

What is Hospice Care?

2 credit hour course

Hospice is not just a type of care, but a belief that places the focus on easing the symptoms of a terminally ill patient. Symptoms vary from physical, emotional, spiritual, and social. While the concept of hospice care has existed since the 11th century, the modern concept of hospice began to emerge in the 17th century. Then, some 300 years later, many of the foundational principles by which today's modern hospices operate were pioneered in the 1950's by Dame Cicely Saunders in the United Kingdom.

Saunders was an English registered nurse who was afflicted with numerous health issues that forced her to pursue a career in medical social work. A relationship she developed with a dying Polish refugee helped her to realize that terminally ill patients needed compassionate care to help them address their fears and concerns as well as easing the pain of their symptoms in their final stages of life. In 1957, Saunders became a doctor, taking a position at St. Joseph's Hospice in London. Her work there helped to formulate her plan of hospice care; focusing on the patient rather than the disease. She came up with the concept of "total pain", which included psychological, spiritual, and physical aspects. She conducted extensive research in medications to control physical pain, but she also looked to include the needs of the patient's family.

In the 1960's, Florence Wald, dean of Yale School of Nursing, spent a month working with Saunders to see first-hand the approach she was bringing to hospice care. Bringing back the principles that she had learned from Saunders, Wald established Hospice, Inc. in the United States in 1971.

Hospice Care in the U.S.

During the 1970's, the philosophies of hospice that Wald had brought over from the United Kingdom began to be implemented throughout the U.S. The hospice movement soon began to transform itself,

separating itself from the British version, placing greater emphasis on volunteers and focusing more on the psychological preparation for death.

In 1982, Medicare added hospice services to its scope of coverage. President Reagan then proclaimed November 7 through the 14th, 1982, as the National Hospice Week.

Since that time, the hospice industry in the U.S. has expanded at a very rapid rate. In 1995, hospices were a 2.8 billion dollar industry, with 1.9 billion coming from Medicaid alone. In that year, 72% of hospice providers in the U.S. were non-profit. By the end of the 20th century, there were more than 3200 hospices operating or under development, increasing at a rate of about 3.5% per year. In 2007, over 1.4 million people had utilized hospice, with nearly one-third of dying Americans using the service. By 2008, Medicare, which pays for 80% of hospice treatment, paid over 10 billion dollars to the 4000 Medicare certified hospices in the U.S.

HOW HOSPICE WORKS

The main purpose for hospice agencies in the U.S. is to provide comfort for the patient. The definition of comfort is determined by the patient or the patient's family if they are unable to do so. Typically, hospices in the U.S. do not perform treatments to diagnose or cure an illness, nor do they seek to speed up the dying process or to unduly extend life. Some, though not all, of hospices do require their patients to sign "Do not resuscitate" orders, in the event their heart or breathing stops. Many patients decide for themselves, refusing to have CPR performed. If the patient does request that CPR be performed, the hospice cannot do it; Emergency Medical Services will need to be contacted by the family. The decision not to extend life along with seeking treatments to cure the condition has become the biggest barrier for patients who seek hospice care.

One question that seems to appear more often than not, exactly what treatments can a patients receive and still qualify for hospice. Hospices are able to provide treatments that have traditionally been seen as curative, such as radiation therapy or antibiotics, if they are used to improve the quality of life.

In order for a patient to qualify for hospice care, a patient must have certification from two doctors that he/she has less than six months to live if their condition runs it's natural course. Patients can and do stay on hospice for longer than six months, as long as the hospice care team deems the condition of the patient is still terminal. Insurance companies will usually continue to pay as well if the condition is continued to be diagnosed as terminal.

In 1994, the average length of stay in hospice before the patient died was 26 days, dropping to 19 days in 1998. By 2004, these numbers had risen to an average length of stay of 57 days, with 33% of patients dying within seven days of admission. This kind of late admission is not at all typical of hospice care, seeking time to develop relationships between the patients, care team, and the family.

As previously stated, in order for a patient to qualify for hospice care they have to be certified as having a prognosis of less than six months to live. There are times however when a patient will live longer than six months. Under the provisions of Medicare, the first six months is broken up into two 90 day benefit periods. At the end of the two periods, the hospice care team will decide whether the patient still has a prognosis of less than six months to live. After these two 90 day benefit periods, the hospice is required to evaluate more closely and review every 60 days. When it comes to commercial insurers, managed care program providers and Medicaid, they often will have their own criteria regarding re-certification.

