

## Dementia: A Call to Action

### Background:

Dementia is an umbrella term that refers to a variety of brain disorders. Different physical changes to the brain cause different dementias.

Alzheimer's disease is the most common form of dementia, accounting for almost two-thirds of all cases. It is irreversible and eventually fatal. Other dementias include vascular dementia, Lewy body dementia, fronto-temporal dementia (including Pick's disease), Creutzfeldt-Jakob disease and other rarer forms of dementia.

Dementia is progressive. Its causes are not fully known, and there is still no cure or effective treatment to prevent the disease. Progression varies greatly from person to person and can last between eight to 10 years – or even longer.

Symptoms worsen over time and include: loss of memory, changes in judgment and reasoning, difficulty performing familiar tasks, problems with language and changes in mood and behaviour.

Age is the biggest risk factor for dementia. After age 65, the risk doubles every five years. Dementia can occur in people in their 50s, 40s and even in their 30s. Dementia can be present in the brain for up to 25 years before symptoms appear.

### Quick Facts:

- Over 22,000 Manitobans have dementia and by 2038, it is expected to reach over 40,700. <sup>1</sup>
- Last year alone, there were over 4,500 new cases of dementia in Manitoba. <sup>2</sup>
- Forty-three per cent of Manitobans have a family member or close friend with Alzheimer's disease or another dementia. <sup>3</sup>
- Three out of four Canadians know someone with dementia. <sup>4</sup>
- Women represent 72 per cent of Canadians living with Alzheimer's. <sup>5</sup>
- For every person with the disease, two or more family members provide care. Women account for 70 per cent of family caregivers. <sup>6</sup>
- The total economic burden of dementia in Manitoba is close to 1 billion dollars and is expected to grow to more than 4.4 billion by the year 2038. <sup>2</sup>

### The Alzheimer Society of Manitoba is asking the Government of Manitoba to:

**Action 1: Create a more dementia aware, inclusive community.**

**Action 2: Support community dwelling people with dementia to enable them to age in place.**

**Action 3: Commit to developing long term care settings that reflect current and emerging best practice in built environments and person centred-care.**

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<sup>1</sup> Banibrata Roy, Manitoba Bureau of Statistics, July 2015

<sup>2</sup> Rising Tide: The Impact of Dementia in Manitoba 2008 – 2038, 2010

<sup>3</sup> Probe Research Inc., Manitoba Ominibus, May 2015

<sup>4</sup> Nanos, 2013

<sup>5</sup> Rising Tide: The Impact of Dementia on Canadian Society, 2010

<sup>6</sup> Sherry L. Dupuis; Tim Epp, Bryan Smale, Caregivers of Persons with Dementia: Roles, Experiences, Supports, and Coping, MAREP 2004

## **Dementia: A Call to Action**

### **Action 1: Create a More Dementia Aware, Inclusive Community**

This action addresses the need for the general public to be more informed about dementia and how to be an inclusive, supportive, dementia friendly environment for people who are experiencing the effects of mild cognitive impairment and those who are diagnosed with dementia.

#### **What we know:**

- 42 per cent of Canadians are aware that memory loss affecting daily activities is a warning sign, only 12 per cent could identify changes in personality as a warning sign. Very few of the respondents could name any of the other eight signs.
- 64 per cent of women said they're worried or somewhat worried about developing Alzheimer's disease or another form of dementia compared to 52 per cent of men.
- 31 per cent of Canadians said what they fear most about Alzheimer's disease is loss of mental or physical ability; 25 per cent were concerned about losing their independence and becoming a burden on others.
- Canadians are divided about whether people can live well with dementia. 47 per cent disagree or somewhat disagree that people can live well with Alzheimer's disease or another form of dementia, while 47 per cent agree or somewhat agree that it is possible to live well with dementia.<sup>1</sup>

#### **Recommended Responses:**

- Promote recognition of the warning signs of dementia and brain health strategies that may be preventative.
- Support the Dementia Friends™ initiative and broaden the scope of Age Friendly Manitoba to include resources and strategies that communities can implement to create dementia friendly communities.
- Partner with the Alzheimer Society of Manitoba and community organizations to implement Minds in Motion®, a program that promotes physical activity, socialization and cognitive stimulation for people with dementia and their family care partners in communities across Manitoba.

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### Action 2: Support for Community Dwelling People with Dementia to Enable Them to Age in Place

This action addresses the need for people with dementia who are community dwelling and their family care partners to have greater support in order to age in place with the greatest possible physical, emotional and cognitive health.

