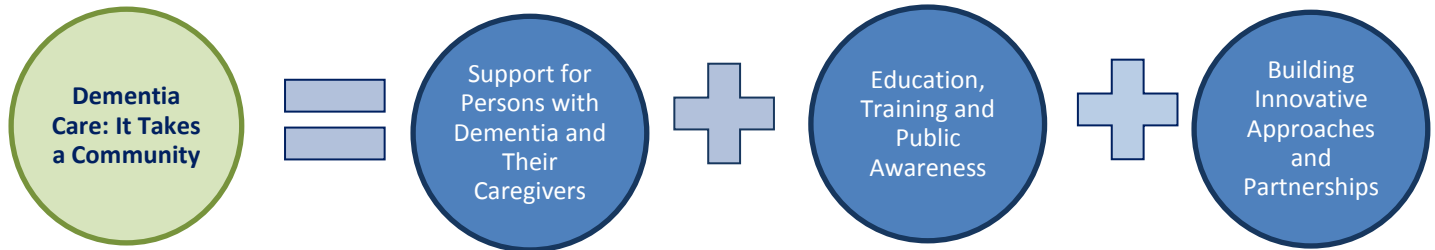


DEMENTIA CARE: IT TAKES A COMMUNITY

POLICY BRIEF

June 2015



BACKGROUND

On May 20, 2014 a group of family/friend caregivers (herein called care partners), care providers, educators, administrators, policy makers, and other professionals from the community, social service, and private sectors participated in a one day, Canadian Institutes of Health Research (CIHR, Grant No. DGE 129655) funded workshop titled: *Knowledge Translation in Dementia Care: It Takes a Community*, in Toronto, Ontario.

The primary objectives of this workshop were to: imagine an ideal dementia-friendly community; determine elements of an action plan that would assist in achieving dementia-friendly communities; create new and diverse partnerships to enhance the quality of life of persons living with dementia and their care partners; and explore ways to advocate for and advance innovative practices and policies relevant to community dementia care and support.

This **Policy Brief** is a result of this discussion and is disseminated to those who have a role to play in ensuring that people with dementia and their care partners receive the care, support, and understanding they need from their communities.

RATIONALE

The majority of Canadian seniors prefer to “age in place”¹, meaning they wish to remain in their own homes and communities for as long as possible. Care partners play a critical role in helping older Canadians “age in place” as they provide 80-90% of the care and support that is provided to seniors living at home². With the number of people living with dementia expected to double within the next 17 years, the demand for care and support in the community is anticipated to increase dramatically^{3,4}. The care demands are complicated by the fact that many care partners are struggling to balance their employment responsibilities with their caregiving responsibilities⁵⁻¹⁰.

DEMENTIA CARE – Growing Trends

Age is the greatest risk factor for Alzheimer’s disease, and the number of Canadians aged 65+ is rising.

It is estimated that between 6-15% of Canadian seniors aged 65 years and older were living with some form of dementia in 2011, and this number is expected to double by 2031.

In 2011, Alzheimer’s disease and other dementias cost the Canadian economy an estimated \$8.3 billion in direct costs alone. The out-of-pocket costs for care partners are approximately \$4,600 annually per individual living with Alzheimer’s disease and other dementias.

By 2031, the direct health sector costs of dementia are projected to be as high as \$16.6 billion.

In 2011, the estimated hours of care provided to people living with Alzheimer’s disease and other dementias was 18 million hours per week; by 2031, this is projected to rise to approximately 38.5 million.

Source: Public Health Agency of Canada. (2014). *Mapping connections: An understanding of neurological conditions in Canada*. Ottawa, ON: Author.

Having an employer who provides flexible work arrangements and/or information about and access to care partner supports and services can go a long way in maintaining the health and wellbeing of care partners¹¹.

