

Participant's Guide

“Care at the End-of-Life”



Module One
Managing Resident Care



Module Two
Preparing the Family



Module Three
After Death



THE INSTITUTE FOR
PALLIATIVE MEDICINE
at San Diego Hospice

CENTER FOR ADVANCED LEARNING



Credits

Project Lead

Paula McMenamin, MSW

Content Experts

Connie Carr, CNP

Frank Ferris, MD

Paula McMenamin, MSW

JJ Nadicksbernd, MSW

Patricia Strunk, RN MSN

Instructional Designers

Barbara Greenstein, MA

Kendra Haddock, MA

Lisa Wortman, MA

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Agenda

This participant's guide is for students in the Care at End-of-Life course. The agenda is as follows:

Topic	Time
Welcome	5
Introduction	5
Module Two: Preparing the Family	
PPT Bite 1: Communicating a Change in Condition	15
PPT Bite 2: End-of-Life Choices	15
Break	30
PPT Bite 3: Making Decisions	15
PPT Bite 4: Cultural Differences	15
Review	15
Test	15
Total Time:	2.0 hours

Activity: Welcome

Introduce yourself.

Describe your background, experience and something that gives the class insight into **you** (e.g. how you came to do this work, your interests or hobbies).

IMPORTANT: Every state has different laws regulating LTC, and it is *your* responsibility to know your specific job duties. The content presented in this course is comprehensive and not tailored to meet the specific needs of LTC professionals in any one state. If you are unsure how it applies to you, ask your supervisor.



Module Two: Preparing the Family

Bite 1: Communicating a Change in Condition

Bite 2: End-of-Life Choices

Bite 3: Making Decisions

Bite 4: Cultural Differences



Bite 1: Communicating a Change in Condition



Activity: Read Objectives

As a healthcare professional who provides end-of life care, you must have good communication skills to do your job. In this bite, you'll learn how to use your skills to communicate with a family whose loved one has had a change in condition.

After completing this bite, you will be able to:

- Define a change in condition
- Recall what causes a change in condition
- Recall the 6 Communication Pearls



Module Two, Bite 1

Time: 15 minutes

Reflect on It

- Have you ever witnessed a resident's last days of life?
- What did you observe?



Change in Condition

A "change in condition" is defined as

A change in condition can be caused by:



6 Communication Pearls

When a resident has a change in condition, use the **Six Communication Pearls** to break the bad news. The six pearls are:



Setting



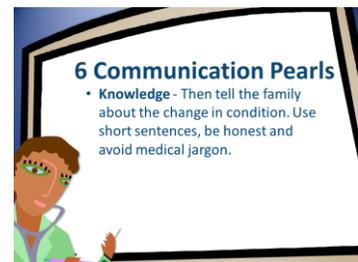
Perception



Invitation



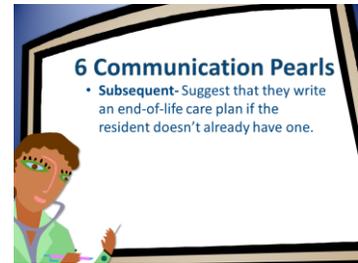
Knowledge



Emotion



Subsequent



Case Study #1

You arrive for your shift and are informed by the charge nurse that resident Mrs. Summers has had a change in condition. She has not eaten for 2 days, is in bed and minimally responsive. Her son Adam is in the room as well as a long-time neighbor Sarah. They greet you as you enter the room. Adam is quiet and serious looking. Sarah is tearful.



Discussion

Question: How can we determine the cause of a change in condition?

Answer:

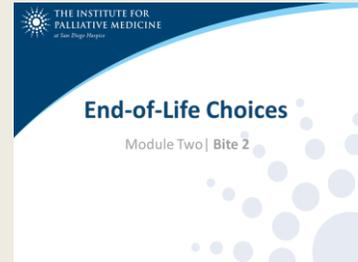
Question: The charge nurse informs you that there has been no **event** to cause the change in condition; she believes the resident is transitioning into the dying process. The charge nurse communicated this change in condition to the family. What can you say or do for Mrs. Summers' family?

Answer:

Question: How can you use the 6 Communication Pearls to communicate with the family?

Answer:

Bite 2: End-of-Life Choices



Activity: Read Objectives

In this bite, you will learn about end-of-life decisions that must be made.

After completing this bite, you will be able to:

- Recall end-of-life healthcare choices
- Recall the definition of an Advanced Directive
- Recall facts about Advanced Directives



Module Two, Bite 2

Time: 15 minutes

Reflect on It

- Have you ever helped a resident or their family make end-of-life choices?
- What was it like?



End of Life Choices: Yes or No?

When a resident is dying, critical choices about end-of-life care must be made. It is essential to make these choices *before* the resident is in chronic pain or is unable to talk, so that care providers know what to do when the time comes.



