



Canadian Academy of Health Sciences
Académie canadienne des sciences de la santé

CAHS Expert Panel Report on *Improving the Quality of Life & Care of Persons Living with Dementia & Their Caregivers*

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Objectives

At the end of of the presentation attendees will be able to:

- Describe why and how the CAHS Report was produced;
- Identify its key findings; and,
- Consider how this information should inform innovations to improve dementia care in Alberta.

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Overview

**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

cahs-acss.ca



Howard Bergman (Chair)
Sonya Kupka (Project
Director)

David B. Hogan

Janice Keefe

Carrie McAiney

Debra Morgan

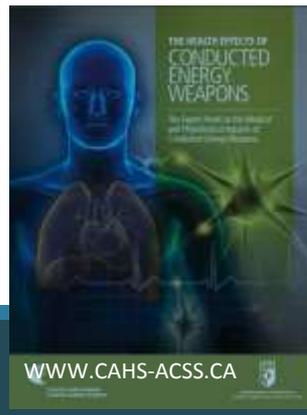
Isabelle Vedel

<https://www.cahs-acss.ca/wp-content/uploads/2019/01/Report.pdf>



Canadian Academy of Health Sciences(CAHS) – Who We Are

- 700 Canadian health scientists widely recognized for academic achievement, creativity and leadership
- A collaborative body producing scientifically validated evidence and unbiased, actionable, solutions to address major health challenges affecting Canadians.
- Fellows from all health disciplines serve as unpaid volunteers to enhance the health and best interests of all Canadians
- Reports available at: www.cahs-acss.ca



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Report of the Panel on the Role of Investments in Health Research
January 2008



Act of Parliament: 2017

National Strategy for Alzheimer's Disease and Other Dementias Act

- develop and implement a comprehensive national strategy to address all aspects of Alzheimer's disease and other form of dementia

Why a national strategy?

- More people will be living with dementia
- Must ensure adequacy and sustainability of the health and social care system to deal with this challenge
- Compelling central vision that provides direction for mobilizing needed resources



Charge to CAHS

Minister of Health of Canada, through the Public Health Agency of Canada (PHAC), charged the CAHS to provide:

- An evidence-informed and authoritative assessment on the state of dementia knowledge and practice
 - Summarize strength/ state of dementia evidence and emerging best practices
 - Inform, not write, the national plan



CAHS Dementia Assessment

- Out of scope
 - Again, not charged to write the plan
 - Elements outside of health/social services
 - Stakeholder consultation
 - Federal/provincial jurisdiction



CAHS Expert Panel

Chair: **Howard Bergman**, MD, FCFP, FRCPC, FCAHS. Chair of the Department of Family Medicine, Professor of Family Medicine, Medicine and Oncology, McGill University

David B. Hogan, MD, FRCPC, Academic Lead of the Brenda Strafford Centre on Aging, O'Brien Institute for Public Health, Cumming School of Medicine, University of Calgary

Janice Keefe, PhD, Professor and Chair, Department of Family Studies and Gerontology and Director, Nova Scotia Centre on Aging, Mount Saint Vincent University

Carrie McAiney, PhD, Schlegel Research Chair in Dementia, Schlegel-UW Research Institute for Aging, Associate Professor, School of Public Health and Health Systems, University of Waterloo

Debra Morgan, PhD, RN, FCAHS, Professor, College of Medicine Chair in Rural Health Delivery, Canadian Centre for Health & Safety in Agriculture, University of Saskatchewan

Isabelle Vedel, MD, PhD, Assistant Professor, Department of Family Medicine, McGill University

Sonya Kupka MAdEd, RD, Project Director, SJK Consulting





Methodology

- An extensive & intensive highly iterative process
 - Three in-person meetings
 - Blend of rapid review of the evidence, emerging ideas and consensus
 - Examined Canadian and international reviews, commissioned a review of AD policies in OECD countries and reports
 - Provincial dementia strategies provided direction
 - Peer review process at the end
- Panel members actively engaged
 - Took responsibility for particular area
 - In setting orientation, reviewing evidence, identifying best practices and writing sections of the report



