

# Policy and Practice Note/Note de politique et pratique

## Dementia Care in Canada: Nursing Recommendations

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### RÉSUMÉ

Au Canada, la prévention et la prise en charge des démences ont atteint un point tournant. Bien que le taux de diagnostic des démences soit encore bas, le nombre de personnes qui en sont atteintes continue d'augmenter. Les politiques canadiennes en matière de soins de santé ont fait en sorte qu'un plus grand nombre de personnes avec démence vivent à la maison, où les soins sont principalement assurés par la famille, des amis ou des proches. Cette *Note de politique* présente un aperçu d'un document conjoint de l'Association canadienne des infirmières et infirmiers en gérontologie (AIIG) et de l'Association des infirmières et infirmiers autorisés de l'Ontario (AIIAO) devant le Comité sénatorial permanent des affaires sociales, des sciences et de la technologie. Le document expose le cadre contextuel et les recommandations pour les soins liés à la démence au Canada dans cinq domaines clés : les ressources du système de santé, la formation des prestataires de soins de santé, le logement, les partenaires de soins et l'intégration des soutiens offerts en services sociaux et de santé. Dans le cadre de ces cinq domaines clés, des interventions en matière de santé et de politiques sociales ont été examinées.

### ABSTRACT

The prevention and management of dementia in Canada is at a crossroads. Despite the low diagnosis rates, the number of persons living with dementia continues to increase. Yet, Canada's health care policies have resulted in more people living with dementia living at home, and with most of their care being provided by family, friends, and significant others. This *Policy Note* provides an overview of a joint submission from the Canadian Gerontological Nursing Association (CGNA) and the Registered Nurses' Association of Ontario (RNAO) to the Standing Senate Committee on Social Affairs, Science, and Technology. This article outlines the background and recommendations in five key areas of dementia care in Canada: health system resources, education and training of health providers, housing, care partners, and the integration of health and social supports. Based on these five key areas, a number of health and social policy interventions are discussed.

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## Introduction

The need to prevent and manage dementia in Canada is critical. In 2014, it was estimated that 402,000 Canadians lived with Alzheimer's disease and related disorders (ADRD) (Pelletier, Robitaille, Mcrae, & Toews, 2017). By 2031, the number of Canadians living with dementia will increase to 1,400,000 (Alzheimer Society of Canada, 2015). Dementia impacts people of all socio-economic classes, genders, and ethnicities, and is not just a disease of older persons. The impact of dementia can be felt on all levels of society. The stigma associated with dementia is significant, creating further barriers to the access and delivery of high quality care and services. Therefore, there is an urgent need to enhance the well-being of individuals living with dementia.

In April 2016, the Canadian Gerontological Nursing Association (CGNA) and the Registered Nurses' Association of Ontario (RNAO) delivered a joint submission to the Standing Senate Committee on Social Affairs, Science, and Technology to inform its review on dementia in Canada. The CGNA is Canada's national organization representing gerontological nurses (registered nurses [RNs] and registered/licensed practical nurses [LPNs]), and promotes gerontological nursing practice across national and international boundaries. In 2010, the CGNA developed care competencies for gerontological nursing, including competencies to provide care for older adults living with dementia. The RNAO is Ontario's professional association representing RNs, nurse practitioners (NP) and nursing students. RNAO has extensive expertise in the area of dementia care from an evidence-based policy and practice perspective. Although RNAO focuses on Ontario, this joint submission aimed to represent a Canadian perspective. RNAO and CGNA appreciated the opportunity to inform the Standing Senate Committee about the reviews and reports on dementia care in Canada. This policy note presents CGNA's and RNAO's perspectives on dementia care in Canada. The authors acknowledge that this policy note does not include the voices of persons living with dementia and their care partners. Their perspectives were presented

in a separate submission to the Standing Senate Committee.

This *Policy Note* provides an overview of the submission, including background and recommendations in five key areas requested by the committee that related to dementia care in Canada: health system resources, education and training of health providers, housing, care partners, and integration of health and social supports.

