Area Agency on Aging
OF NORTH CENTRAL TEXAS

JAMES L. WEST
CENTER for DEMENTIA CARE

Hospice 101:
Everything You Ever Wanted to Know, But Were Afraid to Ask

Tuesday, September 12, 2023

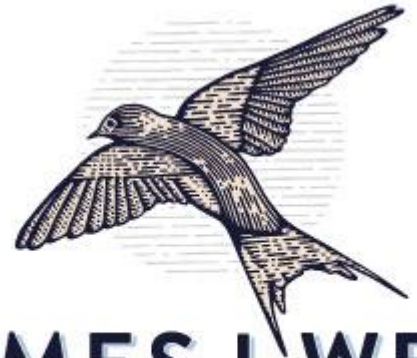
2:00 p.m. – 3:30 p.m.

**Complimentary CEUs available for licensed RNs, LVNs, social workers and LPCs in Texas **

Continuing Education Unit "CEU" Information

- CE Credits are offered for Licensed Nursing, Social Work, LPC, in Texas and Certificate of Attendance.
- You must complete the entire live webinar to receive obtain 1.5 CE Credits **and**
- You **must** complete the **Survey Monkey** evaluation form that will be sent out via follow up email after today's webinar
- Survey Monkey evaluation closes at the end of the day on 9-20-2023
- CE Certificates will be emailed to the email address provides within 3-4 weeks following the evaluation closing date
- NCT AAA will also have a **Google Survey** to complete that is part of our tracking for our funding Goals.

JAMES L. WEST
CENTER for DEMENTIA CARE



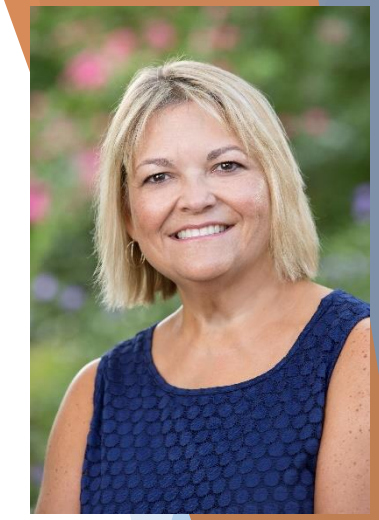
JAMES L WEST
CENTER for DEMENTIA CARE

Hospice 101: Everything You Ever Wanted to Know, but Were Afraid to Ask

Hollie Glover, MA, LPC, NCC
hglover@jameslwest.org
James L. West Center for Dementia Care

JAMES L WEST
CENTER for DEMENTIA CARE

Hollie Glover, MA, LPC, NCC



- Hollie Glover, 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 Certified Grief Counseling Specialist and Dementia Care Expert 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.
- Hollie is married and has one daughter who is following in her footsteps. Joanna graduated from the University of Texas at Arlington in August of 2020 with her Master's degree in Social Work, specializing in hospice care.

JAMES L. WEST
CENTER for DEMENTIA CARE

Course Description

- Hospice is a program designed to assist patients and families dealing with a terminal illness.
- This presentation will review the history of the hospice movement and the structure of the hospice programs.
- Myths concerning hospice and the reasons for choosing hospice will be discussed.
- Diagnoses that qualify the person for hospice care will be reviewed as well.

JAMES L. WEST
CENTER for DEMENTIA CARE

Course Outline

- Date: 9/12/23
- Time: 2:00-3:30
- Location: Zoom
- Type: Social Work, Nursing, and LPC
- CEU Presentation: 1 1/2 Hours
- Presenter: Hollie Glover, MA, LPC, NCC

JAMES L WEST
CENTER for DEMENTIA CARE

Course Objectives

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

- Describe the history of hospice
- Discuss three components of the hospice philosophy
- List four members of the hospice team
- Summarize and dispel five hospice myths
- Identify five different types of terminal illnesses that qualify for hospice care

JAMES L. WEST
CENTER for DEMENTIA CARE

Kinds of Care

- Curative Care: Focuses on quantity of life, a cure and prolonging life. It can cause more suffering when a cure is no longer possible, and treatments and procedures needlessly extend the period of suffering. This can include respirators, intravenous infusions, tube feeding, central lines, resuscitation, etc.

