

# 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



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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## 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 Module 1: After Death is as follows:

Topic	Time
Welcome	5
Introduction	5
Module Three: After Death	
PPT Bite 1: Care of the Body	15
PPT Bite 2: Grief	15
Break	5
PPT Bite 3: Supporting a Grieving Family	15
PPT Bite 4: Community Response to Death	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.”

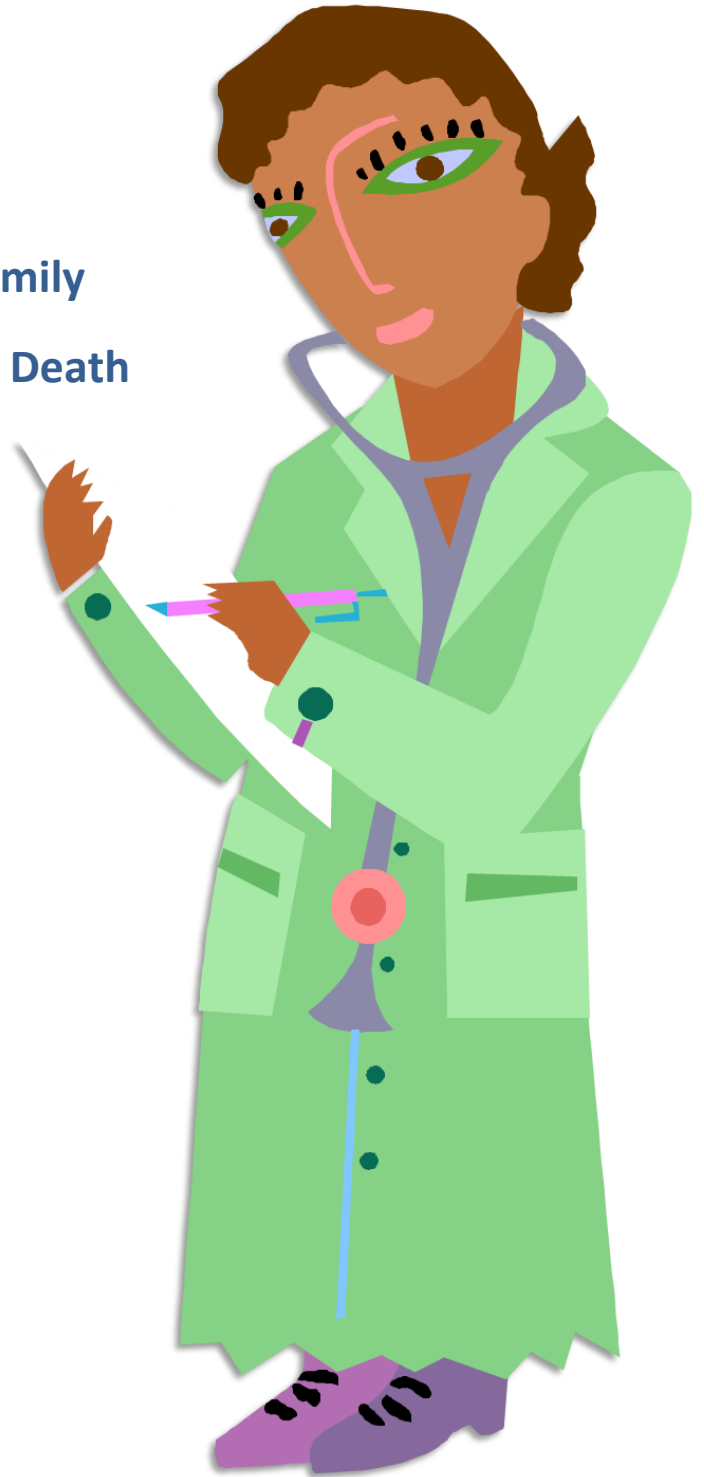
# Module Three: After Death

**Bite 1: Care of the Body**

**Bite 2: Grief**

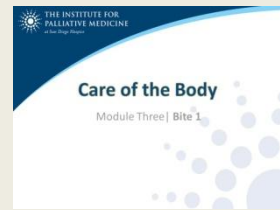
**Bite 3: Supporting a Grieving Family**

**Bite 4: Community Response to Death**





## Bite 1: Care of the Body



### 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 professional who provides end-of life care, your job does not end when a resident dies. You are also responsible for providing post mortem care for the resident. In this bite, you will learn about the physical signs of death and how to take care of the resident's body after they pass away.