## Health System Resources

Dementia is a highly complex illness that requires a response to biomedical, psychosocial, and ethical challenges (Aminzadeh, Molnar, Dalziel, & Ayotte, 2012). Dementia has various pathophysiologies and manifests through a range of symptoms in which individuals experience memory deficits, reduced thinking skills, and an inability to perform activities of daily living (Giebel, Sutcliffe, & Challis, 2015). This multifaceted illness requires a multipronged approach including various nursing, medical, and social supports. Moreover, it requires health human resources personnel equipped with the knowledge and skills to support persons living with this chronic disease. People living with dementia who exhibit symptoms according to behavioural and psychological frameworks often require thorough assessments and tailored care plans to effectively meet their needs (Registered Nurses' Association of Ontario, 2016a). Person-centred care approaches and collaboration among the person, the person's family, and the health care team is essential. These approaches require adequate staffing, proper training, and organizational support (Fossey et al., 2014; Lawrence & Kinn, 2012).

## Medicare

Effectively supporting Canadians living with dementia, as well as their care partners (family members, neighbours, friends, and volunteers), requires resources in both institutions and the community. In 2012, approximately 5,400,000 caregivers provided care to seniors, and caregivers provided longer hours of personal care

to those living with dementia (Turcotte & Sawaya, 2015). Older adults who live in care facilities are mostly women who have serious health conditions (Turcotte & Sawaya, 2015). Most individuals who provide care do so in a household separate from theirs (62%). Other caregivers provide care to older adults who live with them (16%), who live in care facilities (14%), or who live in supportive housing (8%) (Turcotte & Sawaya, 2015). Therefore, more people living with dementia are living in their communities, with most of their care being provided by care partners. There is strong evidence for the cost effectiveness of home care and the importance of home support services as a substitute for the more expensive services provided in long-term care (LTC) facilities (Hébert et al., 2007; Hollander, 2001; Tam-Tham, Cepoiu-Martin, Ronksley, Maxwell, & Hemmelgarn, 2012). Despite the need for home care services, Canada's spending on home care is among the lowest of all member countries of the Organization for Economic Co-operation and Development, with only 3.5 per cent of public health expenditures directed towards home care (Health Canada, 2006). Home health care and support services, along with pharmaceuticals, are not currently included under Medicare, and this represents a significant gap.

Canada has a cherished and valuable public asset that uniquely positions it to effectively respond to the growing numbers of people living with dementia, as well as their care partners: its publicly funded and not-for-profit health system. The time to expand Medicare through parallel legislation to the Canada Health Act is overdue. Tommy Douglas's vision of Medicare (Evans, 2010) was to cover primary care, drugs, dentistry, vision care, home health care, and most other health services. In 1997, the National Forum on Health called for protection of the single-payer model and "expanding publicly funded services to include all medically necessary services and, in the first instance, home care and drugs". In 2002, the Romanow Commission recommended expansion of Medicare to include home health care. Canada's Parliamentary Committee on Palliative and Compassionate Care called on the federal and provincial governments to implement a right to home care, LTC, and palliative care, for all residents of Canada, equal to the current rights in the Canada Health Act.

These expansions are essential to provide effective holistic, person-centred care to Canadians living with dementia and their families. As the federal and provincial/territorial health ministers are engaged in dialogue regarding the future of the health system, it is imperative that a new Health Accord be negotiated. A new Health Accord must enforce the principles and spirit of the Canada Health Act, and have effective increases in funding to include expanded services in community care. Moreover, it is critical to reinstate the Health Council of Canada (HCC), eliminated by the previous federal government, to serve as an independent national agency that monitors and assesses Canada's health system.

