

CANADIAN ACADEMY OF HEALTH SCIENCES STATEMENT ON DEMENTIA

Approved by and submitted by the Research Executive Committee (REC) of the Canadian Consortium on Neurodegeneration in Aging (CCNA), October 13th, 2016**.

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Introduction

The proportion of Canada's population that is 65 years of age or greater has grown over the last number of decades, and this trend will continue. In 2024, Canada will join the group of so-called 'super-aged' countries, which are those where more than 20% of the population is 65 years of age or older. Among those 65 years of age and older the oldest old (those 85 years of age or greater) is the fastest growing segment of the population.

Advancing age is the greatest known risk factor for dementia. If there is no change in age-standardized prevalence, societal aging is predicted to nearly triple the number of individuals living with dementia worldwide by 2050. It is estimated by that year the number of individuals with dementia will rise from 47.5 million people to an estimated 135.5 million with most of this increase occurring among people living in low- and middle-income countries. Aside from the personal cost of dementia, these rising numbers will be associated with an economic burden. The total annual worldwide cost of dementia in 2015 was estimated to be US \$818 billion. This is expected to become a trillion dollars by 2018.

The WHO now recognizes dementia as a public health priority. To respond to this challenge, a global series of actions initiated during the UK G8-Presidency in 2013 are being undertaken by bodies such as the Organisation for Economic Co-operation and Development (OECD), Alzheimer's Disease International (ADI) and by the World Dementia Council.

Dementia Overview

Dementia is an acquired and persisting decline in cognitive abilities that can include learning and memory, language, and/or reasoning severe enough to interfere with independence in everyday activities. It can arise from numerous conditions acting alone or in combination. For many individuals it is due to a neurodegenerative process, which is an umbrella term for a number of debilitating conditions that result in the progressive degeneration and/or death of nerve cells. Alzheimer disease is the most common neurodegenerative cause of dementia. A mixture of brain diseases often underlies dementia with many people showing changes consistent with both Alzheimer disease and cerebrovascular disease.

Women are disproportionately affected by dementia. They are at both greater risk of developing dementia and then living longer with the condition after its onset. Women also provide most of the informal (unpaid) care for people living with dementia.

While there is currently no cure for the neurodegenerative conditions that lead to dementia, emerging research indicates the potential to delay if not prevent its onset through life-style factors (e.g., promotion of physical activity, modifying diets) and to ameliorate its impact on those with the condition and their families. The progress to date in developing effective treatment options has been disappointing, underscoring the need to increase the investment in research directed at understanding mechanisms, and the biology of the dementias. Beyond prevention and finding better treatments for the dementias, we also need to support the development and dissemination of improvements in the care provided to people living with dementia. Greater acceptance and inclusion of people living with dementia within communities is increasingly seen as an important factor in improving their quality of life and minimizing disability.

A Call to Action

Developing a comprehensive strategy to address the challenge of dementia will require wide consultation followed by the implementation of a comprehensive, integrated and responsive series of

actions maintained over years. These would include addressing the following broad areas: (a) increasing public awareness - educating the general population about dementia, how to maintain brain health, and on the importance of addressing this health challenge, accepting people with dementia as they are, and accommodating to their remaining abilities; (b) supporting research - efforts to find and implement effective approaches (both pharmacological and non-pharmacological) to delaying, preventing, treating, ameliorating, and eventually curing the common causes of dementia; (c) investing in the health care system – this would entail both training a sufficient number and mix of providers and building required infrastructure so that timely, competent person-centred care delivered by well-trained work force in the appropriate setting can be offered to those living with dementia and their caregivers through all stages of the illness.

Elements of an Action Plan to Face the Challenge of Dementia

An action plan to face the challenge of dementia in its global context must include a concerted and coordinated series of actions from policies, to research, to care, to social inclusion. Here are seven key elements to such a plan:

- **A National Dementia Plan**

Canada is the only G7 country without a national dementia plan. Good work has been done at a provincial level that should be retained and built upon, but Canadians would benefit from a national dementia plan that could coordinate activities, harmonize where appropriate, promote the sharing of successful provincial initiatives, address identified gaps, ensure efficient use of resources, and mobilize further investment in the area. A national plan would acknowledge dementia as a public health priority and heighten awareness of this daunting health challenge.

