

Guidelines for Care:

Person-centred care of people with dementia living in care homes

Executive Summary

January 2011

"You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die."

Saunders, 1976.

Alzheimer*Society*

This document is a summary of the *Guidelines for Care: Person-Centred Care of People with Dementia Living in Care Homes* framework, available at www.alzheimer.ca.

The Alzheimer Society is the leading, nationwide health organization for people affected by dementia in Canada. The Society is a principal funder of Alzheimer research and training, provides enhanced care and support to people with the disease, their families and their caregivers, and is a prominent voice within all levels of government.

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ISBN 978-0-9733522-2-1

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EXECUTIVE SUMMARY

Currently over 500,000 people live with dementia in Canada. More than 60% of these individuals have Alzheimer's disease. The 2009 Alzheimer Canada report *Rising Tide: The Impact of Dementia on Canadian Society* predicts that as baby boomers age, the number of people with dementia in Canada will rise steeply so that by 2038 there will be about 1.1 million people with dementia in Canada. This will have a profound impact on many aspects of Canadian society.

Dementia is a syndrome consisting of a number of symptoms that include a reduced ability to perform familiar tasks, impairment of memory, judgment and reasoning, and changes in mood and behaviour. Some dementias are caused by treatable conditions such as depression, thyroid disease, infections or drug interactions. However, treatments are not yet available for the progressive, irreversible, dementias in which nerve cells in the brain become sick and eventually die. Because there is no cure, the focus of care for people with dementias like Alzheimer's disease has been on supporting individuals and their caregivers throughout the course of the disease.

The Alzheimer Society believes that people with dementia have the right to enjoy the highest possible quality of life and quality of care. The Society believes that each person with dementia is an individual, regardless of stage of the disease and that care should be individually tailored to their unique needs, interests, habits and desires. In order to achieve this goal, the Alzheimer Society of Canada looked for evidence-based research that shows how to successfully implement person-centred programs and practices in long-term care homes. The result of this research is the *Guidelines for Care Framework*, which includes the input of people with dementia, family caregivers, researchers, educators, long-term care home staff, and various stakeholders.

The *Guidelines for Care Framework* has been developed to ensure that people with dementia are engaged in meaningful relationships which are based on equality, understanding, sharing, participation, collaboration, dignity, trust and respect.

The Alzheimer Society hopes that this Framework will influence the culture of care homes and encourage care home staff to recognize the individuality of people with dementia in the following ways:

- Ensure that people who work in care homes understand what a person-centred philosophy of care means and are able to practice it.
- Make sure that relationships and interactions with people with dementia are respectful.
- Focus on maintaining, supporting, and/or restoring the independence of the person living with dementia.
- Develop strong bonds with family members of people with dementia and engage them in activities whenever possible.
- Provide quality care to all residents with dementia regardless of their cultural background, age or mental ability.
- Anticipate the needs and reactions of people with dementia and adjust individual, social and environmental factors to reduce negative behaviours.
- Encourage and support persons with dementia to make choices in keeping with the person's lifelong values, preferences, and interests.

The Alzheimer Society believes that the *Guidelines for Care* Framework will provide two pathways to change the way care is experienced by people with dementia living in long-term care homes: advocacy to influence the policies, standards, and funding for person-centred care practices, and practical tools to support long-term care home staff in delivering person-centred care.

The *Guidelines for Care: Person-centred care of People with Dementia Living in Care Homes* Framework consists of the following sections:

What does a person-centred philosophy mean?

Our most important objective is to ensure that a person-centred philosophy of care is well understood and put into practice in care homes in order to improve the quality of care and the quality of life for people with dementia. The provision of dignified care must become part of the inherent culture of every long-term care home.

What does person-centred care look like in a care home?

Person-centred care is a philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment. Person-centred care should be incorporated into all aspects of care regardless of the resident's condition or stage of the disease. A person-centred care home values partnerships among care home staff, people with dementia and their families that will lead to the best outcomes and enhance the quality of life and the quality of care of people with the disease. Services and supports are designed and delivered in a way that is integrated, collaborative, and mutually respectful of all persons involved, including the person with dementia, family members, caregivers and staff.

Ensuring family inclusiveness

Family and friends play an integral role in helping the person with dementia to have a “good day” by familiarizing staff with the person's likes and dislikes and prior ways of being. It is critical for staff to receive training around working collaboratively with families and recognizing what a move to a long-term care home represents for families.

Extending a person-centred philosophy through end of life

The overall goals of palliative and end of life care are to improve the quality of living and dying for people with dementia and to minimize unnecessary suffering. The person-centred philosophy of end of life care provides comprehensive comfort care to the person with dementia at a late stage as well as support to their family when attempts to cure the illness are not possible. It is crucial that care home staff work together with the person with dementia and the family to provide the medical, emotional, and spiritual support needed.

*The Alzheimer Society believes that the practice guidelines contained in the *Guidelines for Care* Framework can improve the quality, appropriateness and cost-effectiveness of care for people with dementias and their caregivers. Fostering a person-centred approach to care will improve the quality of life of people with dementia and their families in long-term care homes in Canada.*