In 2017, Canada launched its national dementia strategy to address the scale, impact, and cost of dementia (Alzheimer Society of Canada, 2017). A national home health care framework as part of Medicare, along with standards to support its implementation, would ensure that all Canadians have access to appropriate, publicly funded, high-quality, not-for-profit, timely services and a consistent relationship with a care provider, regardless of where they live or the environment in which the care is provided. Such a framework could include features such as a single entry point through interprofessional primary care, comprehensive assessment of persons living with dementia and their care partners, and integrated care co-ordination that includes the broad determinants of health (Registered Nurses' Association of Ontario, 2014). Social determinants of health are "the conditions in which people are born, grow, live, work and age, and these circumstances are shaped by the distribution of money, power and resources at global, national and local levels" (World Health Organization, 2018). The five determinants of health that are generally recognized include: biology and genetics, individual behaviour, social environment, physical environment, and health services (CDCP, 2014).

In tandem, national organizations like the HCC must be reinstated and empowered to disseminate innovative practices and recommendations to sustain Medicare. The HCC could be tasked with reviewing the delivery of care and support services for persons living with dementia and their care partners, and use its finding to disseminate best practices and areas for improvement.

#### **Dementia Care in Canada: Recommendation 1**

The federal government collaborates with the provinces/territories to negotiate a new multi-year Health Accord that:

- Enforces the principles and spirit of the Canada Health Act;
- Increases federal-provincial/territorial funding;
- Advances interprofessional primary care with registered nurses, nurse practitioners, and all other health professionals working to full scope;
- Reinstates the Health Council of Canada; and
- Expands Medicare to include all medically necessary areas, starting with universal home care and pharmacare without co-payments or user fees.

**Dementia Care in Canada: Recommendation 2**

Ensure that the appropriate supply, distribution, and utilization of registered nurses and nurse practitioners exists in Canada to effectively support persons living with dementia, including specialized roles such as geriatric emergency management (GEM) nurses, psychogeriatric specialists, and clinical nurse specialists in gerontology and/or mental health.

**Dementia Care in Canada: Recommendation 3**

Support efforts to advance a timely diagnostic process for persons experiencing dementia, including the full utilization of registered nurses and nurse practitioners and access to specialized assessment services.

*Health Human Resources*

An adequate supply, distribution, and utilization of health providers working together in teams are critical for responding to people living with dementia. Canadians receive the best care when it is provided through an interprofessional team in which all members are enabled to practice to the full extent of their knowledge, skills, and competencies. The previous Health Accord made interprofessional primary care a staple, and this resulted in substantial progress throughout the country (Health Canada, 2006).

Although a variety of health providers are required to care for people living with dementia and their families, nursing comprises the largest regulated health care workforce, and nurses are deployed across all sectors of the health system (College of Nurses of Ontario, 2015). More RNs and NPs are needed in all areas of Canada's health system to support persons living with dementia, including public health, primary care, hospitals, home health care, and LTC settings. A recent report from the Canadian Institute for Health Information (CIHI) shows that in Ontario, there were 711 RNs for 100,000 people compared with 841 per 100,000 across Canada (Registered Nurses' Association of Ontario, 2016b). These findings are significant because they question the ability to adequately meet the care needs of persons living with dementia in a way that is person centred.

In Canada, less than half of individuals with Alzheimer's disease and/or their caregivers report being told of their diagnosis (Lee & Weston, 2011). Most dementia diagnoses are unrecognized and undocumented in primary care (Paraskevaidi, Martin-Hirsch, & Martin, 2018; Lee et al., 2017). Dementia diagnoses can take months to years to confirm, and studies have demonstrated that in the early stages it is pervasively under-detected, under-diagnosed, under-disclosed, under-treated, and under-managed (Aminzadeh et al., 2012). Delays occur between the time that dementia is suspected and the time that it is reported to a provider, during the wait to see a specialist, and while undergoing the testing period (Aminzadeh et al., 2012). Access to a timely diagnosis of dementia is problematic, and

memory clinics have long wait lists. Often, a diagnosis of dementia is needed to trigger necessary community resources and supports that enable one to live well with dementia. More attention must be given to improving the diagnosis of dementia; and the full utilization of NPs and RNs will be critical to supporting this.