- **Increase investment in Canadian research on dementia**

The Canadian investment in research on dementia is small when compared to other conditions such as cancer and heart disease even though the cost of caring for persons with dementia is estimated to be greater than that for dealing with either of the other two conditions. The CIHR investments in research in dementia is CAN\$ 0.67 per capita, which is less than a quarter of what is invested in the UK, Australia and

US. Despite this, Canada researchers have made and continue to make a substantial contribution to dementia research. A recent innovation in our country that has attracted international interest has been the effort to create through the Canadian Consortium for Neurodegeneration in Aging (CCNA) a vibrant collaborative research platform. Promoting interdisciplinary research across a spectrum of disorders will facilitate the search for common mechanisms and identification of potential therapeutic targets. The CIHR and other funding partners support the CCNA.

Canada committed itself to doubling its investment in research on dementia at the G7 Dementia Summit in December 2013. In order to seriously address opportunities and need, we advocate for an immediate research investment increase to CAN\$100 million per year or approximately CAN\$2.84 per capita - a figure comparable to other G7 countries like the US (in 2016 the American investment in dementia research was US \$936 million, which translates to US\$2.93 per capita - this has recently been substantially increased). This additional investment in Canada will have to be thoughtfully allocated and managed. A national effort, to be coordinated by CIHR, is needed. This should involve collaborations across all the federal research councils (CIHR, NSERC, SHHRC) and agencies (e.g., PHAC), federally supported initiatives (e.g., CCABHI, Brain Canada), provincial funding agencies, non-governmental agencies, and philanthropists. Governance of how these funds will be spent must also involve individuals living with dementia and their caregivers, the research community, and practitioners.

- **This investment must span all aspects of dementia research.**

Allocated research funds should support a broad range of activity from biomedical investigation to inquiries dealing with clinical aspects, health systems and services research, and understanding the social cultural, environmental factors that affect the health of populations. Investments will have to be made in increasing our national research capacity, supporting knowledge transfer, addressing the needs of unique populations (for example, indigenous people and those living in rural and remote communities), investigating sex and gender differences in dementing conditions, and embracing ethical and social dimensions.

- **Risk Reduction**

Canada must support a risk-reduction and empowerment strategy for the public and support the efforts of health professionals to promote healthy brain aging. There is no cure for the major brain diseases that cause dementia once fully manifest. Current evidence, though, can be used to empower the public and health professionals in reducing the risks of a dementia developing, postponing the appearance of its clinical manifestations, and optimizing everyday functioning with the goal of maintaining personally meaningful social activities and roles. There are a variety of other good reasons to embrace the recommended lifestyle changes, but further research is needed on understanding how they work and the best ways to implement and promote their adoption.

- **Training the required workforce**

A well trained and supported workforce of the right mix and number to deal with the needs of this emerging population is required. A national workforce plan will have to be created and implemented with the active involvement of the provinces and territories.

- **We must make Canada a country where it is possible to live well with dementia.**

In 2016 the Netherlands' European Union Presidency convened a conference on "Living well with (out) dementia". It concluded that when a diagnosis of dementia is made, an individual should not be constrained to abandon her/his social role and participation. Creating the conditions within a country where one can live well with dementia includes ensuring that the public is aware of dementia in all its complexity, there are accommodations in the environment (including work) to compensate for changing abilities, there is adequate protection against abuses of all kinds against individuals living with dementia, and legal rights are not automatically withdrawn from people living with dementia.

- **Access**

We must ensure that Canadians with or at risk of dementia have access to the best preventive programs, systems of care, and living environments regardless of where they live or who they are.

The Future of the Dementia Challenge

Sadly, dementia will be part of the Canadian and global landscapes for many decades, reaching prevalence rates that are least double the current 2016 values. Indeed, even if research could provide an ultimate solution tomorrow by eradicating the brain diseases causing dementia, numerous Canadians would already have initiated their trajectory to dementia. Brain diseases causing dementia are now known to start many decades before any clinical signs. For these reasons, a total solution will not be available for some time to come. This is why the Canadian Academy of Health Science is focusing attention on the necessity of engaging in an action plan for dementia which is balanced and designed to address all aspects of the challenge, especially the wellness of those living with dementia and their caregivers

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