



Top 5 Things to Know about Hospice Care for People with PD

1. What is hospice and what does it provide?

- a. Hospice involves support and resources to empower people with chronic illnesses to live well until the natural end of life in their desired location. Hospice helps avoid cumbersome and stressful back and forth trips between home, hospitals and facilities.
- b. The team-based care can include: a nurse, physician, social worker, chaplain, and bereavement support.
- c. Equipment, medications, and additional therapies can also be provided by hospice.
- d. While most insurance plans do not cover additional 24-hour home health aides, hospice has 24-hour support that can be contacted when concerns arise. No more waiting for the doctor's office to open or wondering if 911 should be called.

2. What is the typical timing of hospice?

- a. Hospice is available for people who are possibly in the last 6 months of life and are not seeking curative treatments.
- b. It is difficult to predict the timing of death in PD. If people meet certain criteria that suggest they are at higher risk for dying they may qualify for hospice even if they do not die within 6 months. In fact, some people may be on hospice for longer than 6 months or even "graduate" from hospice if they stabilize or improve with hospice care.
- c. Many people do not access hospice services soon enough. By mistakenly thinking that hospice is only for those who are actively dying, they miss out on extra support that focuses on living with comfort and dignity.

3. How do I choose a hospice organization?

- a. Talk to family, neighbors, community spiritual or faith leaders and friends in addition to your doctor to understand what hospice organizations are recommended.
- b. Ask questions specific to your needs, such as medication needs and resources for support.

4. Being an advocate.

- a. Talk to the organization if there are services not meeting your needs.
 - i. For example: If you are concerned in any way about the care your loved one is receiving, do not hesitate to communicate in specific terms with the care provider.
- b. Education on Parkinson's is important, especially regarding Parkinson's specific medications.
 - i. All hospice providers should be willing to communicate and collaborate with your neurologist and your primary care physician.

Additional Resources:

1. [The Role of Hospice](#): This fact sheet explains what hospice is, how to have a conversation about hospice, and how to obtain hospice services.
2. [Palliative Care and Hospice: 5 Tips for Advocating for Yourself and Your Loved One](#):

- This article explains the differences and commonalities between hospice and palliative care. It also contains tips on how to advocate for yourself and your loved-one when using these services.

3. [Hospice Care and the Myths Surrounding It:](#)

- This podcast provides a deep dive into the many benefits of hospice.