

Caring for People with Dementia at End of Life



Introduction

The Alzheimer Society of B.C. believes that people with dementia need good quality care at the end of their lives. People with dementia, their families, friends, and caregivers also need support and information at this time. Once a person develops dementia their symptoms will worsen over time. Although most people with dementia will live in a care facility toward the end of their lives, care facilities in B.C. do not have programs to support end of life dementia care. People with dementia need an active compassionate approach at the end of their lives. This compassionate approach must be sensitive to each person's personal, cultural and spiritual values, beliefs and practices.

People with dementia and their families need to:

- Understand the disease;
- Talk about what is most important to the person with dementia;
- Put their legal affairs in order;
- Decide who will help the person with dementia make health care decisions;
- Learn how the family can get the information and support they need; and
- Ask for the care they need from the health care system.

Recommendations

The Alzheimer Society of B.C. makes these recommendations to the Ministry of Health Services, health authorities, and health care providers to improve end of life dementia care.

Person-centred care:

Person-centred care focuses on the person with dementia and not on the disease. Person-centred care means working to understand how the person with dementia is experiencing the care environment.

People with dementia deserve high quality care.

- People with dementia need support and education early in the illness. Family physicians need to help families understand what to expect throughout the journey with dementia.
- Family physicians need to refer people to the Alzheimer Society of B.C. at the time the diagnosis is made.
- Health care providers must learn about and understand what is most important to the person with dementia and to see them as an individual. The health care system must value each person's human rights and choices and not try to make people fit

into pre-existing systems. People with dementia, their families and caregivers need care that is person-centered.

- Government, health authorities and health care leaders need to value good quality care and it is critical that good quality end-of-life care for people with dementia and their caregivers be required in the entire care delivery system in the province.
- British Columbia needs a strategy providing leadership and leading the way to an improved end-of-life experience for all citizens, including people affected by dementia.

Listen to the voice of people living with dementia.

- People with dementia and their families and caregivers are the experts in living with dementia. Their voices are critical in planning for improvement.
- People with dementia and their families and caregivers must be included as part of the health care team and be involved in planning and decision-making about health services and programs.

People affected by dementia need support to plan for their care early on in the dementia journey.

- People with dementia need to talk to their caregiver about the kind of end of life care they want, as early on in the disease process as possible.
- Health care providers need to make sure the person with dementia and their caregiver know what to expect at the end of life. Referring people to the Alzheimer Society of B.C. will help.
- Coming to an understanding about what needs to happen at the end of life will lessen stress in a time of a crisis. This is true for the person with dementia, the family, the caregiver as well as the health care providers.
- Preparing for the ongoing dementia journey most often helps the person with dementia and their family and caregiver have confidence in their decisions about the kind of end of life care they desire.
- End of life care must include support for families and friends before and after the death of the person with dementia.

Health care providers need to learn about how to give the best dementia care.

- All health providers in all health care settings need up-to-date education about dementia care. Currently, the education curriculum for most health care providers does not include enough relevant information about providing good quality dementia care.
- Care aides provide the majority of hands-on care and there is an urgent need for this group of care providers to get a solid foundation in dementia care.
- Health care providers need to learn the importance of knowing the background, religion, psychological and spiritual needs of the person with dementia.

The spiritual needs of people at the end of their lives need to be looked after.

- It is critical that health care providers understand the religious needs of the person with dementia.
- Spirituality may be expressed in many different ways. Health care providers need to understand what's important for the person with dementia and their families.
- Health care providers must not make assumptions about the spiritual or religious needs of the people they care for.

The person with dementia needs to get the right care at the right time. Health care providers need assessment tools that prompt them to check the needs of the person with dementia.

- Many people with dementia have pain but do not get pain relievers. Health care providers need a checklist that reminds them to look for signs of pain.
- It is not easy to predict time of death for people with dementia. The health care system needs to invest in research to better help health care providers understand how to predict the approach of death, thus help health care providers to know when to give end of life care. With experience and appropriate education however, health care providers can learn about the symptoms to look for and to better predict when a person is close to the end of their life.
- Aggressive care at the end of life is rarely the best way to care for a person with dementia. Health care providers need to understand why certain kinds of care are not good options for people with dementia at the end of their lives.
- The B.C. government requires the use of an assessment tool called the MDS for residential care facilities and the RAI-HC for assessing home health care needs. These tools could be more effective in helping help health care providers work with families to make end of life health care plans for people with dementia.