Canada's first national dementia strategy A catalyst for change

WRITTEN SUBMISSION FOR THE PRE-BUDGET CONSULTATIONS IN ADVANCE OF THE UPCOMING FEDERAL BUDGET

House of Commons Standing Committee on Finance

August 7, 2020

Alzheimer Society of Canada 2021 Pre-Budget Submission

Recommendations:

Recommendation 1: That the government fully fund the national dementia strategy by increasing its investment of \$50 million to \$150 million, over five years.

Recommendation 2: That the government meets its aspirational goal in the national dementia strategy to increase overall Canadian investment in dementia research.

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Background

Canada has taken significant steps to address dementia. On June 17, 2019, the Minister of Health released **A Dementia Strategy for Canada: Together We Aspire.** Budget 2019 provided funding of \$50 million over five years to support implementation of key elements of Canada's first national dementia strategy. Specifically, the funding is for \$3 million in fiscal 2019 and \$12 million in each of the following four years. The \$50 million provided to the Public Health Agency of Canada (PHAC), which is responsible for the national dementia strategy, includes:

- \$40 million over five years to establish the Dementia Strategic Fund focused on increasing awareness and adoption of guidelines and best practices.
- An additional \$10 million over five years to support better understanding of dementia in Canada through surveillance.

The \$50 million in funding is in addition to \$20 million over five years announced in Budget 2018 for community-based projects to address the challenges of dementia.

Research is essential to finding a disease-modifying treatment for dementia, and is identified as a key objective in the national dementia strategy. In 2019, the Canadian Institutes of Health Research (CIHR) announced funding of \$46 million over five years to support Phase II of the Canadian Consortium on Neurodegeneration in Aging (CCNA), a national platform for collaborative research in dementia that includes 350 researchers. The Government of Canada will contribute \$31.6 million through CIHR's Dementia Research Strategy, of which CCNA is the main initiative. An additional 14.4 million is provided by partners, including the Alzheimer Society of Canada (ASC). ASC is a founding partner and lead funder of the CCNA through the Alzheimer Society Research Program (ASRP).

The start-up funding of \$50 million over five years for the national dementia strategy provides a base upon which to build. Full funding is pivotal to ensuring timely follow-through on the strategy's implementation plan. It is essential that Canadians living with dementia begin to see concrete action on its implementation. Otherwise they will view the strategy simply as another document on a shelf. The current investment in dementia research in Canada falls short of government funding compared to other G7 countries. Despite having a similar dementia prevalence to the UK and US (1.71% and 1.16% respectively), Canada's (1.3%) national research funding is a fraction of these other nations. In 2016, the UK government set aside €159m compared to Canada's €30.4m and have dedicated significantly more since then. This gap in funding limits our ability to find a cure, and makes Canada less competitive on the world stage.

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The burden of dementia

Dementia is a general term that refers to a variety of brain disorders. Today, more than half a million Canadians are living with this debilitating, and ultimately, terminal condition. With the aging of the baby boomer generation, in less than 15 years, this number is expected to nearly double. Approximately 25,000 new cases of dementia are diagnosed each year. There are currently no treatments or medications to stop, reverse or modify its progression.

Dementia is an expensive condition, costing the Canadian economy and the healthcare system more than \$10.4 billion. By 2031, the estimated cost is estimated to grow to \$16.6 billion. It is a prolonged illness – on average people with dementia can live between three and 11 years after diagnosis – some survive 20 years or more. The cost of illness over time can outweigh other diseases. Canadians living with dementia and their families face significant financial impact from the cost of health and social care as well as the reduction or loss of income. According to the *WHO Global Action Plan on the Public Health Response to Dementia 2017-2025*, in high income countries, the costs related to dementia are shared between informal care (45%) and social care (40%).

Women are disproportionately affected by dementia. They represent 65 percent of Canadians with this condition who are 65 and older and account for the majority of caregivers. This gender disparity impacts women's careers and mental health, with depression and exhaustion frequently reported. Dementia has significant economic and workplace consequences, both in lost earnings and employment opportunities.

The COVID-19 pandemic is highlighting the need for increased care and support for Canadians living with dementia. Most residents in long-term care (LTC) homes are over 80 years old and over two-thirds of them have dementia. A recent report by the Canadian Institute for Health Information (CIHI) shows that deaths occurring in LTC is double the OECD average – accounting for 81% of all reported COVID-19 deaths in Canada. With these stark figures, it is clear that the COVID-19 epidemic has exacted a terrible human toll on people living with dementia.

Canada has the highest proportion of COVID-19 related deaths occurring in long-term care compared with the rates in other OECD countries

> **Canadian Institute for Health Information COVID-19 and Long-term care: International Comparisons**

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A fully-funded strategy

While the federal government has taken important first steps in its commitment to dementia research, public awareness and improved surveillance, \$3 million in fiscal 2019 and \$12 million in each of the following four years falls short of the projected \$30 million annually estimated to adequately resource the strategy.

In their January 2019 report outlining priorities for a national dementia strategy, a Canadian Academy of Health Sciences (CAHS) expert panel found that the lack of dedicated resources was an issue in the implementation of national dementia strategies. Drawing upon existing evidence, the panel noted that "the resources committed in several countries were not sufficient for implementing the measures proposed in the [national dementia] plans." The CAHS assessment report was commissioned by PHAC.