Residents moving into, and currently living in, LTC are older with increasingly complex co-morbid conditions (including dementia) compared with the resident profile years ago (Hirdes, Mitchell, Maxwell, & White, 2011). To meet resident care needs, knowledgeable and skilled care providers are necessary to provide competent, dignified, and high-quality care to frail older people and their families (Gaugler, Yu, Krichbaum, & Wyman, 2009; Zimmerman et al., 2005). There is a great need to increase the number of RNs and NPs employed in LTC settings (McGilton et al., 2016). The RN and NP have a strong influence on the resident and staff outcomes (Decker, 2008; Dellefield, Castle, McGilton, & Spilsbury, 2015; Zimmerman et al., 2005). Providing direct care and working with LPNs and personal support workers (PSWs) (or health care aides [HCAs] or personal care assistants [PCAs]), the effectiveness of the RN and NP has been shown to be pivotal in determining the overall quality of care provided. Evidence suggests that a higher ratio of RNs to other nursing personnel in LTC improves quality of life outcomes for residents (Dellefield et al., 2015), reduces the probability of hospitalization (Decker, 2008), and improves the quality of work environments for staff (McGilton, Hall, Wodchis, & Petroz, 2007). The Ontario government has shown leadership by committing to funding 75 NP positions in LTC homes to improve outcomes for residents and decrease transfers to hospitals (Ministry of Health and Long-Term Care, 2015). This is a positive step forward that needs to be expanded within the province and throughout the country.

A growing momentum is emerging across Canada to expand the role of the RN, as the largest regulated health workforce, to include the authority to prescribe medications and communicate a diagnosis within their knowledge, skills, and competencies. The Government of Ontario (2016) has committed to expanding the

scope of the RN to include independent RN prescribing. This means that RNs will not have to rely on restrictive protocols causing delays in urgently needed orders for medications to prevent negative health outcomes for people living with dementia (antibiotics for a urinary tract infection). Independent RN prescribing is complementary to authorizing RNs to order diagnostic testing and communicate a diagnosis (urinary tract infection), which are needed to facilitate continuity of care (Kooienga & Wilkinson, 2016). This will support interprofessional teams to deliver timely and appropriate care to persons living with dementia, thus reducing the need for unnecessary emergency department utilization.

## Education and Training of Health Providers

### *Education and Training of RNs and NPs*

Better prepared RNs and NPs can have a substantial impact on care quality if they work to their full scope of practice (McAiney et al., 2008). Nurses encounter persons living with dementia in all types of settings. System-wide gerontological curriculum content is needed for entry-to-practice to optimize RNs' and NPs' knowledge and skills, and reduce ageism so they can deliver comprehensive and high quality care and services. In addition, moving away from a medically focused care approach to a social model of care is needed.

Evidence suggests a general lack of understanding of gerontological competencies among both nursing students and faculty (McCleary et al., 2014). As a result, the field of gerontology is often deemed undesirable by many health and social service professionals. In particular, negative attitudes and ageism towards gerontological practice remains a long-standing issue within nursing education (Hirst, Lane, & Stares, 2012). Some studies show that nurses and nursing students believe that the field of gerontology inhibits advancement in nursing skills and practice (Boscart, McCleary, Huson, Sheiban, & Harvey, 2016). Moreover, nurses perceive geriatric nursing to be overly complex because of the need to understand and respond to age-related health complexities (Gould, Dupuis-Blanchard, & MacLennan, 2013).

In addition, gerontological content has historically been deemed insufficient in nursing education (McCleary et al., 2014). Reasons for this deficiency may include faculty not being supportive or not having sufficient gerontological expertise, gerontological content being regarded as an extra requirement, and assumptions that such content is integrated throughout the program. Hirst and Lane (2016) suggested that nursing curricula must consider the needs of the older population, and that students should be educated on older