Commissioned Papers

The CAHS Expert Panel requested short papers from experts and researchers to better understand the following areas:

- Rural dementia care
- Ethnic minorities and recent immigrants
- Young-onset dementia
- Indigenous populations in Canada
- Sexual minorities
- Adults with intellectual/developmental disabilities
- Technology for dementia
- International review of Alzheimer's disease policies in OECD countries



Chapters

1. Introduction (Overall approach)
2. Engaging persons with dementia
3. Prevention, awareness and living well with dementia
4. Improving health and social care for persons living with dementia
5. Education and support for caregivers
6. Building and supporting the health and social care workforce
7. Research and innovation
8. Implementation



Chapter Structure

1. Highlight the **challenges** from the perspectives of persons living with dementia and their caregivers, and the health and social care system
2. Summarize **public-policy responses** as expressed in dementia strategies and relevant legislation
3. Identify **evidence informed and emerging best practices** that are relevant to the Canadian context, emphasizing how they can and must be translated in a coherent and practical way into the existing health and social care system
4. Highlight **key findings**



Overarching Themes

Building on the rich Canadian experience

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

Recognizing the centrality of engaging persons living with dementia (PLWD) and their caregivers in a meaningful and respectful manner

- Acknowledging the rights of PLWD 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



Provincial Plans

1999, 2017 – Ontario

2002, 2014 – Manitoba

2002, 2017 – Alberta

2002 – Newfoundland

2004 – Saskatchewan

2009 – Quebec

2012, 2016 – British Columbia

2015 – Nova Scotia

Forthcoming (Public Consultations On-Going) – New Brunswick



Overarching Themes

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 people 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-centered, 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



Overarching Themes

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

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

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 unique opportunities

Creating, seeking out and utilizing evidence/ 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 adaptation



Introduction – Key Findings

- 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 PLWD 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.



Introduction

- d) Canada can be proud of the contributions made by the multiple provincial dementia strategies already developed & 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 & contributions of provincial dementia plans will enhance Canada's engagement with international organizations.
- f) Given the geographic, demographic & cultural diversity across Canada, a national plan that facilitates learning & collaboration is most likely to be well received within Canada.
- g) Current evidence & emerging best practices must be translated in a coherent & practical way for use in the health & social care system.



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.



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.



Prevention, Awareness and Living Well with Dementia

- a) 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.
- b) 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.



Improving Health and Social Care for Persons Living with Dementia

- a) Despite improvements, many PLWD 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-centered approach, rather than a disease-centered approach, is essential to providing good care. Relationship-centered care extends this partnership to include health and social care providers and the influences they have on each other.



Improving Health and Social Care for Persons Living with Dementia

- 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.



Improving Health and Social Care for Persons Living with Dementia

- 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.



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.



Education and Support for Caregivers

- a) The needs of caregivers vary over time. Ongoing needs assessment is essential to understanding how to support caregivers.
- b) 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.



Education and Support for Caregivers

- 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.



Education and Support for Caregivers

- e) 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.
- f) 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.



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.



Building and Supporting the Health and Social Care Workforce

- d) It is important to embed dementia care into the curriculum & practice training of all health & social care providers. Case-based/practice-based & solution-focused dementia training is most beneficial to support the application of learning in practice. Used in isolation, traditional didactic & passive strategies (lecture-style meetings, in-services, printed materials and guidelines, and passive materials) are ineffective strategies for increasing knowledge & confidence in dementia care.
- e) Supports for the implementation of evidence based practice and guidelines are essential for ensuring good quality care.



Research and Innovation – Challenges

“The need for a cure for dementia is pressing, but practical solutions to benefit those with the condition is also vital.”

