

# Understanding Hospice

## Leader's Guide

2025 Annual Lesson Series



### Sara's Story:

Atul Gawande, in his article titled “Letting Go: What Should Medicine Do When it Can’t Save Your Life,” tells the story of a young woman named Sara Thomas Monopoli, who was diagnosed with lung cancer while she was pregnant. Sara was told the cancer had spread to multiple lymph nodes in her chest and that the cancer was inoperable. After Sara’s doctors tried multiple treatments, including chemotherapy, with no promising results, the disease continued to progress. Sara’s healthcare providers continued to offer hope for extending her life through various treatments. Sara went through an enormous amount of pain and suffering during her last months of life. Finally, during the last few days of her life, Sara is offered some relief before she dies.

This story is like many others; personal beliefs about death and dying are clouded by doing everything we can to extend a person’s life, no matter what the cost. We often believe that modern medicine has a fix for every ailment. Of course, we all know that, eventually, we all die. The question is, how should we die, and what kind of death would we hope for? Would it be surrounded at home by family or in a hospital attached to artificial means until the

very last? Hospice can be an option for the dying. An option to help alleviate pain and suffering.

### Lesson Objectives

As a result of participating in this educational program, participants will:

- Increase understanding of hospice.
- Increase understanding of the benefits of hospice to the patient and family.
- Increase understanding of how individuals qualify for hospice.
- Increase understanding of where to find a hospice provider.
- Raise awareness of myths surrounding hospice.
- Know how to start a conversation with their loved ones about hospice and end-of-life wishes.

### Intended Audiences

Although many people think that only older people need hospice, all ages need to understand the benefits associated with hospice. Younger people may also need to consider hospice, whether for themselves

or having a family member or friend that could need hospice services. With so many misconceptions about hospice, this lesson is intended for all adults, particularly older adults, caregivers/families/friends of older adults and individuals with disabilities, new Medicare beneficiaries, and populations who may be unaware of end-of-life care opportunities in the United States.

## Preparation

Before the lesson, prepare by taking these steps:

- Read the Understanding Hospice Fact Sheet (MF3656) and this Understanding Hospice Leader's Guide (MF3657).
- Review the PowerPoint presentation.
- Make copies of the Understanding Hospice Fact Sheet and Evaluation (found at the end of the Understanding Hospice Leader's Guide).
- Familiarize yourself with the activities and determine which one(s) you will incorporate into your program.
- Review suggested resources and determine which ones you will share with your audience.
- Research hospice services available in your local area to be able to refer members of your audience, if needed.

## Supplies and Resources Needed:

- Flip chart, stick-it notes and markers
- Conversation Starter Guides (Refer to resources listed at the end of this guide, "Your Conversation Starter Guide", The Conversation Project)
- Advance Health Care Planning in Kansas (MF3280) fact sheet (as an additional resource for participants)

## Background

Usage of hospice varies by gender, race/ethnicity, and beneficiary location. To best provide the lesson, consider the demographics of the group to whom you are presenting by referring to the following facts and figures.

Facts and Figures: The National Hospice and Palliative Care Organization reported that 1.72

million Medicare beneficiaries were enrolled in hospice for one or more days in 2020. Kansas ranks 11th in the nation in terms of utilization of hospice services, with 52.1% of Medicare deaths occurring while receiving hospice services.

In 2021, 47.3% of Medicare beneficiaries who died received one or more days of hospice and were enrolled in hospice at the time of death. Of those, 52.5% of Medicare decedents who used hospice in 2021 identified as female, compared to 42.1% who identified as male. While 2021 showed an increase in hospice utilizations by most race/ethnicity groups, significant differences remain: 50% of white Medicare decedents utilized hospice, compared to 36.3% Asian American, 35.6% Black, 34.3% Hispanic, and 33.8% North American Native.

Some ethnic and cultural groups' perceptions of hospice may be less favorable than others. Factors such as having a greater preference for life-sustaining therapies, less comfort discussing death, greater distrust in the health care system, and spiritual beliefs can contribute to people preferring not to explore the option of hospice care.

Hospice usage also varies widely based on beneficiary location: 48.5% of Medicare decedents resided in urban areas, compared to 45.1% in micropolitan, 44.9% in rural - adjacent to urban areas, 39.8% in rural - nonadjacent to urban, and 33% in frontier areas. Micropolitan locations have a population of 10,000 to 50,000. Frontier areas are generally defined as counties having a population density of six or fewer people per square mile.

## Discussion and Activities

As the facilitator, you may choose which activities and discussion to use when delivering this program. Getting to know your audience at the start of the program may help you decide which activity to choose. Be sure to allow plenty of time for discussion and completion of the activity.

### Activity 1: Myths vs Facts

Many people have misconceptions about what hospice is and what it isn't. Often, when people hear the word hospice, they think that someone has given up and they only have days to live. These

misconceptions can prevent people from choosing hospice when it could be the most beneficial. Refer to the fact sheet on the common myths of hospice. Ask participants for some ideas of what they think of when they think of hospice. How might these thoughts and beliefs affect their perceptions of hospice? Ask participants to write a word or a few words about their thoughts when they hear “hospice” on a stick-it note. Have participants put the positive thoughts on one side of a flip chart and the negative ones on the other. Review the list with the audience and point out the hospice facts versus the myths information in the fact sheet.

