

Hospice Provides Welcome Support for Caregivers

One of the benefits of hospice care is that it not only provides comprehensive care for the patient, but also supports the caregiver. To help people caring for a loved one, the National Hospice and Palliative Care Organization (NHPCO) has expanded its website to include practical information for caregivers.

Preparing for Giving Care

NHPCO's website at www.caringinfo.org talks about what to expect when you become a caregiver. In the section called "Preparing for Giving Care," caregivers can find resources and ideas for decisions they may need to make, ways to keep their home safe for a loved one, tips to stay organized, and more.

If the patient is still able to make their own decisions, NHPCO urges caregivers to help the loved one with advance directive documents. Since legal wording can vary from state to state, NHPCO makes it easy by offering instructions for completing a valid advance directive for each U.S. state.

In an advance directive, a person states what kind of care they would want in the future, in case they are no longer able to speak for themselves. The site says, "Knowing and understanding your loved one's values and wishes will be important as you become responsible for making decisions for them."

Other tips NHPCO offers for getting and staying organized include making lists of:

- Contact information for medical professionals and emergency contacts, especially the hospice phone number
- The location of important items, like thermometers and blood pressure monitors
- Where medications are stored, and how often each is taken

Providing Care

The website shares practical ideas about providing both physical care and comfort care. In the section about physical care, for instance, NHPCO suggests ways to make sure your loved one has good oral hygiene and skin care, and offers tips for helping morning and bedtime routines go smoothly.



A unique aspect of hospice care is the emphasis on comfort and providing emotional and spiritual support, all of which enhance the patient's quality of life. In the comfort care section of the website, NHPCO mentions that meal times can be special social moments, even if your loved one is confined to bed. You can enjoy meals together by bringing a tray in for yourself so you can sit together and talk.

"Take some time each day to talk to your loved one about their feelings. Be patient and listen to what they want to share with you. Whatever feelings they have, let them know that they have a right to feel that way; do not try to talk them out of their feelings."

Caring for the Caregiver

Caregiving can be a demanding, exhausting job. NHPCO says that it is important to take care of yourself physically and mentally, too, and it provides suggestions for staying healthy and dealing with stress.

Call hospice if you have questions or if you need a break from caregiving. A hospice volunteer can come to your home to provide a much-needed break so you can go shopping, see a movie, and so on. As NHPCO advises, "However you choose to take a break, make sure you do it often enough to maintain a healthy balance between caregiving and your personal needs."

End-of-Life Care Information for Families

Lung Cancer Patients May Live Longer with Hospice Care

A recent study suggests that people with lung cancer who enroll in hospice may receive better quality care and live longer. Noting that a common misconception about hospice is that it hastens death, the authors of the study found that lung cancer patients receiving hospice care actually lived significantly longer than people with lung cancer who weren't enrolled in hospice.

“Lung cancer is currently the second most common cancer diagnosis and the leading cause of cancer-related deaths in both men and women in the United States,” they state. The study, published in the *Journal of Palliative Medicine*, looked at people with non-small cell lung cancer, the most common type of lung cancer.

Researchers think hospice may help lung cancer patients live longer because hospice patients receive:

- Less aggressive care
- Better monitoring
- Better palliative care
- More social support

The study found that lung cancer patients receiving hospice care visit the hospital or emergency room less often near the end of life, and spend less time in the intensive care unit. These patients are also more likely to die as they wish at home or in a hospice facility, and not in a hospital.

Even if someone with lung cancer is unable to remain at home, hospice can help that person get quality care by providing care in an assisted living residence or nursing home. Many hospices also offer inpatient facilities, which the authors say provide “a high level of supervision and skilled nursing care often required at the end of life, but in a less severe and intimidating environment [than the hospital] for the patient, their family, and caregivers.”

Whether at home, in a nursing home, or at a hospice inpatient location, all hospice patients can have access to supportive, gentle care that could help them live longer.

Heart Failure Patients Want to Talk about What to Expect as Their Illness Progresses

It is recommended that heart failure patients and their doctors have more conversations about advance care planning and what to expect. Heart failure is the nation's leading cause of adult hospitalizations, but many heart failure patients say that they still have questions about the cause or prognosis of their disease.

While most heart failure patients have had some discussions with their doctor about what to expect from their illness, most patients who have not had such talks report that they want to. “There is more work to be done to make these important conversations universal,” say the authors of a study found in *Heart Failure Reviews*.

Men were more likely than women to have had conversations with their doctor about what to expect, prognosis, and advance care planning. Younger patients were more

likely to have had these discussions, as well. Patients who have not talked about these issues may be waiting for their doctor to broach the subject.

Researchers say that it may help doctors give heart failure patients better care if they understand the patient's preferences and goals. Talking about who the patient would want as a surrogate decision maker may be a good place to start for patients and their doctors to talk about expectations and care planning. Although 90% of heart failure patients in the study said they had thought about choosing a surrogate decision maker, only about two-thirds said they had talked about a surrogate with their doctor. Most patients who had not discussed these topics also wanted to talk about expectations of their illness and prognosis.

According to the authors, “These conversations are critical to understanding patient and family expectations and to developing mutually agreed-upon goals of care, and not just focus on the diagnosis.”



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