Kinds of Care

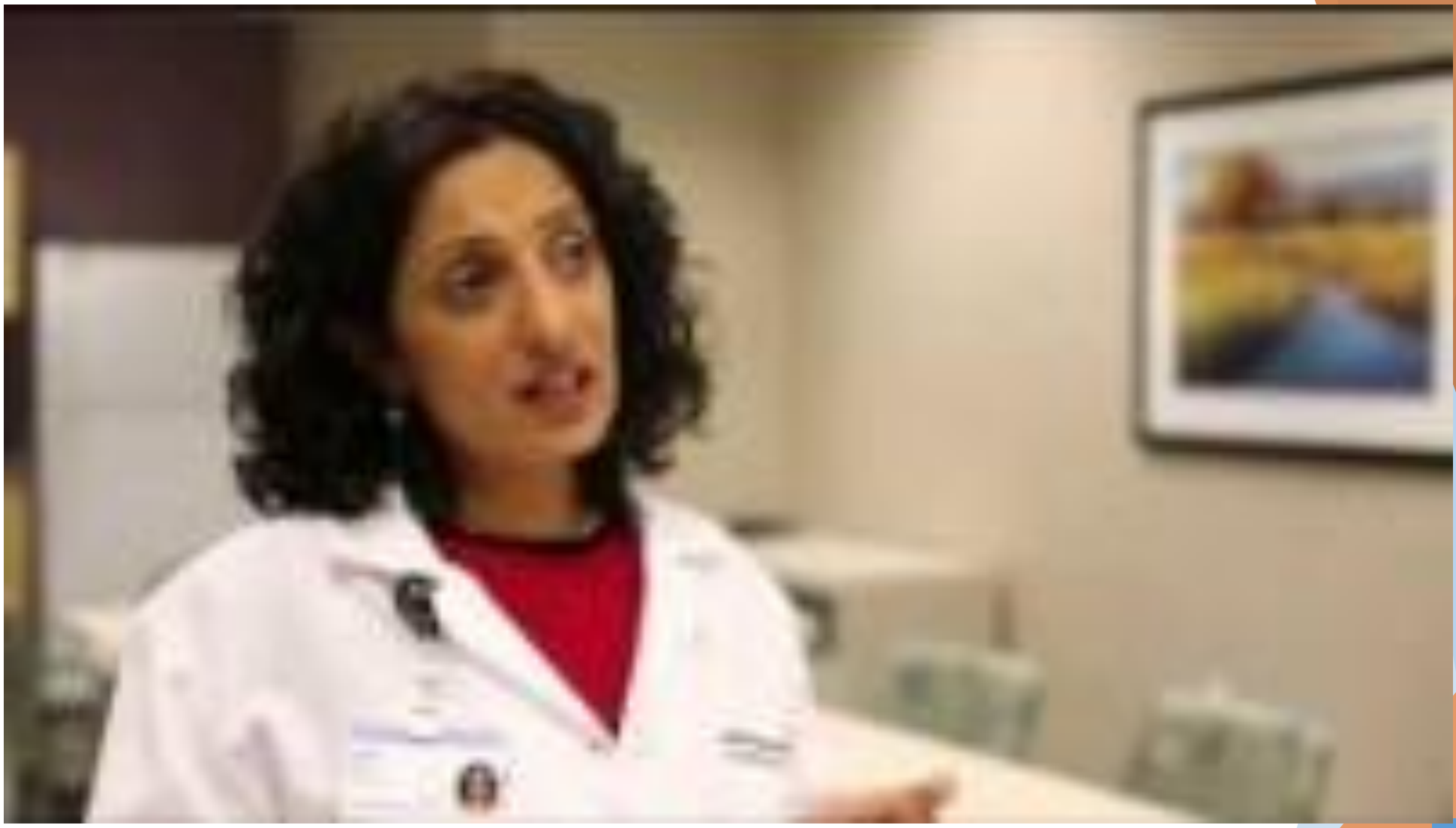
- Palliative Care: Focuses on ***<u>comfort and quality of life (and death) that may be provided with other treatments</u>***. Views death as a natural part of life. Lessens and relieves physical, psychosocial and spiritual suffering so the patient can accomplish their goals and life-closure.

