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ELDER CARE

A Resource for Interprofessional Providers

Hospice Care for Patients with Dementia

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Alzheimer’s disease (AD) usually appears after age 65. It has a progressive course and gradually destroys memory, reasoning, judgment, speech, and movement. 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. AD is a 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.

People with Alzheimer’s, dementia, or Parkinson’s now constitute the largest proportion of Medicare beneficiaries receiving hospice care. Hospice use by patients with a principal diagnosis of dementia has risen to 24%, with 98% of hospice care provided in the patient’s home. The average length of hospice care for patients with a primary diagnosis of dementia is 155 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. As dementia progresses slowly and is difficult to prognosticate, 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 anxiety and pain control, less likely to die in a hospital, and more likely to 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 to help patients remain and receive medical care in their own home where they are most comfortable.

Table 1. Hospice Eligibility Criteria for Alzheimer’s Disease

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| <p>All of the following:</p> <ul style="list-style-type: none"> • 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 <p>One of the following within the past 12 months:</p> <ul style="list-style-type: none"> • 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 |
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Source: Blais CM. *Essentials Practices in Hospice and Palliative Medicine: HIV, Dementia, and Neurological Conditions*. American Academy of Hospice and Palliative Medicine. 2017.

Hospice provides a philosophy rather than a location for care, focused on supporting quality of life through 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 provide respite support when needed.

TIPS on Hospice Care for Patients with Dementia

- Be aware of the hospice eligibility criteria for dementia to identify patients and families who may benefit.
- Focus on providing education and support for caregivers to prevent burnout.
- Assist family in identifying medications and treatments that may cause more burden than benefit.
- Address psychological and behavioral disorders by eliminating medical and environmental factors that may be causing or contributing to them.
- Consider empirical treatment of pain in patients with behaviors to improve quality of life.

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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 more likely to need restraints. There is no evidence that tube feeding helps these patients live longer. Families can instead be instructed in providing hand feeding, which gives human contact and the pleasure of tasting favorite foods.

It is important to consider deprescribing non-beneficial medications when patients have more difficulty swallowing. Cholinesterase inhibitors are prescribed to slow cognitive decline in dementia, but they do not slow its progression or prolong survival and are associated with increased risk of falls and fall-related injuries. It is appropriate to discuss tapering these medications to avoid acute withdrawal.

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 and may present as agitation as patients are unable to verbalize discomfort.

References and Resources

- Blais CM et al. *Essentials Practices in Hospice and Palliative Medicine: HIV, Dementia, and Neurological Conditions*. American Academy of Hospice and Palliative Medicine. 2017.
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- Husebo BS, Ballard C, Fritze F, Sandvik RK, Aarsland D. Efficacy of pain treatment on mood syndrome in patients with dementia: a randomized clinical trial. *Int J of Geriatr Psych*. 2014. 29(8). 828-36
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With progression of dementia, behaviors such as agitation, aggression, and delusions may increase and are associated with greater caregiver distress and a higher rate of nursing home placement. Identification of factors that contribute to these behaviors and, when possible, eliminating them is an important part of care (Table 3). Trying relaxing activities like music, art therapy and massage, or shifting focus to another activity, providing calm reassurance, and avoiding overstimulation can be helpful. It is reasonable to consider empirical treatment of pain in patients with advance dementia with behavior disturbances, given evidence supporting potential for pain treatment to improve agitation, nighttime behaviors, and mood.

Other approaches to behavioral problems in patients with AD are discussed in the Elder Care on "Communicating with Patients who have Dementia."

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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