



JAMES L. WEST
CENTER *for* DEMENTIA CARE

Graceful Departures: The 11th Hour Companionship Program

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Course Outline

Date of Presentation: 4/3/25

Time: 4:00 PM CST

Location: TALA

Type: Nursing, SW, Admin, LPC

Presentation: Graceful Departures

Presenter: Hollie Glover, MA, LPC, NCC



Educational Objectives

Upon completion of this program the participant will be able to:

- ▶ Understand the Role of Compassionate Companionship
- ▶ Enhance Communication and Support Skills
- ▶ Cultivate a Sacred and Peaceful Environment



Hollie Glover, MA, LPC, NCC

- ▶ Hollie Lowe, is a Licensed Professional Counselor, who currently works for the James L. West Center for Dementia Care in Fort Worth. She is the Director of Education and Family Support Services. She facilitates the center's family support groups and is involved in many of the numerous education services provided by the center.
- ▶ Hollie is a Dementia Care Specialist and has over thirty years of experience in education and working with people of all ages. She has degrees from Southwestern Oklahoma State University, Sam Houston State University, and Dallas Baptist University. She also attended Southwestern Theological Seminary to obtain hours in theology.
- ▶ Hollie has been recognized as a national and statewide speaker on topics such as Dementia, Hospice, and Professional and Caregiver Stress. One of the highlights of her career includes getting to meet and speak before First Lady Rosalynn Carter and Senator Elizabeth Dole. She has also written a therapy to be used with patients at the end of life, that focuses on the individual needs of the person and their family.
- ▶ Her passion is educating the public and helping families who have a loved one diagnosed with dementia.



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Goal of the 11th Hour Program: The Power of Connection



- ▶ The goal of the 11th Hour Program is to assign specially trained volunteers to sit with residents during their final hours, to ensure no one dies alone, except by choice and to assure that everyone's death is a sacred transition filled with grace.



Goal of the 11th Hour Program

- ▶ The team members provide companionship by being present and provide support to family members by actively listening and educating them about death. They will sit in silent reflection, play soft music, provide gentle touch, and offer prayers and readings.
- ▶ The team creates a peaceful and sacred environment for the resident and family to share their last hours together and say goodbye.
- ▶ We get one chance to do this with each family. It is a privilege to get to serve them at this precious time.

There is no greater intimacy than sitting with someone traversing that tenuous boundary between worlds, sitting vigil with a spirit trembling on the border, reaching toward the new and releasing the old.

Shannon Hultman Polson

quakancy



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NEW RULES

for end of life care



BARBARA KARNES RM

BK
AWARD WINNING









Education



- ▶ <https://www.youtube.com/@jameslwest1>
- ▶ Hospice 101: Everything you ever wanted to know, but were afraid to ask
- ▶ Progression of Dementia

Shayla Hall



- ▶ “I realized after taking the 11th Hour training that the end-of-life stigma that death is scary is not completely correct. Dying only happens once, and everyone deserves to transition with dignity, peace, and with someone by their side.” Shayla Hall, JLW 11th Hour co-facilitator





Vigil Preparation

- ▶ Once the clinical team and hospice deem the resident is imminent, the vigil begins.
- ▶ The word vigil means “a watch or period of watchful attention.” This is essentially what the team does. We are keeping a loving and careful watch on our resident and their family. We are a compassionate presence during this sacred time.



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The Texts

- ▶ We use an app called Reach
- ▶ “Ms. KL in room 401A on Trinity has become imminent. We need volunteers throughout the day and tonight as the family will not be staying.” Please let me know your availability.”
- ▶ “Mr. AB in room 123 on Brazos has become imminent. He has 6 family members with him. If you are in the building, please go by and check on them. They are having a difficult time.”
- ▶ “Ms. KL passed early this morning. Thank you for your time.”
- ▶ “Mr. AB is passed away this afternoon. Please be in prayer for the family. They are having a very hard time. Please send me anytime you spent with them. Thanks,”

