Facilitator'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

THE scan FOUNDATION.

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Introduction

This facilitator's guide contains one module of the Care at End-of-Life curriculum for Direct Care Workers (DCW), and provides detailed instructions for the facilitator. It is designed to be used with the PPT of the same name. The guide contains a "thumbnail" of each slide in the presentation and the content that goes with that slide.

The participant guide also has a thumbnail of each slide, but contains topic and sub-topic headings and room to take notes *instead of the content*. This is it encourage note-taking, and to help participants to create a study guide for the module test.

Agenda

The agenda for End-of-Life Care, Module 2: Preparing the Family 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	5
PPT Bite 3: Making Decisions	15
PPT Bite 4: Cultural Differences	15
Review	15
Test	30
Total Time:	2.0 hours

Activity: Welcome

Time: 5 minutes

Goal: To establish rapport with audience

Welcome the group and introduce yourself.
Describe your background, experience and something that gives them insight into who you are (e.g. how you came to do this work, your interests or hobbies).

Get to know your students.
Ask the students to share their names, job titles and number of years of experience in Hospice care. If they already know each other, ask each student to share one thing about them that would surprise their co-workers.

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.

Activity: Course Introduction

Time: 5 Minutes

Goals: To set realistic expectations for training, and to preview the course

Introduce the course.
"This course is about End-of-Life Care. It was specifically designed for Certified Nursing Assistants (CNA) or Direct Care Workers (DCW) caring for Long-Term Care (LTC) patients in skilled nursing facilities, residential care facilities and private homes on behalf of the SCAN grant. "

Share the goal of the training.
"The goal of this training is to equip LTC workers with the skills and knowledge they need to provide the best care possible to a unique and growing patient population. "

Describe the structure of the course.
"This module is divided into 4 "bites," or bite-sized chunks of information for your brain to chew on. After we have completed two bites, we will take a break. After we complete all of the bites, we will review the content together and you can ask questions at that time.

After the review, you will take the module test. You must score 80% or higher to pass the test. If you do not get a passing score, you can review the content and re-take the test."

Module Two: Preparing the Family

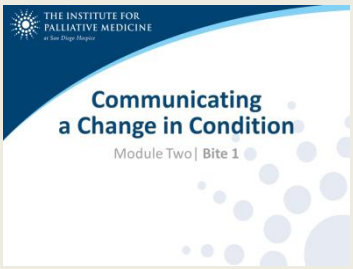
Bite 1: Communicating a Change in Condition

Bite 2: End-of-Life Choices

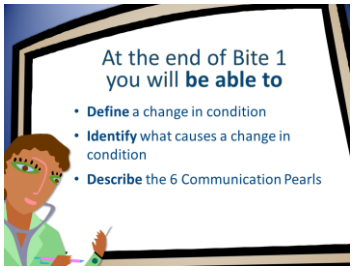
Bite 3: Making Decisions

Bite 4: Cultural Differences

Bite 1: Communicating a Change in Condition



Activity: Read Objectives



Goal: To preview the content and provide an advanced organizer so students know what is important to remember about the module.

As a healthcare professional that 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

Activity: Teach Module Two, Bite 1

Time: 30 minutes

Reflect on It

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

Change in Condition

In Hospice Care, every resident has a change in condition sooner or later. A "change in condition" is defined as a change in status, either mental or physical, that may signal the resident is dying.
A change in condition can be caused by:

- An Illness
- An Infection
- A physical injury, like a broken hip, OR
- A major "event" like a stroke

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

Let's take a closer look at each one.

Setting

- First, prepare yourself for the conversation.
- Talk to the charge nurse before you speak to the family to avoid a miscommunication.
- Then create the right setting.
- Find a private place where you can talk without interruption.
- When you're ready, sit down with the family.

Perception

- Start the conversation by finding out what the family already knows. Ask:
- Tell me what you understand about what is happening
- What has the doctor told you?

Invitation

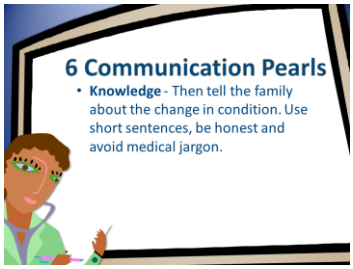
Invite the family to guide the conversation. Ask:

- Who should I speak to?
- How much do you want to know?
- Do you want details?
- Do you have questions for me?

Knowledge

Fire a "warning shot" to let them know that bad news is coming. Say:

- I have some bad news for you, or
- The news is not what we hoped
- Then tell the family about the change in condition. Use short sentences, be honest and avoid medical jargon.



Emotion

After you have told them about the change in condition, stop talking. Give the family time to process what you said and to react.

