

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

© 2011, SDHIPM/ SCAN Foundation

Agenda	4
Activity: Welcome	5
Module One: Managing Resident Care	6
Bite 1: Environmental Control	7
Bite 2: Signs and Symptoms of Dying	10
Module One: Bite 2	10
Bite 3: Giving Comfort.....	12
Bite 4: Food and Fluids.....	14
Activity: Review.....	16
Complete Module Test	19
Activity: Complete Course Evaluation	19
Activity: Closure	19

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	10
Module One: Managing Resident Care	
PPT Module One: Bite 1: Environmental Control	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 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 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

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.”

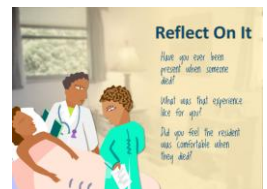


Module One: Bite 1

Time: 15 minutes

Reflect on It: A “Good Death”

- 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.
- What was that experience like for you?
- Did you feel the resident was comfortable when they died?



Defining a “Good Death”

What is a good death?



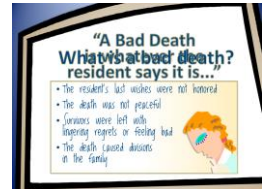
Reflect on It: A “Bad Death”

- 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”

What is a bad death?



Go Wish Cards

- How can you help your resident's have a Good Death?



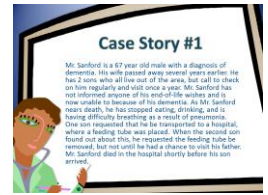
What can you do

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



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

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



Module One: Bite 2

Time: 15 minutes

Actively Dying and Imminent Death

There are two stages residents pass through at the end of life: The first is called **Actively Dying**.

- This is the stage when
- In this stage, symptoms can be measured in

The second stage is called **Imminent Death**.

- This is the stage.....
- Symptoms can be measured in.....



Symptoms of Death

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





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

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



Module One, Bite 3

Time: 15 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...



Comforting Words

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



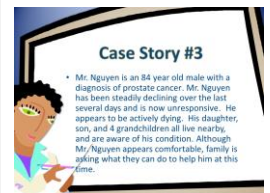
Symptom Management

To comfort dying residents, manage symptoms such as:



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

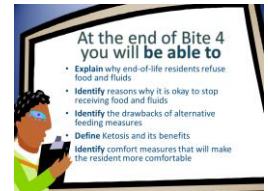
- How can you comfort Mr. Nguyen?
- You notice that Mr. Nguyen is now suffering from increased oral secretions, what can you do for him?
- What can you ask Mr. Nguyen or his family to ease their worries?

Bite 4: Food and Fluids



Activity: Read Objectives

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

Module 1, Bite 4

Time: 15 minutes

Loss of Appetite



Decreased Food Intake

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

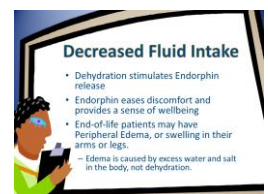
-



Decreased Fluid Intake

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

-



Alternative Feeding Methods?

Dangers of tube feeding include



Comforting Words

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



Case Story #4

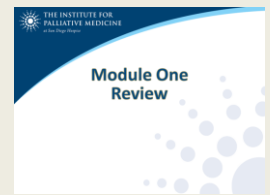
Ms. Blackstone is a 78 year old female with a diagnosis of end stage cardiac disease. She appears to be actively dying with only a few days to live. She is unresponsive. Today when you arrive for your shift, the family is in the room and is concerned that Ms. Blackstone is hungry because she has not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

Review Bites 1-4.

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	Imminent Death	Signs & symptoms of dying:
<ul style="list-style-type: none"> • Dying process is taking place. • Signs last days or hours. 	<ul style="list-style-type: none"> • Death is about to occur. • Signs last minutes or seconds. 	<ul style="list-style-type: none"> • 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:

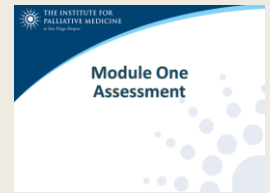
Providing Comfort		Comforting words
Avoid:	Do	
<ul style="list-style-type: none"> • Moving the resident as much as possible • Giving food or fluids unless you can determine the resident is able to swallow • Talking about death in front of the resident • Bathing the resident or taking their vital signs unless the family requests that you do 	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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	Decreased Food Intake	Decreased Fluid Intake
<ul style="list-style-type: none"> • The resident is not starving • This is a natural part of the dying process and is to be expected • They are truly not hungry 	<ul style="list-style-type: none"> • Ketosis is the process when the body burns stored fat and muscle for nutrition. • Ketosis helps maintain mental stability and provides a sense of wellbeing 	<ul style="list-style-type: none"> • Dehydration stimulates endorphin release. • 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	
<ul style="list-style-type: none"> • May cause aspiration or increase patient anxiety • Does not help with feelings of thirst or dry mouth • Does not prolong life 	<ul style="list-style-type: none"> • For residents who can still take some fluids, provide salt-containing liquids • Coat lips with lip balm • 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

Activity: Complete Course Evaluation

Time: 10 minutes

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

Activity: Closure