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# The intersection of two pandemics

WRITTEN SUBMISSION TO THE HOUSE OF  
COMMONS STANDING COMMITTEE ON  
FINANCE IN ADVANCE OF 2022 BUDGET



*Société*  
**Alzheimer**  
*Society*

CANADA

## Recommendations

**Recommendation 1:** That the government heed the urgency of the consequences of the pandemic by fully funding the national dementia strategy with clearly defined implementation milestones and success criteria.

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

## About Us

The Alzheimer Society is Canada’s leading, nationwide health charity supporting people living with Alzheimer’s disease and other dementias 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.

## Background

Dementia is a slowly progressing and debilitating condition with symptoms that may include memory loss, changes in mood, and difficulties with thinking, problem solving and language. There are no survivors. More than 419,000 Canadians over the age of 65 are living with dementia.<sup>1</sup> On average, nine seniors are diagnosed with dementia every hour in Canada.<sup>2</sup> Women are disproportionately impacted by dementia. They represent 63 percent of Canadians with this condition who are 65 and older and account for the majority of caregivers. Dementia does not discriminate. Over 16,000 Canadians under the age of 65 are currently living with young onset dementia and that number is rising. By 2031, with the aging of the baby boom generation, it’s expected that nearly one million Canadians will be living with the disease.<sup>3</sup>

The COVID-19 pandemic has had a devastating impact on Canadians living with dementia. As *The Economist* observed: “For those affected with dementia, the pandemic has been especially grim.”<sup>4</sup> A report released by Statistics Canada found that dementia or Alzheimer’s disease was the most common co-morbidity associated with deaths due to COVID-19. It was the most common comorbidity among women and the second most common for men.<sup>5</sup> Most of the residents in long-term care homes in Canada are over 80 years old and over two-thirds of them have dementia. One of the working groups associated with the Alzheimer Society of Canada’s *COVID-19 and Dementia Task Force* was dedicated to long-term care. This group worked in collaboration with provincial ministries to ensure dementia was considered within evaluations of long-term care and developed guidelines for end-of-life care in long-term care homes.

People living with dementia are at higher risk of developing COVID-19 whether they live at home or in a care setting, for many reasons. They may have difficulty understanding or following guidance to keep them safe and may have less access to their usual family, healthcare or community supports, which in turn, can contribute to the worsening of their dementia and other health conditions, leaving them more vulnerable to this deadly disease. That is why the

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<sup>1</sup> Public Health Infobase. Canadian Chronic Disease Surveillance System Data on Dementia from 2015-16, excluding Saskatchewan and Yukon. *Government of Canada*, 2018.

<sup>2</sup> *Ibid.*

<sup>3</sup> Alzheimer Society of Canada. *Prevalence and Monetary Costs of Dementia in Canada*. 2015. [http://www.alzheimer.ca/~media/Files/national/Statistics/PrevalenceandCostsofDementia\\_EN.pdf](http://www.alzheimer.ca/~media/Files/national/Statistics/PrevalenceandCostsofDementia_EN.pdf)

<sup>4</sup> The Economist International. “For those affected by dementia, the pandemic has been especially grim.” August 3, 2020.

<sup>5</sup> Statistics Canada. *Provisional Death Counts and Excess Mortality January 2020 to February 2021*. Released 2021-05-04.

Alzheimer Society of Canada is pressing for increased, sustainable funding for the national dementia strategy, to achieve better outcomes for people living with dementia.

## The burden of dementia

Dementia is an expensive condition and impacts the Canadian economy. It is a prolonged illness – on average people with this disability can live between three and 11 years after diagnosis. The cost of illness over time can outweigh other diseases. Caring for a family member with dementia is stressful and time-consuming. As a result, Canadians living with dementia and their families face significant financial and workplace consequences, both in decreased productivity, loss of income and missed employment opportunities. According to the Public Health Agency of Canada (PHAC), the total healthcare and out-of-pocket caregiver costs of dementia in Canada were \$8.3 billion in 2011. That figure is estimated to increase to \$16.6 billion by 2031.<sup>6</sup>

## National dementia strategy

Canada has taken significant steps to address dementia. In June 2019, the Government released *A Dementia Strategy for Canada: Together We Aspire*.<sup>7</sup> Canada's first national dementia strategy lays out a bold and ambitious plan for improving the lives of people living with dementia, their families and caregivers. The strategy is now in its second year of implementation. The Public Health Agency of Canada is responsible for development and implementation of the strategy. A Dementia Policy Unit has been established in PHAC's Division of Aging, Seniors and Dementia.

Budget 2019 committed an investment of \$50 million over five years to support implementation of key elements of the national dementia strategy (FY 2019-20 to FY 2023-24). Specifically, the funding is for \$3 million in fiscal 2019 and \$12 million in each of the following four years. In addition, Dementia Community Investment was established through Budget 2018 (\$20 million over five years), to support community-based projects that address the challenges of dementia.