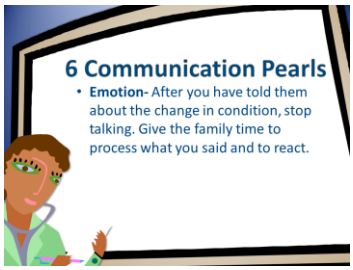
When they're ready, offer comforting words like:

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

Avoid using clichés because they sound insincere and are simply not true, like:

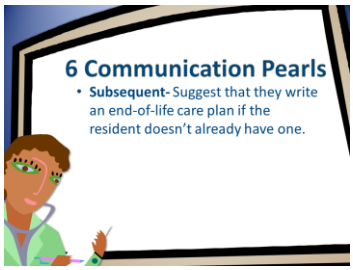
- I know how you feel
- It's going to be okay
- He will be in a better place soon

And never, ever say Please don't cry. Tears are normal at this time. If crying upsets you, excuse yourself and ask another care provider to step in.

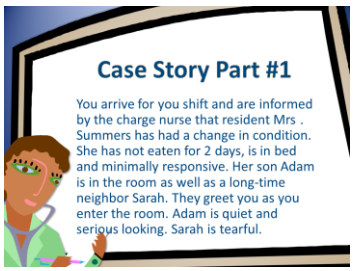


Subsequent

Once the family knows what's going on, they will ask, "What happens next?"
Suggest that they write an end-of-life care plan if the resident doesn't already have one.



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
Q. How can we determine the cause of a change in condition?
A. Was there an event that could have caused this change like: Illness, Infection, Physical injury?

Q. 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?

A. If you are in a SNF you will want to simply reinforce what the charge nurse told the family. This will help ensure that what the family is hearing is consistent.

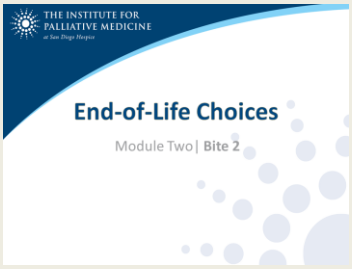
A. Continue to provide care to the resident as normal. By talking to the resident in a supportive, comforting way, you are modeling for the family that you care.

Q. How can you use the 6 Communication Pearls to communicate with the family?
A. In a SNF your scope of practice dictates you focus primarily on words of comfort like, "I'm sorry this is happening," "How can I help or support you?s "or "I really care for your mom".

A. In a RCF-E you may want to utilize the 6 Communication Pearls to help you explain to the family what is happening.

A. Create the right setting, ask what they already know, ask if they have questions, explain the change in condition, give time to process and express emotions, encourage discussion about end-of-life decisions.

Bite 2: End-of-Life Choices



Activity: Read Objectives

Goal: To preview the content and provide an advanced organizer so students know what is important to remember about the module.

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

Activity: Teach Module Two, Bite 2

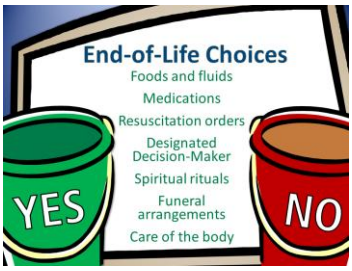
Time: 30 minutes

Reflect on It

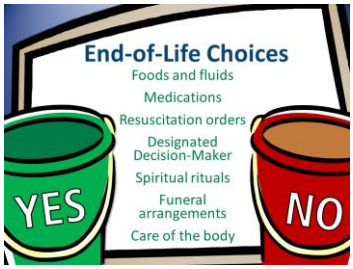
Have you ever helped a family make end-of-life choices? What was it like?

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.



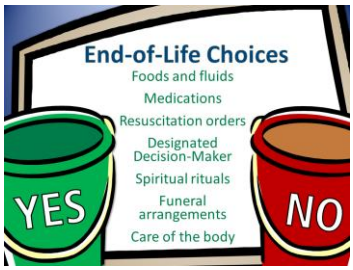
Critical end-of-life care choices include:



- Should a feeding tube or IV be placed when the resident is no longer able to chew or swallow?
- What medications will be used to keep the resident comfortable? What are the risks? What are the benefits?
- Should the resident be resuscitated?
- Who is the designated decision maker?

For many families, death is one of life's most important milestones. That is why it is **so** important to make critical decisions about the resident's spiritual and post-mortem care ahead of time – to allow the resident and their family to decide what their final experience together will be like.

Critical spiritual and postmortem care choices include:



- What rituals, if any, will be performed at the death bed? For example, will the resident receive last rights?
- Which funeral home should be called?
- Will the body be buried or cremated?