JAMES L. WEST
CENTER for DEMENTIA CARE

Kinds of Care

- Hospice Care: Focuses on ***comfort and quality of life*** when a cure is not possible with specialized care and services. Most intensive comfort care available and intended for final months of life.
- Care not cure.

JAMES L. WEST
CENTER for DEMENTIA CARE



JAMES L. WEST
CENTER for DEMENTIA CARE

History of Hospice

- The word “hospice” originated in medieval times, a derivative of the Latin “hospes” meaning *guest*, *visitor, stranger,* or *host*.
- Travel-weary crusaders on their way to the Holy Land found places of refuge in monasteries.
- Eventually, these places of rest came to be called hospices. Because great numbers of the pilgrims were in ill health, many spent their last days there.

History of Hospice, Continued

- Dame Cicely Saunders, introduced hospice to the United States, while visiting Yale in 1963. She established the first purpose-built hospice in London in 1967.
- Her philosophy was that "*you matter because you are you, you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also* ***to live until you die***"
- She lectured on the concept of holistic hospice care to medical students, nurses, social workers, and chaplains. She included photos of terminally ill cancer patients and their families that dramatically showed the differences between before and after symptom control.
- This contact set off the following chain of events, which resulted in the development of hospice care as we know it today.

History of Hospice, Continued

- **1965**: Dame Cicely Saunders became a visiting faculty member of Yale School of Nursing.
- **1968**: Dean of Yale School of Nursing took a sabbatical to work at St. Christopher's and learned everything she could about hospice.
- **1969**: Dr. Elisabeth Kübler-Ross published the book "On Death and Dying," which identified the five stages through which many terminally ill patients progress. The book became an international a best seller and is still used and referred to today.

History of Hospice, Continued

- **1972**: Kübler-Ross testified at the first national hearings about ***death with dignity***, which were conducted by the US Senate Special Committee on Aging.
  - In her testimony, Kübler-Ross stated, *"We live in a very particular death-denying society. We isolate both the dying and the old, and it serves a purpose. They are reminders of our own mortality. We can give families more help with home care and visiting nurses, giving the families and the patients the spiritual, emotional, and financial help in order to facilitate the final care at home."*

History of Hospice, Continued

- **1974:** The first American hospice was opened in Branford, Connecticut. It was called Connecticut Hospice.
- **1974:** The first hospice legislation was introduced to provide federal funds to support hospice programs. The legislation was **NOT enacted**.

History of Hospice, Continued

- **1982**: Congress included a provision to create a Medicare hospice benefit in the Tax Equity and Fiscal Responsibility Act of 1982 with a 1986 sunset provision.
- **1986:** The Medicare Hospice Benefit was made permanent by Congress.
- **1991:** Hospice care was authorized in military hospitals and became part of the Veteran's benefit package.

Most Recent Hospice Data

- There are over 8,200 hospice agencies in the United States
- 2/3 are for profit
- 1.72 million patients on hospice

2022 National Hospice and Palliative Care Organization

JAMES L. WEST
CENTER for DEMENTIA CARE

Who Receives Hospice Care?

- 59% age 85 and older
- 48.3% age 75-84
- 37.2% age 65-74
- 26.5% age 65 or younger

Who Receives Hospice Care?