### **Activity 2: Having a Conversation**

Having a conversation about end-of-life decisions is not an easy topic for anyone. However, some groups of people may struggle more than others. Utilizing good communication skills may make the discussion easier for everyone. Some ethnic and cultural groups’ perceptions of hospice may be less favorable than others. Factors such as having a greater preference for life-sustaining therapies, less comfort discussing death, greater distrust in the health care system, and spiritual beliefs can contribute to people not preferring to explore the option of hospice. However difficult the conversation with family and healthcare providers is, it is important for getting the kind of healthcare the patient wants.

#### **Show the short video from the “Conversation Project” “Practice Makes Perfect.”**

<https://theconversationproject.org/videos>

Participants can discuss the barriers to effective communication when discussing end-of-life issues. What are some barriers to having a conversation? Ask the group to take some time to consider ways they could broach the topic with the people they believe need to know their healthcare goals.

You can use the “Conversations Starter Guide” or the “Let’s talk Guide” from Eldercare Locator located at <https://eldercare.acl.gov/Public/Resources/BROCHURES/Index.aspx>. You can also use the following questions to start a discussion.

#### **Questions for discussion could include:**

- What does a good day look like for me?

- Who supports me during challenging times?
- What matters most when thinking about my end-of-life experience?
- Are there any treatments I would not want to have near the end of my life?
- If my health condition changes, when would it be okay to shift from trying to cure an illness to trying to enjoy the end of life as much as possible?

#### **How to start the conversation**

- “I need your help with something.”
- “Can you and I have a conversation about \_\_\_\_\_?”
- “I was thinking about what happened to \_\_\_\_\_, and it made me realize \_\_\_\_\_.”
- “Even though I’m OK right now, I’m worried that \_\_\_\_\_, and I want to be prepared. Can we talk about some things that matter to me?”
- “Will you help me think about my future?”
- “When \_\_\_\_\_ died, do you think their wishes and priorities were respected toward the end of their life?”

#### **How might you start a conversation with your family?**

- What do you need to tell your family or healthcare proxy about your end-of-life decisions?
- What do you want to make sure DOESN’T happen to you? (I don’t want to be a burden on my family, I don’t want to be alone, I don’t want to be on a respirator, I don’t want to be in pain.)
- Who are the main people you want to be involved in your care?
- How much do you want your family to know about your condition?
- Who will make your medical decision if you cannot do so?

#### **Community Awareness Activities**

Share the fact sheet with:

- Libraries

- Senior centers
- Doctor offices/medical facilities
- Public health offices
- Community health workers and advocates
- Community health fairs or at similar events
- Medicare counselors

Work with local media to sponsor one or more news articles on topics related to the lesson's content. Create social media posts and share information through a variety of social media platforms.

## Conclusion

Summarize the lesson by reviewing information in the fact sheet, highlighting the importance of starting the conversation about end-of-life wishes. Offer the Advance Health Care Planning in Kansas fact sheet (MF3280, [ksre-learn.com/mf3280](https://ksre-learn.com/mf3280)) as a supplemental resource for participants.

Distribute program evaluation and ask participants to complete and return it to you prior to leaving the program. Enter evaluation data into PEARS upon program completion.

## Resources

Gawande A. Letting Go: What Should Medicine Do When it Can't Save Your Life?, *The New Yorker* 2010, 36-49, <https://www.newyorker.com/magazine/2010/08/02/letting-go-2>

Let's Talk: Starting the Conversation about Health, Legal, Financial and End of Life Issues, *Elder Care Locator*, December 2023, [www.eldercare.acl.gov](http://www.eldercare.acl.gov)

Your Conversation Starter Guide, *The Conversation Project*, December 2023, [www.theconversationproject.org](http://www.theconversationproject.org).

NHPCO Facts and Figures, 2022 Edition. National Hospice and Palliative Care Organization, December 2022.

NHPCO Facts and Figures, 2023 Edition. National Hospice and Palliative Care Organization, December 2023.

K-State Research and Extension publication: Advance Healthcare Planning in Kansas, MF3280 [ksre-learn.com/mf3280](https://ksre-learn.com/mf3280)

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# Evaluation

## Understanding Hospice

Please take a moment to respond to the questions below.

Date and location of presentation: \_\_\_\_\_

My county of residence: \_\_\_\_\_

**Gender:**  Female  Male  Non-binary  Other  Prefer not to answer

**Race:**  Hispanic/Latino  Non-Hispanic/Non-Latino  Prefer not to respond

**Ethnicity:**  American Indian/Alaska Native  White  Asian  Black/African American  
 Native Hawaiian/Pacific Islander  Other  Prefer not to respond

**Age:**  under 18 years  18-29 years  30-59 years  60-75 years  76+ years  
 Prefer not to respond

### 1. This program increased my understanding of hospice.

Not At All		Somewhat		Very
1	2	3	4	5

### 2. This program helped me understand the benefits of hospice to both the patient and family.

Not At All		Somewhat		Very
1	2	3	4	5

### 3. This program increased my understanding of where to find a hospice provider.

Not At All		Somewhat		Very
1	2	3	4	5

### 4. This program help me be more aware of the common myths associated with hospice.

Not At All		Somewhat		Very
1	2	3	4	5

### 5. This program taught me ways in which I can start conversations with others about hospice.

Not At All		Somewhat		Very
1	2	3	4	5

### 6. Please share any changes you plan to make in your life as a result of attending today's program.

### 7. Please share any additional comments or suggestions.