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Hospice Services and the Dementia Patient

In the middle ages the term hospice referred to the custom of giving hospitality and shelter to sick travelers. Hospice, meaning specialized care for dying patients, is a relatively new concept. It was first conceived by Dame Cicely Saunders, a physician who began working with the terminally ill in 1948 and founded the first modern hospice, St. Christopher's Hospice, in London, England.

The hospice concept was first introduced to the U.S. by Saunders, when she spoke to medical students, nurses, social workers, and chaplains during a 1963 visit to Yale University. Her lecture included pictures of terminally ill cancer patients illustrating dramatic differences before and after receiving symptom control care. Her teachings sparked a movement that evolved into the hospice services of today.

Hospice aims to address physical, social, emotional and spiritual aspects of a patient's life and well being. Hospice services are generally provided by teams of professionals that include the patient's physician, a hospice doctor, a case manager, registered nurses and licensed practical nurses, a counselor, a dietician, therapist, pharmacologist, social workers, a minister, and trained volunteers.

The hospice team develops a care plan based on the patient's individual needs. All the necessary pain management and symptom relief drugs and therapies, medical supplies, and equipment are provided. Hospice care is most often provided at home and hospice team members make regular visits to assess the patient. Additional care and services may be provided, such as speech and physical therapy, therapeutic massage, dietary assistance, and help with bathing and other personal care. Hospice staff remains on-call 24 hours a day, seven days a week.

Family members also receive emotional and spiritual support, including grief counseling.

Comfort care is at the core of hospice care. Although originally associated with cancer patients, all terminally ill patients may benefit from hospice services. That is also true for dementia patients. Although dementing illnesses (Alzheimer's and other kinds) are the fifth leading cause of death for Americans 65 and older, in 2009 only 11.2% of hospice patients had dementia as their primary diagnosis.

The numbers suggest that people suffering from dementia are underserved by hospice services. Among other barriers in getting access to hospice services, physicians point to the complexity of dementia and to the lack of reliable prognostic tools for Alzheimer's and other dementias.

Medicare has covered hospice services since 1982, and to enter hospice patients must have a life expectancy of six months or less, as determined by a physician. However, determining life expectancy for dementia

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Tips

Questions to ask hospice providers:

Is the hospice program Medicare certified? Is the program reviewed and licensed by the state or certified in some other way?

Who makes up the hospice care team, and how are they trained or screened? Is the hospice medical director board certified in hospice and palliative care medicine?

Does the hospice program have a dedicated pharmacist to help adjust medications?

What services are offered to a terminally ill person? How are pain and other symptoms managed?

How are hospice care services provided after hours?

How long does it take to get accepted into the hospice care program?

What services are offered to the family? What respite services are available for the caregiver or caregivers? What bereavement services are available?

Are volunteer services available?

If circumstances change, can services be provided in different settings? Does the hospice have contracts with local nursing homes? Is residential hospice available?

Are hospice costs covered by insurance or other sources, such as Medicare?

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patients is not a simple matter. The Functional Assessment Staging Test (FAST) is the most accepted scale for evaluating dementia progression but falls short in providing clear guidelines for prognostication. Dementia affects people differently, and many times its progression is complicated by concurrent dementias and/or other health conditions. Ultimately, doctors need to use their own judgment and determine the prognosis to **the best of their clinical ability.**

In general, dementia patients who qualify for hospice services under Medicare guidelines have bowel and bladder incontinence, a vocabulary of one word or less, dependency in all activities of daily living and an additional comorbidity, or complication, such as pneumonia, sepsis, persistent fever or stage 3 or 4 pressure ulcers (bed sores).

Family members also experience difficulties in determining when to bring up to the doctor the potential need for hospice care. The insidious nature of dementia, with its slow progression over many years, and the stresses affecting caregivers after long years of providing care, may hinder an objective evaluation of the need for end-of-life care. It is also not uncommon that a patient will live with stage 7 - the later and last stage of dementia - for several years.

Dementia patients, however, benefit greatly from specialized end-of-life care. They very often can no longer communicate verbally and hospice nurses are specially trained to "read" the signs of discomfort in order to prevent pain and suffering.

Dementia patients are at increased risk of respiratory infections due to aspiration. They are also more likely to have urinary tract infections due to incontinence (which prevents the proper flushing out of infectious agents); many experience atrophy of limbs due to long periods of inactivity, putting them at increased risk for skin tears, bed sores and painful spasms.

Hospice nurses are experienced in watching for symptoms and educating family members on what to expect and how to best assist their loved ones, so they can die comfortably and with dignity.

Medicare, Medicaid (MediCal in California) and most private insurance plans cover hospice services.

In order to qualify for Medicare hospice benefit the physician must re-certify the patient at the beginning of each benefit period (two periods of 90 days each, one of 30 days, and an indefinite fourth period). Medicare regulations require that hospice care be provided at home, with only short stays in an inpatient facility.

It is not uncommon that a patient receiving hospice services outlives the initially prognosticated six months. In such cases, services may be extended if hospice can prove eligibility and document continued decline.

Hospice provides comfort, warmth, kindness, and the serenity dementia patients need. Hospice services can begin after a physician provides a referral. Hospice teams work in collaboration with the patient's physician, or, if the physician prefers, the hospice physician may follow the patient. Family members may refer their loved one themselves, and then the physician is contacted.

Please contact your local hospice provider to learn more about their services and talk to your physician about the appropriateness of hospice for your loved one in the advanced stages of dementia.

Written by Luciana Cramer, Educator and Care Specialist

Tools - Agencies providing hospice services:

Visiting Nurse & Hospice Care - vnhcsb.org - Santa Barbara, (805) 965-5555 - Solvang (805) 693-5555

Assisted Home Hospice - assisted1.com - (805) 569-2000

Dignity Health Hospice - (805) 739-3830

Wilshire Hospice - wilshirehospicecc.org - (805) 782-8608

Central Coast Home Health - mycchh.com - (805) 543-2244

A Prime Home Care Services - primehomecareservices.com - (805) 436-0225

Hospice of Santa Barbara (Offering non-medical hospice related services) hospiceofsantabarbara.org - (805) 563-8820