Palliative and End-of-Life Dementia Care

People with dementia can be in the terminal stage of their illness for several years. As dementia advances into the late stages, it becomes increasingly difficult to recognize or distinguish evolving palliative or end-of-life care needs from the symptoms of late stage dementia disease. If palliative needs are not recognized clinically, and symptoms and behaviours (e.g., restlessness, agitation, etc.) are thought to be simply part of the dementia journey, persons with dementia may die without adequate attention to their physical, psychological, social and spiritual care needs.

For this reason a palliative approach is best used throughout the later stages of dementia.

What is a palliative approach?

A palliative approach to care is focused on improving the quality of life of persons with life-limiting conditions, and their families. It is provided in all health care settings. It involves physical, psychological, social and spiritual care. The palliative approach is not delayed until the end stages of an illness but is applied earlier to provide active comfort-focused care and a positive approach to reducing suffering. It also promotes understanding of loss and bereavement.

When using a palliative approach for persons with dementia, one would assume that the person with late stage dementia is in the last stages of their life and can benefit from a consistent care approach that affirms the person's comfort and dignity, honours preferences and wishes within their advanced care plan, and best support their family.

• Physical aspects of providing care in late stage dementia

Addressing pain in late stage dementia

- Assessment: PAINAD
- Pain Medication Myths: Addiction and Hastened Death
- Pain and Cognitive Impairment: Reading the Cues
- Palliative Sedation

Addressing nutrition and hydration in late stage dementia

The use of feeding tubes for nutrition and hydration is a very emotional and ethically challenging issue in late stage dementia care. While families are often distressed by the idea of malnutrition and dehydration, the research evidence does not demonstrate that artificial feeding and hydration results in better outcomes for persons with advanced dementia. Several studies demonstrate that tube feeds do not aid in preventing or healing bed ulcers, prevent aspiration pneumonia, comfort, function or an extension of life. However, studies show an increased use of restraints and agitation is associated with tube feeds. For these reasons, tube feeds should be avoided and hand feeding continued until it is no longer feasible.

Other Resources

- What is palliative care?
- <u>Caring for People with Dementia at the End-of-Life</u>: Alzheimer Society of B.C. Recommendations
- Chronic Illness, Palliative Care, and the Problematic Nature of Dying
- <u>Canadian Virtual Hospice</u>: The Gallery

Includes topics such as:

- o Being an advocate
- o Challenge of family caregiving
- Dying at home: when the promise can't be kept
- o Improving end of life care: System challenges
- o Need to support home care workers and health care aides
- Supporting family caregivers
- o The importance of being authentic
- Feeding the person with late stage Alzheimer's Disease