

## DEMENTIA IN CANADA: *A National Strategy for Dementia-Friendly Communities*

**DEMENTIA IS A PROGRESSIVE AND DEGENERATIVE CONDITION THAT ROBS AN INDIVIDUAL, OVER THE COURSE OF MANY YEARS, OF THE ABILITY TO LIVE AND FUNCTION INDEPENDENTLY.**

Persons affected by dementia can continue to live independently for some time. However, as their condition progresses, they require increasing levels of care. In the last stage of dementia, individuals lose the ability to convey when they are in pain, as well as to walk, talk, chew and even swallow.

### STAGES OF DEMENTIA

Persons with dementia, especially those with early onset Dementia, can live many years as the disease progresses.



#### Mild cognitive impairment

- Cognitive changes are serious enough to be noticed by the individuals experiencing them but not severe enough to interfere with daily life



#### Early stage

- Recent mild memory loss
- Repeating questions
- Depression and apathy
- Mood swings
- Mild language problems
- Failing sense of direction



#### Middle stage

- Persistent memory loss
- Inability to recognize friends and family
- Delusions and aggression
- Coordination problems
- Requiring assistance with daily living



#### Late stage

- Inability to process information
- Mood problems and hallucinations
- Inability to care for oneself
- Increased communication difficulties

The report cites Alzheimer Society of Canada figures showing the toll dementia takes on Canada's population and its economy will double over the next 15 years as the country's aging population grows and the costs associated with supporting them increase.

It was within this context that the committee undertook this study to determine the actions that should be taken to most effectively and efficiently meet the challenge of the disease and its treatment.

The committee report notes that by 2031 the number of Canadians with some form of dementia will be 1.4 million, nearly twice as many as those who suffered from the disease in 2011.

The direct cost of caring for dementia patients is expected to increase dramatically, to \$16.6 billion in 2031 compared to \$8.3 billion in 2011. By 2040, the total direct and indirect costs associated with dementia are projected to rise to \$293 billion, compared to \$33 billion in 2015.

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**1.4 MILLION**

There is currently no cure for dementia and little treatment available to slow the progression of the condition. However, eating well, keeping physically and socially active and engaging in activities that are intellectually stimulating are all believed to extend the early phase of dementia during which an individual can maintain an independent lifestyle.

Dementia sufferers are often able to stay in their home, with the proper supports, until the later stages of the condition, and as many as 90% of individuals with dementia live within the community.

## THERE IS CAUSE FOR OPTIMISM

Committee members were impressed by the efforts of dementia patients, their families, and their supporters to create "dementia-friendly communities" that are inviting and supportive of people with dementia. These efforts include community-led initiatives such as the creation of Memory Cafés and Blue Umbrella programs that reduce the stigma of dementia, help dementia patients live independently and help sufferers overcome the desire, often expressed by dementia patients, to withdraw from society following a diagnosis.

Committee members were profoundly moved by ordinary Canadians who have proven capable of extraordinary things when thrust into the role of caregivers for loved ones with dementia.

However, a clear strategy with proper funding must be put in place if we are to meet the needs of the hundreds of thousands of Canadians — our parents and grandparents — whose dignity is robbed by this cruel disease.

**"(Individuals with dementia) deserve nothing less than a dementia-friendly Canada in which they are not only accepted but embraced"**

# A NATIONAL DEMENTIA STRATEGY

The committee's report makes 29 recommendations aimed at helping the growing number of Canadians who will develop some form of dementia. Senators urge the government to immediately establish the Canadian Partnership to Address Dementia with a mandate to create and implement National Dementia Strategy. The partnership would include representatives from all levels of government as well as health-related organizations, caregivers, people affected by dementia, researchers and members of the Indigenous community.

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## FUNDING

It was not only obvious to the Committee but imperative that Canadians living with dementia must be included in all aspects of a coordinated approach to dementia care in Canada.

The Partnership should receive at least \$30 million in annual federal funding.

A National Dementia Strategy would ensure that adequate care is provided to people with dementia, that housing options are available for patients, and that funding for research and disease management is in place. The National Dementia Strategy should also help turn new discoveries about treating and slowing dementia into practice.

Part of the strategy should see the Public Health Agency of Canada move beyond its apparent passive approach and create and implement a public awareness campaign regarding prevention, early diagnosis, symptom recognition, quality of life and services and supports.

Meeting the needs of the growing number of Canadians with dementia will require the federal government to make significant financial contributions in areas like home-care services, continuing care infrastructure and research. In the upcoming Health Accord, the committee recommends that the federal government commit \$3 billion over four years for home-care services. This money would come with rigorous evaluation and reporting requirements to ensure effective use of funds.

The committee also believes the federal government should reduce the financial burden on informal caregivers; senators recommend exploring fiscal options including expanding Employment Insurance compassionate care benefits and amending caregiver tax credits to benefit lower-income Canadians.

**\$3** billion over four years for home-care services

In view of the need for provincial and territorial governments to provide more long-term care facilities, the committee recommends that the federal government invest \$540 million in continuing care infrastructure to help meet that demand

# SUPPORT FOR RESEARCH

The committee supports the work being done by the Canadian Institutes of Health Research, the lead agency in dementia research, through its Canadian Consortium on Neurodegeneration in Aging.

Ronald Petersen, Director of the Mayo Clinic's Alzheimer's Disease Research Center in Rochester, Minnesota told the committee that increasing research funding to 1% of cost of dementia care would likely permit researchers to find a disease-modifying treatment by 2025.

The committee recommends the federal government allocate to the consortium 1% of the annual cost of health care for dementia patients which would more than double its current funding level of \$41 million. This is the international standard.

## NEXT STEPS

Much work remains to be done.

The committee urges the federal government to act on the recommendations made in our report without delay. These recommendations are the product of months of study, expert testimony and thorough analysis. They provide a solid basis for swift action.

Dementia touches the lives of millions of Canadians, including the hundreds of thousands who are diagnosed and their family members who become informal caregivers. Senators will continue to give them a strong voice in Parliament.



## READ THE REPORT

*DEMENTIA IN CANADA: A National Strategy for Dementia-Friendly Communities*

<http://sen.parl.gc.ca/dementia>

**#SOI**