



EXECUTIVE SUMMARY

IMPROVING THE QUALITY OF LIFE AND CARE OF PERSONS LIVING WITH DEMENTIA AND THEIR CAREGIVERS

CANADIAN ACADEMY OF HEALTH SCIENCES' ASSESSMENT OF DEMENTIA CARE IN CANADA

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EXECUTIVE SUMMARY

Dementia touches the lives of many Canadians. It has a profound impact on the person living with dementia, their caregivers and other family and friends, as well as on our health and social care systems. It is estimated that approximately one in five baby boomers will develop dementia in their lifetime. Each year, one in three seniors die with dementia. The health and social care system and out-of-pocket caregiver cost of dementia are already very high and anticipated to increase significantly.

Persons living with dementia experience deterioration in memory, thinking and behaviour, reducing their ability to perform everyday activities and live independently. Although dementia mainly affects older people, it is not a normal or inevitable part of aging. Alzheimer's disease is the most common cause of dementia.

A national dementia strategy is needed to provide a compelling central vision that provides direction for mobilizing resources needed to meet the needs of the increasing number of persons living with dementia and their caregivers. A national strategy should also help Canada prepare for the advent of pre-symptomatic biomarkers with associated disease-modifying medications. This exciting development will positively impact the lives of many people, and at the same time may lead to additional pressures on the Canadian health and social care system and raise challenges in ensuring equitable access.

The *National Strategy for Alzheimer's Disease and Other Dementias Act* was passed by Parliament in 2017. It provides for the development of a national dementia strategy for Canada. The federal Minister of Health, through the Public Health Agency of Canada, asked the Canadian Academy of Health Sciences (CAHS) to provide an evidence-informed and authoritative assessment to inform national dementia strategy priorities.

In response, the CAHS convened an Expert Panel to examine the strength and the state of the evidence and emerging best practices and gaps relevant to the Canadian context. This report is the result of an extensive, highly iterative process akin to a rapid review and is best described as a blend of evidence, emerging ideas and consensus.

The CAHS Expert Panel recognizes the central role that must be played by persons living with dementia and their caregivers. The quality of life of persons living with dementia and their caregivers can be improved across all stages of the condition through a complex combination of person-centred, high quality health and social care.

OVERARCHING THEMES:

A. Building on the rich Canadian experience

- Provincial dementia plans have been in place since the late 1990s
- Four Canadian Dementia Consensus Conferences were held since 1989
- Research and emerging best practices exist

B. Recognizing the centrality of engaging persons living with dementia and their caregivers in a meaningful and respectful manner

- Acknowledging the rights of persons living with dementia and accommodating their needs is fundamental
- The needs of caregivers are not identical to those of care recipients and need to be specifically addressed
- Recognizing the diversity of persons live with dementia is essential

C. Addressing dementia as a societal, health and social issue, emphasizing the complex combination of health and social needs of persons living with dementia and their caregivers

- Education on maintaining brain health and preventing dementia empowers individuals and societies to take action
- With timely diagnosis and mobilization of the right amount and type of health and social supports, persons diagnosed with dementia can actively participate in making decisions about their lives and lead personally meaningful lives
- Assessment, management and treatment are anchored in team-based primary care and integrated with other components of the health and social care system
- A person-centered, and not a disease-centred, approach to care is based on knowledge of the person with dementia and their caregiver, a commitment to partner with them, and an understanding that needs will evolve

D. Ensuring an adequately trained and supported dementia workforce is available to deal with current and anticipated demand

- Both training needs and organizational supports for quality team-based care by an appropriate mix of health care providers need to be addressed

E. Assuring an equitable balance in research investment across biomedical, clinical, health services, and social, cultural, environmental, and population health research and between creating and translating knowledge

- Canada has specific research needs and there are opportunities to capitalize on our unique advantages

F. Creating, seeking and utilizing evidence and best practices to implement the strategy in a coherent and practical way

- Key elements include continuous evaluation to inform implementation and flexibility to allow local adaption