Critical end-of-life care choices include:



Critical spiritual and postmortem care choices include:



Advanced Directive

If the resident has an **Advance Directive**, they've already made their end-of-life choices. If not, the family is left to guess what their loved one would want and make decisions of their behalf.

An Advance Directive Is:



Important facts about Advanced Directives:

Case Study #2

Mrs. Summers' daughter Jean arrives that afternoon while Adam and Sarah are still visiting. She is alarmed to see her mother so ill and unresponsive. She asks you if there is anything that can be done at this point.

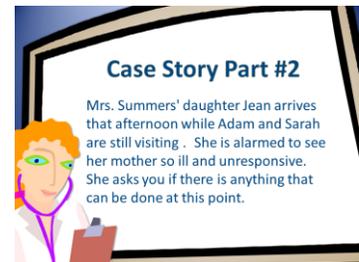
Discussion

Question: At what point does an Advanced Directive become active?

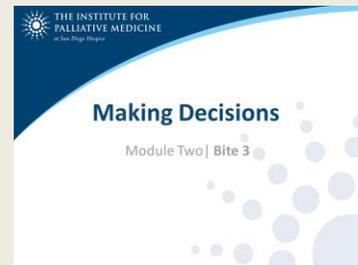
Answer:

Question: The charge nurse informs you that Mrs. Summers **does not** have an Advanced Directive/ Power of Attorney. What happens now?

Answer:



Bite 3: Making Decisions



Activity: Read Objectives

After completing this bite, you will be able to:

- Identify the goals of making end-of life choices
- Identify barriers to making end-of life choices
- Recall ways to help a family who is making end-of-life decisions



Module Two, Bite 3

Time: 15 minutes

Reflect on It

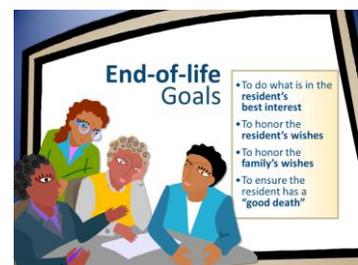
- Have you ever supported families facing the death of a loved one?
- How did you provide support?



End-of-Life Goals

If a resident does not have an Advanced Directive, the family has to make end-of-life care choices for them. You can help motivate the family to make tough choices by sharing the goals of end-of-life healthcare decisions.

The goals are:



Barriers

Sometimes the family will refuse to discuss end-of-life choices, because:



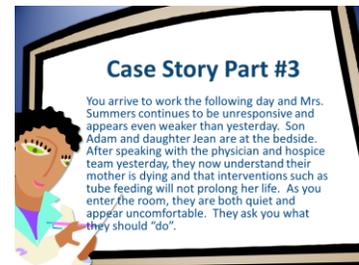
How to Help

You can help break down barriers and help the family make end-of-life choices by:



Case Study #3

You arrive to work the following day and Mrs. Summers continues to be unresponsive and appears even weaker than yesterday. Son Adam and daughter Jean are at the bedside. After speaking with the physician and hospice team yesterday, they now understand their mother is dying and that interventions such as tube feeding will not prolong her life. As you enter the room, they are both quiet and appear uncomfortable. They ask you what they should “do”.



Discussion

Question: What suggestions might be helpful to the family who is faced with making end-of-life goals for Mrs. Summers?

Answer:

Question: Son Adam is refusing to discuss his mom’s end-of-life choices. What could be his reasons?

Answer:

Question: How can we help and support them in creating end-of-life choices for Mrs. Summers?

Answer:

Bite 4: Cultural Differences



Activity: Read Objectives

At the end of this bite, you will be able to:

- Recall why it is important to respect cultural differences
- Recall what five major world religions believe about death
- Recall the funeral rites of five major world religions
- Recall the mourning practices of five major world religions



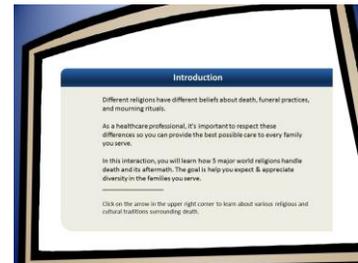
Module Two, Bite 4

Time: 15 minutes

Cultural Differences Surrounding Death

Different religions have different beliefs about death, funeral practices and mourning rituals.

As a healthcare professional, it's important to respect these differences so you can provide the best possible care to every family you serve.



Beliefs about Death

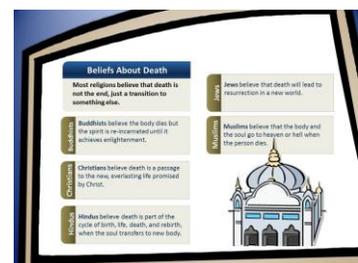
Buddhists:

Christians:

Hindus:

Jews:

Muslims:



Funeral Practices

Funeral customs comprise beliefs and practices performed by a culture or religion to remember the dead.

Buddhists:

Christians:

Hindus:

Jews:

Muslims:



Mourning Rituals

Cultural behaviors in which the bereaved while grieving over the death of a loved one.

