

# **Palliative Care and Hospice: The Who, What, Where, When, Why, & How**

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# Objectives

- Palliative Care
  - Understand the goals and services
  - Discuss how it supports patients and families with serious illness
- Hospice
  - Understand the goals and services
  - Discuss how it supports patients and families at end of life
- Review the benefits and options of advance care planning

# Let's take a poll

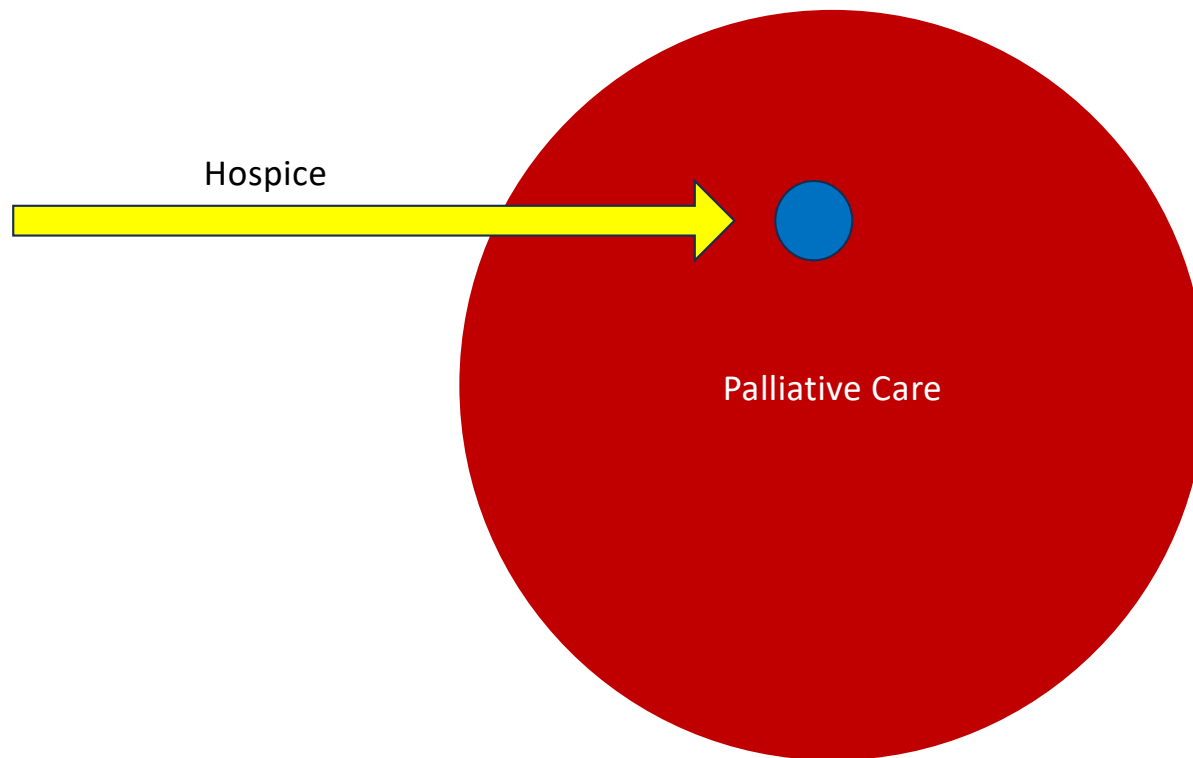
- Who has heard of palliative care?
- Who knows what palliative care is?
- Has anyone had experience with palliative care?
- Who thinks palliative care seems bad or scary?
- Who would be open to seeing a palliative care physician for themselves or with family?

# Palliative Care Myths

- It's the same as hospice
- It's only for people who are at end of life or dying
- You can no longer see your other physicians if seeing palliative care
- It means stopping other treatments
- It is just for people with cancer
- It makes people die sooner
- It means your doctor has given up on you



# All Hospice Is Palliative Care But Not All Palliative Care is Hospice



# What is Palliative Care?

- Specialized care for people living with any serious illness
- Extra layer of **support** for patients and families
- From new diagnoses to late-stage disease
- Care provided along with your other physician