adults' psychosocial and mental health needs as well as common geriatric syndromes and dementia symptom frameworks (Yanamadala, Wieland, & Heflin, 2013). Faculty members must also be equipped with knowledge about older adults in order to teach about older adults and provide proficient clinical supervision (Hirst & Lane, 2016; Smith, Spadoni, & Proper, 2013). A system-wide focus on the content of mandatory curriculum, as well as the refinement and application of knowledge and skill is required for entry-to-practice and licensed RNs and NPs to deliver comprehensive and high quality care and services. Meaningful dementia care requires shifting towards a social model of care. This involves engaging everyone, including the person living with dementia and that person's care partners to make meaningful decisions (Dupuis, Wiersma, & Loiselle, 2011). Moving away from a problem-focused or deficit-based care model towards person-directed and social care models optimizes quality of life for persons living with dementia and fundamentally changes their experiences (Dupuis et al., 2012). This culture change movement should become an integrated care approach not only in the curriculum of future care providers, but also as the standard of practice of care. Also, this culture change should make its way in regulatory and policy changes.

To support RNs and NPs in practice, continuing education design, curriculum content, and delivery are important. This learning needs to be (1) Interactive and multimodal with an emphasis on the application of the new knowledge; (2) reinforced and refined at the point of care by strategies, tools, and mentorship; and (3) supported by trained champions or clinical experts and by leadership and administrators (Registered Nurses' Association of Ontario, 2016a).

Example areas of much needed initial and ongoing education include:

- (1) Fostering gerontological nursing knowledge to include attitudes and knowledge conducive to the care of persons living with dementia, strengthening advocacy and leadership in the care for people living with dementia, and supporting people living with dementia and their families with advance decision making at end of life;
- (2) More knowledge of the personal expression framework and understanding the behavioural and psychological symptoms of dementia, to allow for better communication skills to engage persons living with dementia;
- (3) Understanding the importance and boundaries of care partner engagement;
- (4) Recognizing the importance of chronic disease management for those living with dementia;
- (5) Preventing and managing abuse and neglect of older persons and advocating for the delivery of person-directed care;

- (6) Understanding and appropriately responding to the generational differences among people living with early-onset dementia;
- (7) Promoting meaningful activities for those living with dementia;
- (8) Being aware of the social and financial support systems for people living with dementia and their care partners in a variety of settings;
- (9) Understanding the differences between dementia and other mental/medical issues;
- (10) Accurately documenting behaviours exhibited by people living with dementia; and
- (11) Effectively responding to people living with dementia as their physical and cognitive needs and resultant behaviours change.

Another challenge facing provider agencies is ensuring that health care providers are basing their practice on the best available evidence. Tremendous efforts and resources go into the development of best practice guidelines, tool kits, and recommendations. Unfortunately, health care providers are not always aware that these are available, nor do they always apply the best evidence available. In a systematic review of training manuals for dementia care, Fossey and colleagues (2014)

professional designations across the country, and are known as personal support workers, health care aides, resident care assistants, or nursing assistants. UCPs assist with older adults' activities of daily living (ADL), all provided in the context of social interaction and relationships. These activities represent several opportunities to observe people living with dementia, monitor the effects of care and treatments, and report these observations to supervising registered nursing staff for further investigation (Heckman et al., 2014).

The wide diversity in training for UCPs across this country has resulted in substantial variability in UCP skills and competencies. Several studies conducted in LTC settings indicate that UCPs face many barriers in providing quality care to residents, including a lack of knowledge (Castle, Engberg, Anderson, & Men, 2007) and limited training and orientation when starting a new position (Stone & Dawson, 2008). This situation, in turn, leads to lost opportunities to observe, monitor, and report observations made during care provision, particularly as persons living with dementia often present with complex and non-specific symptoms.

#### **Dementia Care in Canada: Recommendation 4**

All registered nurses complete mandatory gerontology and chronic disease management training in entry-to-practice curriculum including a dedicated placement in geriatrics.

#### **Dementia Care in Canada: Recommendation 5**

Support efforts to enable independent registered nurses prescribing in Ontario and use this as a framework for expansion across the country.

