

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



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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 to 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 1: Managing Resident Care is as follows:

Topic	Time
Welcome	5
Introduction	5
Module One: Managing Resident Care	
PPT Bite 1: Environmental Care	15
PPT Bite 2: Signs and Symptoms of Dying	15
Break	5
PPT Bite 3: Giving Comfort	15
PPT Bite 4: Food and Fluids	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 One: Managing Resident Care

Bite 1: Environmental Control

Bite 2: Signs and Symptoms of Dying

Bite 3: Giving Comfort

Bite 4: Food and Fluids

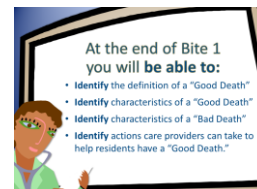


Bite 1: Environmental Control



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 **Module One: Bite 1: Environmental Control**, you will learn what constitutes a “Good Death” and how care providers can help their residents have one.

After completing this module, you will be able to:

- Identify the definition of a “Good Death”
- Identify characteristics of a “Good Death”
- Identify characteristics of a “Bad Death”
- Identify actions care providers can take to help residents have a “Good Death.”

Activity: Teach Module One: Bite 1

Time: 30 minutes

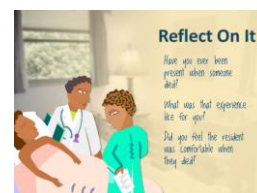
Reflect on It: A “Good Death”

Q. Have you ever been present when someone died?

It may have been a personal loss, or one you’ve encountered in your work. Think about that experience and whether anything should have been done differently for the person or their family.

Q. What was that experience like for you?

Q. Did you feel the resident was comfortable when they died?



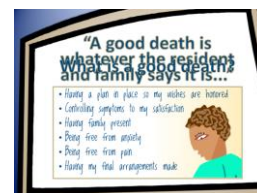
Defining a “Good Death”

Q. What is a good death?

This may seem like a strange question, because we do not think of death as “good” in any way. But knowing that we cannot prevent death, it is important to understand how we can make the experience as peaceful as possible.

The Hospice Community defines a “good death” this way:

“A good death is whatever the resident says it is.....”



Every resident has a personal definition of a “Good Death,” which may include:

- Having a plan in place so my wishes are honored
- Controlling symptoms to my satisfaction
- Having family present
- Being free from anxiety
- Being free from pain
- Having my funeral arrangements made

Reflect on It: A “Bad Death”

- Have you been present at a bad death?
- What was the experience like for you?
- Was the person at peace when they died?



Defining a “Bad Death”

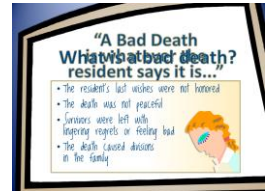
Q. What is a bad death?

The Palliative Care community does not have a formal definition of a bad death, but care providers and families know it when they experience one.

“A Bad Death is whatever the patient says it is...”

A bad death may occur because:

- The resident’s last wishes were not honored
- The death was not peaceful
- Survivors were left with lingering regrets or feeling bad
- The death caused divisions in the family



Go Wish Cards

How can you help your resident's have a Good Death? You can use the “Go Wish” cards to encourage discussion about end-of-life wishes. Go wish cards give residents and their families an easy and open forum to talk about what's important at the end of life. They contain examples of common end of life wishes, such as:

- “To be free from pain”
- “To die at home”
- “Not being a burden to my family”
- “To meet with clergy or a chaplain”



What can you do

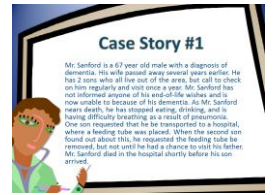
Other ways to help your residents have a good death include:

- Reviewing residents' Physician Orders for Life-Sustaining Treatment (POLST) so that you can support and reinforce the orders with the resident’s family.
- Facilitating family conferences to discuss end of life care goals and the resident's expressed wishes.
- Facilitating communication between the resident's family and the Hospice care team.
- Observing and report changes in the resident’s condition to the Hospice Care team. Hospice will manage the resident's symptoms so that the resident is comfortable.



Case Story #1

Mr. Sanford is a 67 year old male with a diagnosis of dementia. His wife passed away several years earlier. He has 2 sons who all live out of the area, but call to check on him regularly and visit once a year. Mr. Sanford has not informed anyone of his end-of-life wishes and is now unable to because of his dementia.



As Mr. Sanford nears death, he has stopped eating, drinking, and is having difficulty breathing as a result of pneumonia. One son requested that he be transported to a hospital, where a feeding tube was placed. When the second son found out about this, he requested the feeding tube be removed, but not until he had a chance to visit his father. Mr. Sanford died in the hospital shortly before his son arrived.

Discussion

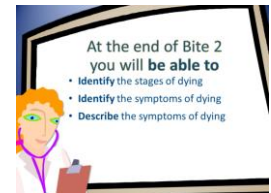
- Did Mr. Sanford have a good death?
- Why did he not have a good death?
- What could have been done differently?