Funding

Complex etiology

Role of biomarkers

Interventions to delay or prevent

Behavioural & psychological symptoms

Caregivers

Health & Social Services

Big Data

Assistive technology and environmental design

Assessment of the dementia strategy



Research and Innovation – Responses

Call for increased commitment to research and innovation in provincial and international dementia strategies

G8 Dementia Summit Declaration

CIHR Dementia Research Strategy

- CCNA
- International Partnerships (e.g., Alzheimer’s Disease Neuroimaging Initiative, Joint Programme – Neurodegenerative Disease Research)

Canadian Longitudinal Study on Aging – following 50,000+ Canadians aged 45-85 at entry for 20+ years

AGE-WELL (Networks of Centres of Excellence) – creation of technologies and services that benefit older adults



Research & Innovation – Current Evidence & Emerging Best Practices

Development of dementia research capabilities

- OECD report – reform regulatory and incentive frameworks/ more effective collection and use of data (Big Data approaches)
- England’s roadmap – 10-point action plan to stimulate needed research
- Training – CCNA, create career opportunities
- Better return on investment – maximize value/ minimize waste (e.g., redundant studies, inappropriate methodologies)

Engaging persons living with dementia as partners in research

- SPOR (Strategy for Patient Oriented Research)
- More than being research subjects – recognize challenges/ not excuse to refuse to try; emerging area

Setting priorities

- US (65+ milestones), UK (5 general goals/ 30 recommendations) – the problem isn’t potential research targets/ its focusing



Setting Research Priorities – Depends Who You Ask

Alzheimer Society of Canada – persons affected (those with dementia, friends, care partners, health/ social care providers) – J Am Geriat Soc 2018, 66: 1608-12

- Questions about the cure and biological mechanisms of dementia, as well as descriptive questions (e.g., descriptive epidemiology), were outside the scope of the study

Dementia researchers and clinicians from around the world – reduce global burden by 2025 - Lancet 2016, 15: 1285-94

Considered similar areas but divergent priorities

- Stigma – first in ASC list/ 32nd on WHO list
- Dementia-friendly communities 8th/ 26th on WHO list
- Four of the top 10 for researchers and clinicians dealt with prevention/ 14th and 16th
- Inclusivity/ equity in setting priorities important but melding all these perspectives will be challenging



Setting Research Priorities

Canadians Affected by Dementia

- Addressing stigma
- Emotional well-being
- Impact of early treatment
- Health system capacity
- Caregiver support
- Access to information/services post-diagnosis
- Care provider education
- Dementia-friendly communities
- Implementing best practices
- Non-drug approaches to managing symptoms

2016 WHO Research Priorities

- Timely and accurate diagnosis
- Diversifying therapies
- Brain health/ dementia prevention communication strategies
- Vascular contributions
- Influence/ interactions of risk and protective factors
- Interventions for risk factors
- Models of care & support in community
- Educating/ training/ support formal and informal carers
- End-of-life care



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 to maximize benefit and avoid waste.



Research and Innovation

- 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.



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:
 - A compelling central vision and direction balanced with flexibility to adapt to local needs and contexts,
 - A long-term commitment and appropriate resources to achieve identified priorities, as well as research and evaluation,
 - A concrete action plan with targets and timelines,
 - Consideration of the various approaches to implementation that have been used, including both widespread and phased implementation, and
 - Planning at the outset for continuous evaluation of the dementia strategy to inform implementation and modifications as needed.
- c) National dementia standards of care along with an accreditation process will complement quality improvement efforts that align with dementia strategy priorities.



Commissioned Reports

<https://www.cahs-acss.ca/wp-content/uploads/2019/01/Report-Addendum.pdf>

- a) Rural dementia care
- b) Alzheimer's disease policies in OECD countries
- c) Indigenous populations
- d) Ethnic minorities and recent immigrants
- e) Young onset
- f) Sexual minorities
- g) Developmental disabilities
- h) Technology



Thank you