Navigating the health and social care system can be a challenge for persons with dementia and their care partners^{3,12,13}. Often care partners do not know where to find information on community supports and services. Those living in rural or remote communities encounter significant challenges accessing home and community services due to the lack of services and other geographical constraints¹⁴⁻²⁰. In addition to the availability of timely services, ensuring the

health and social care workforce is trained in dementia care, and that the health and social care system is responsive to the needs of those with dementia and their care partners is critical. It is also important that the community at large be informed of dementia, its impacts, and how people with dementia can be supported and understood. Raising awareness about dementia among those who provide services in the local community (e.g., grocery stores, churches, taxi companies) could play a significant role in

combatting the stigma and myths surrounding this disease²¹.

Creating a dementia-friendly community involves all members of the community, government, the private sector, non-government organizations, and individuals²¹. Everyone has a role to play in creating and sustaining an inclusive community that provides care, support, and understanding to those living with dementia and their care partners.

RECOMMENDATIONS

SUPPORT PERSONS WITH DEMENTIA AND THEIR CARE PARTNERS

1. Provide support to care partners including respite and financial support (e.g., refundable tax credits, similar to Manitoba and Quebec) as well as information (e.g., care circles, blogs, self-directed portals).
2. Raise awareness among employers about the economic value of supporting employees who are balancing work and care and encourage the provision of flexible hours, paid leave or income replacement.
3. Encourage employers to provide safe work environments to support employees with early onset dementia including work place accommodation and mutually agreeable transitions to retirement.
4. Work towards the creation of an online ‘hub’ that would interconnect the health and social care systems to facilitate easy navigation by persons with dementia and their care partners.
5. Develop a national dementia care strategy recognizing the roles and responsibilities of the federal, provincial and territorial, and municipal governments.

ENHANCE EDUCATION, TRAINING AND PUBLIC AWARENESS

1. Enhance dementia education for current health and social care professionals as well as learners by creating or using existing mechanisms to share best/promising practices.
2. Help create dementia-friendly communities by raising public awareness of dementia among local service providers and others such as banks, grocery stores, churches, and taxi companies.
3. Help de-stigmatize dementia through better understanding and support for persons with dementia and their care partners.

BUILD INNOVATIVE APPROACHES AND PARTNERSHIPS

1. Build and expand on existing partnerships beyond the health and social service sector (including the private sector) to advance community capacity.
2. Examine innovative models, such as alternative housing options and health promotion interventions for people with dementia.

RESEARCH TEAM

Principal Investigator: Dr. Catherine Ward- Griffin, Professor, Arthur Labatt Family School of Nursing, Western University, and Scientist, Lawson Health Research Institute, London, ON. **Co-Investigators:** Dr. Boscart, Conestoga College; Dr. Dupuis, University of Waterloo; Dr. Kloseck, Western University; Dr. McAiney, McMaster University; Dr. Orange, Western University; Dr. Ploeg, McMaster University; Dr. Wiersma, Lakehead University; Dr. Wong, Western University; **Project Coordinator:** Nisha Sutherland; **Project Assistant:** Kay Vallee

PROJECT COLLABORATORS

Aging Brain and Memory Clinic, Alzheimer’s Outreach Services, Alzheimer Society of Canada, Alzheimer Society London and Middlesex, Alzheimer Society of Ontario, Canadian Association on Gerontology, Canadian Coalition for Seniors’ Mental Health, Canadian Dementia Knowledge Translation Network, Canadian Mental Health Association Fort Frances Branch District Mental Services for Older Adults, The Centre for Family Medicine Memory Clinic, Employment and Social Development Canada, Health Canada, McCormick Home, National Institute for the Care of the Elderly, Ontario Association of Non-Profit Homes & Services for Seniors, Ontario Association of Residents’ Councils, Ontario Health Human Resource Research Network, Ontario Long Term Care Association, Public Health Agency of Canada, South West Community Care Access Centre, St. Joseph Care Group, Victorian Order of Nurses – Middlesex Elgin, Victorian Order of Nurses Canada, Waterloo-Wellington Local Health Integration Network

Note: Participation in this project does not necessarily imply endorsement of the recommendations by all collaborating organizations.

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