

Alzheimer Society of Canada
Creating a culture change in long-term care homes for people with dementia
and their families from a person-centred perspective

Project plan overview -April 2012

Preamble

The Alzheimer Society of Canada (ASC) has an obligation to people at *every stage* of dementia - including helping healthy people stay healthy right through to end of life. One can argue that people living with dementia at the late and end of life stages of the disease are the Alzheimer Society's most vulnerable clients. One can further argue that ASC's obligation to Canadians living with dementia is most urgent when it is to people who are, for the most part, unable to speak for themselves.

Consequently, in 2008, ASC made the decision to embark on a "culture change" initiative that would focus on the needs of people with dementia living in long-term care homes and their family members through a person-centred approach. This approach is beneficial for all people with dementia regardless of the stage of the disease or the setting where they live and is based on the values of dignity and respect, information sharing, participation, and collaboration.

Most people with dementia want to live in their own homes for as long as possible. The reality is, however, that many will move to a long-term care home. Fifty-seven percent of seniors living in a residential care home have a diagnosis of Alzheimer's disease and/or other dementia¹, and 70% of all individuals diagnosed with dementia will die in a nursing home². While ASC's initiative focuses on working with others to improve the experiences of people with dementia living in long-term care homes, the process and outcomes of this work are intended to inform conversations about quality of life throughout both the disease and health care continuum.

The culmination of the first phase of this initiative was the launch in 2011 of the document, [Guidelines for care: Person-centred care of people with dementia living in care homes](#) (January 2011). This document, which summarizes current evidence-based guidelines for care of people with dementia living in long-term care, has served as a platform on which we are basing our enquiries into how person-centred care can be provided in a nursing home environment. Stakeholders from diverse walks of life have helped to shape the steps we are now taking to learn from long-term care home management, staff, residents and their families about their experience of person-centred care. What we hear will be shared with others so as to encourage a 'different conversation' about how a person-centered approach can make it possible for residents, families and staff to have 'the best day possible.'

Project objectives

- Work with others to make person-centred care (PCC) the norm - for people with dementia living in long-term care (LTC) homes.
- Learn from LTC homes who are delivering PCC to create a practical, user-friendly guide to help other homes implement PCC.
- Use these findings to develop advocacy and policy plans to address systemic obstacles and enablers to PCC.

¹ Canadian Institute for Health Information, *Caring for Seniors with Alzheimer's Disease and Other Forms of Dementia*, August 2010.

² Mitchell S, Teno J, Miller S, Mor V: *A national study of the location of death for older persons with dementia*. JAGS 2005, 53:299-305.

Overview of major project phases

(Timelines are approximate)

1. Preparation phase (Winter 2012)

Identify six long-term care homes situated across Canada which are believed to be providing person-centred care on a sustained basis to their residents with dementia.

The homes selected are credible, geographically representative, and also reflect the various opportunities and challenges faced by the Canadian LTC sector, including funding, personnel, setting, and socio-demographic profile of people with dementia and their families.

2. Market research phase (Spring 2012)

a) Conduct one-on-one interviews and focus groups in two long-term care homes that are potential users of the guide to get a sense of the type of guide that would be most helpful to them in implementing person-centred care in their homes.

b) Conduct market research in the six selected homes to learn what managers, front-line staff, families, and residents think is key in a “successful” culture change to PCC. This research will help identify:

- Key defining elements of PCC that are in place, why or how the homes chose these elements (over other ones) and how the homes go about providing them on a continuing, sustained basis.
- How family members personally are involved in, and contribute to both the planning for and provision of PCC. What are the resulting benefits to their family member and to themselves?
- “Internal” and “external” challenges/roadblocks the homes face in implementing PCC and specifically how they go about overcoming each.

3. Output phase (Summer - Fall 2012)

The major output from the work in the previous two phases will be a guide for how to provide person-centred care in long-term care homes. This guide will include such things as essential elements of person-centred care, experiential advice on how to implement these elements, and lessons learned from others who have gone before.

We will attempt to enlist partners in change throughout this project, i.e., key management in the selected homes who would be willing to act as mentors to other homes that are using the guide to implement PCC.

A final Steering Committee meeting will be held to:

- Present the guide, marketing plan and other outputs from this initiative; and
- Provide input into a framework for future Alzheimer Society advocacy and policy plans to address systemic obstacles and enablers for PCC.