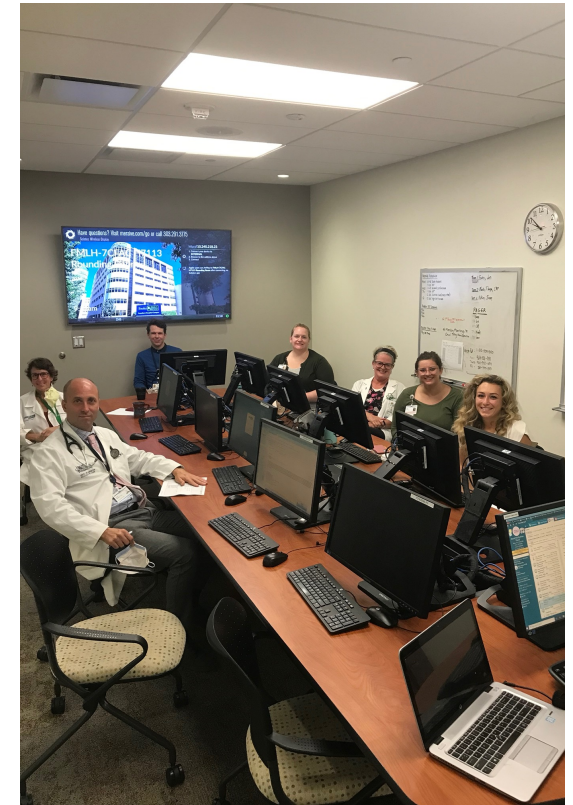


# What is Palliative Care?

- Goal is to improve quality of life for both patients and families
  - Care focused on providing relief from symptoms and stress of illness
  - Provide physical, emotional, spiritual, and social support
  - Ensure patients and families understand their illness and options
  - Ensure patients goals, values, and wishes for their health care are heard and supported

# How Does Palliative Care Work?

- Multidisciplinary team
- Symptom management
- Psychological support
- Social support
- Spiritual and religious aspects of care
- Cultural aspects of care
- Ethical and legal aspects of care
- End of life care



# Where is Palliative Care?

- Hospital
- Clinic
- Home based



# Palliative Care Case

- 57-year-old female with pancreatic cancer
- She has significant pain and nausea
- She has little appetite and has lost a lot of weight
- She has been receiving chemotherapy however testing shows that her tumor continues to grow



# Palliative Care Case

- In addition to discussing her pain and nausea she is asked how she and her husband are coping with her illness
  - She reports often feeling sad and hopeless
  - She wonders why she has been given this illness and questions her faith in God
  - Her husband shares the difficulty of taking care of her
  - He discusses financial concerns due to missing work

# The Role of Palliative Care in this Case

- Manage pain and nausea
- Assess emotional health
- Identify spiritual and religious concerns
- Recognize social stresses
- Have a goals of care meeting
- Hospice referral
- Discuss advance care planning



# Those Palliative Care Myths

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Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010 Aug 19;363(8):733-42.

# Let's Take Another Poll

- Who has heard of hospice?
- Who thinks they understand the goals and services of hospice?
- Who thinks hospice is a scary or bad word?
- Who has had experience with a loved one in hospice?
- Who has had a good experience with hospice?
- Who has had a bad experience with hospice?

# Hospice Myths

- Hospice is only for the last few days or hours of life
- Hospice hastens death
- It means starting morphine
- Hospice is 24/7 care
- Hospice is a place
- All hospices are the same
- You cannot disenroll from hospice
- Hospice is expensive
- You cannot keep your own physician while on hospice
- Hospice is giving up and losing hope



# Goals of Hospice

- Medical care for patients with life expectancy of 6 months or less
- Goal is to focus on comfort
- Have care come to you
- Provide team to address physical, psychosocial, and spiritual needs of the patient, family, and caregivers



# Not the Goals of Hospice

- To treat and cure illness
- To return to the hospital and clinic
- To continue all medications
- To do tests, labs, and vital signs

# Who is the Hospice Team?

- Hospice physician/medical director
- Nurse practitioners
- Nurses
- Aides
- Social work
- Physical and occupational therapy
- Dietary counseling
- Spiritual counseling
- Bereavement services
- Pharmacists
- Homemakers
- Volunteers



# Who Is Eligible?

- Prognosis of 6 months or less
- No age restrictions
- Have insurance benefit

# Where Is Hospice Provided?

- Home
  - House/apartment
  - Assisted living facility
  - Nursing home
- Residential hospice facility
- Hospital



# What Does Hospice Provide?

- Medications and supplies you need to be comfortable
- Interdisciplinary team to support patient and family
- Respite
- Bereavement services



