

Understanding Hospice Care in Parkinson's



How Hospice Helps

- Fewer trips to the hospital or emergency room
- Care in a familiar setting, such as home
- Support for both you and your care partner as needs change
- Help knowing what to expect and how to respond
- A focus on comfort and daily needs

Hospice is specialized medical care for people in the last months of life, including some people living with advanced Parkinson's disease (PD). It focuses on comfort and day-to-day needs and supports both you and your care partner. Care is provided where you live.

Quick Facts

- Hospice care is centered on comfort
- Care is provided by a team that comes to you
- Most insurance plans, including Medicare, cover hospice.

How Hospice Care Works

Hospice care is provided by a team that includes a nurse, doctor, social worker and chaplain. The team visits you at home or in your care setting and works together based on your needs. A nurse is available 24 hours a day for urgent questions or needs.

Care focuses on managing symptoms that affect quality of life such as pain, shortness of breath, nausea and anxiety, as well as emotional and spiritual concerns. Care partners also get guidance on what to expect and how to give care.

As needs change, the team adjusts care and helps keep everyone informed.

Signs Hospice May Be Needed

With Parkinson's, changes are often gradual, and there may not be one clear sign that hospice is needed. Instead, hospice eligibility is based on a combination of changes. Signs may include:

- Trouble breathing or needing oxygen while resting
- Frequent falls or needing help to get out of a bed or chair
- Difficulty eating or drinking, weight loss or repeated infections
- Frequent hospital visits, especially in recent months

You or your care partner can ask any doctor involved in your care, "Am I eligible for hospice?" If not, ask about palliative care, which offers extra support for difficult symptoms and quality of life at any stage.

Resources

Read, Watch & Listen:

- [Parkinson.org/Library](https://www.parkinson.org/Library) (search "hospice")

Learn More About:

Palliative Care

- [Parkinson.org/PalliativeCare](https://www.parkinson.org/PalliativeCare)

Find Hospice Care

- [Medicare.gov/Care-Compare](https://www.medicare.gov/Care-Compare)
- [GetPalliativeCare.org](https://www.getpalliativecare.org)

Helpline

For answers to your Parkinson's questions, contact our Helpline at **1-800-473-4636** or Helpline@Parkinson.org.

We are here for you.

Parkinson's Care in Hospice

There are several Parkinson's-specific factors to consider when receiving hospice care.

- Parkinson's can change in unpredictable ways, so people with PD are more likely to go on and off hospice.
- Some hospice medications, including those for nausea or agitation, may not be safe for people with PD. Share the Safe & Contraindicated Medications list with your hospice team. Download and print the list at [Parkinson.org/HospitalSafety](https://www.parkinson.org/HospitalSafety).
- Continuing Parkinson's medications, when possible, can help with comfort and reduce stiffness or anxiety. If stopped, reduce them gradually to avoid worsening symptoms or withdrawal effects.
- Some treatments, such as physical therapy, specialist visits or higher-cost medications, may not be included. Talk with your neurologist ahead of time about how medications or therapies may need to change. This can help avoid gaps in medications or changes that may worsen symptoms.

Hospice teams may not be familiar with Parkinson's needs, such as how symptoms can return when medications wear off or how device-based treatments like DBS are managed. Delays in medications or changes in care can affect comfort.

Insurance Coverage and Costs

Hospice is covered by Medicare, Medicaid and most insurance plans, with little to no out-of-pocket cost. It includes care and support, equipment, supplies and medications for comfort.

If there are treatments or services you want to continue, you may need to pay out of pocket or delay starting hospice. Ask the hospice agency what services and treatments are not covered.



Tips When Considering Hospice

- **Ask your care team about hospice eligibility.** A referral from a doctor is needed.
- **Learn about hospice options in your area.** While core services are similar, some may be a better fit.
- **Share your care preferences.** A living will and power of attorney communicate your wishes and guide decisions.