

UNDERSTANDING PALLIATIVE AND HOSPICE CARE

(A companion piece to the tri-fold pamphlet of the same name)

Diane Breslow, MSW, LCSW

CurePSP is committed to providing its constituents – patients, families, caregivers, and healthcare providers – with up-to-date educational information about topics relevant to living with prime-of-life neurodegenerative diseases.

The terms Palliative Care, Hospice Care, End-of-Life Care, Comfort Care, and Supportive Care are widely misunderstood and often used interchangeably. They also may conjure up fear, stigma, and myth. One of the most common misconceptions is that palliative care and hospice care mean “giving up.”

This article will help you to understand the care options defined as Palliative Care and Hospice Care. In addition, you will find a list of available resources to assist you in making informed decisions about enlisting Palliative or Hospice services.

INTRODUCTION

Comfort Care is the umbrella term for patient care that is focused on symptom control, pain relief, and quality of life. Comfort Care includes **Supportive Care** to family members by: explaining the care plan, responding to questions and concerns, providing emotional comfort.

MYTH AND FACT

Myth: Palliative Care and Hospice Care are the same.

Fact: Palliative Care and Hospice Care do NOT mean the same thing. This article, and the various agencies listed in the concluding Resource section, can help you understand the differences between Palliative Care and Hospice Care.

Myth: Palliative Care starts at the time of “terminal” diagnosis.

Fact: Palliative Care can start upon diagnosis of a serious, chronic illness like PSP, CBD, or MSA; or *at any time* throughout a patient’s disease progression.

Myth: Medicare covers Hospice but not Palliative Care.

Fact: Medicare pays all Hospice costs. Depending on your Medicare benefits and medical treatments, Medicare *can* also pay for Palliative Care. **It is important that you or your healthcare provider check with your insurance carrier regarding your benefits.**

Myth: Palliative Care does not permit medical, rehabilitation, or curative treatment.

Fact: Palliative Care allows for symptom relief and also for tests, curative treatments, and therapies for disability. Hospice permits the patient to receive symptom relief (e.g. blood pressure or pain medications) but does not authorize the patient to receive curative or life-prolonging treatments. In some cases, patients enrolled in hospice may still receive a treatment typically thought of as “life-prolonging” (such as chemotherapy), when the purpose of that treatment is to bring COMFORT, not to extend life. **Make sure that you, and your physician, understand these distinctions as they apply to your particular case.**

Myth: Palliative Care occurs at home, while Hospice Care is provided in a facility.

Fact: Both Palliative and Hospice Care can be provided wherever a person resides – in their own home, an assisted living facility, or a nursing home. In addition, some hospitals have Palliative

Care teams; while some Hospices offer the option of stand-alone Hospice facilities. **Talk with your doctor or social worker about the best choice for you.**

Myth: Hospice provides full-time care at the end of life.

Fact: Family members, paid caregivers, or the staff of a facility (i.e. assisted living or nursing home) give daily care to people patients who are on Hospice. The Hospice team recommends and sets up a schedule for its staff – the Hospice nurse, social worker, chaplain, volunteers, and others – to see the patient. If a person has chosen to die at home, meaning that family and friends are providing the hands-on daily care, hospice team members teach the lay people how to care for the dying person. Someone from the Hospice team is always available by phone

SIMILARITIES BETWEEN PALLIATIVE CARE AND HOSPICE CARE

BOTH are specialized care for people with serious illnesses.

BOTH require a physician's order. But choosing to use either palliative or hospice care is a joint decision between patient, family, and physician.

BOTH are focused on relief from symptoms, pain, and stress: COMFORT. Even on Hospice, when a patient is not being treated curatively, he or she receives medical care that is helpful and contributes to comfort, e.g. blood pressure medication.

BOTH aim to improve quality of life and dignity for the patient and the family: SUPPORT.

BOTH are made up of teams that include physician, nurse, social worker, nutritionist, and volunteer visitors, and may also include music, art, and massage therapists.

BOTH include the service of helping patients and families to do advance care planning.

BOTH Palliative Care and Hospice Care recognize dying as part of the normal process of living.

Neither Palliative Care nor Hospice Care hastens or delays death.

BOTH result in decreased hospitalizations and decreased use of unhelpful services, and the patient and family's higher perceived quality of care and quality of dying (often seen as "not dying in the hospital"). (See research studies by Mitchell *et. al.*, 2007; Teno *et. al.*, 2011).

An Internet perusal of Hospice Care Research identifies numerous references supporting the premise that palliative care and hospice care do not hasten death:

- 1) "...hospice enrollment is not significantly associated with shorter survival; for certain terminally ill patients, hospice is associated with longer survival times." (*Journal of Pain and Symptom Management*, March 2007).
- 2) "...patients with terminal cancer that disenrolled from hospice care had significantly higher rates of hospitalizations...than patients who remained under the care of hospice. (*Journal of Clinical Oncology*, October 1, 2010).
- 3) Researchers found that patients receiving palliative care reported a higher quality of life through the final course of their illness"

DIFFERENCES BETWEEN PALLIATIVE CARE AND HOSPICE CARE

When the Care begins:

Palliative care can begin at any point in a person's disease process, and can be provided concurrently with curative treatments. A referral for Palliative Care is not dependent upon prognosis or life expectancy. In fact, Palliative Care can help patients, over time and throughout their disease, to understand treatment options.

