for caregivers \$20 Million	\$5 million	\$5 million	\$5 million	\$5 million	
Best practices \$10 million	\$5 million				\$5 million
Quality of life \$20 Million	\$5 million	\$5 million		\$5 million	\$5 million

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Alignment with government priorities

Ensuring Canada’s competitiveness

Dementia has major consequences to the economy and to the workplace in the form of lost earnings and employment. This year, the worldwide cost of dementia will exceed \$1 trillion US. That is greater than the GDP of Norway, Ireland and New Zealand combined. According to Alzheimer’s Disease International, if dementia were a country its GDP would be 18th-highest in the world.

This already enormous cost will double to \$2 trillion US by 2030. The World Health Organization warns that this “could undermine social and economic development globally and overwhelm health and social services, including long-term care systems specifically.”

In Canada, the direct cost of dementia was \$10.4 billion in 2016, of which \$1.4 billion is paid out of the pockets of informal caregivers.

Most of the financial burden falls on caregivers. Eighty-five per cent of people with dementia are supported, at least in part, by informal caregivers at home. Caregivers sacrifice their time, career advancement and mental health to provide round-the-clock care to a family member with dementia, often at great financial expense. According to a 2018 Canadian Institute for Health Information (CIHI) study, informal caregivers spent, on average, 26 hours a week caring for someone with dementia – nine hours more than average time spent caring for someone without dementia.

Across Canada, informal caregivers devoted 444 million unpaid hours caring for someone with dementia in 2011, representing \$11 billion in lost income.

In 2012, Statistics Canada found that about one-quarter of employed caregivers who provided over 15 hours of care per week had to reduce work hours. A full 40 per cent sought a less demanding job, and 10 per cent did not accept and/or pursue a promotion due to the demands of being a caregiver. One in five caregivers report receiving financial assistance.

Aside from the direct costs, dementia has a profound impact on Canada’s competitiveness. Caregivers must often forgo career advancement to meet the responsibilities of caregiving. This limits their ability to contribute to Canada’s greatest competitive edge: its educated, skilled workforce. A fully-funded national dementia strategy should include \$20 million in new supports for caregivers, to help alleviate their stress and allow them to more fully contribute to the Canadian economy.

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The social and economic cost of dementia is not limited to caregivers. While the risk of dementia increases with age, and while the majority of Canadians living with dementia are past retirement age, a significant minority of people continue to work following a diagnosis of dementia. According to the Milken Institute, increased absenteeism and reduced performance of employees with dementia costs the American economy almost \$15 billion US per year.

Early diagnosis, risk reduction and access to support will help mitigate disruption in the work lives of people with dementia, to the benefit of Canada's economy and competitiveness.

Bridging the gender gap

Enhanced funding for dementia care and support aligns with the federal government's stated priority of removing or reducing barriers that disproportionately affect women in Canadian society. Dementia impacts women at a greater rate than men, both in prevalence and in caregiving.

Dementia deprives caregivers of **\$11 billion** in lost income.

The 2018 federal Budget acknowledged the gender divide in dementia by highlighting "improving the quality of life of people with dementia and ensuring that caregivers have the support they need" as a key initiative to advancing Canada's Gender Equality Goals.

In 2014, women over 65 living with dementia outnumbered men of the same age category by nearly two-to-one. The gender gap becomes more pronounced with age; the prevalence of women over 85 with dementia is a full eight per cent higher than men of the same age.

This gender disparity is also reflected among caregivers, 54 per cent of whom are women. Additionally, women are over 50 per cent more likely than men to spend more than 20 hours per week on caregiving.

The caregiver gender gap is most pronounced when looking only at those caring for someone with dementia. Approximately 75 per cent of informal caregivers to a person with dementia are women, according to a 2018 study of dementia in Manitoba.

Considering the gender discrepancy among caregivers and people with dementia, it is not surprising that women also bear a disproportionate burden of the associated costs. In the United States, women assume 76 per cent of the financial burden of dementia. Female caregivers are also 60 per cent more likely than their male counterparts to quit their job due to the stresses of caregiving.

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Although dementia touches nearly everyone in Canada in one way or another, those most impacted are women. A fully-funded national dementia strategy will further the federal government's goal of removing obstacles that negatively impact Canadian women.

Fulfilling Canada's international obligations

In May 2017, the *Global Action Plan on the Public Health Response to Dementia 2017-2025* was adopted by the Seventieth World Health Assembly. The Public Health Agency of Canada supported implementation of this global plan.

The plan includes seven action areas:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation

The initial proposed action for member states is to develop and implement national plans or strategies that address dementia. By developing and fully funding a world-class national dementia strategy, Canada can take immediate, meaningful action to improve outcomes for Canadians affected by dementia and meet the expectations of the international community.

Conclusion

Canada has taken positive steps forward on dementia care and support with the passage of the *National Strategy for Alzheimer's Disease and Other Dementias Act*, the appointment of a Ministerial Advisory Board on Dementia, and hosting a national dementia conference.

The Alzheimer Society looks to the Government of Canada to take the next step, by providing \$150 million over five years for a world-class national dementia strategy. By setting aside dedicated, earmarked funding now, Canada's first national dementia strategy will be fully and sustainably funded when it launches in 2019.

References and citations are available by request to the Alzheimer Society of Canada.