COMPILATION OF KEY FINDINGS

1. Overall Approach

- a) Dementia is a societal, health and social issue.
- b) In Canada, we have the opportunity to improve the quality of care and lives of persons living with dementia and their caregivers. This requires us to recognize that dementia disproportionately impacts women.
- c) With the increasing number of persons living with dementia, there is a need to ensure the sustainability of the health and social care system, including preparing for the demands on the health system that will come with increased availability of biomarkers in the detection of pre-symptomatic Alzheimer's disease (and other dementias) and disease-modifying medications.
- d) Canada can be proud of the contributions made by the multiple provincial dementia strategies already developed and implemented. These plans compare very favourably with international ones. They highlight a number of distinctive features such as an approach anchored in team-based primary care and integrated with other components of the health and social care system.
- e) A national dementia strategy that recognizes the extensive experience and contributions of provincial dementia plans will enhance Canada's engagement with international organizations.
- f) Given the geographic, demographic and cultural diversity across Canada, a national plan that facilitates learning and collaboration is most likely to be well received within Canada.
- g) Current evidence and emerging best practices must be translated in a coherent and practical way for use within the health and social care system.

2. Engaging persons living with dementia

- a) There is increasing interest in promoting, recognizing and protecting the rights of persons living with dementia. This has taken various forms, including statements of principles in dementia strategies, the designation of dementia as a disability, and the recognition of rights for persons with dementia and their caregivers.
- b) It is becoming more common to engage persons with dementia in their own care, as well as in shaping health services and conducting research. This approach is almost unanimously supported in dementia strategies within Canada and internationally as an emerging best practice.
- c) When engaging those with dementia, consideration should be given to the diversity within this population, recognizing that some groups have unique and additional challenges.

3. Prevention, awareness and living well with dementia

- a) There is sufficient evidence to encourage the adoption of health promotion endeavours (improving educational attainment, healthy eating, exercise, smoking cessation, prevention of head injury) and prevention interventions (early detection and treatment of hypertension, hyperlipidemia and diabetes) that address protective and risk factors for dementia.
- b) Public awareness and understanding of dementia is improving, but there are still specific knowledge gaps. Many people continue to believe that dementia is a normal part of aging and that there is nothing they can do to prevent cognitive decline and dementia as they age.

- c) Public understanding is also needed to address the stigma and fear, to show how it is possible to live well with dementia and to empower persons with dementia and their caregivers.
- d) Dementia-friendly communities are emerging as a promising approach to increasing awareness and understanding of dementia while making communities more livable for persons with dementia. These require local adaptation and the meaningful involvement of persons living with dementia.

4. Improving health and social care for persons living with dementia

- a) Despite improvements, many persons living with dementia and their caregivers are still experiencing limited access to dementia assessment and services, fragmented care, and inappropriate end-of-life care.
- b) Most persons with dementia have other chronic conditions and require a complex combination of social and health care. A person-and-family-centred approach, rather than a disease-centred approach, is essential to providing good care. Relationship-centred care extends this partnership to include health and social care providers and the influences they have on each other.
- c) An integrated care approach positions primary health care to provide more timely diagnosis, earlier access to treatments, improved coordination of care and earlier support for caregivers, which may increase quality of life, reduce caregiver burden, and delay long-term care placement.
- d) Within Canada, there are examples of well-supported primary health care, and various approaches to providing comprehensive and coordinated dementia diagnosis, treatment and care are being implemented. Evidence-informed care requires regular updating of clinical practice guidelines and pathways.
- e) As a person's care needs increase and become more complex, they need a widening web of community-based supports. Technology may play a promising role in supporting individuals to remain at home as long as possible.

- f) The current quantity and quality of long-term care homes may not be adequate to meet the future needs of persons living with dementia, even with increased community-based supports. Incorporating a dementia-friendly approach, including design and meaningful activities, will improve the quality of life of all residents.
- g) Having clear goals of care, advanced-planning, a fully informed family and a common understanding of these goals are essential to having a dignified and respectful death and avoiding possible unwanted, futile or burdensome interventions.