The Society's cost estimate for funding the strategy was also supported by the Senate Committee on Social Affairs, Science and Technology (SOCI). In its November 2016 report, *Dementia in Canada, A National Strategy for Dementia-friendly Communities*, SOCI endorsed a fully-funded national dementia strategy by recommending "at least" \$150 million in federal funding over five years.

Similar pan-Canadian strategies such as the Canadian Strategy for Cancer Control have received substantially more funding. The Canadian Partnership Against Cancer (CPAC), an independent organization funded by the federal government, stewards that strategy and received funding for its second mandate, from 2012-17, totaling \$241 million. In March 2016, the federal confirmed announced ongoing funding for the Partnership at \$47.5 million per year. This is almost four times more than the annual funding the national dementia strategy has received.

National dementia strategy, a step in the right direction, but critics concerned it's underfunded The Hill Times, April 29, 2019

The national dementia strategy sets out a broad and impressive vision, but to succeed, it will need full and sustainable funding over and above what was already provided in the 2019 federal budget. **The Alzheimer Society of Canada recommends an investment of \$150 million over five years to realize a fully-funded and robust national dementia strategy.** This ask is not new. It has been made in successive pre-budget submissions over the past three years to the Commons Standing Committee on Finance (FINA) and in briefs to the Department of Finance and the Public Health Agency of Canada (PHAC).

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More investment in research

Compared to the amount of money governments pay out in care, Canada is underinvested in dementia research. A paper published in *The Lancet* in 2019 reported that between 2011 and 2016 six of the G7 countries (all excluding Japan) increased their investments in dementia research by 136.9 percent. Even with this increase, the global investments in dementia research are 4.5 times lower than the equivalent in 2016 in cancer research. Indeed, Canada is one of the lowest funders in dementia research compared to other OECD countries.

There are good reasons for Canada to step up its investment in dementia research. We are starting to make headway towards important discoveries that may lead to a disease-modifying treatment or a cure, but without continued and increased investment, we will not see its impact. This is why the Alzheimer Society aspires to quadruple our investment in dementia research, funding the innovators and bright minds of the future.

We have seen the breakthroughs that large government investments in scientific and medical research have made possible for other public health conditions such as HIV/AIDs. The impact of COVID-19 on residents in long-term care, the majority of whom have dementia, has further focused researchers' attention in this area. Even without a cure, the payback on breakthrough research is high. For example, ASC's *Rising Tide* study (2010) found that delaying the onset of dementia by two years would yield a 30-year reduction in total economic burden of \$219 billion, along with 410,000 fewer prevalent cases equivalent to a 36% reduction in the number of Canadians with the condition.

The current investment in dementia research, including \$9.2 million annually for five years in support of the Canadian Consortium on Neurodegeneration in Aging (CCNA), is over 10 times less than the \$100 million annual recommendation from the 2017 Senate report *Dementia in Canada: A National Strategy for Dementia-Friendly Communities*. In fact, the national dementia strategy released by the Government of Canada acknowledges the need for annual investments in dementia research that exceed one percent of dementia care costs or approximately \$100 million annually.

In addition to health outcomes for Canadians, the investments government makes in research support the economy by leading to innovation and jobs.

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Area of Focus 3.2 in *A Dementia Strategy for Canada: Together We Aspire* speaks to the need for increasing dementia research.

CURRENT STATUS	ASPIRATION
Annual investment in dementia	Annual investments in dementia
research in Canada is less than one	research in Canada exceeds one
percent of dementia care costs.	percent of dementia care costs.

Conclusion – No Time to Lose

For those affected by dementia, the pandemic has been especially grim

The Economist, August 3, 2020

The COVID-19 pandemic has underlined the urgency of fully funding and implementing the national dementia strategy. It will provide a framework for a coordinated response to dementia that is based on the principles of person-centred care and grounded in a collaborative approach for sharing best practices and standards of care. The strategy is supported by expert committees to guide its development and implementation, including the Ministerial Advisory Board on Dementia, an FPT Coordinating Committee on Dementia and a federal "whole-ofgovernment" Inter-departmental Committee on Dementia.

With all this expertise, the strategy is an invaluable resource for policy-makers to begin addressing the immediate priorities required to bring about constructive changes in dementia and long-term care. The Government of Canada was challenged to be bold and ambitious with this first national dementia strategy, but it will need to amplify its investment as the strategy moves into implementation. The Alzheimer Society of Canada looks to the Government to maintain its commitment to a fully implemented, funded and monitored national dementia strategy that will truly benefit Canadians.

About the Alzheimer Society

The Alzheimer Society is Canada's leading nationwide health charity supporting people living with all forms of dementia, including Alzheimer's disease, as well as caregivers and families. We rely on individual and corporate donors, communities and health-care partners to help us deliver on our mission. Active in communities across Canada, the Society offers programs and support services, fundraises to advance research, advocates for policy change, and increases public awareness.

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The Alzheimer Society Research Program (ASRP) is a national, peer-reviewed program which is investing \$3.4 million for dementia research in 2020. The ASRP funds innovative projects, enabling researchers to push the boundaries in their field, and on new investigators who are the hope for the future. The ASRP is also the only funder of quality of life research. The program's aspirational goal is to increase its investment in research to \$10 million in five years.

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