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ELDER CARE
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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, and speech. Eventually, the ability to perform even the simplest task is lost.

The end of life for patients with dementia is similar to the end of life with many other chronic illnesses. Patients demonstrate an overall decline in functional status, lack of desire to eat or drink, withdrawal from social interaction, and confusion in sleep-wake states. Death is usually presaged by a mottling of the limbs, uncontrollable jaw movements, and ultimately a death rattle.

Hospice and palliative care services are underused by patients with dementia in comparison to use by patients with other life-ending illnesses. The reasons for the low rate of hospice care for dementia patients are not fully understood.

Hospice Care for Dementia - Why?

Over 70 percent of people with end-stage dementia live at home and are cared for by family and other caregivers. New research suggests that hospice involvement in the care of these patients may increase their life expectancy. More importantly, however, hospice care improves quality of life for both the patient and the patient's family members and caregivers.

For example, a recent survey of family members of patients who died with dementia found that when hospice care was provided, family members were 51% less likely to report unmet needs or concerns about quality of care in comparison to families of patients who did not receive hospice care. A similar percentage was less likely to report an unmet need for pain management, and also less likely to have wanted more emotional support before their loved one's death. Family members also rated the peacefulness and quality of dying more positively when hospice care was involved.

Hospice Care for Dementia - When?

Eligibility criteria have been established for when hospice care is appropriate for patients with dementia. These criteria are listed in Table 1. Once these eligibility requirements are met, Medicare and most insurance plans will cover a wide variety of hospice services (Table 2).

Table 1. Hospice Eligibility Criteria for People with Dementia

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 consistent meaningful verbal communication; speech is limited to six or fewer intelligible words or only stereotypical phrases

One of the following within the past 12 months:
- Aspiration pneumonia
- Pyelonephritis or upper urinary tract infection
- Septicemia
- Decubitus ulcers, multiple, stage 3-4
- Fever, recurrent after antibiotics
- Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin <2.5 gm/dl

Source: Storey CP. A Quick-Reference Guide to the Hospice and Palliative Care Training for Physicians: UNIPAC Self-Study Program. American Academy of Hospice and Palliative Medicine. 2009.

TIPS For Providing End-of-Life Care for Patients with Dementia

- Be aware of the hospice eligibility criteria for patients with dementia.
- Counsel families and caregivers about the availability of hospice services when patients meet those eligibility criteria.
- Focus palliative care for dementia patients on treatment of pain, dyspnea, nausea, and other physical symptoms, as well as identifying psychological and behavioral disorders that impair quality of life for patients and caregivers.
- Address psychological and behavioral disorders, when possible, by eliminating illness-related and environmental factors that may be causing or contributing to them.

Continued from front page

Table 2. Hospice Benefits Covered by Medicare and Most Insurance Plans for Patients with Dementia
• Physician services
• Nursing care
• Medical equipment and supplies
• Medications for symptom management and pain relief
• Short-term inpatient hospice care, including respite care
• Home health aide and homemaker services
• Medical social services and spiritual counseling
• Dietary counseling
• Bereavement counseling
Source: http://www.hospicenet.org/html/medicare.html

Hospice Care for Dementia - What?

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 (physician, nurse, spiritual counselor, social worker, home health aide, volunteer, bereavement coordinator, and other therapists as needed, such as massage therapist) follow patients in their homes, assisted living or skilled nursing facilities, and ultimately, for some, in inpatient units for end-stage hospice care.

Palliative care for those with dementia is in many ways similar to palliative care for other life-ending conditions. It focuses on relieving symptoms such as pain, shortness of breath, fatigue, nausea, loss of appetite, and difficulty sleeping.

For patients with dementia, however, palliative care also monitors for and addresses dementia-related psychological and behavioral disorders that may impair quality of life for the patients or their families. Such behaviors are particularly common in the later stages of AD. Although depression generally decreases with progression of AD, other behaviors, such as agitation, aggression, and delusions, may increase. The presence of these emotional and behavioral difficulties is associated with greater caregiver distress and a higher rate of nursing home placement.

Thus, part of palliative care for patients with dementia involves identifying illness-related and environmental factors that contribute to these behaviors and, when possible, eliminating them. These 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 http://www.reynolds.med.arizona.edu/EduProducts/providerSheets/Dementia%20Patients%20-%20Communication.pdf

Table 3. Contributors to Behavior Disorders in Dementia
Illness-Related 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

References and Resources

Alzheimer's Association., Medicare's Hospice Benefit for Beneficiaries with Alzheimer's Disease. http://www.alz.org/national/documents/medicare_topicsheet_hospice_benefit.pdf

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Interprofessional care improves the outcomes of older adults with complex health problems

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