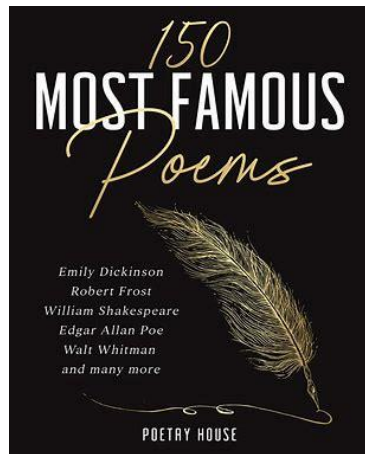


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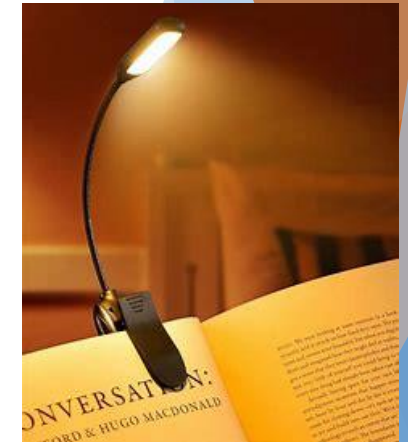
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11th Hour Kit

- ▶ CD Player
- ▶ CDs of different genres
- ▶ Flameless candles
- ▶ Aveeno Lavender scented lotion
- ▶ Note pad
- ▶ Bible
- ▶ Book light
- ▶ Birds for door



- ▶ Pen
- ▶ Kleenex Tissues
- ▶ Burt's Bees Lip Balm
- ▶ Prayer book
- ▶ Books of Readings (poetry, short stories)
- ▶ Folder of program training
- ▶ Resident's information







Call to Action

- ▶ The room is prepared as a sacred place, using the 11th hour kit.
- ▶ The resident is moved to another room if possible and if necessary and/or the roommate is moved temporarily. Call the roommate's family.
- ▶ If they cannot be moved a screen or curtain will be used to allow the family privacy.
- ▶ Remove clutter and arrange furniture to make as home like as possible.
- ▶ This is done in SILENCE.
- ▶ Televisions are off during vigils. If family members want to watch television, they are encouraged to move to a living room area.
- ▶ Notify the kitchen the resident has become imminent. They will prepare a comfort cart of snacks and drinks for the room. They will also provide meals and snacks for the continuous care nurse and nay family members who are sitting vigil with the resident.



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Talking to the Family

- ▶ Introduce yourself to the family if you do not know them.
- ▶ Explain what you are doing and ask if there are any special requests such as a particular prayer, special music, or certain snacks or drinks.
- ▶ Use “active listening.” This allows you to make yourself fully present. Do not think about what to say next, just listen and be present.
- ▶ Be aware of body language (yours and theirs). Lean in toward the person speaking. Look them in the eye and truly “hear” what they are saying.
- ▶ Encourage family members to speak to and touch their loved one. Encourage them to say what they need to say: I love you; I forgive you, please forgive me, I’ll miss you , but I’ll be okay, Thank you, etc.
- ▶ Guide the family to share memories and tell stories.
- ▶ Reassure the that their loved one can hear them.



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Talking to the Family

- ▶ Encourage the family to give their loved one permission to leave. They can tell them that it is okay and that they will be okay.
- ▶ Tears are a normal part of saying good-bye. If someone becomes overwhelmed help them into another room and tend to them. Offer cool water and tissues. Offer to walk with them until they settle down.
- ▶ Sometimes family will refuse to leave. Encourage them to take breaks and get some coffee or take a walk. Let them know that their loved one may be waiting for them to leave before they pass so they don't witness the death.
- ▶ If you ever become uncomfortable with what is happening or being said, excuse yourself, step out and call the facilitator.



Talking to the Resident

- ▶ If you are comfortable praying with the resident, lay your hands on them and pray.
- ▶ Assure them that you are present with them, and they will not be alone.
- ▶ Pay attention to their body language.
- ▶ A non-responsive person will continue to “speak” to you if you focus on what they are doing.
- ▶ Look for grimaces, fist, deep frowns, curled toes, and/or a furrowed brow. (contact the nurse)
- ▶ Speak to them in a soft voice near their ear.
- ▶ Use compassionate touch and apply lotion to the hands and feet.
- ▶ Lightly stroke their hair or forehead.
- ▶ We are there to help them shift from fighting to live to preparing to die.



Prayers/Readings/Songs/Silence

- ▶ Offer to lead prayers or readings if the family would like, or you can do this when alone with the resident. You may read scriptures, poetry, special articles, or sing hymns or other special songs.
- ▶ It is also appropriate to sit with them in silence. You should never be on your phone during your vigil time. Your total attention should be on the needs of the family and resident.
- ▶ You are there to observe, listen, and provide comfort.



