CurePSP is the leading nonprofit organization working to improve awareness, education, care, and cure for devastating prime of life neurodegenerative diseases. These include progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), and others. They often strike when people have careers, family responsibilities, and active lives. Their symptoms are incapacitating and there are no known causes, treatments, or cures.

Research has shown that there are important links between prime of life diseases and more common neurodegenerative conditions, such as Alzheimer’s disease and Parkinson’s disease. Your support will help advance this research, provide resources for families and caregivers of patients, and better educate the healthcare community. Together we are unlocking the secrets of brain disease.

CurePSP is a not-for-profit 501(c)(3) organization. Gifts and pledges of support are encouraged and donations are tax deductible to the extent allowed by law.

Resources for further information

American Academy of Hospice and Palliative Medicine
info@aahpm.org
www.palliativefactors.org

Area Agency on Aging Eldercare Locator
800/445-8106
www.eldercare.gov

Center to Advance Palliative Care
212/201-2670
tcpa@nysuny.org
www.pspalliativecare.org

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.aha.org/haha

Hospice and Palliative Nurses Association
412/787-9301
hpna@hpna.org
http://www.advancingexpertcare.org

Hospice Foundation of America
800/854-3402
info@hospicefoundation.org
www.hospicefoundation.org

Hospice Net
www.hospice.net

Medicare
www.medicare.gov

National Hospice and Palliative Care Organization
800/659-8898
www.nhpco.org
www.nhpco.org

Understanding Palliative and Hospice Care

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THE BASICS

Services.

Informed decisions about enlisting these available resources that can help you make Palliative Care and Hospice Care, and the care means “giving up.”

Misconceptions is that palliative or hospice stigma, and myth. One of the most common interchangeably. They also may conjure up fear, of-Life Care, Comfort Care, and Supportive Care are widely misunderstood and often used 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 or hospice care means “giving up.”

Learn about the Care Options defined as Palliative Care and Hospice Care, and the available resources that can help you make informed decisions about enlisting these services.

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.
- BOTH aim to improve quality of life 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.
- NEITHER hastens or delays death.

Differences between Palliative care and hospice care:

- Palliative care can begin at any point in a person’s disease process, and can be provided concurrently with curative treatments.
- 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.
- 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 healthcare team. Or, in some cases, the palliative care team continues to provide care, but in the new role of Hospice Care. 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.

Talk with your doctor about hospice care, if you are experiencing many of these indicators of final decline:

- Serious coughing and choking episodes
- Frequent falls with high risk for fractures and head trauma
- Severe dementia
- Immobility
- Recurrent urinary tract infections and incontinence

The takeaway message:

- Hospices vary as to the services, professional staff, and frequency of visits they offer. An individual referring practitioner cannot promise or assure which services a patient and family will receive. Families need to consult with hospice agencies on an individual basis to ask questions particular to one’s own situation. With this basic information in hand, we hope you will discuss your needs and questions with your family, your physician, and an experienced social worker or nurse.

MYTH AND FACT

MYTH: Palliative Care and Hospice Care do NOT mean the same thing. This pamphlet, and agencies included in the Resource section, can help you understand these distinctions.

FACT: Palliative Care and Hospice Care are the same.

Fact: Palliative Care and Hospice Care do NOT mean the same thing. This pamphlet, and agencies included in the Resource section, can help you understand the differences.

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.

Fact: Medicare covers Hospice but not Palliative Care.

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

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

Fact: Palliative Care allows for tests, curative treatments, and therapies for disability, as well as symptom relief. Hospice does not permit the patient to receive curative or life-prolonging treatments; Hospice does provide symptom relief, including medication. In some cases, patients enrolled in hospice may still receive a treatment typically thought of as “life-prolonging” (such as chemotherapy), for the purpose of bringing COMFORT, not extending life. Make sure that you, and your physician, understand these distinctions as they apply to your particular case.

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. Palliative Care can also be provided within a hospital. Some Hospice agencies have stand-alone Hospice facilities. Talk with your doctor or social worker about the best option for you.

Fact: Family members, paid caregivers, or facility (i.e. assisted living or nursing home) staff provide daily care for patients who are receiving Hospice services. The Hospice team recommends and sets up a schedule for the Hospice nurse, social worker, chaplain, volunteers, and other staff to visit, and also instructs family members on how to care for the patient. Someone from the Hospice team is always available by phone.