[WHAT DOES HOSPICE COST?](#)

The cost of hospice care can be met by health insurance providers, including Medicare and Medicaid for those who qualify. 100% of hospice care is covered with no co-pay or deductible by Medicare Part A,

patients being responsible for co-pay on outpatient drugs and respite care. By 2008, Medicare was responsible for 80% of hospice payments, reimbursing \$600 a day if care was in a facility and \$125 per day if care was provided at home. Most commercial health insurance companies as well as Medicaid also have similar plans to that of Medicare. The majority of non-profit hospices have plans for patients who lack insurance and will provide care free of charge or at a reduced rate.

WHAT KINDS OF HOSPICE CARE ARE THERE?

There are four primary levels of care involved in hospice care; routine home care, continuous care, general inpatient and respite inpatient. All hospices in the United States certified by Medicare are required to offer these four levels of care.

1. **Routine home care-** This is the most common form of care that is provided. Routine home care does not refer to the location of care, but the level of care that is provided. This type of care can take place in a nursing home or in an assisted living facility, though the majority takes place in a private residence. A variety of services are carried out during routine home care, including medical supplies, equipment, medications, and incidentals (diapers, bed pads, gloves, etc). 24 hour care services must be available as needed.
2. **Continuous care-**This is a service that is provided in the patient's home. This level of care is for those patients that need temporary extra support. When a patient is put into this type of care, the hospice provides services for a minimum of eight hours a day. Due to the strain placed on staffing extended hours in the home, continuous care is designed for short periods of time.
3. **General inpatient care-** Intensive level of care provided in a nursing home, hospital, or a free-standing hospice unit. This type of care is reserved for patients whose symptoms require around-the-clock care, being in the "active phase" of dying; prognosis being measured in days as

opposed to weeks or months. This is normally a short duration of care, averaging five to seven days.

4. **Respite care**- This is a brief level of care, provided for the needs of the family, not the patient. This care is used to give family members a chance to take a break from their role as caregiver. During this time, the patient is transferred from home to a care facility such as a nursing home or assisted living. The only difference between this type of care and routine care is that the hospice pays for the room and board charges at the facility. Respite care can be used for five days during a benefit period.

Hospice is a Team Effort

Every hospice provides what is called an *interdisciplinary team* to patients and families. This sets hospice apart from other types of care. Instead of professionals working independently on various issues a patient may have (called a *multidisciplinary team*), the *interdisciplinary team* works together toward the same goal of affording the patient a comfortable dying experience and the support the family needs.

The hospice team is required by Medicare to meet every two weeks. During this meeting, needs of the patient are discussed and planned for the next two weeks. They will also review to ensure the patient still meets all the criteria for hospice care.

Your Role as a Caregiver

It is not required that every patient on hospice receive a professional caregiver. Most patients do however receive this service. You will quickly discover that your job is the one most depended on by both the patient and the family. You will typically visit the patient anywhere from 3-7 days per week, usually 1-2 hours per visit. You will have a great opportunity to be both a source of strength and

comfort, behaving in a way that instills confidence in the patient and the family. Developing an attitude and approach to this type of situation is never easy, that will come with experience. Here is a list of things you can keep in mind:

- Make your responses consistent, guided by the patient and the plan of care.
- Always remember the patient is in the process of dying. Be open and receptive, their attitude may change daily.
- Always make sure that you inform the nurse of incidents that reflect the patient's mood and needs.
- Everyone has different ideas on what death means. Be open to your patient's ideas and not force your own upon them.
- You are sure to have strong emotions when dealing with death. Talk with others, explore your feelings, and resolve any conflicts you may have. Look at death as a natural occurrence; it will help you to meet patient needs in a realistic manner.
- Be at your best. See to the needs of your patient, giving special attention to mouth care and fluid intake.
- You should conduct yourself in a quietly empathetic way, carrying out your duties in a calm, efficient way.
- Encourage the person to carry out as much self care as possible.
- Be available to listen. Spend as much time with the patient as possible and desired by the patient.
- Get to know the family and be supportive of them.
- Give the same care you would if a terminal diagnosis had not been made.