After completing this module, you will be able to:

- Identify the six signs of death
- Identify who can legally pronounce a resident dead
- Explain the goal of post-mortem activities
- List typical post-mortem activities

### Activity: Teach Module Three, Bite 1

#### Reflect on it

Have you taken care of a resident after they have died?  
How did you feel about it?



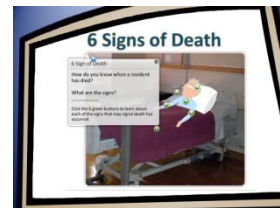
## Six Signs of Death

How do you know when a resident has died?

What are the signs?

There are 6 distinct signs of death:

- There is no heartbeat, and the resident has stopped breathing.
- The eyes have stopped blinking and the gaze is fixed. The eyes are open because the muscles that control the eyelids relax.
- The mouth is slightly open, because the jaw muscles go slack.
- The body temperature drops.
- The resident's color changes. They get very pale, and may appear to be gray, yellow or blue.
- The bowel and the bladder release.

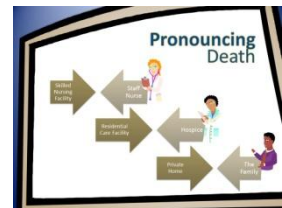


## Pronouncing Death

Q. After a resident dies, what happens next?

A. The next step is for someone to officially pronounce the resident dead. By law, this depends on where the resident dies:

- In a Skilled Nursing Facility, a staff nurse does it
- In Residential Care Facility, the Hospice nurse usually does it.
- In a private home, the family can do it.



## Post-mortem care

After a resident dies, the caregiver provides “post-mortem” care.

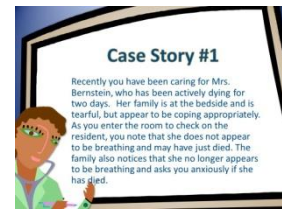
The goals of post mortem are to prepare the remains and to create a comfortable environment for the resident’s family. We do this by:

- Closing the resident's eyes and mouth
- Cleansing the body
- Changing the bed sheets
- Positioning the body in the bed
- Controlling odor with aromatherapy or air freshener



## Case Study

Recently you have been caring for Mrs. Bernstein, who has been actively dying for 2 days. Her family is at the bedside and is tearful, but appear to be coping appropriately. As you enter the room to check on the resident, you note that she does not appear to be breathing and may have just died. The family also notices that she no longer appears to be breathing and asks you anxiously if she has died.



## Discussion

Q. What signs do you look for to determine she has died?

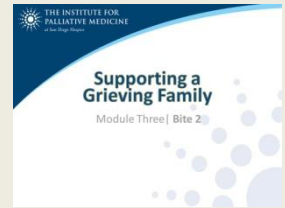
A. Lack of apparent breathing; fixed gaze; no signs of movement.

Because many residents have long periods of apnea (no breathing) when they near death, it is helpful to sit with the family to observe the resident for at least 2 minutes to determine she is no longer breathing. Remain calm!

Q. What do you tell the family?

A. Although you most likely can confirm that the resident has died, it is important to notify the charge nurse to check vital signs. The best practice is to calmly let the family know that you will summon the charge nurse to check her vital signs. It is best to stay present in the room when the nurse arrives to help support the family when given the news that their loved one has died.

## Bite 2: Supporting a Grieving Family



### 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:

State comforting words you can say to support a grieving family  
List actions you can take to support a grieving family

### Activity: Teach Module Three, Bite 2

## Focusing on the Family

After the resident dies and the body has been cared for, the focus of care shifts to the resident's family.

- Call the family to the bedside and ask if they want to say goodbye. Some people will want to, others will not.
- Either way, be prepared for a strong emotional reaction to the question. Some people cry, some yell, and others go silent.

Culture plays a **huge** role in how people react to death. As a care provider, it is important that you understand each family's cultural heritage so you can provide the support *they* need.

