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Hospice - What is it Really About?

by Christine L. Vaughan, MD, MHS

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What is hospice?
A team-oriented approach to care at the end of life for those with serious or life-limiting illness (such as advanced dementia). Hospice focuses on caring, not curing. The hospice team goes to wherever the patient is living (often at home) and seeks to optimize quality (not quantity) of life. The team provides expert medical care, symptom management, and emotional and spiritual support expressly personalized to the patient's needs and wishes. Hospice affirms life and regards dying as a normal process, and neither hastens nor postpones death. At the heart of hospice care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Who makes up the hospice team?
Hospice physician (or medical director); patient's personal physician; nurse; social worker; spiritual counselor or other counselor; dietary counselor if needed. Non-core but required hospice services include physical, occupational, and speech therapy, an aide supervised by the hospice nurse, to provide personal hygiene needs, and volunteers.

What services are provided?
The hospice team seeks to provide comprehensive care and members of the team make regular visits to assess the patient and provide additional care or other services. Typically, a family member serves as the primary caregiver and the hospice team provides education on how to care for the patient. Hospice staff is on-call 24 hours a day, seven days a week, but does not provide custodial care.

The team: manages the patient's pain and symptoms; assists the patient with the emotional and psychosocial and spiritual aspects of dying; provides needed medications, supplies, and equipment (such as a hospital bed); coaches the family on how to care f or the patient and educates on what to expect with the dying process; makes short-term inpatient care available when pain or symptoms become too difficult to manage at home,

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or the caregiver needs respite time; provides bereavement care and counseling to surviving family and friends for up to 13 months following the patient's death.

Who is eligible for hospice?

Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations. The Medicare hospice benefit is available to patients certified by 2 physicians (patient's attending/personal physician and Hospice Medical Director) to have a prognosis of 6 months or less if the disease runs its natural course. The patient or representative must sign an election of benefits indicating understanding of the palliative rather than curative nature of hospice care, and waiving curative care for the terminal condition. The most typical hospice conditions include: cancer, advanced dementia, end-stage heart disease, end-stage lung disease, and HIV-related conditions. There are Local Coverage Determinations (LCDs) for the hospice's geographic area which are used as guidelines to help a physician determine hospice eligibility. Certifying a patient for hospice is based upon a physician's clinical judgment, and is not an exact science. For a patient with a neurodegenerative disorder such as advanced dementia, the estimation of prognosis is challenging. The hospice physicians rely on their end-of-life expertise to give their best estimate at prognosis, but sometimes they over- or under-estimate the amount of time a patient has to live. Occasionally a patient will show temporary improvement in condition upon receiving hospice care, and in such cases may no longer qualify for hospice (and prognosis may be estimated at >6 months). In these cases, hospice will end involvement until the patient is once again deemed to have a prognosis of 6 months or less.

What is the difference between hospice and 'palliative care'?

Palliative care is an approach to care which is very similar to the hospice approach, but is intended for people with serious or life-limiting illness at any stage of disease (including at the time of diagnosis). It is another layer of support, with an emphasis on quality of life. It may also be delivered in a team-based way, making use of a social worker, spiritual

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counselor, nurse, and physician. Palliative care can come in the form of an inpatient consultation while the patient is in the hospital, , or can consist of an outpatient clinic visit, or home-based palliative care visits can sometimes occur. Patients can follow with a palliative care team over time, or can be assessed on an as-needed basis.

It is never too early to speak with your healthcare provider about hospice services, as although we can continue to hope for the best, it is helpful to be prepared for whatever comes along. If your provider has not discussed the role of a palliative care team, consider inquiring about this at your next visit – knowing that palliative care can be helpful at any stage of disease.

Clinical Practice

Dr. Vaughan has fellowship training in both Movement Disorders and Palliative Medicine. She practices within the new section of Neuro-Palliative care and takes care of patients with advanced or end-stage neurologic disease through the course of their illnesses. She provides botulinum toxin injections for symptom management (dystonia, spasticity, drooling, and migraine). Dr. Vaughan sees patients at the University of Colorado Hospital and at satellite clinics.

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