



**embodied  
labs**

# **The Clay Lab: End of Life Conversations**

## **FACILITATION GUIDE**

**Long-term Care & Home Health**

**INSTRUCTOR VERSION**



Embodied Labs Facilitation Guide

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# EMBODIED LABS VR SIMULATIONS FOR TRAINING

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## embodied labs framework



### Uses & Goals

#### **Knowledge & Training**

To educate and provide information on End of Life issues and symptoms.

#### **Insight & Transformation**

To empower healthcare professionals and care partners to deliver compassionate, person-centered care to persons at the End of Life.

#### **Communication & Team Building**

To have meaningful dialogue across your team about the shared experience of embodying the same person at the End of Life.

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- 1 Prepare by taking a pre-assessment and discovering your existing knowledge.



## PREPARE

- 2 Embody someone by putting on a VR headset and transporting yourself into their perspective.



## EMBODY

- 3 Take a post-assessment, then use this facilitation guide to further reflect on how the VR experiences changed your views, mindset, and knowledge based on the insight you gained by embodying someone else.



## REFLECT

# BEST PRACTICES FOR USING EMBODIED LABS IN DIFFERENT SETTINGS

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Depending on how you will be using Embodied Labs for individuals or a large group, your setup needs may differ to maximize the user experience. Here are suggested equipment and discussion formats for each mode.



## Individual Mode

<b>Technology</b>	<ul style="list-style-type: none"><li>• Computer, sensor, and headset from kit</li></ul>
<b>Environment</b>	<ul style="list-style-type: none"><li>• Quiet, separate area</li><li>• Moderate amount of privacy while in the headset</li></ul>
<b>Materials</b>	<ul style="list-style-type: none"><li>• Facilitation Guide for individual reflection while waiting for the headset or right after the experience</li></ul>

## Group Mode



### Technology

- Computer, sensor, and headset from kit
- Big screen (if available). Use HDMI cord **AND** adapter that come with your VR kit to attach screen to back of computer
- Mirrored sound through both the computer speakers **AND** headset
- Set volume on audio set all the way up to 100



**Note:** The computer defaults to the Rift headphones when the headset is plugged in. To get audio through computer speakers so that the group can hear, click on sound icon at the bottom right-hand side of your screen and choose “Speakers”)

### Environment

- Quieter area, separate from larger area where most people are congregating
- Space for people to gather around without crowding the person in the headset

### Materials

- Facilitation Guide for partner and group reflection while waiting for the headset or right after the experience
- Adult learners often can use the guide themselves; younger learners may need more direction on which question to discuss

# THE CLAY LAB

## Introduction

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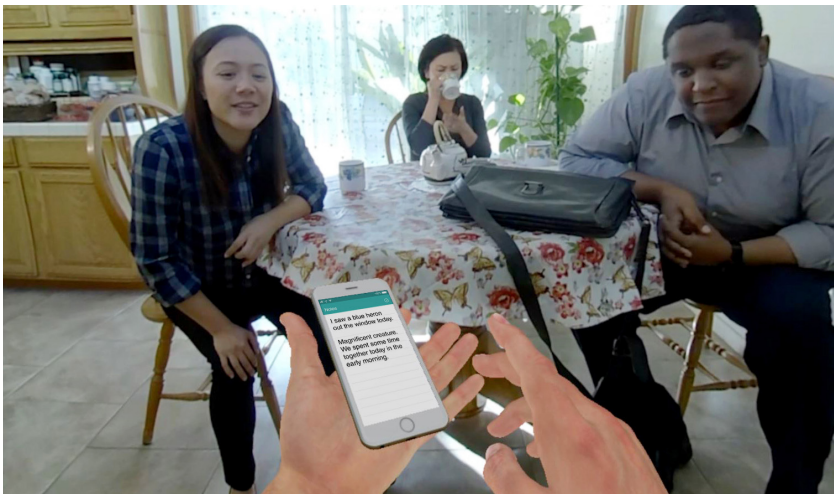
### From the Creators

Embodied Labs is excited to release our next embodied experience: “The Clay Lab: End of Life Conversations.” This lab allows learners to embody a 66-year old veteran named Clay, as he approaches and then reaches the end of his life. This experience helps learners explore the conversations and issues that come up when a person with a terminal prognosis changes from a curative path to a palliative care path.