- 50.8% Caucasian
- 35.5% African American
- 33.3% Hispanic
- 36.1% Asian/Pacific Islander
- 33.5% Native American

Hospice Philosophy

The hospice philosophy embraces a holistic approach that encompasses physical, emotional and spiritual concerns. **The patient and family are seen as the unit of care.**

Care is individualized to meet the patient's and family's needs, as well as being responsive to differences in lifestyles.

Hospice Philosophy, Continued

The hospice philosophy:

Affirms life.

Promotes self-determination, as patients and families participate in their plan of care.

Provides education to help patients and families provide appropriate care.

Promotes understanding and accepting that the journey of life eventually leads to death and encourages people to view this experience as an opportunity for growth.

Emphasizes palliation (***to make a disease or its symptoms less severe without removing the cause),*** which includes physical, psychosocial and spiritual comfort delivered by a multidisciplinary staff.

Why Choose Hospice?

- When medical treatments have been exhausted or the burden of treatment outweighs the benefits, it may be time to consider hospice.
- Most people would like to end their lives surrounded by family and friends. By bringing services into the home, hospices help patients and families provide the necessary care.
- Patients and families can retain a greater sense of control
- Hospice will also provide services in nursing homes to ensure pain and symptom management and to provide support to families.
- The hospice experience can foster spiritual and personal growth as the hospice team empowers patients and families to manage difficult situations.

Hospice Eligibility Guidelines

- 6 months or less prognosis if the illness stays on anticipated projected course
- Patient chooses to forego life prolonging, aggressive treatments for terminal illness OR there are no treatments
- 10% loss of body weight in last 4-6 months
- Observable and documented deterioration in overall clinical (and cognitive in case of dementia) condition in the last 4-6 months

Where is Hospice Provided?

51.5% at Home

17.4% in a nursing facility/long term care

12.8% in a Freestanding hospice facility

12.3 in an Assisted Living Facility

2% in a Hospital/Shelter/Correctional Facility, etc.

Structure of Hospice

- In hospice, care of patients and families is managed by an Interdisciplinary Team (IDT) that develop a Plan of Care (POC) depending on the individual needs of the patient and family. The IDT meets and discusses every patient at least every 14 days and more often if needed.
- The members of this team include:
  - Medical Director - certifies patients as eligible, gives direction and support, writes orders, and visits patients as needed.

Structure of Hospice, Continued

- Director of Patient Care Services - manages team of providers, supervises patient care staff, and makes sure care is delivered according to Plan Of Care across continuum (right level of care, right time, right place).
- Nurse Case Manager - manages all care, provides skilled services, supervises LVNs and CNAs, and coordinates with SW.
- HHAs – (home health hospice aides)- help with ADLs, companionship, light housekeeping and assist at mealtime.
- Social Worker/Counselors - emotional/mental support and counseling, financial evaluation, assists to find resources, organizes transfers, admission to facilities, transportation, etc.

JAMES L. WEST
CENTER for DEMENTIA CARE

Structure of Hospice, Continued

- Spiritual Care Coordinator - emotional and spiritual support, coordination with religious affiliation, non-denominational, prayer support, and assists with funeral planning/memorials.
- Bereavement Coordinator - follows families after patient's death, provides support for up to 13 months after death (emotional support, dealing with grief).
- Therapists-Music, Speech, Physical, Occupational, Massage
- Volunteers - non-patient care, they provide companionship, and assist with administrative support/special projects.

JAMES B. WEST
CENTER for DEMENTIA CARE

Things Hospice Helps With

- Expert Symptom Control/Pain Management/Medication/Medical Equipment
- Skin Breakdown
- Nutritional Counseling
- ADLs (Activities of Daily Living)
- Social and Family Problems/Stress Management
- Need for Companionship/ Volunteers/Respite Care
- Current and Anticipated Spiritual/Emotional /Psychosocial Needs
- Advanced Directives/DNR/POA

More Things Hospice Helps With

- Safety Issues/Instruct families how to provide care
- Community Resources
- Quality of Life/PT, OT, ST, Music, Massage
- 24-hour Professional Support
- Short Term inpatient care for respite or symptom management
- Funeral Planning
- Grief and Bereavement Counseling

