

COMMUNITY DEMENTIA ACTION PLAN: DESIGNING A WAY FORWARD

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With the number of people living with dementia expected to more than double within the next 25 years^{1,2}, the demand for community living for people with dementia and their families is anticipated to increase dramatically. By 2030, it is expected that there will be over 750,000 persons affected by dementia in Canada, with approximately half of these individuals residing in the community for five or more years before transition to a long-term care home^{3,4}. A major challenge^{2,5,6,7} faced by family/friend caregivers (herein called care partners), researchers, and health policy personnel is the need to create opportunities for people with dementia and their care partners to live well, grow, and contribute to the community⁹. This has led to a call for the creation of dementia-friendly communities, where all persons with dementia feel respected and have opportunities to remain actively and meaningfully engaged in their community.

It is for this reason that a commitment was made to assist with the creation of dementia-friendly communities by developing an action plan*. The plan, underpinned by five guiding principles, has three objectives: **1) Raising Awareness 2) Creating Safe Spaces and 3) Building Partnerships and Coalitions** (See Figure 1):



Figure 1. Community Dementia Care Action Plan: Designing a Way Forward

Within the action plan, there is a concerted effort to build on the talents and resources that exist locally and also develop external partnerships across the public, private and voluntary sectors. Everyone has a role to play in creating a dementia-friendly community.

Five Principles

1. **Inclusive:** Dementia-friendly communities would involve and engage persons with dementia, acknowledging and appreciating their existing abilities and life accomplishments, and their care partners. Stigma would be eliminated and all community agencies would expand their mandate to include persons with dementia in decision-making.
2. **Connected:** Persons with dementia, care partners, organizations/agencies, and all levels of government would be connected through social networks that enable open communication and strong relationships. These open communities would actively engage persons with dementia and their care partners and work with inter-disciplinary, inter-generational, and interdependent teams that are proactive and consider the social determinants of health.
3. **Safe and Accessible:** Dementia-friendly communities require the creation of safe spaces that are both physically and emotionally accessible. Physical accessibility would mean clear and readable signs for navigation or easily accessible walking paths and roads. Accessibility also means emotional safety and freedom from discriminating and stigmatizing language. Persons with dementia should have opportunities to live a meaningful and purposeful life. These safe communities would be friendly places where everyone is accountable to ensure that safety is a priority.
4. **Informed:** Informed communities would understand, respect and involve persons with dementia and their care partners. There would be accessible education through publicity and social media platforms. A well-educated workforce would focus on creating spaces for opportunities for persons with dementia and their care partners to live well.
5. **Responsive and Adaptive:** A dementia-friendly community that is flexible to individual and community needs. Each person with dementia has unique qualities, characteristics, and needs, as do their care partners. A responsive and adaptive approach ensures that people with dementia and their care partners are respected, recognized, and included.

In sum, a dementia-friendly community is a community that does not exclude nor put obstacles in the way of people with dementia and their families. A dementia-friendly community is shaped around the growth and aspirations of people living with dementia and their families and friends. It creates opportunities for persons with dementia to remain active and meaningfully engaged in their communities, focusing on the quality of life for people with dementia, as well as quality of care. This principle-based framework was created as a guide for people to increase awareness of, and improve services for, people living with dementia. Developed for a multi-sectorial audience, we envisioned this framework to be used as a guide for people with dementia, their care partners, various levels of government, different disciplines (e.g., police), organizations (e.g., church groups) and other invested members of the community (e.g., high school students) to customize their own dementia-friendly communities. To help create dementia-friendly communities, *three objectives* must be addressed: **Raising Awareness, Creating Safe Spaces and Building Partnerships/Coalitions.**

1. Raising Awareness

Eliminating Stigma

Initiate a campaign to inform the public about the experiences of people with dementia and their family members. The goal would be to 'normalize' the life experiences of people living with dementia, which ultimately would lead to the de-stigmatization of dementia. Employ specific strategies to raise public awareness: use one consistent message tailored for different audiences; share narratives from people with dementia and their family members; initiate a change in the language used to describe persons with dementia (e.g., move away from discriminating and stigmatizing language); challenge negative assumptions; and create messages that promote positive images and living well with dementia.

Enhancing Education

Creating education and training opportunities for the community that include persons with dementia, care partners, the public, healthcare providers, elementary and high school students, and students from all disciplines (medicine, nursing, social work). Educational strategies should ensure persons with dementia have opportunities to be actively and meaningfully engaged in their communities.

2. Creating Safe Spaces

- Foster supportive environments in which persons with dementia and their care partners have opportunities to be active and involved in the community.

- Work towards interconnecting systems to facilitate ease of navigation. Collaborate with persons with dementia and care partners in decision-making about health care services and support. Ensure that people receive extensive follow-up after diagnosis.
- Create supportive workplaces for persons with early onset dementia (e.g., safe environment for disclosure, workplace accommodation and a mutually agreeable transition to retirement).
- Encourage employers to promote care partner-friendly workplaces that support employees who are balancing work and care responsibilities (e.g., raising awareness, understanding the experience, and offering flexible hours, paid leave or income replacement, job sharing, work from home).
- Develop supportive and accessible physical environments (e.g., navigation, design, transportation).
- Foster opportunities for persons with dementia to grow, contribute, and engage in the community.
- Create spaces for peer support groups, social media, user-friendly web sites or other innovative ways to connect with and learn from others within the community.
- Ensure easy access to programs and services that support care partners in their roles.
- Develop policies to financially support care partners (e.g., tax credits or compassionate care benefit program).

3. Building Partnerships/Coalitions

- Foster partnerships that include persons with dementia and their care partners. Facilitate involvement and collaboration with adult day programs, recreation centres, all levels of government (e.g., municipal, provincial, federal, citizen groups), various disciplines (e.g., health care workers, employers, urban planners, bus drivers, taxi drivers, police), businesses, organizations (e.g., Alzheimer Society, Canadian Home Care Association) and systems (e.g., ministries including health, transportation, employment) to address issues. These authentic partnerships/coalitions should foster a collaborative, interactive approach to address the five principles of a dementia-friendly community.
- Consider information from all partnerships/sources. Include and integrate agencies and organizations such as Community Care Access Centres, Local Health Integration Networks (LHINs), Alzheimer's Society (regional, provincial, national), Canadian Mental Health Association, Canadian Home Care Association and others.

RESEARCH TEAM

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PROJECT COLLABORATORS

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DEMMENTIA FRIENDLY RESOURCES

[Alzheimer's Disease and Related Dementias Planning Framework](#)

[Alzheimer's Disease and Related Dementias Planning Framework - Toolkit](#)

[Creating a Dementia Friendly York](#)

[Dementia Action Alliance - UK](#)

[Dementia Friendly Communities - Alzheimer Australia](#)

[Dementia Friendly Communities - Alzheimer Scotland](#)

[Dementia Friendly Communities - Alzheimer Society of Ireland](#)

[Dementia Friendly Communities - Alzheimer Society UK](#)

[Dementia Language Guidelines - Fight Dementia Australia](#)

[Dementia Friendly Communities - Innovations in Dementia CIC](#)

[Dementia Friendly Communities - UK Department of Health](#)

*On May 20, 2014 a group of 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. This action plan was developed in response to a commitment made by the workshop participants.