- In some Middle Eastern societies, wailing is a normal reaction to death.
- In some Southeast Asian societies, controlling emotion and keeping feelings in check are normal reactions to death.



## Support with words

After death, you can support the family with comforting words like:

- I'm sorry for your loss.
- Can I get you some water?
- I know this is a hard time for you.
- Is there anyone I can call for you?



## Support with Actions

You can also support a family by your actions, including:

- Staying calm. The last thing the family needs is an excited or upset caregiver.
- Offering family members a hug.
- Hold their hand if they wish. This reconnects the person to the living, and reassures them that “we are still here.”
- Quietly sitting with them family.
- Allowing them to express their feelings. Do not ask them to stop crying, even if it makes you uncomfortable.
- Being patient with the family. Tell them they can stay as long as they want.



## Case Study

The charge nurse arrives and confirms that Mrs. Bernstein has indeed died. The resident’s 2 daughters, son, and grandson are present.

One daughter is crying and states “I thought I was prepared for this, but it doesn’t seem real”. The other daughter states “Although I will miss mom, I am relieved she is finally at peace”.

The son and grandson are sitting quietly in the room and have not spoken much since they arrived.

## Discussion

Q. What grief reactions can you briefly identify in Mrs. Bernstein’s family?

A. Sadness, Shock, Relief, Silence

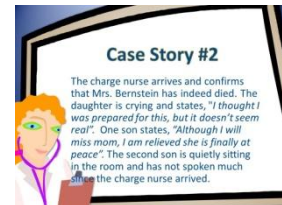
Q. Are any of these reactions unusual or of concern?

A. All these reactions are normal, but we don’t know how the son and grandson are feeling. Ask them how they are feeling, and if there is anything they need to make the situation “normal” for them. It is important to offer support to everyone, regardless of how they “appear” to be coping.

Q. How can you support this family?

A. You can comfort them with words and actions.

- “I’m sorry for your loss”
- “How can I support you?”
- Validate feelings of relief as being normal
- Sit with them as they process what has happened



## Bite 3: Grief



### Activity: Read Objectives

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

Grief is a normal reaction to the loss of a loved one. As an end-of-life caregiver, it is important that you understand what grief is and how it is expressed.

After completing this bite, you will be able to:

- Define grief
- Identify the stages of grief
- Explain what we know about the grieving process
- Describe the signs of complicated grief



### Activity: Teach Module Three, Bite 3

**Time: 30 minutes**

#### Reflect on it

What is grief?

How have you seen others grieving?



#### What is grief?

When a loved one passes away, most people experience Grief.

- Grief is the emotional response to loss.
- Grief is intense, immediate and difficult
- It is an intimate, personal experience

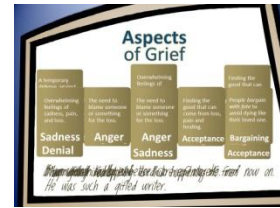




## Stages of Grief

There are 5 stages of grief:

- **Denial:** A temporary defense against feeling grief. “I am fine, really”
- **Bargaining:** People “bargain with fate” to avoid dying like their loved one. “I am going to take better care of myself from now on.”
- **Sadness:** Overwhelming feelings of sadness, pain, and loss. “Why did this happen?”
- **Anger:** The need to blame someone or something for the loss. “This is not fair!” “Why is this happening to me?”
- **Acceptance:** Finding the good that can come from loss, pain and healing. “I remember when she used to read to me.” “He was such a gifted writer.”



## How We Grieve

We used to think that everyone experiences grief the same way: by passing through all five stages, one after another, starting with denial.

We now know this is not true; we have learned that:

- Everyone experiences grief differently- there is no systematic order to the grieving process.
- Every person does not experience every stage of grief. For example, some people's grieving experience starts with sadness and continues onto anger and acceptance.
- Other people only feel anger.
- There is no “right or wrong” way to grieve.
- Most people grieve for about 13 months after a loved one dies

## Complicated Grief

Some people experience “complicated grief,” and need extra help to recover from a loss.