#### **Dementia Care in Canada: Recommendation 6**

All unregulated care providers complete mandatory geriatric and Chronic Disease Management training as part of their certification that includes:

- Communication and documentation skills;
- Interprofessional collaboration and teamwork;
- Effective responses to personal expressions and responsive behaviours; and
- Person- and family-centred care and services.

found a major disconnect between education in training manuals and best practices for dementia care; 80 per cent of the programs were of variable quality and only 2 per cent were evidence based. It is imperative that health care providers across all settings are maintaining, augmenting, and refining their competencies in caring for people living with dementia according to best practices.

#### *Education and Training of Unregulated Care Providers (UCPs)*

UCPs work alongside RNs and R/LPNs to provide day-to-day assistance in a variety of settings ranging from residential care to the community (Simoens, Villeneuve, & Hurst, 2005). These UCPs have different

## **Housing**

As previously identified, living well with dementia means remaining in one's own home and community; therefore, efforts should be made to support persons in doing this. This requires access to appropriate home and community supports and assistance for care partners.

To enable people with dementia to live at home longer, some services are absolutely required. Well-organized home health care services and sufficient and suitable day programs are important staples of supporting aging at home and providing care partners with the resources and supports needed (Forbes et al., 2008a; Landi et al., 2001). Specifically, day programs providing care and services for older Canadians living

with dementia need to be age, culturally, spiritually, and gender appropriate and should be offered in rural, suburban, and urban areas (Herron & Rosenberg, 2016). Currently, these services are limited, with scattered availability and delivery across the country. Furthermore, it is difficult, and at times impossible, to find out what services are available for what costs and in what area. As a result, decision making and patient choices are hindered because of limited access

areas; (5) regulation—cost, quality, and safety can be limited; and (6) long waiting lists. In asking care partners and people living with dementia to identify aspects of an “ideal” housing model for persons living with dementia, responses included: a model that resembles an ordinary home or neighbourhood, a space that feels and looks like home, and a care model that accommodates varying levels of abilities (Canada Mortgage and Housing Corporation, 2015).

#### Dementia Care in Canada: Recommendation 7

Develop accessible care models for people living with dementia, which accommodate various levels of care needs and abilities, and resemble living at home.

to information on these services (Hicks, Sims-Gould, Byrne, Khan, & Stolee, 2012)

Supportive housing is an example of congregate living that links affordable housing to staff who can provide a comprehensive and co-ordinated package of services and programs to help individuals maintain their optimal level of health and well-being (Canada Mortgage and Housing Corporation, 2015). Such models of living are said to promote mental and physical health by encouraging independence, providing opportunities for socialization and friendship, ensuring a secure living environment, and providing opportunities for meaningful activities and social engagement (Lum, Sladek, Ying, & Holloway Payne, 2007).

When a person living with dementia is no longer able to live safely and independently at home, he/she may consider transitioning to a more supported care setting (e.g., supportive housing, assisted living) to avoid premature or inappropriate institutional care. Although each situation is different, this decision is often influenced by health and safety issues for the person living with dementia, the person’s care partner, and/or the people around that person. Some factors to consider when transitioning a person living with dementia to a supportive living environment include cost, environment, amenities, provision of meals, services, staff and management, location, culture, and religion.

Current challenges that impact housing for persons living with dementia include: (1) inadequate resources—not enough supportive housing and assisted living available, creating significant waiting lists or inappropriate stays in acute care or LTC; (2) financial constraints—persons and families that are living with dementia often have significant financial constraints, which requires affordable housing; (3) vulnerability—some persons living with dementia may have physical and cognitive impairments that can increase the risk of being taken advantage of (e.g., financial abuse); (4) northern/rural (non-urban area)—access to effective housing options may be limited in these

#### Care Partners

The role of care partners (family members, friends, neighbours, and volunteers) is critical to support persons living with dementia. Care partners provide 20 hours or more of support per week for someone living with dementia (Pauley, Chang, Wojtak, Seddon, & Hirdes, 2018). Currently, care partners provide up to 90 per cent of the in-home health care for persons living with dementia. Although the costs for people requiring care at home are 40 per cent to 70 per cent less than those for people living with dementia in residential facilities (Hollander, 2001), health care costs will rise substantially if care partners are not adequately supported when caring for persons living with dementia (Hux et al., 1998). Of greater concern, however, is that if care partners are inadequately supported, quality of life and care will drop significantly. Health care providers should offer effective support and resources to those caring for people living with dementia because caregiver stress can be detrimental to caregivers’ physical and psychological well-being (Jensen, Agbata, Canavan & McCarthy, 2014; McKechnie, Barker, & Stott, 2014).

