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ELDER CARE

A Resource for Interprofessional Providers

Hospice Care for Patients with Dementia

Amy S Klein, MD, Department of Geriatrics, General Internal Medicine, and Palliative Medicine, University of Arizona

Alzheimer’s disease (AD) usually appears after age 65. It has a progressive course and gradually destroys memory, reasoning, judgment, and speech. Patients have an overall decline in functional status, lack of desire to eat or drink, withdrawal from social interaction, and confusion in sleep-wake states. It is terminal illness, and at the end stages patients are unable to speak, incontinent of bowel and bladder, and unable to walk or sit without assistance.

Hospice and palliative care services are underutilized by patients with dementia compared to use by patients with other life-ending illnesses. The reason for the low rate of hospice care for dementia patients is not fully understood. Hospice use by patients with a principal diagnosis of dementia has, however, risen to 18%, with 98% of hospice care provided in the patient’s home. The median length of hospice care for patients with a primary diagnosis of dementia is 54 days - longer than other illnesses.

Hospice Care for Dementia - When and Why?

Patients with dementia are considered hospice eligible if they have a life expectancy of 6 months or less if the disease runs its natural course. The National Hospice and Palliative Care Organization has set guidelines for when hospice may be appropriate at the end of life in dementia (Table 1).

Dementia patients who die with hospice are more likely to have better pain control, are less likely to die in a hospital, and have families with greater satisfaction with their end-of-life care. Frequently, patients with dementia have repetitive hospitalizations for infection and dehydration; these can be especially difficult for those with dementia as they are at higher risk for developing delirium or behavioral problems while hospitalized. Hospice can help limit these transitions of care and improve quality of life for both patients and their families or caregivers.

Table 1. Hospice Eligibility Criteria for Alzheimer’s Disease

All of the following:

- Unable to ambulate without assistance
- Unable to dress without assistance
- Unable to bathe without assistance
- Urinary or fecal incontinence intermittent or constant
- No meaningful verbal communication; stereotypical phrases only or speech is limited to six or fewer intelligible words

One of the following within the past 12 months:

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Decubitus ulcers, multiple, stage 3-4
- Fever, recurrent after antibiotics
- 10% weight loss during the previous six months or serum albumin <2.5 gm/dl

Source: Blais CM. Essentials Practices in Hospice and Palliative Medicine: HIV, Dementia, and Neurological Conditions. American Academy of Hospice and Palliative Medicine. 2017.

Hospice care provides a philosophy rather than a location for care. It supports the physical, psychosocial, and spiritual needs of dementia patients and their families. A hospice interdisciplinary team consisting of a physician, nurse, spiritual counselor, social worker, home health aide, volunteer, and bereavement coordinator follow patients in their homes, assisted living, or skilled nursing facilities.

Family Support

Hospice can help families nurture and work with what remains of the affected person’s functions while adjusting for diminished capacity. Caregivers are frequently overwhelmed by caregiver burnout and hospice can assist with providing support and respite care when needed.

Hospice can provide caregiver support and respite care for patient’s families.

TIPS on Hospice Care for Patients with Dementia

- Be aware of the hospice eligibility criteria for patients with dementia.
- Emphasize managing pain and symptoms that increase discomfort in end-of-life dementia.
- Focus on providing support for caregiver to prevent burnout, and identify and address factors that impair quality of life for patients and caregivers.
- Address psychological and behavioral disorders by eliminating medical and environmental factors that may be causing or contributing to them.

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Table 2. Signs of Pain in Dementia

- Anxiety or agitation
- Guarding parts of the body
- Appearing withdrawn or frightened
- Increasing confusion
- Shouting or yelling
- Sleeping problems
- Refusing to eat
- Grimacing or frowning
- Pulse and blood pressure elevations

Source: Abbey Pain Scale

As dementia progresses, patients often develop difficulty eating and aspiration, and families may ask about feeding tubes. Patients with severe Alzheimer's who receive feeding tubes are more likely to develop pressure ulcers and pneumonia, and there is no evidence that tube feeding helps these patients live longer. Families can instead be instructed in careful hand feeding, which gives human contact and the pleasure of tasting favorite foods.

Symptom Management

Many patients with dementia receive inadequate pain relief because they lose the ability to tell us they are in pain. Common causes of pain include osteoarthritis, skin tears or ulcerations, stiffening of joints from immobility, and constipation. Signs of pain (Table 2) are frequently nonverbal.

As patients have more difficulty swallowing, it is important to consider deprescribing non-beneficial medications. Cholinesterase inhibitors are prescribed to slow cognitive decline in dementia, but they do not slow its progression or prolong survival, and they are associated with significant adverse side effects. It often is appropriate to discuss tapering these medications to avoid acute withdrawal.

References and Resources

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With progression of dementia, behaviors such as agitation, aggression, and delusions may increase. These behaviors are associated with greater caregiver distress and a higher rate of nursing home placement.

Thus, part of care for patients with dementia involves identifying factors that contribute to these behaviors and, when possible, eliminating them. Possible medical or environmental factors are listed in Table 3. Other approaches to behavioral problems in patients with AD are discussed in the *Elder Care* on "Communicating with Patients who have Dementia" which can be viewed at https://www.uofazcenteronaging.com/document/communicating_with_patients_who_have_dementia.html.

Table 3. Contributors to Behavior Disorders in Dementia

Medical Factors

- Constipation
- Urinary Retention
- Fatigue
- Impaired vision and hearing
- Inability to interpret words or actions
- Infections
- Pain
- Medication side effects
- Visual hallucinations

Environmental Factors

- Feeling vulnerable and insecure
- Inability to recognize noises or people
- Excessive noise level
- Sensory overload, including too many people
- Startling noises
- Sudden movements
- Forced to engage in personal hygiene behavior, i.e.: take a bath or shower

This Elder Care is an update of a 2013 edition written by Alfred Kaszniak and Evan Kligman.

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The University of Arizona, PO Box 245027, Tucson, AZ 85724-5027 | (520) 626-5800 | <http://aging.arizona.edu>
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