Levels of Care

- Routine Hospice Home Care: the most common level of care. This is hospice care in the home.
- Continuous Home Care: care is provided between 8-24 hours a day to manage pain and other acute medical symptoms. Predominantly nursing care with assistance from caregivers and aides. Used during a time of crisis in the home.
- Inpatient Respite Care: provides temporary relief to the patient's primary caregiver. Can be provided in a hospital, hospice facility, or long-term care facility with 24-hour nursing.
- General Inpatient Care: provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. Only used when other methods are not sufficient. Can be provided in a hospital, hospice facility, or long-term care facility with 24-hour nursing.

Who Pays for Hospice?

- Medicare
- Medicaid
- Private Insurance
- Self pay/reduced or free care
- Medicare covers 100% of hospice services with no copay

What is NOT Covered?

- Nursing facility room and board
- Care unrelated to terminal or related diagnoses
- Care sought without consulting and approval from the hospice team
- Non-formulary medications and supplies
- Curative or aggressive treatment

Common Barriers To Hospice Care

Fear of taking away hope

Death VS. Failure

I don't want to disappoint or let down my _____

Misconceptions about hospice

Lack of consistency between physicians

How Much Care is Received?

- 10% on service 1-2 DAYS
- 25% on service 3-5 DAYS
- 50% on service 6-18 DAYS
- 75% on service 19-87 DAYS
- 10% on service more than 88 DAYS

**Patients with a principal diagnosis of dementia had the largest number of days of care on average.*

JAMES L. WEST
CENTER for DEMENTIA CARE

Hospice Myths

- If a patient lives longer than six months, he or she will be automatically discharged from Hospice.
  - Many hospice patients live longer than six months and remain on hospice. Medicare regulations give unlimited 60-day recertification periods.
- Hospice is *only* for dying people.
  - As a family-centered concept of care, hospice focuses as much on the grieving family as on the dying patient.

Hospice Myths, Continued

If a physician orders hospice for a patient who lives longer than six months, the physician will be in trouble for fraud.

- All that a physician is stating when they give a patient a prognosis of six months or less is that if the patient's disease progresses as expected then the patient will live six months or less.

Patients on hospice can no longer go to see their doctor.

- Hospice encourages patients to continue to see their physicians. If it comes to a point where the patient can no longer get to the physician's office, the hospice nurse keeps the physician updated.

Hospice Myths, Continued

- If patients go on hospice, they can no longer seek any treatments.
  - Symptom management and pain control are the main goals of hospice treatment. There are many treatments that are for palliation. Only “curative” treatments cannot be sought.

JAMES LEE WEST
CENTER for DEMENTIA CARE

Hospice Myths, Continued

Hospice is only for people who can accept death.

- Hospice is for the living and many patients and families have not made the decision to accept death.
- Hospice offers no magic formula, but hospice professionals are trained to help people move at their own speed toward these decisions.

Hospice is for people who don't need a high level of medical care.

- Hospice is serious medicine. Most hospices are Medicare certified, requiring that they employ experienced medical and nursing personnel with skills in symptom control.
- Hospices offer state of the art palliative care, using advanced technologies to prevent or alleviate distressing symptoms.

Hospice Myths, Continued

- Hospice is for when there is no hope in sight.
  - When death is in sight, there are two options:
    1. Yield to hopelessness, or
    2. Live life as fully as possible until the end
  - The gift of hospice is its capacity to help families see how much can be shared at the end of life through personal and spiritual connection and sharing.

Hospice Myths, Continued

- Hospice care is expensive.
  - Most people who use hospice are over 65 and are entitled to the Medicare Hospice Benefit.
  - This benefit covers virtually all hospice services and requires few, if any, out-of-pocket expenditures by families.
  - Even younger patients may have private insurance which covers hospice care and is far less expensive than the alternative hospital or nursing home care.