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What to say to Grieving Families

- ▶ I'm so sorry.
- ▶ I'm sad for you.
- ▶ What can I do for you?
- ▶ Do you feel like talking?
- ▶ Take all the time you need.
- ▶ Tell me about _____. What was he/she like as a _____.
- ▶ What do you remember most?
- ▶ I'm here for you and here to listen.
- ▶ How long have you been together? How did you meet?
- ▶ Would you like some time alone or would you like me to stay a while longer?
- ▶ *Listen more than you talk. This is about them NOT you. Allow for silence. Let them tell their stories. Encourage them to be patient with themselves. Ask for special requests that would make them more comfortable.*



What NOT to say to Grieving Families

- ▶ I understand how you feel.
- ▶ Death was a blessing.
- ▶ It was God's will.
- ▶ It happened for the best.
- ▶ Something good will come of this.
- ▶ You must be strong, don't cry.
- ▶ Don't take it so hard.
- ▶ You will soon get over it.
- ▶ It has happened. You must accept it.
- ▶ You have the rest of your life ahead of you.
- ▶ You're lucky to have had him/her for so long.
- ▶ You must be relieved.
- ▶ At least he/she led a full life.
- ▶ I know exactly how you feel.
- ▶ God will never give you more than you can handle.
- ▶ Don't dominate the conversation. **Don't pass judgement.** Don't avoid the bereaved because of your own discomfort. Don't change the subject.
- ▶ Don't attempt to answer questions if you don't have the answers.
- ▶ Don't give any advice you aren't qualified to give.



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Understanding the Final Days

- ▶ During the final days of life, the body begins its final process of shutting down all physical systems. It is usually orderly and progressive. It is NOT a medical emergency. It is a natural way that the body prepares itself to stop.
- ▶ The spirit of the person also begins the final process before release from the body. Reconciliations and receiving permission to let go are some of the events that can happen during this time. When a person's body is ready, but they are holding on due to the need for reconciliation they may linger.
- ▶ There are physical, emotional, and spiritual signs and symptoms of death. Not every person will have all the signs and symptoms, nor do they appear in any order. **Each person is unique and the way they lived will affect the way they experience death.** This is the time to provide comfort of the resident and support the family.



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Signs and Symptoms of the Dying Process

- ▶ **Unresponsive:** The resident may be in a comatose-like state. This is an indication that they are letting go. Hearing remains intact until the end of life. As death approaches the resident must focus solely on the process of dying. Many will focus on a corner of the room or stare at a particular spot on the wall. They will become withdrawn and not respond to voices. They don't have the energy. Being present with them is the best thing loved ones can do at this time. Tell them they did a good job and that they did the best they could. Encourage them to resident but others who have passed. Tell them that their loved ones left behind will be okay and well taken care of.
- ▶ **Incontinence:** they will lose function of bowel and bladder as their muscle functions diminish. They need to be kept clean and dry. Output will decrease due to decreased intake.
- ▶ **Congestion/Loud snore like breathing:** they will likely have noisy respirations at some point.(death rattle) This is caused from secretions in the back of the throat. It is not painful for the resident but can be hard to listen to. Suctioning is uncomfortable. There are medications that will help. Elevating the head or placing the resident on his/her side often helps as well.



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Signs and Symptoms of the Dying Process

- ▶ Visions: the resident may speak to or see people who have already died. They are detaching from this life and preparing for transition. It is not usually frightening to them. Affirm what they are seeing or hearing. Do not argue or dispute anything they say.
- ▶ Life Review: days to weeks before death looking for meaning and contributions
- ▶ They are part of two worlds: the seen and the unseen. Many times, people will reach out their hands to someone they see. They may turn their head as if listening to someone or stare at a chair or corner of the room. They may smile or mumble. As long as they are not afraid there is no reason to intervene.