Hospice care is for people in the final phase of life-limiting illness when life-saving treatment no longer works or is wanted, and the physician believes that the person has 6 months or less to live

if the illness were to run its natural course. The patient who agrees to Hospice understands that his or her illness is not responsive to treatments that intend to slow or cure it. Provided that a proper re-evaluation is conducted and appropriate hospice eligibility criteria are met, Hospice services can be renewed beyond the initial 6 months. Likewise, a person could choose to discontinue hospice care and to re-enroll at a later date.

Who provides the Care:

Palliative care is provided by a healthcare team of doctors, nurses, and other specialists *who work with the patient's current treatment team.*

Hospice care is provided by a designated Hospice multidisciplinary healthcare team of practitioners: nurses, doctors, social workers, spiritual counselors, massage therapists, creative arts therapists, and trained volunteers. In some cases, if the patient has had a palliative care team, those practitioners continue to provide services, but in the new role of Hospice Care. A hospice team member is available by phone 24 hours a day, 7 days a week.

Patients receiving Palliative or Hospice care can continue to see their primary care physician and other specialists, though insurance coverage may vary; check with your insurance carrier for limitations.

FAMILIES' EXPERIENCES THAT ARE ASSOCIATED WITH HIGH SATISFACTION WITH HOSPICE SERVICES

(National Hospice and Palliative Care Organization, 2005 - based upon 116,974 surveys from 819 hospices; National Institute on Aging, July 2016)

1. Family members concurred that the hospice team regularly informed them about their loved one's condition.
2. The family felt that the hospice team provided family members with the right amount of emotional support.
3. Family members felt that the hospice team provided them with accurate information about the patient's medical treatment.
4. Family members could identify one nurse as the team leader in charge of their loved one's care and care plan.

TALK WITH YOUR DOCTOR ABOUT HOSPICE CARE IF YOU (OR YOUR LOVED ONE) ARE EXPERIENCING INDICATORS OF FINAL DECLINE WITH PSP

Significant speech, chewing, and swallowing difficulties that precipitate serious and more frequent episodes of coughing and choking

Frequent falls with high risk for fractures and head trauma

Severe dementia

Immobility, which puts a person at risk for blood clots and other complications

Recurrent urinary tract infections and incontinence, particularly instances which might indicate a hospitalization that the patient refuses

More sleep time and increased withdrawal in general

THE TAKE-AWAY MESSAGE: *Although similar, Palliative Care and Hospice Care are two distinct care options available to people living with chronic illness or disease. In particular, Hospices vary widely as to the services, professional staff, and frequency of visits they offer. A referring practitioner cannot (and should not) promise or assure which services a patient and family will receive from a hospice organization. Families need to consult with hospice agencies*

on an individual basis in order to ask questions specific to one's own situation. We at CurePSP hope that you will discuss your needs and concerns with your family, your physician(s), and an experienced social worker or nurse; and then interview a couple of different Palliative Care and/or Hospice agencies to determine which one is the best "fit" for you.

RESOURCES FOR FURTHER INFORMATION

- American Academy of Hospice and Palliative Medicine
info@aahpm.org, www.palliativedoctors.org
- Area Agency on Aging Eldercare Locator
800/445-8106, www.eldercare.gov
- Center to Advance Palliative Care
212/201-2670, capc@mssm.edu, www.getpalliativecare.org
- Centers for Medicare & Medicaid Services
800/633-4227, www.medicare.gov
<https://www.medicare.gov/coverage/hospice-respite-care>
- Education in Palliative and End-of-Life Care (EPEC)
312/503-3732, info@epec.net, www.epec.net
- Family Caregiver Alliance-National Center on Caregiving
800/445-8106, www.caregiver.org
- Hospice Association of America-National Association for Home Care and Hospice
202/546-4759, www.nahc.org/HAA
- Hospice and Palliative Nurses Association
412/787-9301, hpna@hpna.org, <http://hpna.advancingexpertcare.org>
- Hospice Foundation of America
800/854-3402, info@hospicefoundation.org, www.hospicefoundation.org,
www.hospicedirectory.org
- Hospice Net
info@hospicenet.org, www.hospicenet.org
- National Hospice and Palliative Care Organization
800/658-8898, caringinfo@nhpco.org, www.caringinfo.org, www.nhpco.org
- National Institute on Aging Information Center
P. O. Box 8057 – Gaithersburg, MD 20898-8057
800/222-2225, niaic@nia.nih.gov, www.nia.nih.gov
- U. S. Department of Veterans Affairs
https://www.va.gov/GERIATRICALS/Guide/LongTermCare/Hospice_Care.asp

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