

*Indiana Extension Homemakers Association Lesson***Understanding Hospice: Getting the Answers**

Lesson Overview: Each of us make life decisions every day. According to the National Institute on Aging, when it comes to end of life decisions it is important to understand the support and medical care given during the time surrounding death. Such care does not happen only in the moments before breathing ceases and the heart stops beating. Older people often live with one or more chronic illnesses and need a lot of care for days, weeks, and even months before death. Increasingly, people are choosing hospice (HOS-pis) care at the end of life. It is important to understand the approach to care provided by hospice care.

Participants will learn:

- Hospice model for care at end of life
- Eligibility guidelines for hospice care
- Resources for learning more about hospice care

Begin the lesson with a group activity.

Start the lesson by asking group members to stand and take three long, deep, breaths and out-breaths. Breathe in through the nose and out through the mouth. Follow this by leading participants in a big, slow stretch. Next, smile and invite participants to exchange shoulder massages with the person to their left before sitting down for the lesson.

A Real Story to Share. Read the story aloud.

Early one afternoon I arrived at the long term care facility to visit my aging father-in-law who was in hospice care for congestive heart failure. It was such a beautiful sunny summer afternoon. As I walked up the hillside to the front door, I could feel a cool breeze blowing on my face outside the facility, so I decided to take a moment for me and just sit for a while enjoying the summer sunshine. I found a comfortable rocker to use on the front porch. While I was sitting and rocking, two aging male residents joined me on the porch and began a conversation. I wasn't trying to listen to their conversation, but it was just impossible not to

hear their words as their voices grew louder and louder. Perhaps each had challenges with their hearing.

What they said to each other both took me by surprise and rang so true for me at the time. Here's the conversation I overheard:

"Do you ever think about dying?"

"Not much."

"I've been thinking about it some lately. (A long pause) You know it's going to happen."

"Yeah. What ya thinking?"

"Well, I've been thinking, (long pause) I'm not afraid of death, but it's the dying part that worries me."

"Me, too."

Questions to ask after reading the story:

1. What do you think was meant when shared ..."it's the dying part that worries me"?
2. Do you think it difficult for us to share our thoughts about the end of life? If so, why might this be? If not...

Follow-up response to the discussion:

The National Hospice and Palliative Care Organization reports that many Americans die in facilities such as hospitals or nursing homes receiving care that may not consistent with their wishes. To make sure that doesn't happen, people need to know what their end-of-life care options are and state their preferences to their families or caregivers in advance. For example, if an older person wants to die at home, receiving end-of-life care for pain and other symptoms, and makes this known to healthcare providers and family, it is less likely he or she will die in a hospital receiving unwanted treatments. Caregivers have several factors to consider when choosing end-of-life care, including the older person's desire to pursue life-extending or curative treatments, how long he or she has left to live, and the preferred setting for care.

What is Hospice Care?

Hospice care is the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's family as well. Hospice focuses on caring, not curing. In most cases, care is provided in the patient's home but may also be provided in freestanding hospice facilities, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients with any terminal illness or of any age, religion, or race.

Lesson Activity: Before the lesson, copy and cut apart the Understanding Hospice: True or False Questions activity cards. The activity will inform members about hospice care. The questions and answers were created by the Hospice Care Foundation and the University Of Maryland School Of Social Work and is provided as an online interactive quiz. The online quiz can be found at the Hospice Foundation of America website:

<https://hospicefoundation.org/Hospice-Care/Hospice-Knowledge-Quiz>.

After the story and discussion, hand each member a question or questions depending upon the number of members at the lesson. After a member reads their question, poll the group asking how many believe this to be true? To be false? After the members respond, ask the member who read the question to share the correct response. Continue until all members have asked their question(s) and shared the correct responses. Prizes may be provided.

References used for lesson content and resources to learn more:

Barbara Karnes, RN; <https://bkbooks.com/> Something to Think About: End of Life Blog

National consumer website, sponsored by National Hospice and Palliative Care Organization,

www.caringinfo.org

National Cancer Institute, End-of-Life Care for People Who Have Cancer, www.cancer.gov/about-cancer/advanced-cancer/care-choices/care-fact-sheet

National Institute on Aging, What are Palliative Care and Hospice Care? www.nia.nih.gov/health/topics/hospice,

National Institute on Aging, Providing Comfort at the End of Life, www.nia.nih.gov/health/providing-comfort-end-life,

NHPCO Facts and Figures: Hospice Care in America. National Hospice and Palliative Care Organization, Rev. ed. April 2018.

