“You matter because you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to live until you die.”

Dame Cicely Saunders
Hospice Orientation Topics

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Helping People **Live Every Moment**
The WesleyLife Hospice team knows that hospice is about living. Living every moment of life with dignity and comfort. Living even the final moments of life on your own terms. Celebrating a spirit for living.

**Why WesleyLife Hospice?**
WesleyLife Hospice was created to provide our community members with the hope, care and comfort they deserve as they face serious, life-limiting illnesses. It is their right and a benefit as a WesleyLife community member to have access to the hospice created especially for them. WesleyLife Hospice is the only hospice contracted in our WesleyLife community facilities to provide hospice services.

WesleyLife Hospice has now expanded its mission to serve patients “wherever they call home.” This might be in a private home in the community, assisted living facility or nursing facility. The program serves eight counties, including Polk, Dallas, Warren, Boone, Story, Hamilton, Jasper and Marion.

**Who May Qualify for WesleyLife Hospice Care?**
- Patients must have two physicians agree that the patient has six months or less to live if the disease runs its normal course:
  - Any resident who has been diagnosed with a terminal illness and is not seeking aggressive treatment.
  - Any resident who is experiencing a decline in their overall health, their level of comfort, and their ability to function.
- Examples of decline:
  - Frequent hospitalizations in the last six months
  - Poor performance and lack of improvement during a skilled stay
  - Spending most of the day in the bed or chair
  - Frequent falls
Needing assistance for most activities of daily living
Noticeable weight loss
Increasing shortness of breath, especially if at rest
Difficulty swallowing
Desires to die

How Do I Make a Referral for Hospice Care?

Anyone may make a referral to hospice care. Contact your supervisor if you believe that a resident might qualify for hospice services. WesleyLife Hospice will evaluate the patient and get approval for admission from both the facility’s medical director and our hospice medical director.

Remember, it is never too soon to begin to discuss care options with a patient, even if the patient or family does not need hospice services right now. One of the most common things we hear from families who have been helped by hospice is, “We wish we had known about hospice sooner.”

To make referral, call 515.271.6777
The phone is answered 24/7, including evenings, weekends, and holidays.

What Your Residents and You Can Expect from WesleyLife Hospice

- Your resident’s comfort is of utmost importance. Hospice will focus on pain and symptom management to maintain comfort.
- Hospice will provide support and care for your resident’s emotional and spiritual needs.
- Hospice is responsible for managing your resident’s hospice services and any care related to the terminal diagnosis.
- Hospice will provide hospice aide services if these services are determined necessary to supplement the aide services provided by your facility.
- Hospice will provide supplies, medications and DME needed for the management of the terminal illness and related conditions.
- Hospice will take financial responsibility for all medical supplies, appliances, medications and biologicals related to the terminal illness and related conditions with prior approval from the hospice team.
- The hospice team will determine the appropriate level of care to be given and obtain an order from the physician for the level of care. The hospice team member will inform the facility staff and business office of the level of care and any changes in the level of care.
Hospice will work as a team to provide the needed care and services to your resident, including:

- Coordinating hospice care with the facility staff.
- Informing facility staff of hospice team member visit times.
- Communicating with your facility’s medical director, your resident’s attending physician and any other physician involved in the care of the resident.
- Maintaining the required documentation, including the most recent plan of care for the patient, the hospice election form and any advance directives, the physician certification and recertification of terminal illness, names and contact information for hospice personnel, instructions on how to access the hospice’s 24-hour on-call system, medication information specific to each resident and orders from the hospice physician and attending physician.
- Ongoing documentation of all hospice services.

**WesleyLife Hospice patients can be identified by a bright neon sticker placed on the spine of the chart and a green page inside the chart that stays “STOP” and indicates that this is a hospice patient.**

**Volunteer Services**

Another integral part of the hospice program is our volunteers. Hospice volunteers receive special training in the care and needs of hospice patients. Volunteers can be assigned to any resident based on the resident’s needs. They are able to assist the resident and family in numerous ways, such as running errands, helping with light housekeeping, scrapbooking or letter-writing and providing companionship. Hospice volunteers cannot provide direct patient care such as toileting or bathing.

To request a volunteer for a resident, notify any of the resident’s hospice team members, or call 271-6777 and ask for the volunteer coordinator.