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Signs and Symptoms of the Dying Process

- ▶ Restlessness: residents may perform repetitive behaviors, such as picking at their blankets or cloths. They may work such as crocheting, sewing, cooking fishing, etc. If they appear to be in any pain notify the nurse at once. Talking about pleasant memories, reading aloud, or playing music often helps. If they appear anxious or worried medication can be administered to ease their discomfort.
- ▶ Cooling of the body: The body will cool and begin to mottle (purplish discoloration). It is a normal indication that the circulation is being sent to the vital organs and away for the extremities. Their overall color may become gray. They may start to turn blue or purple around the mouth. It is common for the earlobes to develop a deep crease and fold back as well. Place a blanket on the resident if they feel cool.
- ▶ Twitching or seizure like activity



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Signs and Symptoms of the Dying Process

- ▶ Cessation of food and fluid intake: The first system that shuts down completely is digestion: *Residents DO NOT die because they stop eating or drinking, they stop eating and drinking because they are dying.* This is very hard for the family to understand, and we can educate them. The body cannot handle food and water and doesn't know what to do with it anymore. DO NOT force food or water on a dying patient. If they appear to be thirsty and if they can swallow a small spoon with ice chips or a swab with water may be used.
- ▶ Hearing: if family members begin to argue or discuss unpleasant events, remind them that their loved one can hear them and escort them to another room



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Signs and Symptoms of the Dying Process

- ▶ **Breathing Changes:** Apnea is common as death approaches. The resident may go 30-60 seconds between breaths. “Fish breathing” may happen near the end of life or deep panting. Sometimes they may take deep breaths or sigh. Oxygen may be offered if the nurse feels it will help them remain comfortable. The dying person is generally not aware of their breathing, but it can be disturbing to those in the room. Remind them that their loved one is not in pain or discomfort and that this is normal. Sometimes turning the person or repositioning them will help.
- ▶ **Fever:** it is common for a fever to occur near death. Place a cool damp towel on the resident’s forehead or pull back their covers. They may appear to be flush or sweaty for a while.



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What if it doesn't go well?

- ▶ Family Fights? Ask them to take their discussion outside of the room
- ▶ Uncontrolled pain/agitation: alert the nurse on duty and let them know what you are seeing/hearing that is concerning to you
- ▶ Bad death? Not all deaths are peaceful. Do what you can to make them comfortable. They may be working through some unresolved issues.



After the Resident Passes Away: Now What?

- ▶ Allow the family as much time as they need with their loved one.
- ▶ Alert the nurse on duty and text Hollie “AB passed at 11:30”
- ▶ The family may ask you what will happen next: a nurse will pronounce them and then the funeral home will be called. They may stay or go. Some families choose to stay until the body leaves the center, but others leave immediately after the death. Stay with the family during this time or step in the hallway to provide them privacy.
- ▶ When the funeral home arrives, you may ask the family to step out to the hall with you. Seeing their loved one put on the gurney can be upsetting. Once they are positioned on the gurney and covered up, the funeral director will allow them to come back in one more time if they would like.
- ▶ You can stay to walk with the family during the **final salute/farewell** or follow behind them and assist them to their car.



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▶ Final Farewell/Final Salute



Taking Care of Yourself

- ▶ We will have quarterly in-services to refresh and discuss our experiences.
- ▶ This will give you a time to discuss any feelings that have come up while being on the team.
- ▶ Remember this isn't for everyone.
- ▶ You may need to take a break from it time to time as well. It is okay. Do what is right for you.
- ▶ You may contact me or Shayla anytime with questions or concerns.



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Taking Care of Yourself after the Resident Dies

- ▶ Think: really think about everything that you just witnessed. What was upsetting to you? What was rewarding? What will you do different? You will need some transition time for yourself after witnessing a death. Keep in mind that witnessing a death is like witnessing a birth. Be honored.
- ▶ Talk: Talk to someone you feel safe with, but don't talk about one's death as gossip. It is sacred.
- ▶ Write: Journaling after sitting with someone is therapeutic. It will help you go back and remember special moments with families. It will remind you of all the people whose lives you will make a difference in. You can write about sadness, guilt, beliefs, etc.
- ▶ Cry: crying is healing
- ▶ Exercise: take a walk, it is a great way to clear your head and prepare yourself to go on with your service
- ▶ Thankful: be thankful that you were part of something that will never happen again. Be thankful that you got to witness another person leave this world and enter into the next. Be thankful to be part of a team that makes such a difference in peoples lives.



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Mornin', Cathy –

Thank you so much for your thoughts and the time the “11th Hour” folks spent with Susan and us. I’m afraid I might have bent your ear too much, but reliving all the memories was very helpful.