Although it is often a highly rewarding experience, compared with care partners of those older adults who retain cognitive abilities, care partners of a person living with dementia are more likely to experience chronic health problems, depression, and social isolation. Female care partners report difficulties including insensitive interactions with health care providers, ineffective or inappropriate resources, and an overall lack of support (Neufeld, Harrison, Hughes, & Stewart, 2007). Male care partners reported similar unsupportive interactions. Care partners seek a contact person who would be consistently available over time in case of questions or emergencies, relate with sensitivity to their changing situation, recognize and facilitate the caregiving experience in relation to multiple sources of support, and be their advocate (Neufeld & Kushner, 2009). In a mixed-methods study

(Forbes et al., 2008b) examining the role of home health care services in dementia care, care partners reported most frequently that they were not eligible for home health care services, or that services were discontinued by health care providers because of inconsistency of professional care providers.

Other issues identified by care partners included insufficient information on the disease process and a lack of guidance on how to support expressions and behaviours that result from diminished cognition. Additional concerns identified were inappropriate treatments and provision of care; lack of respectful, gender-sensitive, and culturally sensitive care; inflexible programs, especially for employed care partners; and the high cost of supportive services (Forbes et al., 2008b). The abovementioned challenges indicate the importance of a care model that ensures continuity of care, person-centred care approaches, and care provider consistency.

across various types of services (Hollander, 2006). This is possible if there is a shift in values, from the current focus on acute care to an inclusive vision of home- and community-based care that puts more emphasis on prevention and chronic care management (Shamian, Shainblum, & Stevens, 2006) and includes not only medical care but also social care, health promotion, and disease/disability prevention (Chappell, 2000).

The highest performing health systems in the world have primary care as their foundation, and use it to co-ordinate care delivery (Starfield, Shi, & Macinko, 2005). Interprofessional primary care delivery that utilizes teams of regulated health providers practicing to full scope supports alignment between health and social supports. It is critical that health systems across Canada make primary care their foundation. Ontario's Health Links program is a start to developing coordinated care plans to serve persons with

#### **Dementia Care in Canada: Recommendation 8**

Increase funding to long-term care homes to expand the services they offer so they become community care hubs.

#### **Dementia Care in Canada: Recommendation 9**

Amalgamate information about local services and programs under one body. Features of the services and programs should be clearly communicated to the public (i.e., provision of meal, length of session, age requirements).

### **Integration of Health and Social Supports**

Health is broadly influenced by a number of social, physical, mental, and cultural factors. The World Health Organization (2016) identifies five elements needed to achieve a state of primary health care: (1) reducing exclusion and social disparities in health (universal coverage reforms); (2) organizing health services around individuals' needs and expectations (service delivery reforms); (3) integrating health into all sectors (public policy reforms); (4) pursuing collaborative models of policy dialogue (leadership reforms); and (5) increasing stakeholder participation.

A shift is needed in Canadian health policy from a focus on individual sectors to a broader, integrated model of health and social supports. Hollander (2003a) argues that an integrated system will produce cost effectiveness (Hollander, 2003a, 2003b, 2006). The essence of the proposed model is the integration of medical, health, supportive, community, and institutional care into one system. Such a model would ensure that care continue over time and

complex needs (e.g., persons living with dementia). Health Links work to organize health and social supports around the needs of people (Rural Hastings Health Link, 2014). This initiative could be optimized and expanded by explicitly making primary care the foundation on which a health system is built. Proposals for structural reform through legislative amendments and corresponding policy changes are being considered, and these are welcomed changes that have the potential to significantly evolve the system.