**What WesleyLife Hospice Expects from the Facility Staff**

- Continue to furnish 24 hour room and board care, meeting the personal care needs of the resident/hospice patient. Hospice RNs provide the skilled nursing care with facility staff assisting in the administration of prescribed therapies only to the extent hospice would use a patient’s family to provide care.
- Promptly notify hospice of a change in the hospice resident’s condition, including falls, skin breakdown and change in level of consciousness.
- Call to request a visit from the nurse, social worker or chaplain.
• Call to request a change in the plan of care.
• Notify hospice **prior** to any hospitalization.
• Include hospice in resident care conferences.
• Immediately notify hospice of the death of a hospice resident.
• Coordinate with hospice to provide hospice orientation to new facility staff.

**What Can the Facility Expect from Hospice When a Resident is Actively Dying or Dies?**

• The hospice team will increase visit frequency.
• At the time of death, someone from the hospice team will make a visit and assist the facility staff as requested at the time of death.

Facility staff are responsible for disposal of medications, according to facility policy.

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**Desire**

*When my life is finally measured in months, weeks, days, hours,*  
*I want to live free of pain,*  
*Free of indignity, free of loneliness.*  
*Give me your hand,*  
*Give me your understanding,*  
*Give me your love.*  
*Then let me go peacefully*  
*And help my family to understand.*

This poem was written by a fourteen-year old girl, a victim of the terrible nuclear accident at Chernobyl in 1986, while she was being cared for by the hospice in Minsk, Belarus. It very eloquently describes what hospice care is all about.
Introduction to Hospice Care

What is Hospice?

Hospice is a philosophy of care for terminally ill patients and for their families during the last months of life. The term “hospice” (from the same root word as “hospitality”) can be traced back to medieval times when it referred to a place of shelter and rest for weary or ill travelers on a long journey. The name was first given to specialized care for dying patients in 1967 by physician Dame Cicely Saunders, who founded the first modern hospice, St. Christopher’s Hospice, in London, England.

Saunders holistic philosophy of care for the dying included emphasis on:

- Quality of life for patients and for their families. Hospice neither hastens nor postpones death. It celebrates life and regards dying as a normal process.
- Care that provides comfort, not cure of the disease. The goal is to help the patient be as comfortable as possible so that the patient and family can make the most of the time that remains.
- Treating the whole person using a team of professionals and trained volunteers who support the physical, emotional, social and spiritual needs of the patient and family. The patient and family are involved in making decisions about the care that they receive.
- Recognizing the family as the unit of care. Hospice staff support families as they care for the patient. Bereavement support is offered to the family for at least a year after the death of the patient.

Hospice care is provided to people of all ages who are in the last six months of life. The patient must choose to receive care to promote comfort, not curative treatment for their illness.

The Hospice Interdisciplinary Team

Hospice uses an interdisciplinary team to provide care to the patient. The team consists of physicians, nurses, hospice aides, social workers, counselors—including spiritual care counselors, dieticians, pharmacists, and bereavement counselors, therapists—including physical, occupational, speech, massage and music therapy as well as trained volunteers.

The patient and family are key members of the interdisciplinary team. They guide the care by making decisions about the care they need, want and will or will not accept.
The interdisciplinary team is responsible for determining the plan of care for each patient. The plan of care identifies which services and the frequency of each service are needed to meet the goals and needs of the patient. Any change in the plan of care must be approved by the interdisciplinary team and discussed with the patient before the change is made.

The interdisciplinary team meets at least every 15 days to review the plan of care for each patient, and to revise the plan if necessary in order to meet the patient’s needs and goals.

Services Provided by the Team

The hospice interdisciplinary team focuses on these major responsibilities:
- Managing the patient’s pain and other symptoms;
- Assisting the patient and family with emotional, psychosocial and spiritual needs;
- Providing the needed medications, medical supplies and equipment;
- Coaching the family on how to care for the patient;
- Delivering special services like speech and physical therapy when needed;
- Making short-term inpatient care available when pain or symptoms become too difficult to manage or when the caregiver needs a break;
- Providing bereavement care and counseling to surviving family and friends.

The Management of Pain

Pain control is one of the central goals of hospice care. The right to receive effective pain management is included in the federal Hospice Conditions of Participation.

Pain is considered to be whatever the patient says it is and it occurs whenever the patient says it does. It is normal for people who have experienced chronic pain to show no outward signs of pain. Even their vital signs may be unchanged.

Constant pain needs around-the-clock regularly scheduled pain medication and is best treated by using a long-acting oral pain medication along with a short-acting pain medication for breakthrough pain. Breakthrough pain is an increase in pain between doses of long-acting pain medication.

Morphine is commonly used in hospice patients, and sometimes concern is expressed that morphine may cause patients to die sooner because it causes them to stop
breathing. This is not true. Patients quickly adjust to any effect that the morphine may have on their breathing. In fact, morphine is sometimes used to help patients with heart or lung disease breathe more comfortably.