By embodying Clay, you will gain insight into the experience of being diagnosed with a terminal disease, learn what options are available (with a focus on hospice care), how the healthcare team works together in end of life care, and what the last days, hours and minutes of a person’s life might be like. It is our hope that this experience will help the professional and family care partners who care for people at the end of their life to become more comfortable and confident in that role.

Thank you for taking another journey with us!

— The Embodied Labs Team





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## Please Note

This Embodied Lab was created by documenting first hand accounts of patients, families, and care teams in end of life situations. Embodied Labs does not endorse any particular practice, treatment, or care plan detailed in this lab; rather, this is meant to provide perspectives for informed discussions about the many facets of care at the end of life.

### Content Advisory

This lab contains content that deals with sensitive issues surrounding end of life decisions, conversations and care. The learner will embody someone who is in the process of nearing the end of their life — eventually experiencing the moment of death.

*Content may not be suitable for all viewers.*

# THE CLAY LAB

## Insight Statements

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After experiencing The Clay Lab: End of Life Conversations, learners will develop insights around the following themes:

### Effective Communication

Learners recognize the elements of effective communication when discussing end of life care, including: presenting all options objectively, using a compassionate tone of voice and manner, making eye contact with and addressing the person at the end of their life, and being responsive of the person's choices and opinions.

### Role in an Interdisciplinary Team

Learners recognize that each member of the interdisciplinary team contributes uniquely to the provision of patient-centered care at the end-of-life.

### Purpose of Hospice Care

Learners recognize that the purpose of hospice care is to provide a support system for the physical, emotional, and spiritual pain experienced at the end of life. Learners also recognize that at the end of life, healing is still possible even when curing is not.

### Understanding End-of-Life Symptoms

Learners recognize that at the end of life, healing is still possible even when curing is not. Learners also recognize the most common physical signs and symptoms that are often present in the final days and hours of a person's life.

# THE CLAY LAB

## Part 1: Receiving a Terminal Diagnosis

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### Effective Communication

1. What did you feel like the doctor did well when communicating with Clay and his family about his prognosis and options? What could the doctor have done better?
  
2. Make a list of the ways a member of the health care team should communicate with a person in a setting where the news is unwelcome and upsetting.
  
- 3a. How do you think parents feel when their adult children become involved in their health care decisions?
  
  
  
  
  
  
  
- 3b. How do adult children feel when their help is required, needed, or wanted in making health care decisions with their parents?

# THE CLAY LAB

## Part 1: Receiving a Terminal Diagnosis (cont.)

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### Role in an Interdisciplinary Team

1. What information is a doctor responsible for communicating to the other members of the healthcare team?
  
  
  
  
  
  
  
  
  
  
2. How did it feel to receive information about your diagnosis from Dr. Chatterjee? How would it have been different to receive this information from another member of the healthcare team, such as a nurse or social worker?

**After discussion talking point:**

Many people with a terminal disease report that they first hear that they have been recommended for hospice or palliative care from a nurse or social worker, not their physician, or from their own chart or medical record with no explanation.

- 3a. What information should the family members of a person with a terminal diagnosis receive?
  
  
  
  
  
  
  
  
  
  
- 3b. How can doctors do a good job communicating information to family members without making the person with a terminal disease feel like they are being left out?

# THE CLAY LAB

## Part 2: Transitioning to Home Hospice

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### Purpose of Hospice Care

1. How did you feel when the nurse told you that your chart said that hospice care was the recommendation of your doctor?

**After discussion talking point:**

Many people with a terminal disease report that they first hear that they have been recommended for hospice and/or palliative care from a nurse or social worker, not their physician, or from their own chart or medical record with no explanation.

2. What should an ER nurse or other healthcare professional do when they are asked to give their opinion about hospice care?

**After discussion talking point:**

As a healthcare professional, it is important to make sure you are following best practices when talking about hospice care, including:

- Referring a person or family to the appropriate person (palliative care team, social worker, etc.) at the organization who is most appropriate to give this information
- Giving information as objectively as possible
- Not endorsing one specific hospice facility or organization
- Giving multiple options for care in any print materials you give to a person or family
- Remaining calm and compassionate toward people, even when they are experiencing distress or emotion.

# THE CLAY LAB

## Part 2: Transitioning to Home Hospice (cont.)

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### Purpose of Hospice Care (cont.)