Advanced Directive

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

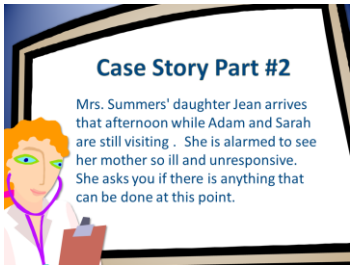
An **Advance Directive Is**:

- A legal document that must be signed in front of 2 witnesses
- A living will that contains choices about end-of-life medical care
- A document identifying a Medical Power of Attorney, or a person who can make healthcare decisions if the resident can not
- A document that can only be changed by the resident

Important facts about Advanced Directives:

- They only go into effect after 2 doctors certify that the resident is unable to make medical decisions for themselves, and that their condition is terminal.
- They do not apply if the resident regains the ability to make decisions for themselves
- They cannot be honored by emergency medical personnel because they are legally obligated to take lifesaving actions.
- They do not expire.

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

Q. At what point does an Advanced Directive become active?
A. They only go into effect after 2 doctors certify that the resident is unable to make medical decisions for themselves, and that their condition is terminal.

Q. The charge nurse informs you that Mrs. Summers **does not** have an Advanced Directive/ Power of Attorney. What happens now?
A. If there is no document in place, the family has to make

decisions for her as her surrogate.

Bite 3: Making Decisions

Activity: Read Objectives

Goal: To preview the content and provide an advanced organizer so students know what is important to remember about the module.

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

Activity: Teach Module Two, Bite 3

Time: 30 minutes

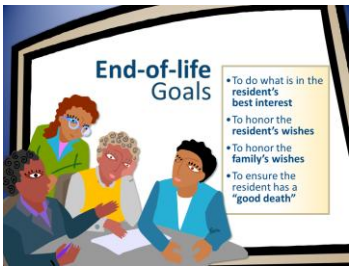
Reflect on It

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. **Y**ou can help motivate the family to make tough choices by sharing the goals of end-of-life healthcare decisions.
The goals are:

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

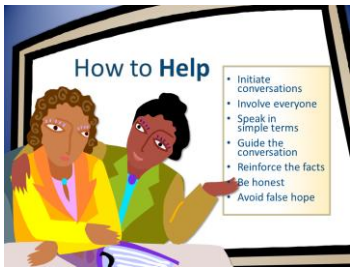


Barriers

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

- They are afraid of death
- They have no experience making difficult decisions
- They want to avoid facing painful emotions
- They disagree about the decisions
- They feel a sense of guilt

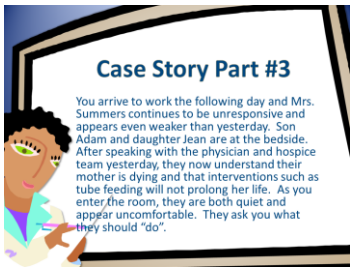
How to Help



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

- Initiating end-of-life conversations
- Involving everyone in the family in the decision making process
- Speaking in terms the family can understand.
- Guiding the conversation so that an necessary decisions are made
- Reinforcing the facts by reminding them of the resident's condition
- Being honest, and avoiding giving false hope that their loved one will get better

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

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

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

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

- Fear
- Inexperience
- Emotional Pain
- Disagreement
- Guilt

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

- Initiate conversations
- Involve everyone
- Speak in simple terms
- Guide the conversation
- Reinforce the facts
- Be honest
- Avoid false hope

Bite 4: Cultural Differences

Activity: Read Objectives

Goal: To preview the content and provide an advanced organizer so students know what is important to remember about the module.

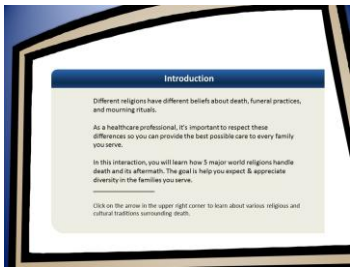
At the end of this bite, you will be able to:

- 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

Activity: Teach Module Two, Bite 4

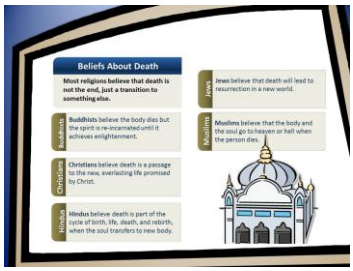
Time: 30 minutes

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



Most religions believe that death is not the end, just a transition to something else.

Buddhists believe that the body dies but the spirit is re-incarnated until it achieves enlightenment.

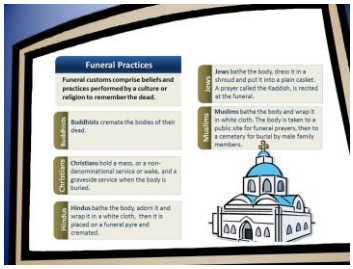
Christians believe that death is a passage to the new, everlasting life promised by Christ.