Canada's first national dementia strategy is ambitious and progressive. It is aligned with national dementia plans in other G7 countries, integrates a sex and gender lens, a health equity approach, focuses on caregivers, and building a skilled workforce – including recognition of the essential role of personal care workers. The strategy provides a focus and rallying point for the dementia community. However, the strategy will need full and sustainable funding to ensure measurable progress on its vision and three national objectives.

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<sup>6</sup> Public Health Agency of Canada: *Mapping Connections: An understanding of neurological conditions in Canada*. Government of Canada, 2014.

<http://www.phac-aspc.gc.ca/publicat/cd-mc/mc-ec/assets/pdf/mc-ec-eng.pdf>

<sup>7</sup> Public Health Agency of Canada. *A Dementia Strategy for Canada: Together We Aspire*, June 2019. Cat: HP25-22/1-2019E; SBN: 978-0-660-31202-6; Pub: 19088.

What does a national Pan-Canadian strategy cost? The Alzheimer Society of Canada has been asking for an investment of \$150 million over five years to realize and fully-funded and robust national dementia strategy. This cost estimate was supported by the Senate Committee on Social Affairs, Science and Technology (SOCT) in its November 2016 report on dementia in Canada which recommended “at least” \$150 million in federal funding over five years for a national dementia strategy.<sup>8</sup> The Government’s response has been that the broad scope and ambitious goals of the strategy are not amenable to a resource estimate.

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 government 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. In May 2021, the Australian Government announced an AUD \$229.4 (CAD \$221) million funding allocation to dementia over five years in its 2021-2022 budget.<sup>9</sup>

#### Investment in dementia research

Increased research is identified as a key area of focus in the national dementia strategy. But Canada is underinvested in dementia research compared to the scope and scale of the disease. The \$41 million in funding from the Canadian Institutes of Health Research (CIHR), Canada’s federal funding agency for health research, represents a fraction of the amount spent on research into other diseases. An additional \$14.4 million is provided by partners, including the Alzheimer Society of Canada. ASC is also a founding partner and lead funder of the Canadian Consortium on Neurodegeneration in Aging (CCNA), a national platform for dementia research.

*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.<sup>10</sup> Even with this increase, the global investments in dementia research are 4.5 times lower than the equivalent in 2016 in cancer research.<sup>11</sup> Indeed, Canada is one of the lowest funders in dementia research compared to other OECD countries.

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. Even without

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<sup>8</sup> Senate of Canada. *Dementia in Canada: A National Strategy for Dementia-Friendly Communities*. November 2016. [www.senate-senat.ca/social.asp](http://www.senate-senat.ca/social.asp)

<sup>9</sup> Maree McCabe. *Australia’s \$229m commitment to dementia*. July 9, 2021. Blog. Website of Alzheimer’s Disease International.

<sup>10</sup> The Lancet. *The Scale and Profile of Global Dementia Research Funding*. Vol 394 November 23, Vol 394 November 23, 2019, pp. 1888-89.

<sup>11</sup> Alzheimer’s Disease International. *From Plan to Impact IV: Progress towards targets of the WHO global action plan on dementia*. May 2021.

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.<sup>12</sup> The aspirational goal in *A Dementia Strategy for Canada: Together We Aspire* calls for a benchmark annual investment in dementia research to exceed one percent of dementia care costs or about \$100 million annually.

There are good reasons for Canada to step up its investment in dementia research. Research is critical to support prevention, early detection and better treatment options. We are starting to make headway towards important discoveries which have led to disease-modifying treatments, but without continued and increased investment the impact will not be fully realized. The gap in research funding limits our ability to find a cure, and makes Canada less competitive on the world stage.

The Alzheimer Society Research Program (ASRP), one of Canada's most innovative hubs for dementia research, invested \$3.4 million in research in 2020. The ASRP is funded through donations and focuses on research in areas that are important to patient care – not typically funded by federal granting councils. This includes supporting early career researchers and new investigators who are key to the future success of our health and innovation ecosystem. But the pandemic has severely impacted the capacity to support scientific research for many health charities.<sup>13</sup> The ASRP turned away 80 percent of qualified researchers who passed peer review but did not get funded for the 2020 competition.

## Conclusion

Dementia must remain a national policy priority in a post-pandemic Canada. Canada's first national dementia strategy presents an opportunity for transformational change in research, care and support. This submission highlights the need for continued federal commitment to implementation of the national dementia strategy with full and sustainable funding as well as accountability metrics in the Annual Report to Parliament to benchmark progress. The start-up funding of \$50 million over five years in Budget 2019, provides a base upon which to build. Increasing this investment is pivotal to ensuring timely follow-through on the strategy's implementation plan.

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<sup>12</sup> Alzheimer Society of Canada. *Rising Tide: The Impact of Dementia on Canadian Society*, 2010.

<sup>13</sup> Lindsay Borthwick, Research Money. *Health charities fear a slow pandemic recovery will undermine research programs*. May 30, 2021.

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