Interprofessional team-based primary care models demonstrate the alignment between health and social supports. These settings enable providers to enter into long-term therapeutic relationships as a center whereby all of a person's health and social needs can be coordinated, in collaboration with service providers within the community. It is clear that persons living with dementia and their care partners want to have consistent access to a single point of contact. Primary care is the setting where this can happen.

#### **Dementia Care in Canada: Recommendation 10**

Advance federal initiatives to support provinces/territories to make interprofessional primary care teams the foundation of their health system. Locate and embed care co-ordination and dedicated care co-ordination registered nurse roles within primary care.



## Conclusion

This *Policy Note* details recommendations in five key areas related to strengthening health system resources, education and training of health providers, housing, care partners, and the integration of health and social supports to improve dementia care in Canada. Dementia requires a multifaceted approach including various medical, nursing, appropriate health human resources, and social supports. There has been an increase in people living within their communities, with service delivered by health providers and care partners. Despite the need for an increase in home care services, Canada's spending on home care is among the lowest of all member countries of the Organization for Economic Co-operation and Development. A new Health Accord has been negotiated that enforces the principles and spirit of the Canada Health Act, to deliver effective increases in funding according to national standards, and that expands covered services. Therefore, it is critical to reinstate the HCC, eliminated by the previous federal government, to serve as an independent national agency that monitors and assesses Canada's health system.

A diagnosis of dementia is needed to trigger necessary community resources and supports that enable a person to live well with dementia; however, less than half of individuals with Alzheimer's disease and/or their caregivers report being told of their diagnosis (Cheng & Lam, 2017). Therefore, there is a strong need to examine the appropriate utilization of RNs and NPs to effectively respond to persons living with dementia across the system and continuum of care. There is also a need to ensure that all providers, including unregulated providers, maintain knowledge and skills in understanding the needs of people living with dementia. This can be accomplished through adequate education and maintaining knowledge of evidence-based best practices.

Geriatric nursing is perceived to be overly complex because of the need to understand and respond to age-related health conditions and complexities (Gould, Dupuis-Blanchard, & MacLennan, 2013). A system-wide focus on the content of mandatory curriculum, as well as the refinement and application of knowledge is required for entry-to-practice and licensed RNs and NPs to deliver comprehensive care and services. Therefore, it is imperative that health care providers across all settings are maintaining and augmenting their competencies in caring for people living with dementia according to best practices, as the wide diversity in training for UCPS across Canada has resulted in substantial variability in UCP skills and competencies. In addition to health system resources and education, well organized home health care services,

and sufficient and suitable day programs are important staples of supporting aging at home and providing care partners with the resources and supports needed. Limited availability has resulted in difficulty regarding the costs and availability of services.

Currently, care partners provide up to 90 per cent of the in-home health care for persons living with dementia. If care partners are not adequately supported when caring for persons living with dementia, health care costs will rise substantially (Hux et al., 1998). Furthermore, quality of life and care will drop significantly. Such challenges accentuate the need for a care provider that ensures consistency and willingness to develop trusting partnerships with persons who have dementia and their care partners.

Issues affecting care partners include (1) uncoordinated services; (2) inconsistent structured support; (3) lack of financial support; and (4) limited options for respite care.

Lastly, a shift in Canadian health policy from a focus on individual sectors to a broader, integrated model of health and social supports is needed, as health systems across Canada make primary care their foundation. It is clear that persons living with dementia and their care partners want to have consistent access to a single point of contact, and primary care is the setting where this can happen.

It is important to note that the voice of the persons living with dementia and feedback from persons with dementia and their care partners were discussed during a separate presentation to the Standing Senate Committee. Their lived experiences are an integral part of enhancing dementia care in Canada.

These nursing recommendations (RNs, registered LPNs, NPs, and nursing students) provide a first step towards discussing necessary health and social policy interventions in dementia care. Additionally, recommendations in Canadian health care policy, the role of Alzheimer's organizations and treatments, and best practices for dementia care will be required to support those Canadians and their families living with dementia. Several of these gaps have been included in Canada's national dementia strategy (2017).

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