Hospice FAQ's

What does hospice really do? Hospice provides specialized care services including symptom management, emotional support, spiritual support, and psychosocial intervention, addressing issues most important to the patient's needs and wants at the end of their life focusing on improving the individuals' quality of life.

How do I know when it is time for end-of-life care? Patients are eligible for hospice care when they have been diagnosed with a terminal illness with a prognosis of 6 months or less. At that time, comfort, care, and symptom management become the primary focus, and curative treatment is no longer the patient's choice or option.

When should hospice be called? Hospice should be called at any time the patient has been diagnosed with a life-limiting illness. It is appropriate to discuss all of the patient's care options, including hospice.

Hospice FAQ's continued

- Where is hospice care provided? Hospice care is provided in a setting that best meets the needs of each patient and family. The most common setting is the patient's home. Hospice care is also provided in nursing homes, assisted living facilities, and hospitals according to patent care needs.
- Are all hospices the same? No. Some are for profit, and some are not for profit. They all have the same general philosophy, but their services may differ.
- Can my pain and symptoms be controlled at home? Yes. Pain and other symptoms can be controlled in the patient's home. If a symptom (pain, nausea, vomiting, difficulty breathing) becomes a problem the hospice nurse can be reached 24 hours a day 7 days a week. Most symptoms can be controlled without the use of injections or IV medication. Hospice medical directors are always available to adjust medications.

Hospice FAQs continued

- Does hospice provide 24-hour in-home care? No. Hospice provides intermittent nursing visits to assess, monitor and treat symptoms as well as teach family and caregivers the skills they need to care for the patient. Team members are available 24 hours a day, 7 days a week to answer questions or visit anytime the need for support arises.
- Can I live alone and still receive hospice services? Yes. However, part of the admission and ongoing care process is to plan and prepare for the time in a patient's illness when 24 hour a day care will be necessary.
- Can a hospice patient choose to return to curative treatment? Yes. Receiving hospice care is always a choice. A patent may leave hospice and return to curative treatment if that is their choice. If the patient later chooses to return to hospice care they may.

Hospice FAQs continued

Can I go to the hospital and still receive hospice care? Yes. However, many symptoms that would normally require hospitalization or an emergency room visit can be successfully managed at home by the hospice team, thus preventing the stress of hospitalization. Hospice patients generally only have the need for short hospital stays to stabilize a symptoms and then are able to return home.

Is the decision for hospice care giving up hope or wanting to die? No. Hospice is about living. Hospice strives to bring quality of life and comfort to each patient and their family, helping a patient and family live fully until the end. Often patients will feel better with good pain and symptom management. Hospice is an experience of care and support, different from any other type of care.

Hospice FAQs continued

Does hospice do anything to bring death sooner? No. The goal is to alleviate suffering and manage symptoms. Hospice does nothing to speed up or slow down the dying process. The role of hospice is to lend support and allow the disease process to unfold as comfortably as possible.

Do I have to be homebound to receive hospice services? No. Hospice is about living fully. Patients are encouraged to do what they enjoy as they are able. The hospice team assists patients and families in achieving their goals and dreams as much as possible.

Does hospice provide support to the family after the patient dies? Yes. Bereavement Services follow family and caregivers for 13 months following the patient's death These services may include personal visits, providing information concerning the grief process and offering periodic opportunities for group support. Bereavement Services provides information and referral to other resources when needed.

What is the Difference in Hospice and Palliative Care?

- Palliative Care isn't defined by the 6-month hospice benefit.
- It is treatment that enhances comfort and improves the quality of life of an individual who is facing a serious illness, but many not qualify for hospice or may be continuing treatment
- Palliative Care doesn't have to provide the same services as hospice such as the interdisciplinary team, spiritual services, social workers, etc.
- All hospice is palliative, but all palliative isn't hospice.