- Remember, there will be times when hospice care seems to go against everything you believe. Follow the plan of care.

One of the most important issues you will have to deal with as a caregiver will be the stages of grief that a patient will go through after they have been given a terminal prognosis. Here are the stages to be aware of and how to best handle them:

Denial- Reflect patient's statements, try not to confirm or deny that the patient is dying.

Patient- "The tests can't be right, I don't have cancer."

Caregiver- "It must have been difficult to learn the results of your tests."

Anger- Understand the source of the patient's anger. Be supportive. Listen to them, and try to meet reasonable demands quickly.

Patient- "This food is terrible."

Caregiver- "Let me see if I can find you something better."

Bargaining- If it is possible to meet a patient's request, do so. Listen to them.

Patient- "If God will spare me this death, I'll go to church every week."

Caregiver- "Would you like a visit from your clergyperson?"

Depression- Don't ever dismiss a patient's pain. Be caring and supportive of them. Let them know it is ok to feel depressed.

Patient- "There is no use going on."

Caregiver- "I understand you feeling depressed."

Acceptance- Do not assume that, because a patient has accepted death, they are unafraid, or need emotional support. Be there to listen to them, being supportive and caring.

Patient- "I feel so alone."

Caregiver- "I am here with you. Would you like to talk?"

Test Questions

1. The concept of hospice care has been around since:
 - A. 10th century
 - B. 11th century
 - C. 1912
 - D. 13th century

2. The modern concept of hospice care was pioneered by:
 - A. Dame Judith Dentch
 - B. Dame Clara Barton
 - C. Dame Cicely Saunders
 - D. Dame Margaret Hath

3. One of the main tenants of modern hospice care is focusing on the _____ rather than the disease.
 - A. symptoms
 - B. cure
 - C. doctor
 - D. patient

4. The concept of “total pain” includes all the following except:
 - A. spiritual
 - B. mental
 - C. psychological
 - D. physical

5. In 1971, Hospice Inc. was established in the U.S. by:
 - A. Florence Nightingale
 - B. Florence Wald
 - C. Florence Henderson
 - D. Florence Wright

6. One of the things that separated American hospice care from the British was emphasis on:
 - A. Seeking a cure

- B. use of placebos
- C. volunteers
- D. proper diet

7. The first National Hospice Week in the U.S. was recognized by President Ronald Reagan in:

- A. 1982
- B. 1983
- C. 1992

8. In 1995, _____ of hospices in the U.S. were non-profit.

- A. 64%
- B. 72%
- C. 88%
- D. 59%

9. Today, Medicare pays for _____ of hospice treatment.

- A. 40%
- B. 50%
- C. 70%
- D. 80%

10. In 2008, there were approximately _____ Medicare certified hospices in the U.S.

- A. 2500
- B. 3500
- C. 4000
- D. 4500

11. The main purpose of hospice agencies in the U.S. is to provide _____ to the patient.

- A. a place to stay
- B. treatment towards a cure
- C. counseling
- D. comfort

12. Many hospices require patients to sign a _____ order to be accepted into their program.

- A. non disclosure

- B. do not resuscitate
- C. privacy
- D. research agreement

13. To qualify for hospice care in the U.S., two doctors must certify that the patient has _____ or less to live.

- A. 3 months
- B. 6 months
- C. 9 months
- D. 1 year

14. In 2008, the average length of stay for patients in a hospice was:

- A. 27 days
- B. 37 days
- C. 47 days
- D. 57 days

15. The four levels of hospice care include the following except:

- A. Respite care
- B. Segmented care
- C. General inpatient care
- D. Continuous care

16. The most common form of hospice care is:

- A. Segmented care
- B. Continuous care
- C. Routine home care
- D. Respite care

17. Hospice patients that require temporary extra support in the home would require:

- A. Respite care
- B. Continuous care
- C. Segmented care

18. When a patient's prognosis is measured in days, not weeks or months, it is called the _____ of dying.

- A. final stage

- B. final phase
- C. active phase
- D. active stage

19. Respite care is a brief level of care provided for the needs of the _____.

- A. patient
- B. family
- C. caregiver
- D. doctor

20. The five stages of grief included all the following except:

- A. Fear
- B. Anger
- C. Acceptance
- D. Denial

