

Palliative and Hospice Care

Many people understand hospice or end-of-life care, but the term “palliative care” can still be unfamiliar. Both palliative and hospice care can provide services to assure the highest quality of life and, when the time comes, the best possible end-of-life care. The information here will help you to better understand the differences between the two and make informed choices for care. By learning about and discussing the available options before they are needed, people with Parkinson’s and family members can make careful, thoughtful decisions instead of being pressured or rushed during a stressful or crisis situation.

Palliative Care

The National Hospice and Palliative Care Organization defines palliative care as patient- and family-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care involves not only care of physical needs, but also the emotional, social and spiritual needs of patients, family members and caregivers. Palliative care stresses patient autonomy, access to information and choice, and it can be delivered from time of diagnosis through end of life, as a complement to other treatments.

Studies have shown that people who receive palliative care report less pain and other adverse symptoms like nausea or shortness of breath. In addition, patients report that they communicate better with their doctors and family members and experience more emotional support. Studies have also shown that palliative care ensures that care is more in line with people’s wishes and meets their emotional and spiritual needs.

Palliative care is usually provided by a team of professionals that may include doctors, nurses, social workers, chaplains, pharmacists, nutritionists, counselors and others. Most insurance plans cover all or part of the palliative care treatment costs. If the patient is an enrolled veteran, palliative (and hospice) care are part of the Standard Medical Benefits Package if the need for clinical service requirement is met. If you are worried about the cost of this type of treatment, the social worker from the palliative care team can help answer your questions. The palliative care team can help patients and family members make decisions about treatment options in advanced disease and can segue into hospice care if that is desired.

Hospice

Hospice is not giving up on life or withdrawing care, nor is it a form of physician-assisted suicide. Rather, it is an approach to treatment that recognizes death as the natural ending to life and provides the person with Parkinson's the maximum amount of autonomy, dignity and comfort during the dying process.

Medicare has established three eligibility criteria for entering hospice care, and most other insurers use these as well: 1) The patient must have a life-limiting illness, and the physician must determine that to the best of his or her knowledge, the patient has six months or less to live. 2) The patient (or the healthcare power of attorney) must accept hospice rather than curative care. 3) The services must be provided by a Medicare-approved hospice program. As mentioned above, Veterans are covered under the Veterans Health Administration Standard Medical Benefits Package.

Hospice services are not actually limited to six months, though. At designated intervals, a doctor can certify that eligibility criteria continue to be met, so the person in the final phase of life can receive care for as long as necessary.

People with Parkinson's can receive hospice services wherever they reside – home, assisted living facility, skilled nursing facility or even in the hospital, but this will require two payor sources. For example, if the patient has Medicare and state-funded (Medicaid) or private insurance, one source will pay for hospice and the second one will pay for room and board at the hospital or other facility (or you will have to pay out-of-pocket). The hospice care team consists of many of the same professionals included in the palliative team, but may also include integrative therapists (massage, art, music) and volunteers.

Because PD is a chronic and progressive disease with an individualized course, it can be difficult to determine when the end of life is near. However, hospice may be appropriate if the person has symptoms such as advanced dementia, recurrent pneumonia, weight loss, urinary incontinence, infections and pain. Unfortunately, there are still some doctors who are not well versed in hospice services. If you request hospice instead of aggressive treatment, you may contact the hospice provider of your choice. The hospice will work with the treating physician to obtain the necessary referral.