Symptoms of complicated grief may include:

- Grieving that lasts longer than 13 months
- Difficulty accepting the death
- Chronic yearning that disrupts daily life
- Suicidal thoughts, like “I wish I were dead” and “I can’t go on without her”
- A sense of meaninglessness, or that “Life isn’t worth living anymore”
- Numbness and detachment from everyday life
- A history of mental illness in the family



- Drug or alcohol abuse
- The desire to cause harm to themselves or others

If you think someone is suffering from complicated grief, notify the appropriate person at your facility.

### Case Study

Several days after Mrs. Bernstein's death, her daughter comes to the facility to say "hello" to everyone and pick up the last of her mother's belongings. This is the same daughter who was present when Mrs. Bernstein died, and was very upset and tearful.

Today, she seems to be very cheerful and states that she is doing well. She acts as though nothing happened and is laughing and joking with the staff. You are thinking to yourself "How can she be so happy? Shouldn't she be crying that her mom has died?"



### Discussion

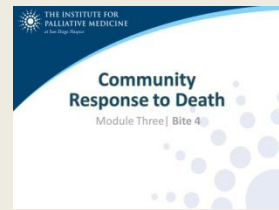
Q. What stage of the grieving process could Mrs. Bernstein's daughter could be experiencing?

A. Mrs. Bernstein's daughter appears to be in the Acceptance stage of grieving process. This is likely because she experienced a very strong emotional reaction on the day her mother died, meaning that she understands that it happened and is not in denial.

Q. What do we know about grief that indicates the daughter is reacting normally?

A. We know that the stages of Grief are not predictable and can come and go. We cannot assume Mrs. Bernstein's daughter is not grieving just because she does not seem sad when we see her. She appears to be grieving normally because exhibited appropriate sadness at the time of the death. She may also have experienced other stages of grief that we are not aware of. It is also possible that coming to the facility to visit might have lifted her spirits and made her feel close to her mother and memories of when her mother was alive.

## Bite 4: Community Response to Death



### 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:

- Identify ways to help residents cope with the loss of another resident in their facility
- Describe ways to help ourselves when a resident passes away



### Activity: Teach Module Three, Bite 4

**Time:** 30 minutes

### Reflect on it

Who is affected by the death of a resident in your facility?



## Suffering from Loss

### Residents.

Many residents have already suffered a lot of loss in their lifetime, including:

- Home
- Independence
- Health
- Control of their daily life

### Staff.

Staff has also endured a lot, including:

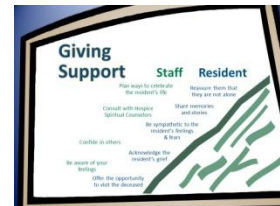
- Years long attachments from giving care
- Loss of relationships with the families
- Periods of frequent death---holiday, flu season
- Burn-out or compassion fatigue



## Supporting Residents

You can help residents cope by with a death at their facility by:

- Acknowledging their grief by allowing them to talk about their feelings.
- Allowing them to visit the resident before they die **if** they were close **and** the family is comfortable with it. Having a chance to say good-bye helps the grieving process.
- Imagining the way they might feel. They may be worried they will be the next to die.
- Sharing memories and stories with them about the resident.
- Reassuring them that they are not alone.



## Supporting Ourselves

You can help yourself and other staff at your facility by:

- Being aware of your feelings
- Consulting with Hospice Spiritual Counselors
- Speaking with trusted others
- Planning ways to celebrate the resident's life, by having a party or a memorial service where they are remembered.



## Case Story

Several weeks after Mrs. Bernstein's death, three other residents die within days of each other. You have noticed that you are dreaming about work a lot, and even broke down and cried when your co-worker called you on your day off to tell you that another resident had died. You wonder if you are getting "burned out" at work and start to dread going to work.

## Discussion

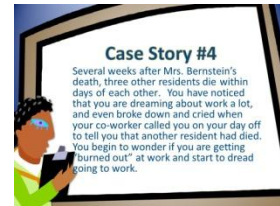
Q. Is it possible you are grieving the loss of your residents and the recent deaths?

A. Yes, it is. Grief can be mistaken for burn out or stress, but it is much different. It is not unusual for grief to take different forms in the workplace, where we must be careful not to cross the "professional" line and keep feelings in check. Given that you have not suffered other losses in your life, you might want to consider that your reaction is grief and/or compassion fatigue.