Thanks again,

Jimmy
4/3/25



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Featured in:

- ▶ Leading Age Story Collector
 - ▶ Fort Worth Report
 - ▶ James L. West Website Blog
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- ▶ Resources:
 - ▶ “The Eleventh Hour: A Caring Guide for the Hours to Minutes Before Death” by Barbara Karnes
 - ▶ “Gone from my Sight: The Dying Experience” by Barbara Karnes

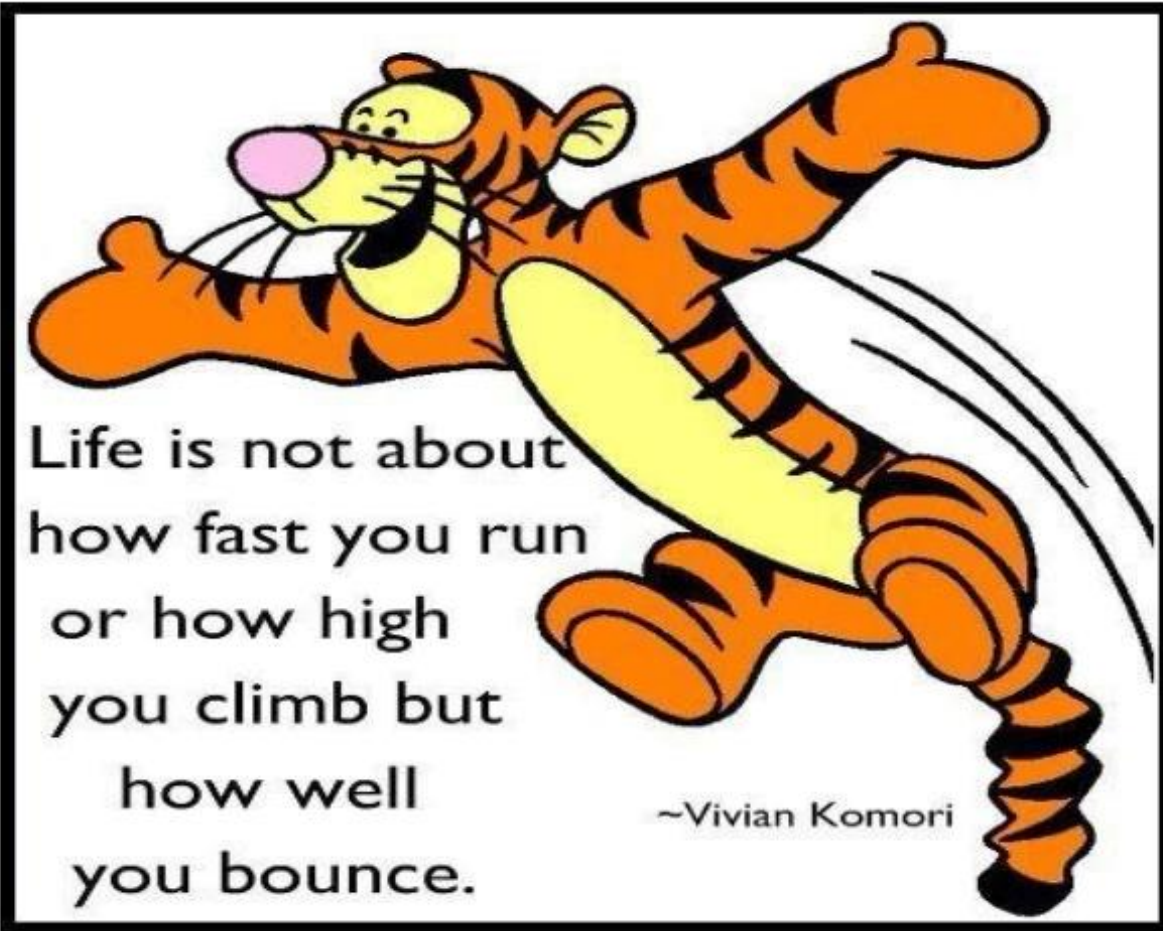


BECOME
better,
NOT BITTER

— *Ephesians 4:31-32* —



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Life is not about
how fast you run
or how high
you climb but
how well
you bounce.

~Vivian Komori

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James L. West is a faith inspired, not-for-profit organization serving persons impacted by dementia. As a trusted expert, we provide personalized, innovative care and support for families, as well as specialized education for caregivers, healthcare professionals and the community at large.

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