Some patients worry about becoming addicted to pain medication. Terminally ill patients do not become addicted to their pain medications. They don’t have drug-seeking behavior. When their pain is in good control, hospice patients don’t have the desire more drugs. However, if patients take pain medications for a while, their body does become used to it and it should not be stopped suddenly.

Food and Fluids
“Beyond Chicken Soup”

Poor appetite is very common during the last months of life. This can be distressing to many families who blame the patient’s decline on not eating enough. It can also be very difficult for families and caregivers since for most of our life food has been not just a bodily necessity but also a universal symbol of love.

However, as we begin to die, it is natural that eating and drinking should slow and then gradually stop. The body is not dying because of not eating...the body is not eating because it is dying. The body is telling us that it needs a different kind of energy...not the energy from food or fluids, but the spiritual energy that continues to provide for us.

Research has found that artificial fluids become more of a burden than a blessing to the dying patient. The absence of artificial fluids can cause beneficial physical changes to occur in the body. As the body goes through natural dehydration at the end of life, the cells can no longer tolerate fluids. Literature supports the following advantages of natural dehydration at the end of life:

- Pain awareness and restlessness decrease
- Fluid in the body tissues and urine output decrease
- Nausea and vomiting decrease
- Secretions and difficulty swallowing decrease
- Difficulty breathing, cough and congestion decrease

The decision to not give artificial fluids does not mean nourishment or liquids would be withheld should the patient desire them. Comfort measures, such as ice chips or popsicles to suck on, chapstick to moisten the lips, and artificial saliva may also be offered.
Dehydration does not cause death, but reduces pain and allows the dying process to take its natural course. The cause of death is the underlying illness, not the absence of artificial fluids.

When Death is Near

Each person’s death is as unique as the individual who is experiencing it. However, there are some signs and symptoms that are common to those getting close to death:

- Increased pulse
- Increased body temperature
- Mottling of extremities
- Decreased blood pressure
- Cold extremities
- Respiratory changes
- Diminished consciousness
- Cyanosis
- Near death awareness
- Near death awareness

Near death awareness is a special communication of the dying. People who are experiencing signs of near death awareness may appear confused and disoriented or may state they have spoken to those who have already died. Speaking to people and seeing places not visible to you. They may talk to people who have died before them. They may make “out of character” statements, gestures or requests or describe another world of peace and beauty. They often make hand gestures—reaching for or holding unseen objects, or waving to unseen beings.

These behaviors do not mean they are confused, hallucinating or having a reaction to their medications. It is believed the person is beginning to transition from this life. The person may be trying to describe the dying experience or something they need to do before they die. These messages of the dying may be symbolic communication, often having meaning to them and are linked between this life and death.

Patients may also need “permission to die.” A dying person will normally try to hold on, even though it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be all right. It is important that loved ones are able to let go without making the dying person feel guilty for leaving or trying to keep him or her here in order to meet their own needs.
May I Go?

May I go now?
Do you think the time is right?
May I say good-bye to pain-filled days
and endless lonely nights?
I’ve lived my life and done my best,
an example tried to be.
So can I take that step beyond
and set my spirit free?
I didn’t want to go at first,
I fought with all my might.
But something seems to draw me now
to a warm and loving light.
I want to go.
I really do.
It’s difficult to stay.
But I will try as best I can
to live just one more day
to give you time to care for me
and share your love and fears.
I know you’re sad and afraid
because I see your tears.
I’ll not be far,
I promise that, and hope you’ll always know
that my spirit will be close to you
wherever you may go.
Thank you so for loving me.
You know I love you, too.
That’s why it’s hard to say good-bye
and end this life with you.
So hold me now, just one more time
and let me hear you say,
because you care so much for me,
you’ll let me go today.

Susan A. Jackson, R.N.
Quality Care Nursing Service
Dayton, Ohio
Payment for Care

WesleyLife Hospice receives reimbursement from Medicare, Medicaid and private health insurance. Third party payors are billed for hospice services as appropriate. However, all patients who meet the requirements for admission are accepted, regardless of ability to pay.
Hospice Patient Rights

The hospice patient has the right to the following:

- **Receive effective pain management and symptom control;**
  Pain management and symptom control must be provided by hospice for conditions related to the terminal illness.

- **Be involved in developing his/her hospice plan of care;**
  Involvement of the patient and/or representative in the plan of care must be documented.

- **Refuse care or treatment;**
  Every individual has the right to refuse care or treatment. Hospice emphasizes the right to self-determination.

