



## When to Refer to Hospice

*By Lisa Wayman, RN, MSN*

Hospice has long been acknowledged as the gold standard of end-of-life care. The hospice philosophy of comprehensive holistic care delivered compassionately by a multidisciplinary team greatly improves the quality of life lived while dying. This is well known among most professionals and much of the general public, yet patients continue to come to hospice too late to reap the full benefits of hospice services. “The National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA, released figures showing that a record number of people received hospice care in 2002, yet one-third of hospice patients died within one week of admission” (“Demand For Hospice,” 2004, p. 37). The short length of stay for hospice patients is a complex and multidimensional problem. One way to increase hospice length of stay is by more accurately identifying when it is time to access hospice care.

Entering hospice care is not just a practical decision but an emotionally laden decision. I discovered this when my son, Joe, was dying from cancer. As a nurse, I knew that hospice was a valuable service. I wanted that service for him, but was unsure of when it should start, and hesitant to talk about it. Saying the word “hospice” does, after all, admit that death is the probable outcome of an illness. Hospice also requires a shift in focus from curative treatments to palliative treatments. Deciding the appropriate time for the shift of focus is difficult for professionals and nonprofessionals alike. Pikes Peak Hospice & Palliative Care, who cared for my son (and where I now work), has developed guidelines for when it is time to refer to hospice. The guidelines can be divided into two categories: the efficacy of treatment, and the patient’s perception of quality of life.

Hospice is appropriate when a patient is no longer responding as expected or anticipated to the disease treatment. Treatments that may have been effective no longer have the same beneficial effect. This can be seen in patients with chronic illnesses, for example congestive heart failure or chronic obstructive pulmonary disease, who become more ill even when compliant with their usual regimen. Hospice-ready patients continue to decline even with new treatments and medication regimens. Patients may also experience a sudden event, such as a stroke, that causes their decline even with appropriate treatments. Events such as recurrent infections with diminished success in treatment, multi-system failure, and repeated short-term hospitalizations or trips to the emergency room can signal the need for hospice care.

Hospice is valuable for any patient for whom disease treatment is no longer effective. However, cancer patients remain the core of hospice census. I am familiar with the difficulty of enrolling a cancer patient in hospice. My son, Joe, had cancer when he was eleven years old. When he was first diagnosed, we wanted to do anything, everything to help him get better. At first this seemed reasonable, and we had hope of his recovery. After less than a year of treatment, it became apparent that nothing would make him better. His brain tumor grew when he was taking chemotherapy. It slowed, but did not disappear, with radiation. His symptoms and his care became much more complex and he grew more ill. I knew several families who, at this point, had left the oncologist's care for a desperate search for treatments. Some went to Mexico. Some lost large amounts of money here in the U.S. on well run hoaxes (including one involving injections with purified horse urine). All their children died.

Our family struggled with the multitude of options, the need to try for a cure, Joe's increasing suffering, and the guilt and grief over his impending death. We decided, with the help of his oncologist, that the burden of his treatment was outweighing the benefits. Joe's persistent difficulty with pain and symptom control, and our need for ongoing support, helped us make the decision to use hospice care. When we entered hospice care, we no longer hoped for a cure, but instead hoped that Joe would be able to live well until he died and that he would die a peaceful death. With the help of hospice, Joe was able to stay home and live a life full of growth and joy until his death in 1998.

Joe was part of his hospice enrollment decision. He was disappointed and grieving but felt, as many patients do, that his quality of life was unlikely to improve. Patients may make statements such as, "Nothing seems to be working" or "I wish this were over" or "I don't want to go back to the hospital." Patients may also be declining options for additional treatment interventions. These remarks and decisions can be a patient's way of trying to open a discussion about the end of life. Honestly responding to a patient's concerns can lessen their fears. "With death imminent, patients worry that no one is listening and fear dying with unnecessary pain and suffering" (Quill, 2000, p. 2503). Comments by patients are a way of addressing their death, the "elephant in the room" (Quill, 2000), that is made more fearful by not acknowledging it. Discussion of hospice at this point can start conversations that explore a patient's fears and facilitate a care plan for the end-of-life, a care plan that focuses on the patient's goals and tasks.

Timely admission to hospice gives the patient needed support as they work on the tasks of dying. "Even as they are dying, most people can accomplish meaningful tasks and grow in ways that are important to them and to their families" (Byock, 1997, p. 32). A hospice consult that comes the week a patient dies not only delays appropriate symptom management but also curtails his/her ability to work on end-of-life tasks. Joe was only a child, but he still had goals at the end of his life. He made a will, wrote letters to his parents and his sister, said goodbye to his classmates and his friends and, in his last month, sent Valentines to those he loved. He also told jokes, went to the movies, had parties and enjoyed his life. By acknowledging his impending death and allowing hospice to help, Joe had the time and the support to finish the tasks important to him, and the people he loved were able to say goodbye. Our healthcare providers guided us to

recognize the decreased efficacy of his treatment and Joe's decline to help us make our decision to enter hospice. The last part of Joe's life was heart wrenchingly difficult. Hospice care in his last months also helped make it a sacred time full of joy. Hospice is not what you do in the last week when there is nothing left to do. Hospice is what you do in the last months because there is so much left to do.

### **References**

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