Hindus believe death is part of the cycle of birth, life, death and

rebirth, when the soul transfers to a new body.
Jews believe that death will lead to resurrection in a new world.

Muslims believe that the body and the soul go to heaven or hell when they die.

Funeral Practices



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

Buddhists cremate the bodies of their dead.

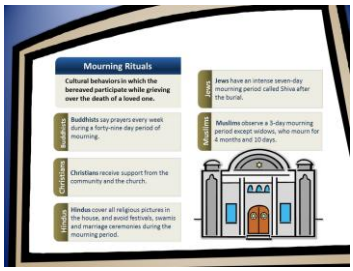
Christians hold a mass, a non-denomination service or wake, and a graveside service when the body is buried.

Hindus bathe the body, adorn it and wrap it in a white cloth, then it is placed on a funeral pyre and cremated.

Jews bathe the body, dress it in a shroud and put it into plain casket. A prayer called the Kaddish is recited at the funeral.

Muslims bathe the body and wrap it in a white cloth. The body is taken to a public site for funeral prayers, then to a cemetery for burial by male family members.

Mourning Rituals



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

Buddhists say prayers every week during a forty-nine day period of mourning.

Christians receive support from the community and the church through the mass and the wake.

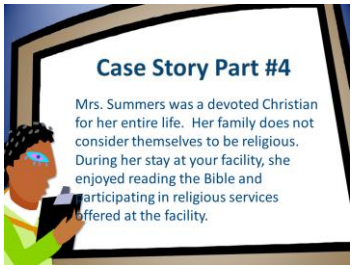
Hindus cover all the religions pictures in the house, and avoid festivals, swamis and marriage ceremonies during the mourning period.

Jews have an intense seven-day mourning period called Shiva after the burial.

Muslims observe a 3-day mourning period except widows, who mourn for 4 months and 10 days.

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

Q. Why is it important to have a basic understanding of Mr. Summers' religious background?
A. So we respect her beliefs and honor her beliefs and rituals regarding death.

Q. What would be helpful to know about Mrs. Summers' wishes?
A. It would be helpful to know if Mrs. Summers belonged to a local church or if any family members did.

Q. How can you support Mrs. Summers' at the end of her life?
A. Suggest that the family meet with a hospice Chaplin or a Pastor to identify any end-of-life rituals or practices needed to be performed.

Activity: Review

Time: 15 minutes

Goal: To prepare the class for the module test.

Review Bites 1-4. Answer questions and address concerns at this time.

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 tha the resident is dying.

A change in condition is caused by:	The Communication Pearls, 6 Steps for Bad News are:	Comforting words for a family that has just received bad news :	Comments to avoid when comforting a family that has just received bad news include:
An illness An infection An injury An event	1. Setting 2. Perception 3. Invitation " Warning Shot" 4. Knowledge 5. Emotion 6. Subsequent	I wish things were different. I can see this makes you sad Tell me what you are thinking	They will be in a bett place soon They've lived a long l 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
Should a feeding tube be placed when the resident is no longer able to chew and swallow?	Should the resident be given IV liquids when they are no longer able to swallow liquids?	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
Which funeral home will the resident's body go to? Will they be buried or cremated? Where will their final resting place be? Will there be a funeral or a memorial service?	Will the resident receive last rites? What rituals, if any, will be performed at the death bed?	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:	Identifying barriers to making end-of-life choices:	Helping a family who is making difficult decisions by:
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"	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	Being an effective communicator Initiating end-of-lif 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

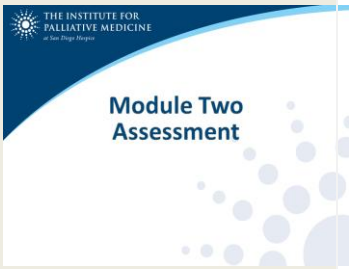
In this bite you learned:

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
Body dies but the spirit is re-incarnated Body cremated Praying weekly during 49 day period of mourning	Soul transfers to new body upon death Body bathed then cremated on pyre Religious pictures, festivals and ceremonies avoided during mourning	Death passage to everlasting life Body buried after mass, wake, service Church, community support family	Dead resurrected in new world Body bathed then buried 7 day mourning period called "Shiva"	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

Proctor the test.

Be available to answer questions and help struggling students. Remind them that they can review the material and retake the test it as many times as necessary to pass the test.

Activity: Complete Course Evaluation

Time: 10 minutes

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

Pass out course evaluations or direct students to the URL for the online course evaluation.

Activity: Closure

Time: 10 minutes

Goal: To give the class an opportunity to learn from each other and to gain insight into the experience.

- Ask the students to share one thing they learned today
- Praise each contribution and thank the class for sharing.

Dismiss the class.