

BRIEF



CANADIAN
NURSES
ASSOCIATION*

DEMENTIA IN CANADA: RECOMMENDATIONS TO SUPPORT CARE FOR CANADA'S AGING POPULATION

Brief prepared for the Senate Standing Committee on Social
Affairs, Science and Technology

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INTRODUCTION

Dementia in Canada is increasing to the point of being called an epidemic.¹ Our aging population and the population-wide growth in risk factors have led to a greater number of individuals with dementia and a corresponding need for care² — both in health-care facilities and the community.

Caring for persons with dementia requires a collaborative, multiprofessional approach that is centred on patients and their families. As Canada's largest group of health-care providers, nurses are an essential part of this approach.³ The Canadian Nurses Association (CNA), representing almost 139,000 registered nurses across Canada, has a long history of protecting and improving care for vulnerable populations while highlighting nurses' central role in achieving better health outcomes for Canadians. On this basis, CNA can offer useful input on dementia's impact on patients and families and what it means for nursing practice.

An essential step for improving outcomes in dementia care (and many other conditions) is to do a better job of integrating health-care delivery.

The current approach, bogged down by sectors and health professionals working within their own silos, is no longer serving Canadians. According to the OECD (Organisation for Economic Co-operation and Development):

- ▶ Canada ranks 10th out of 11 member countries on health-system performance and return on investment.⁴
- ▶ Canada's health-care system is lagging behind other OECD countries on key indicators of performance and sustainability.

While these findings are troubling enough, Canada's health system is also facing pressures from shifting demographics and population-wide increases in risk factors for chronic disease.⁵ Recent discussions about how best to meet these challenges have focused on how to better integrate health-care services. Generally, this means managing and delivering these services so that "clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system" (World Health Organization, 2008, p. 1).⁶



Yet, crucial⁷ to a high-performing, integrated health system are principles that can apply in all health-care settings, including:

- ▶ Accessibility
- ▶ Public engagement
- ▶ Collaboration and coordination
- ▶ The best use of technologies
- ▶ Emphasis on health promotion and chronic disease prevention and management

In keeping with these principles of integration, CNA proposes that the federal government use them to address all current and potential national health strategy initiatives, such as:

- dementia
- palliative care
- home care
- Indigenous health
- mental health
- medical assistance in dying
- pharmacare
- environmental health

To this end, CNA recommends that the standing committee support a national commission for integrated health-care for Canadians.

This commission could set guiding principles, similar to those in *Principles to Guide Healthcare Transformation in Canada*⁸ (developed by CNA and the Canadian Medical Association in 2011), that support the Institute for Healthcare Improvement's Triple Aim objectives: "better care for individuals, better health for populations, and lower per capita costs."⁹ With a 10-year mandate (2017-2027), the commission could help develop and apply these integration principles through the upcoming health accord. Aligning these principles on the accord's foundation would increase efficiency, reduce duplication and greatly improve the experience of health care for Canadians.

In terms of solutions on dementia, we believe meeting the challenge of the rising number of persons living with dementia must take into account Canadians' strong desire to age at home¹⁰ and nurses' proven ability to develop cost-effective care models that help them do precisely this. In addition, we must expand patient-centred care, improve quality of life and reduce adverse outcomes. With such issues in mind, CNA recommends the following plan for dementia care:

- ▶ Develop a national strategy that includes prevention, early detection and management
- ▶ Use community-based health supports for people living with dementia



- ▶ Shift to dementia-friendly care in acute and long-term health-care facilities
- ▶ Provide financial support and education for caregivers
- ▶ Offer support and education for nurses and other health-care professionals

BACKGROUND

WHAT IS DEMENTIA?

Dementia is a set of symptoms that are the result of disorders affecting the brain. The disease is progressive and neurodegenerative; that is, it worsens over time as brain cells incur damage and die. Symptoms may include memory loss, impairment in reasoning and problem solving, and changes in mood and behavior that rob a person of his or her independence. While Alzheimer's is the most common form of irreversible dementia, other forms, like vascular dementia caused by strokes, are all too common.¹¹

Risk factors can be grouped into two basic categories: modifiable and non-modifiable (e.g., aging and genetics). Modifiable risk factors include having a history of clinical depression, type 2 diabetes, head injuries, strokes, high cholesterol, high blood pressure, arthritis, inadequate intellectual stimulation, obesity¹² and environmental factors.¹³