Bite 2: Signs and Symptoms of Dying



Activity: Read Objectives

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



This bite will help you recognize the natural changes that occur when a resident is dying, which is a fundamental skill for all health care providers.

After completing this bite, you will be able to:

- Identify the stages of dying
- Identify the symptoms of dying
- Describe the symptoms of dying

Activity: Teach Module One: Bite 2

Time: 30 minutes

Actively Dying and Imminent Death

There are two stages residents pass through at the end of life:

1. The first is called **Actively Dying**. This is the stage when the dying process is occurring. In this stage, symptoms can be measured in days or hours.
2. The second stage is called Imminent Death. This is the stage resident's pass through just before they die. Symptoms can be measured in minutes or seconds.



Symptoms of Death

During these stages, Actively Dying and Imminent Death, the resident may suffer from symptoms including:

- Social Withdrawal
- Decreased Intake
- Increased Sleep
- Disorientation
- Restlessness
- Decreased Senses
- Incontinence



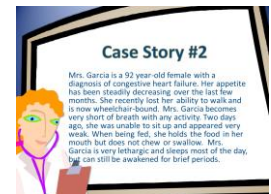
- Physical Changes

These symptoms can occur when the resident is actively dying or when death is imminent, and in no particular order. Some may not occur at all.



Case Story #2

Mrs. Garcia is a 92 year-old female with a diagnosis of congestive heart failure. Her appetite has been steadily decreasing over the last few months. She recently lost her ability to walk and is now wheelchair-bound. Mrs. Garcia becomes very short of breath with any activity. Two days ago, she was unable to sit up and appeared very weak. When being fed, she holds the food in her mouth but does not chew or swallow. Mrs. Garcia is very lethargic and sleeps most of the day, but can still be awakened for brief periods.



Discussion

- What are 3 signs that Mrs. Garcia is transitioning toward death?
- How close do you think Mrs. Garcia is to dying, days or hours?
- What advice can you give to the family to deal with Mrs. Garcia's sleepiness?

Bite 3: Giving Comfort



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:

- Recall the definition of comfort
- Identify ways to comfort end-of-life residents and their families
- Manage end-of-life symptoms
- Identify ways to avoid causing discomfort



Activity: Teach Module One, Bite 3

Time: 30 minutes

Reflect on it

- How do you comfort your residents' families?
- How do you make your residents comfortable at the end-of-life?
- How do you avoid making them uncomfortable?
- What does it mean to provide comfort?



To provide comfort is to...

- To soothe in a time of affliction or distress
- To ease physically; to relieve
- To provide solace in a time of grief or fear
- To help or provide assistance



Providing Comfort

What should you avoid because it may make the resident uncomfortable?

- Avoid moving the resident
- Avoid giving them food or fluids
- Avoid talking about death
- Avoid bathing the resident or taking their vital signs

What should you do to comfort the resident and their family?

- Check on them frequently



- Tell the family what you are doing
- Use positive words
- Offer privacy
- Identify and manage symptoms

Comforting Words

To help our dying residents and their families, it is good practice to ask questions and actively listen to their answers. Here are some effective questions to ask:

- Is there anything we can do for your family?
- Is there anything I can get you?
- Do you want some privacy?
- And use positive words like
- I am here for you. You are not alone.



Symptom Management

To comfort dying residents, manage symptoms such as:

- Cool extremities
- Flushing from fever
- Increased oral secretions
- Incontinence
- Increased Sleep
- Sadness

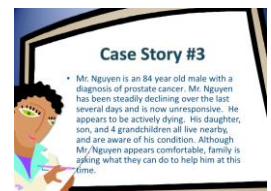


Case Story #3

Mr. Nguyen is an 84 year old male with a diagnosis of prostate cancer. Mr. Nguyen has been steadily declining over the last several days and is now unresponsive. He appears to be actively dying. His daughter, son, and 4 grandchildren all live nearby, and are aware of his condition. Although Mr. Nguyen appears comfortable, family is asking what they can do to help him at this time.

Discussion

- How can you comfort Mr. Nguyen?
- You notice that Mr. Nguyen is now suffering from increased oral secretions, what can you do for him?
- What can you ask Mr. Nguyen or his family to ease their worries?

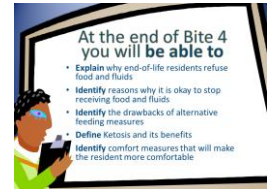


Bite 4: Food and Fluids



Activity: Read Objectives

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



When a resident is dying, their need for food and fluids diminished significantly. This change of condition often causes the family stress. Care providers must understand the reasons for this change, and be able to respond appropriately. In this bite, you will learn the role that food and fluid play in end-of-life care.