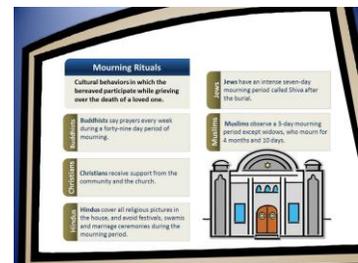
Buddhists:

Christians:

Hindus:

Jews:

Muslims:



Case Study #4

Mrs. Summers was a devoted Christian for her entire life. Her family does not consider themselves to be religious. During her stay at your facility, she enjoyed reading the Bible and participating in religious services offered at the facility.

Discussion

Question: Why is it important to have a basic understanding of Mr. Summers' religious background?

Answer:

Question: What would be helpful to know about Mrs. Summers' wishes?

Answer:

Question: How can you support Mrs. Summers' at the end of her life?

Answer:



Activity: Review



Time: 15 minutes

Goal: To prepare the class for the module Assessment.

Review Bites 1-4.

Bite 1: Communicating Change to Family

In this bite you learned:

A change in condition is defined as a change in status, either mental or physical, that may signal that the resident is dying.

A change in condition is caused by:

- An illness
- An infection
- An injury
- An event

The Communication Pearls, 6 Steps for Bad News are:

1. Setting
 2. Perception
 3. Invitation
- “ Warning Shot”
4. Knowledge
 5. Emotion
 6. Subsequent

Comforting words for a family that has just received bad news :

- I wish things were different.
- I can see this makes you sad
- Tell me what you are thinking

Comments to avoid when comforting a family that has just received bad news include:

- They will be in a better place soon
- They’ve lived a long life
- Its going to be ok
- Stop Crying

Bite 2: End-of-Life Choices

In this bite you learned:

When a resident is dying, the family must make critical choices about end-of-life care and what happens after death.

Eating	Drinking	Medications
<p>Should a feeding tube be placed when the resident is no longer able to chew and swallow?</p>	<p>Should the resident be given IV liquids when they are no longer able to swallow liquids?</p>	<ul style="list-style-type: none"> • What medications will be used to keep the patient comfortable? • What are the risks? • What are the benefits? • Legal document • End-of life choices • Power of Attorney for Healthcare • Healthcare decisions only • Changed by resident only
Funeral arrangements	Spiritual/Religious practices	Advanced Directive
<ul style="list-style-type: none"> • Which funeral home will the resident's body go to? • Will they be buried or cremated? • Where will their final resting place be? <p>Will there be a funeral or a memorial service?</p>	<ul style="list-style-type: none"> • Will the resident receive last rites? • What rituals, if any, will be performed at the death bed? • 	<ul style="list-style-type: none"> • Legal document • End-of life choices • Power of Attorney for Healthcare • Healthcare decisions only • Changed by resident only

Bite 3: Making Decisions

In this bite you learned:

When a loved one is dying, some families must make difficult end-of-life choices. Care providers can help by:

Identifying the goals of end-of-life care:

- To do what is in the patient's best interest
- To honor the resident's wishes
- To honor the family's wishes
- To ensure the resident has a "good death"

Identifying barriers to making end-of-life choices:

- Family members are afraid of death
- Family members have no experience making difficult decisions
- Family members may want to avoid facing painful emotions
- Family members may disagree about the decisions
- Family members may feel guilty

Helping a family who is making difficult decisions by:

- Being an effective communicator Initiating end-of-conversations
- Involving everyone in the decision-making process
- Speaking in terms they can understand
- Guiding the conversation so decisions are made
- Reinforcing facts
- Being honest
- Not giving false hope

Bite 4: Cultural Differences

In this bite you learned:

Cultural differences play a large role in how people react to death. Care providers should expect and appreciate diversity in residents' families.

It is an integral part of a care provider's job to respect and support people of all faiths. In order to do so, it helps to have an understanding of different beliefs about death.

Buddhist	Hindu	Christian	Jewish	Muslim
<ul style="list-style-type: none">• Body dies but the spirit is re-incarnated• Body cremated• Praying weekly during 49 day period of mourning	<ul style="list-style-type: none">• Soul transfers to new body upon death• Body bathed then cremated on pyre• Religious pictures, festivals and ceremonies avoided during mourning	<ul style="list-style-type: none">• Death passage to everlasting life• Body buried after mass, wake, service• Church, community support family	<ul style="list-style-type: none">• Dead resurrected in new world• Body bathed then buried• 7 day mourning period called "Shiva"	<ul style="list-style-type: none">• Dead resurrected in heaven or hell• Body bathed, prayed over and buried• Community mourns for a week, widow for 4 months, 10 days

Activity: Complete Module Test

Time: 30 minutes

Goal: To evaluate learning and retention

Activity: Complete Course Evaluation

Time: 10 minutes

Goal: To gather feedback on the course that will be used to improve future sessions.

Activity: Closure