3. How is palliative care different from curative care? Can a person be healed when receiving palliative care?

#### After discussion talking point:

**Curative care** is pursued when it is expected that a person could overcome or eliminate their disease with treatment.

**Palliative care** is generally defined as care that helps provide relief from symptoms of disease but does not have the goal of eliminating the disease.

**Hospice care** provides holistic care for someone who is nearing the end of their life, which often includes palliative care treatment. Anyone whose life span is estimated to be 6 months or less is eligible for either home or facility-based hospice care — and reimbursement for related costs.

**Healing** is still possible even when a cure is not, through gentle touch, good symptom management, and all other supports and relief of physical, emotional or spiritual pain.

# THE CLAY LAB

## Part 2: Transitioning to Home Hospice (cont.)

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### Purpose of Hospice Care (cont.)

4. Have you ever felt that receiving hospice care is like saying “I give up?”  
Have you ever thought that hospice could shorten a person’s life?  
Have you ever worried that medications could shorten yours, a loved one’s, or a client/resident’s life?

**After discussion talking point:**

The above questions are common ones that people have. We can help eliminate misinformation about hospice, knowing that studies have shown that:

- Hospice can provide symptom control and increased quality of life
- Hospice care, nor the use of pain medications, will not shorten a person’s lifespan.
- The incurable disease is what ends person’s life, not the use of pain medications.

# THE CLAY LAB

## Part 2: Transitioning to Home Hospice (cont.)

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### Role in an Interdisciplinary Team

1. What members of the hospice care team did you see in this part of the Clay Lab? What were their roles?

#### After discussion talking point:

The core, mandatory members of a hospice care team are the:

- **Nurse case manager** — who coordinates the team, determines resource needs, and communicates with the doctor about medication for symptom/pain control.
- **Social worker** — who helps with interpersonal conflicts, helps with financial concerns, and determines other resources needed, such as medical equipment.
- **Chaplain** — who provides spiritual support not tied to any particular religion or denomination to the person nearing the end of their life. It is not mandatory to receive services from the chaplain.

- 2a. What are some of the challenges that would be present in working together as a home hospice team?

- 2b. How are those challenges in the previous question the same or different from the ones you experience in the work you do each day?

- 2c. What new insights about working as a team do you have now that you have embodied Clay?



# THE CLAY LAB

## Part 2: Transitioning to Home Hospice (cont.)

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### Understanding End-of-Life Symptoms

1. What are some of the symptoms\* you experienced as Clay, particularly in the latter part of the module? Think about physical, emotional, and spiritual aspects for this answer.

**After discussion talking point:**

- **Physical** — increased pain
- **Emotional** — Feeling less connected to family conflict and/or care decisions
- **Spiritual** — New interest in talking about spiritual matters

*\* These symptoms look different for every single person.*

2. How does the heron relate to end-of-life symptoms? Did you think the heron was real or not when Clay first brought it up?

**After discussion talking point:**

Many people nearing the end of their life see things that others cannot. Examples often include animals and/or people who have died previously.



# THE CLAY LAB

## Part 3: Last Days

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### Effective Communication

- 1a. How did you feel when your family and the nurse addressed you, even when it was clear you couldn't speak?
  
  
  
  
  
  
  
  
  
  
- 1b. How did you feel when the nurse was talking to Clay, even after he had died?

**After discussion talking point:**

It is a common practice in hospice care to verbally address the person who is nearing the end of their life, even when they cannot respond, including after they have died.

This is done to show both respect for the person at the end of their life and because it is not known exactly when a person's senses cease to work. Most experts believe hearing is the very last sense to become non-functional.

2. When the nurse responded to the daughter's question about whether or not to include a feeding tube, was she using best practices?

**After discussion talking point:**

Best practices for advising family members about care decisions includes:

- Giving information objectively, avoiding personal opinions.
- Consulting available resources that express the opinion of the person at the end of life, such as an advanced directive or last wishes document.

# THE CLAY LAB

## Part 3: Last Days (cont.)

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### Effective Communication (cont.)

3. How did it make you feel to have your daughters making decisions for you about your care?

**After discussion talking point:**

It can help to have a discussion where one family member is appointed “medical power of attorney”, like Grace in this story. Ideally, this person’s decisions are guided by an advanced directive or last wishes document.

# THE CLAY LAB

## Part 3: Last Days (cont.)

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### Role in an Interdisciplinary Team

- 1a. How might it feel for the person at the end of their life, as well as their family members, to have many different healthcare professionals in and out of the home, particularly at the time of death?
  
