

HOSPICE CARE

An Overview of Hospice Care and Policy Considerations

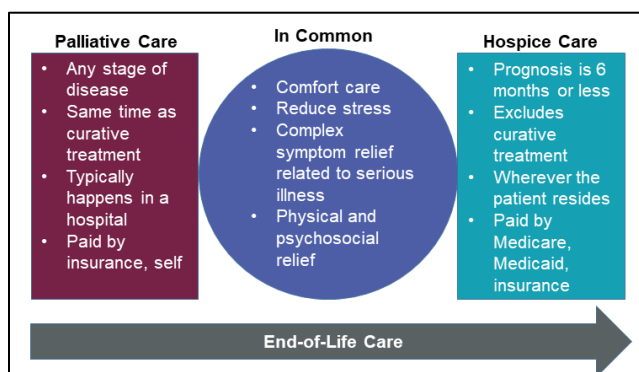
Introduction

Hospice care, one aspect of the continuum of end-of-life care, is care designed to optimize comfort for individuals with terminal illnesses regardless of age. There is a growing need for increased hospice care access due to a growing older population in the U.S. Since 2006, the U.S. has experienced a 33% increase in the number of adults 65 and older, with approximately one in seven Americans now considered an older adult.¹ Discussions of the long-term care needs of an aging population should include care needs at the end of life.

WHAT IS HOSPICE CARE?

Hospice care is a form of palliative care, a type of medical care provided to seriously ill patients to manage their symptoms, including pain, sometimes alongside curative treatment. Figure 1 shows the differences and commonalities between palliative and hospice care along the end-of-life care spectrum.²

FIGURE 1: PALLIATIVE CARE VS. HOSPICE CARE



Hospice care is for individuals who have been diagnosed with a terminal illness and are expected to live six months or less. The goal is to provide symptom management and maintain the patient's quality of life. It is not provided alongside curative treatment.³

Unlike curative care, hospice care provides patients and their families support through “comfort care,” with the aims of managing pain and other symptoms of a terminal illness.⁴

Hospice care is provided through a hospice service or agency, which may be a for-profit or nonprofit company. While for-profit hospices accounted for only 5% of hospices in 1990, by 2011 approximately 51% of hospices were identified as being for-profit.⁵

Once a patient and the patient’s family make the decision to begin to hospice care, it is important that this transition be managed well by both the facility where the patient is currently located (often an inpatient hospital setting) and the hospice agency that will be assuming care for the patient. Common issues with transitions to hospice care include late referrals (when a patient could have benefited from an earlier transition) and care coordination issues between providers.

WHAT SERVICES ARE INCLUDED IN HOSPICE CARE?

Hospice care includes a wide range of services to assist patients and their families, as illustrated in Figure 2.

Each hospice patient receives an individualized care plan that describes the frequency of hospice staff visits, medication needs, and needs for other services such as speech pathology or dietary consultation.⁶

A hospice patient’s family member(s) serves as the primary caretaker for the patient with support from the hospice team, unless care is provided in a skilled nursing facility or a hospital. Often, the same hospice staff members are assigned for the duration of hospice care and include an interdisciplinary team of nurses, physicians, hospice aides, social workers, and bereavement counselors. Hospice agencies also offer short-term respite care (temporary

FIGURE 2: TYPES OF SERVICES INCLUDED IN A HOSPICE CARE PLAN

- Doctor services
- Nursing care
- Medical equipment
- Medical supplies
- Prescription drugs
- Hospice aide
- Physical and occupational therapy
- Speech-language pathology services
- Social worker services
- Bereavement counseling
- Short-term inpatient care
- Short-term respite care
- Any other Medicare-covered services needed to manage a terminal illness and related conditions, as recommended by hospice team

caregiving duty relief) and grief counseling for the families of hospice patients, often provided by agency volunteers.

WHAT ARE THE LEVELS OF HOSPICE CARE?

