

## Planning for the End of Life: The Role of Hospice in Parkinson's Disease Care

As Parkinson's disease (PD) progresses into the advanced stages, its symptoms can often become increasingly difficult to manage. The daily care needs for a person with PD may overwhelm the family caregiver's physical, mental and emotional capabilities and require more help than the caregiver alone can provide.

In such situations, hospice can be an option. Although hospice is often associated with a terminal disease such as cancer, it is an option for individuals with chronic diseases, such as PD. Hospice can provide services and support with the goal of providing a quality, peaceful death while allowing the person with PD to stay in a familiar environment.

### What is Hospice?

Hospice is a program of care designed to improve quality of life through pain relief and symptom management for individuals who are facing the end of life. It can also provide valuable caregiver and family support with bereavement services for up to 11 months after the death of a loved one.

### What Benefits Will Hospice Provide for a Person and Family Living with Parkinson's Disease?

Hospice care is provided through home care agencies or in a facility (nursing home or hospice facility). Home hospice services are the most common type of hospice service used by a person with Parkinson's and offer the opportunity for the individual to remain at home during his or her last days and months of life surrounded by friends and family.

Hospice care provides a person with PD, his or her caregiver and family with health care providers who have expertise in the complex dying process.

The core home hospice staff is comprised of a physician, nurse, social worker and home health aides. Other personnel may include physical, occupational and speech therapists, and pastoral services.

Hospice may also provide durable medical equipment, medical supplies, medications and counseling. Other services may be provided depending on the needs of the person with PD and the structure of the home hospice agency.

### When is the Right Time for Hospice?

Determining when the time is right to consider hospice services can be a difficult decision for the person with Parkinson's, their family and health care providers. Parkinson's, while a chronic and progressive disease, has a course that can be uncertain with no clear indication of the end of life. Yet, those with PD often have additional significant medical problems — such as advanced dementia, recurrent pneumonia, weight loss, urinary incontinence, infections and pain — that could be better managed through hospice.

Current Medicare benefit guidelines ask health care providers to project that an individual has six months or less to live to enroll in

Medicare reimbursed hospice programs. However, many individuals live beyond six months while enrolled in hospice. At the end of the initial six-month period, the hospice agency will reevaluate the care plan and needs of the person with Parkinson's and either reenroll the individual for an additional three months or discharge the individual from hospice. Patients are discharged from hospice if the individual improves and doesn't meet the criteria any longer.

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## How Should Hospice be Discussed with a Loved One?

There are four parties involved in enrolling a person in hospice and managing end-of-life care: the family/caregivers, the person with Parkinson's, the hospice agency and the health care provider.

Hospice often has negative associations for individuals and is thought to be a sign of "giving up" or accepting "no hope." Overcoming these negative associations is an important first step in having the conversation about the benefits of end-of-life care in hospice. Discussing end-of-life issues is difficult and often avoided. As part of the care team, individuals with PD, caregivers, and health care providers can participate equally in ongoing discussions about planning for end-of-life care.

## How Does One Pay For Hospice?

Private health insurance may provide hospice benefits. Medicare does provide hospice coverage. More information on Medicare hospice benefits can be found at [www.medicare.gov/publications/Pubs/pdf/02154.pdf](http://www.medicare.gov/publications/Pubs/pdf/02154.pdf).

## What is the Application Process for Home Hospice Services?

Physicians initiate the enrollment process for a person with PD by making a referral to a hospice agency. Families can have input in the selection of the hospice agency by getting recommendations from outside resources (i.e., support groups) or by researching local hospices. The National Association of Home Care and Hospice provides information on how to locate hospice services at [www.nahc.org/home.html](http://www.nahc.org/home.html).

Once the doctor has sent a referral to the hospice agency, a hospice nurse will come to the home for an initial assessment to determine if the person with PD is eligible for hospice. If the individual qualifies, he or she will be evaluated for their specific needs, types of services, frequency of care and equipment.

## Is Hospice the Only Option?

Not all people with Parkinson's will decide to enroll in a hospice program for end-of-life care. There are alternatives to hospice. Persons with PD and caregivers who are not ready for hospice services but who need assistance with care might consider respite services, nursing home placement or home health aides to assist with care.

Respite care is a temporary care service that provides patients with care based on his or her needs and allows a break for the caregiver. Nursing homes or assisted living facilities may offer respite services. Often a caregiver uses this time for his or her own health care or to visit family members or friends that live at a distance. Nursing home placement is an option for persons who need full-time care that the caregiver or family is not able to provide in the home.

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## Questions to Ask When Considering Hospice:

1. Does the person with PD understand his or her prognosis and health care needs?
2. Does the person with PD want to remain at home until the end of life?
3. Has the family, caregiver and person with PD discussed long-term care options?
4. Has the person's health care provider been consulted in planning for end-of-life care?
5. Is there a living will and/or power of attorney in place for the person with PD?
6. If the person with PD is unable to communicate their wishes for end-of-life care, can someone represent their wishes for end-of-life care?
7. How much does the person with PD know about hospice and how does he or she feel about it?
8. Does the person with PD have insurance or is he or she Medicare-eligible for hospice care?
9. What other resources can be used to ease caregiver burden?

To find additional resources for managing advanced Parkinson's disease, visit [www.pdf.org/en/resourcelink](http://www.pdf.org/en/resourcelink) or order a copy of PDF's Parkinson's Disease Resource List at (800) 457-6676 or [www.pdf.org/en/brochures](http://www.pdf.org/en/brochures).

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.

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