# How Does it Work?

- Enroll with an agency
- Nurse will visit anywhere from once a day to once a week
- 24-hour nurse availability
- Aide may come by two times per week
- Social work visits
- Chaplain visits
- Other members of interdisciplinary team based on needs and goals of the patient

# When Is the Right Time for Hospice?

- When you're ready to:
  - discontinue medical treatment for your health conditions
  - stop going to the hospital and clinic
  - goal is to focus on being comfortable
  - goal is for care to come to you



# Why Do Hospice?

- Treatment of symptoms
- Avoid having to go to the hospital or clinic for symptoms
- Provides support to help keep people in the home at end of life
- Bereavement services



# Hospice Case

- 78 yo female with heart and kidney disease
- Doctors didn't have any additional treatments to offer to help her get better
- She was weak and short of breath but was able to walk short distances with a walker
- She lived with her husband
- Her doctor suggested she consider hospice

# Hospice Case

- Provide her with a wheelchair
- Brought in a hospital bed
- Provide home PT/OT
- Brought in a bedside commode
- Provide oxygen
- Aide comes by 2 times per week to help her bathe
- Nurse comes 1-2 times a week to check on her symptoms
- When her breathing worsened, medication provided



# Addressing the Hospice Myths

- Hospice is only for the last few days or hours of life
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- Hospice is giving up and losing hope



Morita T, Tsunoda J, Inoue S, Chihara S. Effects of high dose opioids and sedatives on survival in terminally ill cancer patients. J Pain Symptom Manage. 2001 Apr;21(4):282-9. doi: 10.1016/s0885-3924(01)00258-5. PMID: 11312042.

MYTH: HOSPICE IS GIVING UP AND LOSING HOPE

TRUTH: HOSPICE IS ABOUT LIVING THE BEST YOU CAN IN WHATEVER TIME  
YOU HAVE LEFT



# Advance Care Planning

- Sharing your values and wishes for your medical care in case you become seriously ill and are unable to make decisions for your self
- Discussions with your physician and family about what is important to you when you are sick and nearing end of life
- May involve putting decisions in a document

# Advance Care Planning Documents in WI

- Living Will
- Health Care Power of Attorney
  - Opportunity to name someone you trust to legally make health care decisions for you if you are unable
  - Can avoid conflict among family
  - Can avoid court costs
  - Is an opportunity to discuss your goals and values for your health care
  - Can be a gift to your loved ones
- Other documents

POWER OF ATTORNEY FOR HEALTH CARE

Document made this \_\_\_\_\_ day of \_\_\_\_\_ (month), \_\_\_\_\_ (year).

CREATION OF POWER OF ATTORNEY FOR HEALTH CARE

I, \_\_\_\_\_

(print name, address, and date of birth), being of sound mind, intend by this document to create a power of attorney for health care. My executing this power of attorney for health care is voluntary. Despite the creation of this power of attorney for health care, I expect to be fully informed about and allowed to participate in my health care decision for me, to the extent that I am able. For the purposes of this document, "health care decision" means an informed decision to accept, maintain, discontinue, or refuse any care, treatment, service, or procedure to maintain, diagnose, or treat my physical or mental condition.

In addition, I may, by this document, specify my wishes with respect to making an anatomical gift upon my death.

DESIGNATION OF HEALTH CARE AGENT

If I am no longer able to make health care decisions for myself, due to my incapacity, I hereby designate \_\_\_\_\_

(print name, address and telephone number) to be my health care agent for the purpose of making health care decisions on my behalf. If he or she is ever unable or unwilling to do so, I hereby designate \_\_\_\_\_

(print name, address and telephone number) to be my alternate health care agent for the purpose of making health care decisions on my behalf. Neither my health care agent nor my alternate health care agent whom I have designated is my health care provider, an employee of my health care provider, an employee of a health care facility in which I am a patient or a spouse of any of those persons, unless he or she is also my relative. For purposes of this document, "incapacity" exists if 2 physicians or a physician and a psychologist who have personally examined me sign a statement that specifically expresses their opinion that I have a condition that means that I am unable to receive and evaluate information effectively or to communicate decisions to such an extent that I lack the capacity to manage my health care decisions. A copy of that statement must be attached to this document.

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# Advance Care Planning Case

- 68 yo male with stomach cancer



IT ALWAYS  
SEEMS  
TOO EARLY,  
UNTIL IT'S  
TOO LATE.