- 1b. What best practices should a hospice care team and others follow when they are inside the home where there is a person nearing the end of their life?
  
- 1c. How can these best practices be applied in a long term care facility or skilled nursing setting?
  
2. What activities did you see the different members of a hospice care team and related personnel doing after the time of death?

#### After discussion talking point:

What happens after the person has died?

- A nurse from hospice will come and confirm that the person has died by checking their pulse and breathing. This is often not the nurse case manager who has been the point person for the hospice team.
- The nurse or another person from hospice will bathe and dress the body — with assistance from the family if desired.
- The funeral home will send people to transport the body to their premises.

NOTE: Some practices may vary from state to state, or depending on whether the person was on hospice, in their home, or in a facility.



# THE CLAY LAB

## Part 3: Last Days (cont.)

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### Understanding End-of-Life Symptoms

1. What did you learn and observe from beginning the last module inside the animation of a body entering it's last hours of life?

**After discussion talking point:**

In the body animation, the learner experienced:

- Digestion slowing down as blood stops circulating as well to the organs.
- Fast, shallow breathing and rapid heart beat as the body works very hard to continue the circulation of blood and oxygen.
- The effect of pain medication on the organ systems.

2. How did it feel to have your hands look mottled and the finger tips be purple? How did it feel to hear yourself breathing abnormally? How would it feel to experience these things as an observer?

**After discussion talking point:**

- It is often very distressing for family members to observe a person with a “rattle” in their lungs, breathing rapidly and shallowly, and seeing their skin change colors.
- Pain medication can help make these symptoms less distressing for the person, and as a result — less distressing for the family members.

# THE CLAY LAB

## Part 3: Last Days (cont.)

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### Understanding End-of-Life Symptoms (cont.)

3. What are the most common end-of-life symptoms that you observed while embodying Clay?

#### **After discussion talking point:**

Some of the physical symptoms the learner experienced as Clay were:

- Body temperature changes
- Mottling of skin
- Purple fingers/toes
- Decreased urine output
- Increased sleepiness/decreased alertness
- Rattle in lungs
- Rapid heartbeat

Some of the spiritual/emotional symptoms the learner experienced as Clay were:

- Being withdrawn/non-communicative
- Seeing things that others cannot (the blue heron)

NOTE: End-of-life symptoms vary greatly from person to person.



# NOTES

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# THE CLAY LAB

## Resource List

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### General End-of-Life Information

#### **Gosnell Hospice House Resource List**

A comprehensive resource list on all aspects of hospice and end-of-life issues and care.

<https://www.nhpco.org/resources/end-life-care--resources>

#### **Medicare: Hospice & Respite Care**

Information from Medicare about what is covered when a person receives hospice care.

<https://www.medicare.gov/coverage/hospice-and-respite-care.html>

#### **The National Institute of Health: What is End-of-Life Care?**

Basic details about end-of-life options for families.

<https://www.nia.nih.gov/health/what-end-life-care>

### Information about End-of-Life Symptoms

#### **Stanford School of Medicine: Palliative Care**

Description of the most common symptoms seen at the end of life, and practical ways to help/comfort those experiencing them.

<https://palliative.stanford.edu/transition-to-death/signs-of-impending-death/>

### Advanced Directives & Living Will Documents

#### **FiveWishes.Org: Advanced Care Planning**

Information from an organization with an easy to use advance care planning tool.

<https://fivewishes.org/five-wishes/advance-care-planning>

#### **MayoClinic.Org: Living Wills & Advanced Directives**

Information and definitions of different living wills and advanced directives.

<https://www.mayoclinic.org/healthy-lifestyle/consumer-health/indepth/living-wills/art-20046303>

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## Books & Misc.

### **Being Mortal by Atul Gawande**

Influential book by a practicing surgeon about living a “good life” all the way until the end-of-life.

<http://atulgawande.com/book/being-mortal/>

### **End of Life Guideline Series Booklets by Barbara Karnes**

Books written in simple, practical language that relays aspects of the end-of-life experience and process for caregivers of all types.

<https://bkbooks.com/products/end-of-life-guideline-series-a-compilation-of-barbara-karnes-booklets>

### **“Gone From My Sight”: A Poem by Henry Van Dyke**

Poem partially heard in module three of The Clay Lab.

<https://allpoetry.com/Gone-From-My-Sight>