#1 Understanding Hospice: True or False

“Hospice staff are available by phone any time, day or night.”

TRUE

- Families can depend on 24/7 assistance and advice by phone.
 - When a crisis or concern arises while receiving care, hospice should be your first call.
- If a crisis cannot be handled over the phone, it is common for a nurse to make an in-person patient visit.

#2 Understanding Hospice: True or False

“Hospice must stop services if an individual lives longer than 6 months.”

FALSE

- Care can be extended past 6 months if a person’s health continues to get worse or the physician believes he or she still has 6 months or less to live.
- Under Medicare guidelines, hospices are required to stop care if the patient’s condition improves beyond a brief or temporary period so that life expectancy is now greater than six months. Hospices refer to this as a discharge.
- The Hospice Medicare Benefit, which pays for the vast majority of hospice, does not expire.

#3 Understanding Hospice: True or False

“Hospice care is available only to individuals with cancer.”

FALSE

- The majority of patients have conditions other than cancer.
- Hospice serves those with other life-threatening illnesses including heart and lung disease, dementia, kidney failure, and many other conditions.

#4 Understanding Hospice: True or False

“Hospice services are typically paid for by health insurance.”

TRUE

- Hospice is covered by nearly all insurance plans, including Medicare and Medicaid.
- Individuals and families typically do not pay out of pocket for hospice services. However, there are some limits to what is covered by hospice. For example, nutritional supplements, disposable supplies (e.g., bed pads), nursing home room and board, and over-the-counter medications unrelated to the patient’s primary illness are not typically covered.

#5 Understanding Hospice: True or False

“Hospice provides grief support for families.”

TRUE

- Hospices are required to offer bereavement services to the grieving family for at least a year after a loved-one dies.
- Grief support may be offered in a variety of formats: one-on-one counseling, group sessions, or periodic phone calls. Many hospices also offer grief support to the general public, regardless of whether hospice was involved in caring for the person who died.

#6 Understanding Hospice: True or False

“Hospice care can be provided in a nursing home.”

TRUE

- Patients can get hospice care in a variety of residential settings, including nursing homes, assisted living communities, or private residences.

#7 Understanding Hospice: True or False

“Hospice care is only appropriate for people who have a few days to live.”

FALSE

- After experiencing the quality and comfort that hospice provides, a majority of individuals and families state that they wish they had started receiving hospice care earlier in the course of the illness.
- Hospice care tends to be most beneficial when families receive the full range of skilled medical, emotional and spiritual support services for at least a month or more.

#8 Understanding Hospice: True or False

“While in hospice, spouses, partners or children of the dying individual are not allowed to directly participate in his or her care.”

FALSE

- Hospice provides education and assistance to family caregivers.
- Hospice works to support the entire family and support system, by partnering with them to improve their ability to cope with the stress involved in providing care.
- In many cases, family members provide much of day-to-day patient care. Hospice nurses, social workers and other team members provide education and support to the family caregivers.

#9 Understanding Hospice: True or False

“Hospice care helps the dying individual by speeding up the dying process.”

FALSE

- Hospice providers do not speed up the dying process, nor can they or other medical professionals cure terminal illnesses. Some studies suggest hospice care may actually extend life.
- Hospice tries to maximize patient quality of life for the remainder of his/her life by addressing pain and symptoms. Hospice can also offer opportunities to do important things – such as attend a wedding, graduation, church service, or other significant event.

#10 Understanding Hospice: True or False

“Hospice care cannot be provided at home.”

FALSE

- The majority of hospice care (66%) is provided in the home.
- A smaller, but growing, percentage of hospice patients receive care outside of the home – for example, in a nursing home community, hospital, or hospice residence.

#11 Understanding Hospice: True or False

“Only individuals over age 65 are eligible for hospice services.”

FALSE

- Anyone expected to live 6 months or less can receive hospice care, regardless of age.

#12 Understanding Hospice: True or False

“Anyone can make a referral to hospice.”

TRUE

- A patient, family member, friend or doctor can contact a hospice to ask about whether hospice care would be appropriate.
- After a conversation and assessment of the condition, the patient’s doctor and hospice professionals (in consultation with the patient) will determine whether the individual could benefit from hospice care.