#### What we know:

People with dementia and the family members who support them want the person they care for to live in their home and community of choice for as long as possible.

Providing care to a person with Alzheimer's disease or dementia is the fifth most common caring giving responsibility. Family caregivers make vast contributions to the care and support of the person with dementia through tasks inclusive of transportation, household work including meal preparation, coordinating appointments, managing finances, assisting with medical treatment and providing personal care.

- 32% of caregivers of people with dementia spend greater than 10 hours per week providing assistance.
- 55% of caregivers indicate that they are worried or anxious and 51% indicate that they are tired.<sup>1</sup>

Family caregivers of people with dementia are more prone to developing depression and anxiety disorders, with female caregivers being at greatest risk.<sup>2</sup>

Family caregivers of people with dementia experience compassion fatigue as they find themselves constantly vigilant concerning the quality of care the person is receiving and due to the reality of coping with inconsistently delivered care due to inconsistent staffing.<sup>3</sup>

In order to meet the societal and personal goal of aging in place, people with dementia need services that are compassionate, skilled and accessible in their community. It is also vital to recognize the importance of assisting family care partners to remain healthy as they fulfill the demands of caregiving. Services provided must recognize and respond to the integrated needs of the person with dementia and their care partner(s.)

#### Recommended Responses:

- Design, promote and implement consistently across Manitoba options for Home Care delivery that allow for flexible implementation such that the program is enabled to meet the needs of people with dementia and their care partners.
- Set standards for mandatory Home Care in-service education that includes a requirement for annual updating about best practices in dementia care.
- Create longer stay respite options that are more reflective of home-like environments and that are able to engage the person in activities of daily living that are strengths based and cognitively stimulating.
- Increase the availability of Supportive Housing in communities throughout rural Manitoba.
- Increase the number of "rent geared to income" spaces in Supportive Housing throughout all areas of the province in order to increase accessibility to all Manitobans.
- Implement a caregiver assessment model that insures that the needs of the care partner are considered when developing the care plan for the person with dementia.

<sup>1</sup> Statistics Canada, General Social Survey, 2012

<sup>2</sup> Alzheimer Disease International, Dementia: A Public Health Priority, 2012

<sup>3</sup> Beth Perry, Exploration of Factors Contributing to Compassion Fatigue in Family Caregivers Providing Care to Older-Adult Relatives, 2012

## Dementia: A Call to Action

### **Action 3: Commit to Developing Long Term Care Settings that Reflect Current and Emerging Best Practice in Built Environments and Person-Centred Care**

This action addresses the need for people living with advanced dementia to have living environments that support them with quality psychosocial and physical care.

#### **What we know:**

As the number of people living with dementia is increasing the current number of long term care spaces is falling short of the demand. People are facing lengthy waits at home after their need for care has increased and family members are finding care stressful.

Some people with dementia are awaiting placement in hospitals because of the complexity of their care exceeding what family care partners are able to provide. Because hospital settings are purpose built to facilitate medical care, people with dementia who experience lengthy hospital stays may become deskilled while awaiting placement in a personal care home because the hospital setting lacks a home like environment that promotes the person's abilities, strengths and interests.

Following moving to a personal care home, people with more advanced dementia often live approximately 18-24 months as they experience greater health complexity that leads to end of life.

It is observed that well planned physical environments promote person-centred care that leads to quality of life for residents. It is also noted that the most important attribute of a care setting is compassionate, caring, person-centred staff members who believe that they "work in the person's home; the person does not live in their workplace."<sup>1</sup>

The goal of quality of life for people with dementia who reside in long term care can be achieved through integration of commitment to provide living spaces that exemplify best practice and to prioritize development of a care staff that is committed to person-centred care.

#### **Recommended Responses:**

- Plan new personal care homes and upgrade existing environments to respond to emerging best practice in building standards and principles.
- Develop policies and procedures to facilitate an integrated approach to movement of individuals between providers of care inclusive of Home Care, Acute Care and Long Term Care.
- Align personal care home standards with principles of person-centred care so as to move from task based care to care that recognizes the person's uniqueness and understands the world from the person's perspective.
- Continue support of dementia care education for all staff of long term care homes.
- Inaugurate a dementia care education initiative for staff of acute care sites.

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<sup>1</sup> Alzheimer Society of Canada, PC P.E.A.R.L.S.® 7 elements of person-centred care, 2014