Q. What can you do to help yourself cope with grief?

A. Acknowledge that you are grieving the recent losses of multiple residents.

A. Confide in someone you trust or to whom you are close. Talk to your colleagues and/or manager about scheduling a "Celebration of Life" event to honor the lives and grieve the losses.



## Activity: Review



**Time: 30 minutes**

**Goal: To prepare the class for the module test.**

Review Bites 1- 4.

Answer questions and address concerns at this time.

### Bite 1: Care of the Body

In this bite you learned:

<b>Signs of Death</b> <ul style="list-style-type: none"><li>• No heartbeat</li><li>• No breathing</li><li>• Cool skin</li><li>• Pale skin that may be white, gray, yellow or blue</li><li>• A strong odor</li><li>• Release of the bowels and bladder</li><li>• Eyes and mouth stay open</li></ul>	<b>Pronouncing death</b> <ul style="list-style-type: none"><li>• Skilled Nursing Facility: Licensed Nurse</li><li>• Residential care Facility: Staff Nurse</li><li>• Home: Family member</li></ul>	<b>Goals of post-mortem care</b> <ul style="list-style-type: none"><li>• Make resident presentable for family</li><li>• Create a pleasing environment</li></ul>
<b>Post-mortem Care</b> <ul style="list-style-type: none"><li>• Cleanse the resident</li><li>• Close their eyes and mouth</li><li>• Position the body</li><li>• Control odor</li></ul>	<b>Different Cultures</b> <ul style="list-style-type: none"><li>• Expect differences</li><li>• Treat all families with respect</li></ul>	

## Bite 2: Supporting a Grieving Family

In this bite you learned:

After a resident dies, the focus shifts to the family.

### After the resident dies:

- Call the family to the bedside
- Ask if they want to say goodbye. Expect a strong emotional reaction
- Expect different cultures to respond differently

### Comforting Words

- I'm sorry for your loss
- Can I get you some water?
- I know this is a hard time for you
- Is there anyone I can call?

### Comforting Actions

- Stay calm
- Offer family members a hug
- Hold their hand
- Quietly sit with the family.
- Allow them to express their feelings
- Being patient

### Bite 3: Grief

In this bite you learned:

#### Grief

Definition of Grief	Stages of Grief	The Grieving Process	Signs of Complicated Grief
<ul style="list-style-type: none"><li>• Grief is the emotional response to loss.</li><li>• Grief is intense, immediate and difficult</li><li>• It is an intimate, personal experience</li></ul>	<ul style="list-style-type: none"><li>• Denial</li><li>• Bargaining</li><li>• Sadness</li><li>• Anger</li><li>• Acceptance</li></ul>	<ul style="list-style-type: none"><li>• Everyone experiences grief differently</li><li>• Every person does not experience every stage of grief.</li><li>• There is no “right or wrong” way to grieve.</li><li>• Most people actively grieve for about 13 months</li></ul>	<ul style="list-style-type: none"><li>• Intense grief lasting longer than 13 months</li><li>• Difficulty accepting the death</li><li>• Chronic yearning that disrupts daily life</li><li>• Suicidal thoughts</li><li>• Sense of meaninglessness</li><li>• Numbness and detachment from everyday life</li><li>• History of mental illness in the family</li><li>• Drug or alcohol abuse</li><li>• Desire to cause harm to themselves or others</li></ul>



#### Bite 4: Community Response to Death

In this bite you learned:

Supporting residents and ourselves after a resident dies is very important to the grieving process.

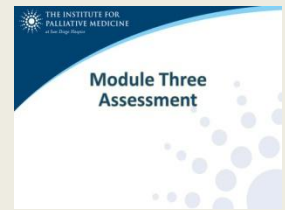
##### Support residents by:

- Letting them talk about their feelings and actively listening
- Letting them say goodbye
- Sharing memories and stories with other residents
- Reassure them that they are not alone

##### Support yourself and other staff:

- Be aware of your own feelings
- Consult with Hospice Spiritual Counselors
- Speak with trusted others
- Plan ways to celebrate the resident's life

## 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.**

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.**