The Medicare hospice benefit includes four levels of care, depending on an individual hospice patient's needs. Payment to each hospice agency is also dependent upon the level of care needed by each patient, and includes the cost of services, medication, medical equipment, and other supplies provided to care for the patient. The four levels of care are:⁷

1. Routine Hospice Care – This level of care includes patients who have elected to receive hospice care at their personal residence, and is the most common level of hospice care provided.
2. Continuous Home Care – This level of care is for patients needing more intensive care than what is provided in Routine Hospice Care, providing patients with up to around-the-clock care from hospice providers to manage pain and other acute medical symptoms when the patient is experiencing a crisis. Continuous home care services must be predominately nursing care that is supplemented with primary caregiver and hospice aide services.
3. Inpatient Respite Care – This level of care is intended to provide short-term relief to a patient's primary caregiver. Inpatient respite care can only be provided in a facility with sufficient 24-hour nursing personnel, such as a hospital, hospice-owned facility, or nursing facility.
4. General Inpatient Care – This level of care is intended for patients who require a high level of care, not feasible in another care setting, to manage pain and other acute medical symptoms. It is initiated when other efforts to manage a patient's symptoms have been exhausted. General inpatient care can be provided in a hospital, hospice-owned inpatient facility, or nursing facility with registered nursing available 24 hours a day.

WHERE DOES HOSPICE CARE TAKE PLACE?

The majority of hospice patients receive services in their homes, with hospice care teams making regular visits to the patient's home and meeting with the patient's primary caregiver.

Patients residing in a nursing facility, or who enter a facility following a terminal diagnosis, are also eligible to receive hospice care. In this case, a hospice agency contracts with a nursing facility to coordinate care of the patient with the hospice staff, including medication management and other daily care needs (e.g., eating, bathing, dressing). Some hospice agencies have developed their own facilities to provide hospice care, including both medical and custodial care.

Medicare and most other private-payer hospice benefits do not include coverage for room and board at a facility for hospice care. However, if a patient meets certain financial and other eligibility requirements, Medicaid may cover the cost of room and board. Patients with long-term care insurance may also be able to utilize coverage to help pay for private aides or for room and board in a nursing or hospice-owned facility, depending on the coverage in their specific plan.

WHO PAYS FOR HOSPICE CARE?

While most private health insurance plans include hospice care coverage, because older adults have more frequent needs for hospice care as they age, Medicare pays for the majority of hospice care. In 2017, approximately 1.5 million Medicare beneficiaries received hospice care services at an estimated cost of \$19.9 billion.⁸ When a Medicare beneficiary elects to utilize the Medicare hospice benefit, the beneficiary also agrees to forgo coverage for curative treatment. However, Medicare will continue paying for covered services for other health issues unrelated to a patient's terminal illness.⁹

Since Medicare pays for the majority of hospice care, most hospice agencies follow Medicare requirements for services, medical equipment, and other items to assist in managing a hospice patient's needs. Most state Medicaid programs, including Arkansas's, have opted to provide hospice benefits for terminally ill beneficiaries.

Because the goal of hospice care is to provide optimal comfort- and quality-of-life-focused care to patients, there are several services excluded from the Medicare hospice benefit. These exclusions include:¹⁰

- Curative medical and prescription drug treatment for a patient's terminal illness, along with curative medical treatment for unrelated conditions
- Room and board in a nursing facility or a hospice residential facility (care settings for hospice are discussed below)

- Medical care given in an emergency room, an inpatient facility care, or an ambulance during transportation, unless the care is arranged by a hospice team or is unrelated to the patient's terminal illness

WHAT RESOURCES ARE AVAILABLE TO HELP SELECT A HOSPICE AGENCY?