- **Choose his/her own attending physician;**
  The hospice team physician is used as a consulting physician. The patient’s attending physician continues to manage the patient’s care.

- **Have a confidential clinical record;**
  Hospice organizations are bound by the same HIPAA regulations as other healthcare providers.

- **Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property;**
  All team members are mandatory reporters of any suspected abuse or neglect of the hospice patient.

- **Receive information about the services covered under the hospice benefit;**
  WesleyLife Hospice provides a Patient Information and Admission Booklet to the patient and family at the time of admission, which outlines covered hospice services.

- **Receive information about the scope of services the hospice will provide and specific limitations on those services.**
  Hospice services and any limitations on services are discussed initially with the patient and family prior to admission to hospice and reviewed with them as needed.
Myths of Hospice Care

Myth: **Patients receiving care from hospice die sooner.**
Hospice does not hasten the process of dying, but simply allows the death to occur naturally. Research shows that when a person receives hospice care they actually live longer and with a better quality of life.

Myth: **Hospice is for patients who are “giving up” when there is “nothing else to be done.”**
Hospice is the “something more” that can be done for the patient and family when the illness cannot be cured. The focus is on quality of life, comfort and support. And if the patient’s health improves, hospice discharges the patient. The service will still be available later when it is needed.

Myth: **Patients must be ready to die to receive hospice services.**
Each patient and caregiver is unique and may resist the thoughts and discussions related to death. The hospice team meets the patient and caregiver where they are emotionally with their disease process. The hospice team walks the journey with each patient to help them with a dignified and peaceful death.

Myth: **Hospice is for the last days or weeks of life.**
Hospice provides care during the last months of life. When patients and families have more time with hospice than just a few days, they benefit more from the support and additional services provided. Families often say they wished they would have had services sooner.

Myth: **Hospice is a place you go.**
While some hospices have an inpatient unit or hospice house, hospice is a type of care that can be provided anywhere. Most hospice patients stay in their own home and hospice comes to them. Patients residing in assisted living and nursing facilities may also receive hospice care.

Myth: **Patients must be homebound to receive hospice care.**
Hospice patients are encouraged to participate in any activity that they desire and are able to do. There are no restrictions. Hospice care focuses on living and completing all that you can.
Myth: **Hospice can only help if family members are available to provide care.**
Hospice recognizes that terminally ill patients may live alone or with family members unable to provide care. In these circumstances hospice coordinates community resources to make home care possible, or finds an alternative location where the patient can safely receive care.

Myth: **Hospice care is only for patients with terminal cancer.**
Hospice care is for patients in the last months of life with any health condition. This includes heart disease, lung disease, liver disease, Alzheimer’s disease, and more.

Myth: **Hospice patients must sign a DNR.**
Having a Do Not Resuscitate Order (DNR) is not a requirement to receive hospice care. While many patients on hospice elect to have a DNR in place, it is not the right choice for everyone. The goal of hospice is patient comfort with the patient directing the care, including the choice of signing a DNR.

Myth: **Patients must give up their own physician to be enrolled in hospice.**
Hospice has a medical director available to the hospice team and for your physician to consult. Each patient continues care with their own primary physician. The hospice team will work directly with the primary physician to provide care to each patient.

Myth: **Patients will have to stop taking all medications and treatments if they choose hospice care.**
Hospice patients do not stop taking all medications and treatments. They continue to take medications and treatments that provide comfort and quality of life.

Myth: **Hospice withholds nutrition.**
Each patient’s intake and nutrition is unique to their needs and symptoms. An individual under the care of hospice is able to eat and drink as they desire. The hospice team provides education and support to each patient to assist quality of life and patient choice.
Myth: **Patients who don’t have pain, don’t need hospice.**
Hospice care is much more than pain control. Hospice focuses on the whole person and the social, emotional and spiritual needs that arise during the last months of life. Support is given to patients, caregivers and family. Grief support is available to the family during caregiving, as well as the year following a loss.

Myth: **Once patients choose hospice, they can’t change their mind.**
If patients choose hospice now, they are free to change their mind. Most people are relieved to know that they can receive the support of hospice, but can stop it at any time.

Myth: **All hospice programs are the same.**
Like other health care providers, each hospice program is unique. And while all hospice programs must provide certain services, the range of services and the amount of services provided may differ.

Serving the counties of Polk, Dallas, Warren, Boone, Story, Hamilton, Jasper, and Marion

Phone: 515.271.6777      www.wesleylife.org
Congratulations!

You have finished our online course: WesleyLife Hospice Care.

Now click on the EXIT key in the upper right of your screen. You can then take the exam to complete this course.