THE IMPACT OF DEMENTIA IN CANADA

The rising prevalence of dementia in Canada corresponds to the disease's emergence as a leading health-system challenge around the world.¹⁴ Simply put, Canada is facing a dementia epidemic¹⁵ that affects about 500,000 people and costs the health-care system \$15 billion each year. Projections show that the number of persons living with dementia will more than double within 20 years, to 1.1 million. Yet, since we also anticipate the demand for long-term care (LTC) to increase 10-fold, the economic burden of dementia care is expected to surpass \$153 billion.¹⁶

People living with dementia are not the only ones affected by the disease. The challenging course it imposes includes long-term physical, emotional and financial burdens for caregivers and an impact on health-care providers, the health-care system and society at large.¹⁷ These broader effects of dementia's mental deterioration, which happen over a period of 3 to 20 years, require that we adopt a multipronged strategy of prevention, diagnosis and management.



IMPROVING CARE FOR VULNERABLE POPULATIONS

CNA's long history of advocating for care, funding and support to assist vulnerable populations includes system changes that would enable seniors to age at home and experience a better quality of life. These recommendations are based on the principles of primary health care, which emphasize:

- ▶ The promotion of health and wellness
- ▶ The prevention of injury and illness¹⁸
- ▶ Social justice¹⁹ and a fairer distribution of society's resources
- ▶ Integrating care across the continuum²⁰

1. A National Strategy for Dementia Care

Because Canada has no national strategy for dementia care, Canadians are facing gaps in service and a lack of continuity and collaboration as provinces and territories try to meet the growing demand. Yet, as the Alzheimer Society of Canada points out, "the scale, impact and cost of dementia mean that no single province or organization can address [it] on their own."²¹ A national dementia strategy would address these gaps by establishing a coordinated approach and organizing the country's research, resources and knowledge.²² Comparable OECD countries, such as Australia and the U.K., have already implemented such strategies.²³

The Alzheimer Society of Canada is not alone in advocating for a unified approach to dementia research, prevention and care. For several years, organizations across the country (including CNA) have advocated for a national strategy — a strategy 83 per cent of Canadians endorse.²⁴

The submission of two private members bills, from the NDP (C-356)²⁵ and Conservative (C-233)²⁶ parties, offer additional support for establishing such a strategy.

CNA's recommendations

1. That the federal government support the Alzheimer Society of Canada's call for a comprehensive national dementia strategy as a key measure in addressing the growing impact of dementia on Canadians, the health system and the economy.²⁷
2. That the federal government collaborate with provincial and territorial health ministries to support dementia prevention, early diagnosis and management that lead to positive outcomes for people who have the disease and better support for the families and friends who provide their care.²⁸



3. That the federal government promote Canadians' health and well-being as they age by supporting chronic disease prevention and management and by increasing the capacity of the system to help frail and vulnerable populations, as outlined in the Alzheimer Society of Canada report: *Rising Tide: The Impact of Dementia on Canadian Society*.²⁹

2. Shift to Community Care

Canadians' preference to age in place (i.e., in their home of choice) presents an opportunity to improve outcomes for persons with dementia. Patients at home can be diagnosed sooner and managed for longer periods, if we improve health-system coordination. Early detection is key, since it allows us to take advantage of health promotion and disease management strategies, most of which can be done in a person's home or community setting. In fact, such diagnosis and management are essential for mitigating the impact of dementia on patients, caregivers and the health-care system.^{30,31} Yet, to achieve this goal, we must enhance the capacity of community-based care.^{32,33,34,35,36,37,38}

Basing dementia care in the community means better patient outcomes and savings for the health-care system. But we must enhance community-based care to meet the growing demand. Forecasts show that the 55 per cent of persons with dementia (65 and over) living in their own homes in 2008 will grow to 62 per cent by 2038. This growth corresponds to over half a million people who will need community- and home-based care in 2038³⁹ — with a projected shortfall of 157,000 residential care beds by that time. Community care must therefore be prepared to meet this demand.

