Emergency departments are called upon to care for an amazing variety of patients with a plethora of conditions, but perhaps none can be as puzzling as the decision about how to treat, or not treat, a patient who has been enrolled in hospice care.

Modern hospice programs, under Medicare guidelines, frequently are misunderstood. While it is true that 2 physicians must sign that a patient, given the current situation and medical knowledge, and using their best judgment, will die within 6 months, hospice care is palliative, and more and more patients are living well past the magic “6 months” timeline. In fact, it is not unusual, with good attention to symptom management, for a patient receiving hospice service to survive for 2 years or longer.

Unfortunately, many patients and their families still consider the suggestion of “hospice” to be a death sentence. It is estimated that only approximately 1 in 20 persons who could benefit from the program actually are referred or choose this care.

The current hospice program in the United States has been in effect since 1982. It is a spin-off of the approach used by Dame Cicely Saunders in the United Kingdom, and was adopted by the U.S. government as a palliative rather than curative approach to treat the incurable. When a patient has a problem that cannot be fixed, be it cancer, end-stage chronic obstructive pulmonary disease, end-stage dementia, or some other problem, then it is time to quit trying to “fix” it and turn to approaches that help the patient and the family live with the situation. Hospice also seeks to contain costs by eliminating overtreatment of terminally ill patients while helping to maintain quality of life. Patients are not dying with cancer; they are living with a cancer that cannot be cured. There is no further need for laboratory tests, radiographs, magnetic resonance imaging scans, and returns to the hospital. This point is where hospice steps in to provide comfort care at home or wherever the patient resides. Often just having hospice involved means the patient improves; some patients improve to the point where they are discharged from hospice as chronically ill, not terminally ill.

Not all hospice patients have do not resuscitate (DNR) status, but most have signed a DNR form. The majority of hospice patients also have an advance directive, and many will have a durable power of attorney for health care. This does not mean that the patient does not get care. An example is a hospice patient with end-stage chronic obstructive pulmonary disease who falls and breaks a hip. Of course that patient is going to be treated and may end up in the emergency department.

It is important to understand that when a patient or the family (if the patient is not competent) elects hospice, hospice becomes the primary insurance carrier. Just like with a health maintenance organization, all approval for treatment must be authorized by the hospice program. If the situation for which the patient presents to the emergency department is not connected to the hospice diagnosis, then the patient’s Medicare or other insurance may become the primary coverage.

When a patient receiving hospice care arrives in the emergency department, one should check to be sure that the hospice organization has been notified. Families are instructed to call hospice and not to call 911, but of course that does not always happen. If hospice has not been notified, then it behooves the ED staff to do so. Not notifying hospice may result in denial of payment for treatment. Normally a hospice nurse will come to the emergency department and participate in decision-making regarding the patient’s care. Hospice is a 24/7 operation, and a nurse is always available. If the patient resides at an inpatient hospice center, someone from that facility will usually accompany the patient to the hospital.

Emergency nurses and physicians also need to be aware that patients receiving hospice care may be taking enormous dosages of drugs—one patient, for example, was receiving 100 mg of morphine sulfate every hour delivered by a preset pump. Many patients are able to take oral medications and also may be taking large doses. Some patients
may have fentanyl patches in place—sometimes more than one. Withholding needed medication from these patients for fear of “overdosing” amounts to torture and is not acceptable. If there are questions about pain or other medication dosing, the hospice nurse or the hospice medical director should be asked for guidance. Doing so is especially important if the patient will be kept in the emergency department for an extended length of time. Patients receiving hospice care routinely take their pain medications around the clock and may be on extended-release drugs that will need to be given at the appropriate time. MS Contin is one example of a drug given every 8 or 12 hours to patients receiving hospice care. It is very important that the ED staff accept these prescribed dosages and not make comments suggesting that the patient is “overmedicated.”

Any hospice patient has the right to revoke hospice at any time. Losing a loved one is a stressful situation, and watching that loved one die without anyone “doing anything” may be more than someone can bear. Hospice staffs work very hard to ensure that this situation does not happen, but occasionally, despite all the best efforts and support, the family calls 911 and the patient arrives in the emergency department with the family demanding “everything” be done, including CPR. The hospice nurse still needs to be notified, and he or she will come to the hospital to be with the family. Revoke papers will be signed, and the patient’s insurance probably will return to the pre-hospice state. Patients covered by the Hospice Medicare Benefit can revoke and return to hospice at will; other insurance programs limit this revolving-door policy. Hospice benefits for children and adults not covered by Medicare may or may not be consistent with the Medicare guidelines.

Hospice is a wonderful and underused benefit available across the United States. Emergency nurses are in a unique position to recognize situations where a referral to hospice may be appropriate—“frequent flyers” who obviously are never going to be well again, for example. One great benefit of hospice is that all of the care provided under the Hospice Medicare Benefit pertaining to the hospice diagnosis is 100% covered—there is no charge to the patient or the family, so it is “affordable.” Table 1 contains a summary of some of the important components of hospice and knowledge that may be useful to emergency nurse and physicians. Knowledge about the special needs of patients receiving hospice care and the family also should be part of ED care plans.

Submit descriptions of procedures in emergency care and/or quick-reference charts suitable for placing in a reference file or notebook to: Renee Semonin-Holleran, RN, PhD, CEN, CCRN, CFRN, CTRN, FAEN, Section Editor
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