#13 Understanding Hospice: True or False

“Hospice provides medications, treatments, medical equipment and supplies that are related to the patient’s primary illness.”

TRUE

- Hospices vary, but they should provide medication, treatments, medical equipment and supplies associated with the patient’s terminal illness. Families should be aware of the exceptions, as they may need to pay out of pocket for these items.

#14 Understanding Hospice: True or False

“Hospice services end when the hospice patient dies.”

FALSE

- Grief support is available for the surviving family members up to a year after the patient’s death.
- Social workers are available to assist families in navigating services after the patient dies — such as connecting the family with bereavement resources or providing information about survivor benefits.

#15 Understanding Hospice: True or False

“Hospice care is available to any individual expected to live 6 months or less.”

TRUE

- Individuals can remain in hospice care for longer than 6 months. However, their health status must be reviewed on a regular basis by the hospice team to determine whether they are still eligible for services. Hospices may be required to end services if, after observing patients for a few months, they seem to have stabilized, or show signs of continued improvement.

#16 Understanding Hospice: True or False

“People who live alone are able to receive hospice services.”

TRUE

- A majority of hospices (over 80%) will enroll patients who do not have a caregiver. Those living alone may need a caregiver at some point, but adaptations can usually be made so that the patient does not have to relocate.
- Hospice volunteers can provide help to patients living alone by preparing meals, performing light housekeeping, or just being present to provide some company.

#17 Understanding Hospice: True or False

“A primary goal of hospice is to treat the emotional needs of the dying individual and their family.”

TRUE

- Dealing with a serious illness or loss of a loved one can be very difficult. The hospice team supports families by providing emotional support. Social workers, grief counselors, and spiritual support personnel are part of the hospice team.
- Individuals and family can decide the extent of services they want and need to receive.

#18 Understanding Hospice: True or False

“A person with Alzheimer’s disease or dementia cannot have hospice services.”

FALSE

- Patients with Alzheimer’s disease or other types of dementia are welcome in hospice. In fact, they are a large and fast-growing segment of the hospice population, currently making up nearly 13% of all hospice patients.

#19 Understanding Hospice: True or False

“While receiving hospice care, individuals can also receive treatments such as chemotherapy, radiation, or surgery to cure the person’s primary illness.”

FALSE

- In rare cases chemotherapy, radiation and surgery can be used to relieve pain or other symptoms while receiving hospice care. However, in order to receive these high risk treatments for purposes other than comfort, the individual must stop hospice care.

#20 Understanding Hospice: True or False

“Individuals receiving hospice care cannot be taken to the hospital for treatment.”

FALSE

- Although the need for hospitalization is rare while patients are in hospice care, it is allowable. For example, patients can get hospital care for conditions that are unrelated to their terminal illness.
 - While receiving hospice care, hospitalizations are usually unnecessary.
- While hospice should be notified before going to the hospital, a patient can seek other care at any time.
- Caregivers should tell emergency medical staff that their loved one is receiving hospice care.

#21 Understanding Hospice: True or False

“Hospice care focuses on managing an individual’s pain and other symptoms.”

TRUE

- Hospice provides high quality pain and symptom management, which is central to its mission.
- Most patients can expect pain relief and an increase in their quality of life while receiving hospice care.

#22 Understanding Hospice: True or False

“Hospice care helps caregivers and family members, as well as the dying individual.”

TRUE

- Caregiver burdens are significantly eased with hospice and the team of professionals who provide supportive services.
- Hospice can provide a break for caregivers who need one

#23 Understanding Hospice: True or False

“The hospice care team includes physicians, nurses, social workers, and chaplains.”

TRUE

- Hospice uses a team approach to care for the physical, emotional, social and spiritual needs of patients and their families.
- All hospice team members are involved in patient care. Some other team members may include hospice aides, physical and occupational therapists, pharmacists, trained volunteers and others providing direct and indirect care.

#24 Understanding Hospice: True or False

“Hospice care includes a minimum of 12 hours of daily bedside care provided by a clinician.”

FALSE

- Hospice patients generally receive a few visits each week. However, the frequency and duration of visits may vary depending on the patient’s condition, and resources and staff availability.
- Families may find it necessary to supplement hospice services with care from other sources.