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## Palliative Dementia Care

*The following, on end-stage care for residents with Alzheimer's disease, focuses on the dying process itself. Its purpose is to provide caregivers, not only with the level of confidence and comfort essential for this challenging area, but to raise the standard of excellence in palliative dementia care.*

*By Irene Barnes*

# End-of-life care for residents with dementia

## Knowing the unique aspects of the dying process in Alzheimer's will promote better palliative interventions

Palliative or end-stage dementia care presents with many challenges. The words themselves (*palliative and dementia*) occasion tremendous controversy. For example, when is someone with dementia considered to be in a palliative state? When the initial diagnosis is made? Or does the palliative care aspect become a reality when the patient is bed-ridden?

### Palliative interventions

It is commonly accepted that it is next to impossible to determine exactly when someone will die; yet, to be eligible for hospice care, in some jurisdictions, the person must have only six months left of life. Does this mean that the care and funding are cancelled because someone lives beyond the established date?

Strong emotions are frequently evoked when the words "death," "dying," "end-of-life," and "quality of life" are uttered. These abstractions have many emotionally-charged interpretations. Undoubtedly, part of the prob-

lem lies in a lack of consensus. Even if a standardized acceptance of the meaning of the words could be established, there still remains the challenge of the type of care to be provided, who is to provide it, and what this care should look like?

### Palliative care guidance

Health Canada (2000) provides some guidance when it proffers the following areas to be considered when the focus is on "quality of life at the end of life:"

*"Treatment of physical and emotional symptoms, support of function and autonomy, advance care planning, patient and family satisfaction, global quality of life, family burden, survival time, health care and social service provider continuity and skill, and bereavement."*

Some direction pertaining to care for the dying person is also provided through "Advance Directives." How-

ever, the issue of "rights" become muddled and convoluted when a family member (or surrogate decision maker) decides, in the best interests of the patient, to contravene the directive. The inherent threat of litigation often results in the reversal of planned palliative care approaches.

Since Alzheimer's disease is a terminal illness, does a person with dementia become "palliative" from the day of diagnosis - even though death may not occur for many months?

Much discussion and consensus is needed before end-of-life dementia care can be properly articulated.

### Thorny ethical issues

An especially thorny issue is the tube feeding controversy. One aspect of the issue is that once a tube is inserted, no one wants to make the decision to have it stopped or removed (Lubart et al., 2004).

Family members feel unqualified to make the decision, and staff members feel it is a family decision. It