Terminal Illnesses

1. Cancer 7.5%
2. Heart Disease 9.3%
3. Dementia 18.5%
4. Pulmonary/Respiratory Disease (COPD, etc.) 6%
5. Stroke/Coma 5%
6. Chronic Kidney Disease/Kidney Failure/Renal Failure 1.5%

Terminal Illnesses, Continued

- Multiple Sclerosis
- Muscular Dystrophy
- Non-Specific Terminal Illness
- Parkinson's Disease
- Amyotrophic Lateral Sclerosis (ALS)
- Adult Failure to Thrive is now Protein Calorie Malnutrition Mild/Moderate/Severe 1.3%
- Huntington's Chorea
- Liver Disease
- Advanced End Stage Senescence or Debility
- COVID-19 .9%

2022 National Hospice and Care Organization

JAMES L. WEST
CENTER for DEMENTIA CARE

Resources

- NHPCO Facts and Figures 2022 Edition
- Johns Hopkins Medicine: Study Documents Racial Difference in U.S. Hospice Use and End-of-Life Preferences
- Vitas Hospice: Is Your Patient Eligible for Hospice Checklist
- National Hospice Foundation
- www.caringinfo.org tools to help with advance care planning, caregiving and grief

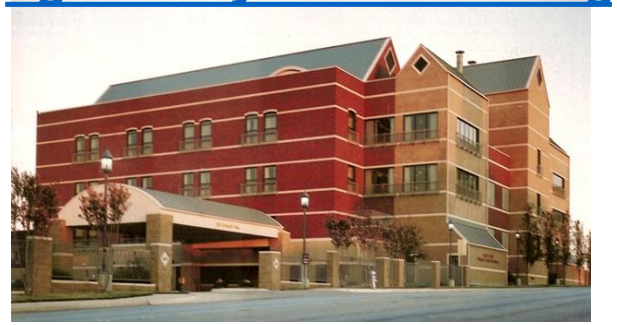
James L. West Center for Dementia Care

Jaime Cobb, V.P. of Community Education

jcobb@jameslwest.org

Hollie Glover, MA, LPC, NCC
Director of Education and Family Support Services

hglover@jameslwest.org



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.

Residential & Respite Care

West Center Day Program

Dementia & Caregiver Education

www.jameslwest.org
www.jameslwestLEARN.org

817-877-1199

JAMES L. WEST
CENTER for DEMENTIA CARE

Continuing Education Unit "CEU" Information

- CE Credits are offered for Licensed Nursing, Social Work, LPC, in Texas and Certificate of Attendance.
- You must complete the entire live webinar to receive obtain 1.5 CE Credits **and**
- You **must** complete the **Survey Monkey** evaluation form that will be sent out via follow up email after today's webinar
- Survey Monkey evaluation closes at the end of the day on 9-20-2023
- CE Certificates will be emailed to the email address provides within 3-4 weeks following the evaluation closing date
- NCT AAA will also have a **Google Survey** to complete that is part of our tracking for our funding Goals.

JAMES L. WEST
CENTER for DEMENTIA CARE

Area Agency on Aging
OF NORTH CENTRAL TEXAS

JAMES L WEST
CENTER for DEMENTIA CARE

Te invitan a un SEMINARIO EN LINEA GRATUITO para familiares y profesionales

Demencia virtual en vivo:

Experimente cómo es funcionar con demencia

(Virtual Dementia Live: Experience What It's Like to Function with Dementia)

CEU complementarios para trabajadores sociales con licencia y consejeros profesionales con licencia en Texas

martes, 24 de octubre de 2023
2:00 pm. - 3:00 pm. hora central

Information Contact:

Marty Mascari (940) 202-4500 ext 101 Marty@NTADS.net

Area Agency on Aging
OF NORTH CENTRAL TEXAS

JAMES L WEST
CENTER for DEMENTIA CARE

Sexuality and Dementia

Tuesday, October 10, 2023

2:00 p.m. — 3:30 p.m.

**Complimentary CEUs available for licensed RNs, LVNs, social workers and LPCs in Texas **

Information Contact:

Marty Mascari (940) 202-4500 ext 101 Marty@NTADS.net