5. Education and support for caregivers

- a) Caregivers want to provide care and derive positive benefits from their role. Caregivers experience challenges related to their increasing responsibilities for the person living with dementia, which impacts their own health, employment and finances.
- b) It is critical that caregivers be supported in their caring roles. Certain interventions (i.e., education, training, counselling, supportive workplace) may help preserve their quality of life and resiliency and may help sustain or increase their availability as caregivers.
- c) The needs of caregivers vary over time. Ongoing needs assessment is essential to understanding how to support caregivers.
- d) The economic and health consequences of providing care are exacerbated by gender-based expectations. Any policy or program to support caregivers must include a gender-based analysis to assess the intended and unintended consequences for women.
- e) Alzheimer Societies and caregiver associations in Canada play an essential role in empowering, educating and supporting caregivers.
- f) Timely access to needed health and social care for the person living with dementia has a significant impact on caregiving and on the caregiver.
- g) No one policy or practice for providing financial support is a panacea for caregivers. Caregivers are a diverse group and require a flexible range of services and supports applicable to a diverse population.

- h) In-home or in-facility respite is the most common support offered to caregivers through home care programs. However, such services for caregivers can only be accessed if the person living with dementia is a client. Greater efforts must be made to improve access to these programs.
- i) Workplace policies with supportive cultures need to be developed and expanded along with commitment from supervisors and managers to enable caregivers of persons living with dementia to continue to be employed.

6. Building and supporting the health and social care workforce

- a) All provincial strategies and most international ones recognize the need to support and strengthen the workforce. Workforce planning is critical to ensure there are adequate numbers of the needed type of care providers to meet the quality-of-life and care needs of persons living with dementia and their caregivers.
- b) Special attention is needed to address workforce planning and training for the large numbers of direct care providers who provide most of the hands-on care to this highly vulnerable and medically and socially complex population.
- c) Training alone is insufficient to achieve the desired changes in care. Work environments that value and support health and social care providers in providing good dementia care address factors such as time constraints, workload, compensation, leadership and managerial supports. Task-sharing models involving specialists, primary care and other health and social care providers are a key element in workforce planning, training and organization.
- d) It is important to embed dementia care into the curriculum and practice training of all health and social care providers. Case-based/practice-based and solution-focused dementia training is most beneficial to support the application of learning in practice. Used in isolation, traditional didactic and passive strategies (lecture-style meetings, in-services, printed materials and guidelines, and passive materials) are ineffective strategies for increasing knowledge of, and confidence in, dementia management.
- e) Supports for the implementation of evidence-based practice and guidelines are essential for ensuring good quality care.

7. Research and Innovation

- a) An equitable balance in research investment is required across the four research themes (i.e., biomedical, clinical, health services, social, cultural, environmental, and population health) and between creating and translating knowledge.
- b) While international collaborations must be strengthened, the Canadian dementia research agenda needs to address our specific needs and capitalize on our unique advantages.
- c) More research funding is required, along with coordination between the different levels of government, industry, and charitable funders in order to maximize benefit and avoid waste.
- d) The engagement of persons living with dementia is critical, but our understanding on how best to do this is at an early stage and should be considered an emerging practice. Examples can be built upon to improve the acceptance and recognition of contributions from persons living with dementia.
- e) Different research priorities have been identified and are best established with broad stakeholder input, which must include persons living with dementia and their families, friends, caregivers, and health and social care providers as well as the research community and funders.
- f) When putting the dementia research and innovation plan into action there is a need to move from abstract, broad goals to specific performance measures, indicators and targets that are quantifiable, accountable and feasible within a predetermined time horizon. There is also a need to support studies on how to effectively scale up evidence-based interventions to large populations.

8. Implementation

- a) Strong government leadership with broad stakeholder collaboration and clearly defined roles is critical to leading, inspiring and evaluating change.
- b) A dementia implementation action plan requires:
 - i. A compelling central vision and direction balanced with flexibility to adapt to local needs and contexts,
 - ii. A long-term commitment and appropriate resources to achieve identified priorities, as well as research and evaluation,
 - iii. A concrete action plan with targets and timelines,
 - iv. Consideration of the various approaches to implementation that have been used, including both widespread and phased implementation, and
 - v. Planning at the outset for continuous evaluation of the dementia strategy to inform implementation and modifications as needed.
- c) The introduction of national dementia standards of care along with an accreditation process will complement quality improvement efforts that are aligned with dementia strategy priorities.