Already, access to dementia care is being delayed because it is mostly delivered by geriatric nurses and physician geriatric specialists, which are in short supply. To meet the growing demand, we urgently need a coordinated, national system of geriatric care⁴⁰ with a greater capacity and expertise in dementia care — including more timely access to early screening and assessment.^{41,42} Anticipating this need, innovative models are now being used to educate and prepare nurses for primary care screening and cognitive assessments. This promising practice will help improve access to early diagnosis and the development of care plans. In addition, new models are being implemented that include care coordination roles for registered nurses (similar to those used in cancer care services).⁴³



CNA's recommendations

1. That the federal government invest in increasing the number of nurses in community-based care and providing education on dementia care to meet the growing burden on our system (further discussed in Section 5, below). Of Canada's 406,817 regulated nurses (registered nurses, nurse practitioners, licensed practical nurses and registered psychiatric nurses), just 14.6 per cent are employed in community care, while 14.7 per cent are in long-term or residential care and 58.6 per cent are in acute care.⁴⁴
2. That the federal government provide funding to home- and community-based care for the long-term implementation of best practices for home care of older adults. These resources should be geared at spreading and sustaining best practices over time, as this has been shown to improve patient, provider and health-system outcomes.⁴⁵
3. That the federal government support the shift to community-based care with innovation, both through technology that helps keep individuals with dementia active, engaged, healthy and safe^{46,47,48} and through progressive care-delivery models.
4. That the federal government innovate and invest in infrastructure to prevent and manage dementia in the community and provide the support caregivers and families need. Built environments that keep seniors active can help prevent dementia^{49,50} and keep seniors active in their communities. Dementia-friendly community initiatives can also improve quality of life.⁵¹
5. That the federal government move away from the policies and funding models that drive acute, episodic and hospital-based care and increase accessible community-based care approaches that emphasize health promotion, chronic disease prevention and management, and client-centred, accessible, team-based care. The government should also include a needs-based top-up for each province and territory based on demographics and population health priorities.⁵²

3. Create Dementia-Friendly Care

While early detection is crucial for enabling persons with dementia to remain in their homes and communities longer, many are diagnosed at later stages and have multiple comorbidity and complex care needs. Often, persons with dementia are diagnosed only after being hospitalized for a different condition. Given that chronic disease is also a risk factor for dementia, a lot of seniors who need hospital care will have diagnoses that are complicated by cognitive decline. Yet, hospitalizing persons with dementia can mean



negative outcomes for patients — as well as longer, more expensive hospital stays,^{53,54} which are significant issues given the rates of dementia in our hospital system. As an example, in a 1,000-bed district hospital, 660 will be occupied by older adults. Among these individuals, in an average day:

- ▶ 135 will have dementia
- ▶ 290 will have a mental disorder
- ▶ 127 will have depression
- ▶ 87 will have delirium
- ▶ 30 will have other major mental health issues⁵⁵

While a shift to community-based prevention and care for persons with dementia is optimal, some hospitalization and long-term care may be unavoidable. Under this structure, both the health-care system and its staff need to be well prepared in dementia-friendly care to help patients in hospital, so they can return to their place of residence with as little disruption as possible.

Dementia-friendly care is an umbrella term for an evidence-based approach to using the appropriate assessment, intervention and environment to reduce negative patient outcomes. Research shows that such reductions occur when health-care providers have the knowledge and skills to identify unmet needs and use suitable behavior-management interventions.⁵⁶ In addition, dementia-friendly care can lessen the inappropriate use or overuse of antipsychotic medication, which means fewer falls and premature admissions to long-term care and less time in hospital.⁵⁷

For LTC settings, there is a projected shortage of 157,000 beds by 2038.⁵⁸ With only 14.7 per cent⁵⁹ of regulated nurses working in LTC, a corresponding shortage of human resources will occur in relation to the growing number of people who will require care.

CNA's recommendations

1. That the federal government support a shift to dementia-friendly facilities. Apart from the need to establish the required number of beds and staff, facilities need effective design elements⁶⁰ to enhance accessibility. Examples include coloured privacy doors that help patients orient themselves to unfamiliar surroundings and signs developed for those who are cognitively impaired.^{61,62}
2. That the federal government support the expansion of innovative dementia care models that use evidence-based methods to improve outcomes in various types of facilities, from acute or long-term care to residential villages.



Examples of Dementia-Friendly Care Innovations

Mid Cheshire Hospitals NHS Foundation Trust (U.K.) has made their hospital environment more accessible to those with cognitive impairments.

Colville Manor in P.E.I., which provides dementia care in a home-like atmosphere with 24-hour nursing supervision and person-centred care that promotes independence.⁶³

SIPA⁶⁴ in Montreal, which provides integrated care for elderly clients with disabilities. SIPA's increased accessibility for health and social home care has reduced the need for alternate hospital beds by 50 per cent. Researchers have concluded that the SIPA model has the potential to reduce hospital and long-term care facility use without higher costs.⁶⁵

Hogewey (Holland), a village created for persons living with dementia staffed (in part) by trained geriatric nurses and caregivers, which offers patients a balance between autonomy, safety and health.⁶⁶

4. Financial Support and Education for Caregivers

Caring for patients at home improves health outcomes and can reduce health-system spending by redirecting clients to more affordable home- and community-based care services.⁶⁷ Over six million employed Canadians are also caregivers.

