

End-of-Life Care Tailored for Dementia Patients

BY HEIDI SPLETE
Senior Writer

The Alzheimer's Association has released new recommendations to guide end-of-life care for dementia patients in nursing homes; the recommendations focus on planning for end-of-life care as soon as possible after a dementia diagnosis is made.

The evidence-based recommendations, which were released at the Alzheimer's Association's 15th Annual Dementia Care Conference in Chicago, have been supported by more than 30 organizations, including the American Medical Directors Association, which has a clinical practice guideline on this same issue, as well as a

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palliative care/end of life. "AMDA fully supports individualized care in persons with dementia and recognizes how important end-of-life care planning is when a diagnosis of dementia is made," said Jacqueline

Vance, AMDA's director of clinical affairs.

The recommendations state that the goals of end-of-life care should include following the resident's wishes as closely as possible, which is easier if a patient-centered care plan is designed early. This includes documenting a patient's preferences for medical treatment once he or she reaches an advanced stage of dementia and designating a proxy to make decisions on the patient's behalf when he or she can no longer do so.

In addition, the care goals include supporting families, other residents, and nursing home staff when a resident is actively dying and after the person has died. And finally, end-of-life care plans must be flexible enough to accommodate changes in a resident's preferences.

The end-of-life care recommendations are the third of three phases of a document—Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes—that was conceived as part of the Alzheimer's Association Quality Residential Care campaign. Phase 1 of the recommendations focused on basic care for dementia patients, with attention to nutrition, pain management, and social involvement. Phase 2 provided guidance for managing wandering, falling, and the need for physical restraint in dementia patients.

The phase 3 recommendations emphasize developing consistent, personalized care to the extent possible and increasing staff members' knowledge of residents' preferences. The recommendations fall into the following categories, which include guidelines for end-of-life care for dementia patients:

► **Communications with residents and family members.** Schedule regular care

planning meetings that the resident, proxy decision maker, and other family members can attend (even if only by conference call). Effective communications means acknowledging the cultural and spiritual beliefs of the resident and family and taking these beliefs into account.

Be sure to allow residents and families time to respond to questions and help them understand what policies and situations would cause a resident to be moved to palliative care or a hospice.

► **Decision making.** Discuss a resident's preferences and doctor's directions, such as "comfort care only," "do not resuscitate," or "do not hospitalize." Involve the resident as much as possible, because a dementia diagnosis doesn't mean that the person lacks the ability to make decisions regarding their care. But it is important to designate a proxy decision maker who can make decisions on the resident's behalf when necessary.

► **Hospice service issues.** When a resi-

dent and his or her family members opt for hospice care, establish a plan for communication about the resident's health and care issues and identify which hospice or residence staff members will be the primary contact for family members.

► **Assessing physical symptoms.** Pain-assessment guidelines are addressed in detail in phase 1 of the recommendations, but monitoring pain is just as important when a patient is actively dying. Comfort care strategies may include such things as

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► **Assessing behavioral symptoms.** Behavior changes in dementia patients at the end of life may be signs of distress, so be sure that staff members know to report any differences, such as hallucinations, changes in arousal level, or mood, or striking out in discomfort or distress. Determine whether the cause of the behavior is physical or emotional and use nondrug methods to help, such as reducing environmental irritants or providing companionship for an isolated resident.

► **Psychosocial and spiritual support.** Residents with dementia can still find

comfort in meaningful interactions. Staff members need to know a resident's religious or cultural outlook if possible and provide appropriate psychological and spiritual support. And don't forget the family. Grieving for a patient with dementia at the end of life can be a long, emotionally draining experience for family members. A trained nurse or staff member can help by explaining some of the signs of approaching death so that families know what to expect and by offering resources for dealing with feelings of guilt and grief.

► **Family participation in end-of-life care.** Staff members can support families

who want to feel involved in the comfort of the resident at the end of life by providing pillows and blankets for overnight stays and offering comforting music, books, and anything else that might help family members spend meaningful time with loved ones.

► **Staff training.** Dementia-specific end-of-life training for nursing home residents is an important part of providing quality care. Staff members need to be able to recognize the signs that death is imminent, and they need to be trained in pain management and communication skills so that they can explain the resident's condition to family members.

► **Death and bereavement.** When one of the residents dies, encourage the staff members who were involved in caring for that person to pay tribute to them with a poem, card, or other acknowledgment. Also, consider conducting periodic in-house memorial services to bring together residents, staff, and family members to recognize the lives of residents who have died. ■

For a complete version of the *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes*, visit www.alz.org/documents/DCPRPhase3_.pdf.

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