The Centers for Medicare and Medicaid Services (CMS) maintains a tool to assist consumers in selecting a prospective hospice provider. Similar to the Hospital Compare or Nursing Home Compare websites, Medicare.gov features a tool called Hospice Compare, which provides a comparison of hospice agencies in a certain geographic area based on certain quality measures. Users can select up to three hospice agencies to compare within the tool. The information on Hospice Compare includes general information about an agency, the medical conditions of their patients, average daily census, location of care, family experience of care, and the quality of care provided by the agency.¹¹

POLICY CONSIDERATIONS

As demand for hospice care continues to increase among patients and their families facing end-of-life decisions, there are key challenges and policy considerations to address. At the individual level, it is important for families to consider their role as the patient's primary caregivers and their available financial resources. In general, although Medicare does not pay for room and board in a facility or for full-time private aides for hospice care, the hospice benefit does cover all services and supplies related to a hospice patient's care. Without adequate financial means, families can face difficult monetary and personal challenges in managing the care of their loved ones.

More globally, the financing of long-term care needs, including palliative and hospice care, requires meaningful consideration with an increasing number of older Americans needing such services, including programs to support family caregivers. As the hospice industry continues to grow, close regulatory monitoring of agencies is prudent, with a recent Department of Health and Human Services report citing serious issues in 20% of U.S. hospice programs. Common types of issues cited in the report include poor care planning for hospice patients, mismanagement of aide services, and poor patient assessment.¹² The report includes six recommendations to strengthen federal oversight of hospice agencies, such as having CMS expand reporting of deficiency data, including

posting survey reports from state agencies on the Hospice Compare website, and increasing oversight of hospices with a history of repeated deficiencies. State agencies are also required to survey hospice agencies, and the report suggests that deficiency data collected by states and accrediting organizations be added to Hospice Compare.

¹ U.S. Department of Health and Human Services, Administration for Community Living. (2018). 2017 profile of older Americans. Retrieved from

<https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2017OlderAmericansProfile.pdf>.

² Visual adapted from VITAS Healthcare, “Palliative Care vs. Hospice Care: What’s the Difference?” Accessed June 15, 2020. Retrieved from <https://www.vitas.com/hospice-and-palliative-care-basics/about-palliative-care/hospice-vs-palliative-care-whats-the-difference/>.

³ U.S. Department of Health and Human Services, National Institute on Aging. (Accessed Jan. 10, 2020). What are palliative care and hospice care? Retrieved from <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>.

⁴ National Institute on Aging, What are palliative care and hospice care?

⁵ Aldridge, M.D., et. al. (2014). National hospice survey results: For-profit status, community engagement, and service. *Journal of the American Medical Association*, 174 (4), 500-506.

⁶ Centers for Medicare and Medicaid Services. (Accessed Jan. 9, 2020). Medicare Hospice Benefits. Retrieved from <https://www.medicare.gov/pubs/pdf/02154-Medicare-Hospice-Benefits.pdf>.

⁷ National Hospice and Palliative Care Organization, “NHPCO Facts and Figures 2018 Edition” (Revision 7-2-2019). Retrieved from https://39k5cm1a9u1968hg74aj3x51-wpengine.netdna-ssl.com/wp-content/uploads/2019/07/2018_NHPCO_Facts_Figures.pdf.

⁸ The Medicare Payment Advisory Commission (MEDPAC). (2019). Report to the Congress: Medicare Payment Policy, Chapter 12: Hospice services. Retrieved from http://www.medpac.gov/docs/default-source/reports/mar19_medpac_ch12_sec.pdf?sfvrsn=0.

⁹ Centers for Medicare and Medicaid Services, Medicare Hospice Benefits.

¹⁰ Hospice Foundation of America. What is Hospice? Accessed Jan. 31, 2020. Retrieved from <https://hospicefoundation.org/Hospice-Care/Hospice-Services>.

¹¹ Centers for Medicare and Medicaid Services. Medicare.gov Hospice Compare. Accessed Feb. 3, 2020. Retrieved from <https://www.medicare.gov/hospicecompare/#>.

¹² U.S. Department of Health and Human Services, Office of the Inspector General. (2019). Hospice Deficiencies Pose Risks to Medicare Beneficiaries. Retrieved from <https://oig.hhs.gov/oei/reports/oei-02-17-00020.pdf>.