Continuous Care: A Home Hospice Benefit

Amy Newman, RN, BS, CHPN, Janeen Thompson, MPA, MT-BC, and E. Mitchell Chandler, DO

Hospice professionals are aware of the difficult transition that occurs when patients and their loved ones arrive at the end stages of metastatic cancer and desire to reach the end of life in their home. However, the actual practice of caring for someone who is dying at home requires specific skills and support from those trained in end-of-life care.

Amy Newman, RN, BS, CHPN, is a regional clinical manager, Janeen Thompson, MPA, MT-BC, is a crisis care and utilization specialist, and E. Mitchell Chandler, DO, is a physician, all in hospice and palliative care at the Visiting Nurse Service of New York in New York, NY. The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. No financial relationships relevant to the content of this article have been disclosed by the authors or editorial staff. Newman can be reached at amy.newman@vnsny.org, with copy to editor at CJONEditor@ons.org.

Case Study

R.G. was a 64-year-old woman with breast cancer with metastases to the lung, bone, liver, and, most recently, brain. Her initial cancer diagnosis was five years prior to her hospice admission. She was discharged from a cancer treatment center after an admission for increased CO₂ levels where she was treated in the intensive care unit for five days. During that admission, positron-emission tomography scans revealed brain metastases. The patient and family were aware that death was imminent and wanted a home setting for the end of life. Discharge planners initiated a home hospice referral and arranged for the family and caregiver to be supported by the component of the hospice benefit known as continuous or crisis care. R.G. would be home with her husband, who was an overwhelmed healthcare professional, and her three young adult children aged 18–32 years. It was determined that her family required education on end-of-life care and emotional support.

Continuous Care

Continuous care most commonly is provided for two to three days; however, it can remain for a longer period of time if the acute medical crisis continues and the goal is for the patient to remain at home. At times, patients in continuous care transition to inpatient hospice settings for more acute interventions than those that can be provided at home. Continuous care LPNs frequently administer ordered medications and monitor for their effectiveness while under the supervision of an RN. LPNs educate the family on the purpose of the administered medications, what to expect during the end stages of the disease, how and why to maintain good skin care, and how to monitor pain and anxiety. Hospice professionals regularly work with families who have the desire and ability to care for their loved ones when given the proper teaching and emotional support. A key component of hospice care is allowing patients to remain in their chosen environment, and continuous care provides the support and ability for patients to stay in the comfort of their own home.

Home Health Aides

HHAs are a key component when continuous care is initiated. They are trained to monitor for pain, shortness of breath, signs and symptoms of distress in the patient, as well as signs of caregiver fatigue and breakdown in the household. In addition, HHAs instruct caregivers in areas of personal care, turning and positioning for comfort, and skin care. Therapeutic touch is a nonpharmacologic intervention for management of pain and anxiety that HHAs may employ at times. All of that is done in collaboration with the interdisciplinary team that reports findings to the RN who then coordinates the episode of care.

A caregiver expressing concern and fear when administering medications such as morphine and atropine, which often are used at the end of life, is not uncommon. Therefore, LPNs provide a valuable service to patients and families when giving proper instructions regarding purpose, side effects, and methods of administration.
Continuous Management

Continuous care was initiated to address R.G.‘s physical pain symptoms and provide adequate medication management as well as seizure precautions. After her hospitalization, R.G. returned home with dexamethasone 10 mg via colostomy twice per day. Considering alternative routes of medication administration in a hospice care plan is not uncommon, and R.G.‘s ability to take in only sips of water required that approach (Stevens & Ghazi, 2000). She also was on seizure precautions; however, she had not shown any seizure activity prior to her hospice admission. Pain management was required and the family’s primary goal was obtaining adequate pain control. The RN collaborated with hospice and primary physicians who increased R.G.‘s doses of breakthrough hydromorphone to 6 mg orally every three hours via liquid form, which she was able to tolerate. Her pain also was managed with a fentanyl patch of 37 mcg every 72 hours. The HHA provided personal care and monitored for changes in R.G.‘s symptoms.

Continuous Support

In R.G.‘s case, her family was supportive of her desire to die at home but was very overwhelmed with grief and the responsibility of caring for her themselves. Although a medical professional, her husband was experiencing loss and required education and emotional support from hospice professionals. The team provided physical and psychosocial support including medication instructions, placement of supplies and equipment in the home, as well as monitoring for the effectiveness of new pain medication regimens and seizure activity. Spiritual care counselors and social workers also participated in the interdisciplinary approach and were involved in R.G.‘s care management.

In accordance with the hospice benefit, R.G.‘s husband and children were offered bereavement support for 13 months following her death. Bereavement support allows families to move through the grieving process supported by professionals. During those 13 months of follow-up, professionals are available for all of the first events after a patient’s death, including first birthday, anniversary, major religious holidays, and the first anniversary of death. Support groups are available and private counseling sessions are offered as needed.

R.G.‘s wish to die at home was managed successfully by her family and caregivers. Continuous care can be the key to supporting a person in the wish to die at home surrounded by loved ones and supported by hospice care.

References