

# Understanding Palliative and Hospice Care



As symptoms of progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) or multiple system atrophy (MSA) change and progress, many people require additional healthcare supports to manage their complex care needs. Palliative care and hospice care services can play important roles in maintaining and enhancing quality of life over time.

There is much stigma around palliative and hospice care. As a result, many people are referred to palliative and hospice care very late in the course of their disease, or never referred at all, when they could have benefited from services for a long time while living with PSP, CBD or MSA.

Additionally, there are common myths and misconceptions around these services, and the terms “palliative care” and “hospice care” are often used interchangeably. While neither aim to extend life and they both fall under the same model of comfort care, there are differences between palliative and hospice care. It is our hope to provide you with clarification on these care resources so that you and your family can make informed decisions about enlisting these services.

## Palliative Care

- This model of care is focused on easing the burden of symptoms and supporting a person’s comfort and dignity while living with a serious and chronic disease.
- Teams often consist of a doctor, a nurse and a social worker. Services include:
  - Talking through goals of care
  - Responding to questions and concerns that arise
  - Emotional support
  - Medications and strategies to manage and relieve uncomfortable symptoms
  - Collaboration with your other healthcare providers, such as your primary care physician and neurologist, to decide on an appropriate plan of care
- Palliative care is still most frequently offered in a hospital setting, however in-home palliative care teams and outpatient palliative care are increasingly available.
- The biggest difference between palliative and hospice care is that palliative care can be provided concurrently with testing as well as therapies and life-prolonging interventions, such as rehabilitation, Botox injections, chemotherapy, radiation and ventilation. Still, the services and policies vary by each individual palliative care and hospice care agency.
- When is the right time to consider palliative care?
  - Palliative care can be implemented at any point during a person’s disease process to provide an extra layer of support within the healthcare team, serve as an additional consultation as issues arise, guide advance care planning and ease the transition to hospice.
  - Palliative care is particularly helpful when someone is experiencing symptoms that are impacting their quality of life and are difficult for their current healthcare team to manage, such as pain, nausea, difficulty with breathing, constipation, anxiety, depression, fatigue, trouble sleeping and/or, existential or spiritual angst.

## Hospice Care

- Hospice is the same model of palliative care applied to those who are thought to have six months or less to live if the illness were to run its natural course.
  - The biggest misconception about hospice is that it is only for people who are imminently dying, when the reality is that most people can qualify for and benefit from hospice services for much longer.
  - It can be difficult to predict how much time a person has left to live, so many people benefit from hospice services longer than six months. Hospice teams do regular assessments to determine if a person is eligible to continue services based on symptoms and disease progression.
  - Hospice neither hastens nor delays death.
- Hospice teams are similar to palliative care teams, involving a doctor, nurse and social worker, and provide the same services to ease the burden of symptoms. They can also involve:
  - Certified nursing assistants to help with regular baths
  - A chaplain to address spiritual distress and meaning making
  - Volunteers to offer engagement for the patient
  - Bereavement services for the family after a person passes away
  - Coverage of medications for the primary disease and symptoms as well as necessary durable medical equipment (e.g., hospital bed)
  - Temporary respite stays in a hospice or long-term care facility
  - 24/7 phone consultation, in addition to regular or as-needed visits
- Most hospice services are provided in someone's home setting but can also be in the hospital or a long-term care facility. Some hospice agencies also have their own stand-alone units or facilities.
- In the United States, many health insurances, including Medicare, cover 100% of hospice services.
- Once someone is under the care of hospice, health insurance typically will not cover appointments with your primary care doctor, neurologist or other specialists. No matter what, the hospice team often will continue to consult with certain healthcare providers, especially those who help to manage the primary disease and symptoms for which someone is seeking hospice services.
- When is the right time to consider hospice care?
  - When rehabilitation and other therapies geared toward managing the person's symptoms and functioning are no longer as helpful.
  - It is too much effort to travel for appointments with the neurologist or other healthcare providers.
  - The person is experiencing increased falls, infections, hospitalizations, sleepiness, pain or other uncomfortable or distressing symptoms, skin breakdown, weight loss and/or confusion.

Both palliative care and hospice care require a referral, which can come from a primary care doctor, neurologist or other specialist, although you can also request a free informational visit beforehand if you would prefer.

**Talk to your family and healthcare team about your goals for care and if or when palliative or hospice care is right for you.**