After completing this bite, you will be able to:

- Explain why end-of-life residents refuse food and fluids
- Identify reasons why it is okay to stop receiving food and fluids
- Identify the drawbacks of alternative feeding measures
- Define Ketosis and its benefits
- Identify comfort measures that will make the resident more comfortable

Activity: Teach Module 1, Bite 4

Time: 30 minutes

Loss of Appetite

When residents refuse food and fluids, care providers or family members may misinterpret the change in condition as “giving in,” or worry that their loved one is “starving to death”. As the care provider, it is important that you reassure the family that loss of appetite is to be expected, and is a natural part of the dying process. It does **not** mean that their loved one is starving to death; they are just not hungry, and food holds no appeal to them.



Decreased Food Intake

When an end-of-life resident is refusing food, remember that:

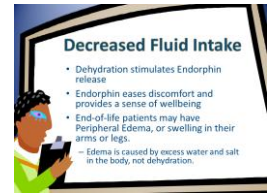
- Their body burns stored fat and muscle for nutrition, a process called Ketosis. This is also a natural part of the dying process.
- The benefits of Ketosis are that it helps the resident maintain mental ability, and provides a sense of well being.



Decreased Fluid Intake

When an end-of-life resident is refusing fluid, remember that:

- Dehydration will stimulate Endorphin release
- Endorphins ease discomfort and provides a sense of wellbeing
- End-of-life patients may have peripheral Edema, or swelling in their arms or legs.
- Edema is caused by excess water and salt in the body, not dehydration.



Alternative Feeding Methods?

The family of a dying resident may request that a tube be placed to feed their loved one. As the resident's care provider, it is important that you tell them about the dangers of tube feeding, including:

- The patient may aspirate or become anxious
- A feeding tube does not relieve thirst or a dry mouth, or prolong life.



Comforting Words

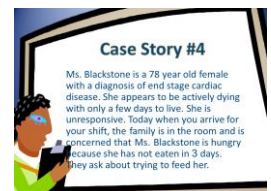
Once a resident has stopped taking food and fluids, there are several things you can do to keep them comfortable, including:

- Applying lip balm or another lip moisturizer,
- Giving them water on a toothette, and providing good oral care to ease the effects of having a dry mouth by rinsing the mouth out every 15 to 30 minutes.



Case Story #4

Ms. Blackstone is a 78 year old female with a diagnosis of end stage cardiac disease. She appears to be actively dying with only a few days to live. She is unresponsive. Today when you arrive for your shift, the family is in the room and is concerned that Ms. Blackstone is hungry because she has not eaten in 3 days. They ask about trying to feed her.



Discussion

- How do we know if Ms. Blackstone is hungry?
- What are the risks of feeding her?
- If the family assumes Ms. Blackstone is hungry, how would you respond to them?

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 “good death” is whatever the resident says it is.

A “bad death” is whatever the resident says it is.

A resident’s definition of a “good death” may include:

Having a plan in place so my wishes are honored

Controlling symptoms to my satisfaction

Having my family present

Characteristics of a “bad death” may include:

The resident’s last wishes were not honored

The death left the survivors with lingering regrets or feeling bad

The death caused divisions in the family

Care providers can help a resident have a “good death” by:

Reviewing POLST orders

Holding care conferences with the family

Facilitating communication between the family and the Hospice team

Reporting changes in condition

Bite 2: Signs and Symptoms of Dying

In this bite you learned:

Dying

Actively Dying

Dying process is taking place.
Signs last days or hours.

Imminent Death

Death is about to occur.
Signs last minutes or seconds.

Signs & symptoms of dying:

Social withdrawal
Decreased intake
Sleepiness
Disorientation
Restlessness
Decreased senses
Incontinence
Physical Changes

The signs and symptoms of dying may occur as the patient passes through either stage, and in no particular order. Some may not occur at all.

Bite 3: Giving Comfort

In this bite you learned:

Providing Comfort

Avoid:

Moving the resident as much as possible
Giving food or fluids unless you can determine the resident is able to swallow
Talking about death in front of the resident
Bathing the resident or taking their vital signs unless the family requests that you do

Do

Check-on the resident and their family frequently
Tell the family what you are doing when you give care
Use positive words
Offer privacy
Identify and manage symptoms

Comforting words

Is there anything we can do for your family?
Is there anything I can get you?
Do you want some privacy?
I am here for you.
You are not alone.

Bite 4: Food and Fluids

In this bite you learned:

Loss of appetite		
The resident is not starving	Decreased Food Intake	Decreased Fluid Intake
This is a natural part of the dying process and is to be expected	Ketosis is the process when the body burns stored fat and muscle for nutrition.	Dehydration stimulates endorphin release.
They are truly not hungry	Ketosis helps maintain mental stability and provides a sense of wellbeing	Endorphins ease discomfort and provide a sense of well being
		End-of-life patients may have Peripheral Edema, or swelling in their arms or legs. Edema is caused by excess water and salt in the body, not dehydration.
Drawbacks of tube feeding	Comfort Measures	
May cause aspiration or increase patient anxiety	For residents who can still take some fluids, provide salt-containing liquids	
Does not help with feelings of thirst or dry mouth	Coat lips with lip balm	
Does not prolong life	Moisten mouth with a damp toothette	
	Rinse mouth out every 15 to 30 minutes	

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.