Palliative Care for Persons Living With Parkinson Disease

Palliative care (also known as supportive care) can improve the quality of life of persons living with serious illnesses, including Parkinson disease.

Palliative care is a whole-person approach that addresses physical, spiritual, emotional, and functional sources of distress. Palliative care helps people understand how their diagnosis may affect them now and in the future. It helps clarify personal values to make health care decisions consistent with life goals and make a person’s wishes known in case they cannot speak for themselves in the future (advance care planning). Palliative care may be helpful at any stage of illness after diagnosis. Services can be provided at a hospital, outpatient clinic, facility, or home, in person or via telemedicine.

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Medical advances have led to significant progress in treating Parkinson disease (PD). However, these advances have limits, and no curative treatments are currently available. Recent research has shown that integration of palliative care and PD improves quality of life and reduces the severity and burden of symptoms. Palliative care in PD involves treatment of nonmotor symptoms such as pain, fatigue, and depression. It also consists of treating difficult emotions, such as caregiver stress, demoralization, and grief. Practical challenges, such as getting more help at home, and advance care planning are also explored. There is no right time for starting palliative care. Some services, such as talking about the future, are best done early because advanced PD can affect communication skills.

Palliative care is not yet a standard part of care for PD. Use of palliative care does not mean that a patient must give up their treating PD neurologist. A palliative care team and neurologist work together, often along with a pharmacist, nurse, chaplain, and/or social worker. They provide support primarily to the person with PD but also offer support to family members.

Advance Care Planning

During appointments, the palliative care team assists with advance care planning, which helps clarify what quality of life means now and how it may look in the future. It involves assignment of a health care power of attorney, education about diagnosis and prognosis, and completion of paperwork (advance directive). This activity is crucial as it gives peace of mind to the person with PD and their loved ones. It also helps ensure a person’s wishes are honored should they be unable to speak about their goals of care. This includes thinking about values, goals, and preferences for health care beyond the illness. For example, spending time with family or attending an important family event may help shape decisions about care. The palliative care and neurology team can help align these personal goals with current and future medical care. It is recommended that persons with PD undertake advance care planning yearly.

Hospice

Advanced PD is often characterized by weight loss, swallowing difficulties, severe dementia, and recurrent infections. In patients with advanced PD who have a prognosis of 6 months or less of life, palliative care can also include hospice, which focuses on maximizing comfort and quality of life. This may be a suitable service for patients who prefer not to go to the hospital. Hospice includes access to a visiting health care team, medications, medical equipment, social work, and a chaplain. Notably, 90% of hospice is provided at home, and 100% of hospice is covered by insurance, including Medicare. A hospice caregiver may visit a person’s home once or twice a week, with after-hours care available by phone.

FOR MORE INFORMATION

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