Canada's caregivers assume an unpaid role to care for someone with an illness or disability.⁶⁸ Caregivers are an integral part of dementia care in the community, though they have little formal support, high rates of burnout and often experience financial hardship.⁶⁹ Being a caregiver often means taking leave from paid work to care for a family member or loved one. Lost wages for dementia caregivers totalled \$5 billion in 2008, a figure projected to reach \$55 billion in 2038.⁷⁰

Family members or friends who are caregivers for older adults living with depression or cognitive impairments have high rates of distress,^{71,72} while about one-third of family dementia caregivers report symptoms of depression.⁷³ Offering respite, counselling, and other support services will be essential to the continuation of caregiving in the home. Such programs have been able to delay the admission of persons with dementia into long-term care by a median of 557 days.⁷⁴



Financial support to caregivers will help alleviate the burden individuals and families experience, keep individuals with dementia in the community longer and meet Canadians' stated desire to be age at home. Research shows that both financial and educational support to caregivers improves outcomes and reduces costs. Increased support for caregivers was also specifically mentioned in the prime minister's mandate letter to the minister of health.⁷⁵

CNA recommendations

1. That the federal government assist provinces and territories to assess and disseminate best practices for improving the quality of life for persons with dementia and their caregivers. Such practices include greater integration of care, chronic disease prevention and management, and community support and care aimed at minimizing the impact on families.⁷⁶
2. That in 2017 the federal government convene a consultation with employer stakeholders to develop federal tax measures that protect workers' incomes while providing supports and guarantees for workplace leave protection and respite care to employers and employees, including those who are family caregivers.⁷⁷ These measures would reduce productivity losses for public and private sector employers while recognizing and supporting the needs of working caregivers.
3. That the federal government increase the health system's capacity to manage dementia with initial and annual funding of \$30 million over four years. For those affected by dementia, such funding would strengthen surveillance, early diagnosis, awareness, the coordination of caregivers and the delivery of care services.⁷⁸

5. Support and Education for Nurses and Other Health-care Professionals

To ensure appropriate prevention and management of dementia, standardized, evidence-driven dementia care is required across professions.⁷⁹ As nurses make up the largest group of health-care providers in Canada, and will likely be responsible for a large part of formalized dementia care across all sectors, it is imperative that nurses receive routine, specialized education on dementia in their undergraduate programs and beyond. And it is not only nurses' care that would benefit from specialized education:

- ▶ The Japanese Nursing Association have an advanced education program to prepare managerial staff in a number of health and long-term care settings.⁸⁰



- ▶ In 2014, England’s NHS pledged that all staff members would have specialized dementia education by 2018. This program helps staff identify symptoms early, understand how to interact with those who have dementia and determine the most appropriate care.⁸¹

In addition to providing adequate education and support for existing nurses, it is essential for Canada to prepare by having an appropriate supply of nurses who will work collaboratively with other disciplines across the spectrum of dementia care. Therefore, as the number persons with dementia requiring LTC rises⁸² (from 183,268 in 2008 to 442,682 in 2038), LTC nursing positions should increase accordingly. So too should the number of nurses in the community, with the growing demand of persons with dementia who prefer to age at home. With about 59,000 regulated nurses working in community health and about 60,000 in long-term care,⁸³ current staffing levels are unlikely to meet the care needs of the nearly one million persons with dementia who will require long-term and community care by 2038.⁸⁴

CNA’s recommendations

1. That the federal government provide educational resources for health professionals across all sectors that will enhance dementia care knowledge and skills.
2. That the federal government assist the provinces and territories in developing and disseminating information to health-care professionals and the general public on the importance of early intervention, prevention and management for Alzheimer’s disease and other forms of dementia.⁸⁵

CONCLUSION

CNA is calling on the federal government to invest in a national vehicle that will apply the fundamental principles of integration to create a seamless pathway for dementia care. This vehicle will serve as the foundation for developing and implementing all health-related strategies.

CNA believes dementia care requires immediate federal government action. With 1.1 million Canadians expected to be living with dementia by 2038, at an annual cost of \$153 billion and requiring 756 million hours of care, the time for acting on dementia is now. By adopting the recommendations in this report, the standing committee can address the growing need for prevention, diagnosis and care through a national dementia strategy that supports the goals of better health, better care and better value for all Canadians.



ENDNOTES

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