LIFE BEFORE DEATH

LIVING A BETTER NOW BY PLANNING AHEAD

PROGRAM LEADER

Reverend Paula Waite, M. Th., ACC
Palliative Care Chaplain
Beebe Healthcare

PROGRAM OUTLINE

- Advance Care Planning
- Possible Medical Interventions
- Palliative Care Overview
- Talking to your loved ones

WHY NOW?

- Most of us don't want to think about being very sick.
- Many people find it hard to talk about the end of life.
- The unexpected can happen to anyone at any age including medical crisis or debilitating disease.
- An advance directive can protect your wishes about the care you receive.

ADVANCE CARE PLANNING

"We call them healthcare decisions, but it is really about values.

The emphasis is not on 'what is the matter with you.'

The question is, 'what matters to you?'"

Kate Debartolo, director of the Conversation Project
at the Institute of Healthcare Improvement

WHAT IS AN ADVANCE DIRECTIVE?

- Designates your healthcare decision-maker: Medical Power of Attorney
- It records your end of life healthcare wishes in case you cannot speak for yourself.
- Standard Care in a medical emergency may use life sustaining treatments such as:
  - CPR, Cardiopulmonary Resuscitation
  - Mechanical Ventilation
    (Breathing Machine)
  - ANH, Artificial Nutrition and Hydration
    (Feeding Tube)

ADVANCE DIRECTIVES

- You can make choices for yourself as long as your medical team determines that you have capacity
- Advance Directive is effective when you cannot speak for yourself
- If you do not designate a medical decision-maker in advance, your medical team will follow the applicable state laws

DELAWARE LEGAL DECISION –MAKER HIERARCHY:

Without a designated agent, family or individuals in descending order (if reasonably available), may act as surrogate:

1. Spouse, unless a petition for divorce has been filed or a court issued restraining order is in place

2. Adult child, or ALL adult children have equal say

3. Parent

4. Adult sibling

5. Adult grandchild

6. Adult niece or nephew

7. Adult aunt or uncle

In some circumstances:

8. Close friend

9. Court appointed guardian

CPR – CARDIOPULMONARY RESUSCITATION

- Used if your breathing or heart stops
- May combine chest compressions, rescue breaths, intubation, electric shocks to the heart, and medicines
- Requirements:
  - Hospitalization – ICU
  - Being hooked up on machines (mechanical ventilation)
- Risks:
  - Often does not work
  - Damage to ribs, lungs, brain, or other organs

MECHANICAL VENTILATION INTUBATION

- Intubation
  - Breathing tube is inserted into airway through your mouth
- Ventilator
  - Breathing machine breathes for you if you cannot breathe on your own

ANH
ARTIFICIAL NUTRITION & HYDRATION

- Liquid nutrition when you cannot swallow or feed yourself.
- Tube pushed into stomach through mouth, belly, nose, sometimes directly with surgery.
  - Will sustain life, but not cure illness
- Risks:
  - Aspiration
  - Lung and other infections
  - Nausea, vomiting, ulcers
  - Fluid overload

IT IS ABOUT YOU AND YOUR WISHES

"What really makes these decisions 'hard choices' has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual… These are decisions of the heart, not just the head."

Hank Dunn, *from Hard Choices for Loving People*

THINGS TO CONSIDER AT THE END OF LIFE: WHAT CARE DO YOU WANT?

- Do you want your life prolonged for as long as it is possible if you are at end of life or permanently unconscious (in a coma or persistent vegetative state)?

ADVANCE DIRECTIVE RECAP

- Names a surrogate decision maker (or Durable Power of Attorney for healthcare)
- Records your end of life healthcare wishes in case you cannot speak for yourself
- Generally more "open-ended" format to express your preference
- Two witnesses to make it official

DURABLE POWER OF ATTORNEY FOR HEALTHCARE

- Legal form names a person as your healthcare agent
  - This person will make decisions for you if you cannot speak for yourself
  - Must be at least 18 years old
    - Should be someone who knows you well, knows your values, and is accessible
    - Should be someone who will carry out your wishes, whether or not they agree with them for end of life care
    - Should be someone not afraid to speak up for you who is trustworthy and stable
    - Should be ONE person instead of a group

OTHER ADVANCE CARE PLANNING

- **DNAR** (Do Not Attempt Resuscitation)
  - Tells the healthcare team not to use CPR in the case of cardiac arrest
    - Sometimes one prefers a peaceful passing
    - Sometimes the risks of CPR are too great
    - 65 or over, frail, depend on others for care, more than one serious health issue, end-stage illness
    - Valid only in the clinical setting

TREATMENTS DURING A SERIOUS ILLNESS

- Good fit if they –
  - Relieve pain or suffering, increase quality of life, are in line with your values, improve function
- NOT a good fit if they –
  - Cause pain, decrease quality of life, not in line with your values, keep you alive with no other benefit

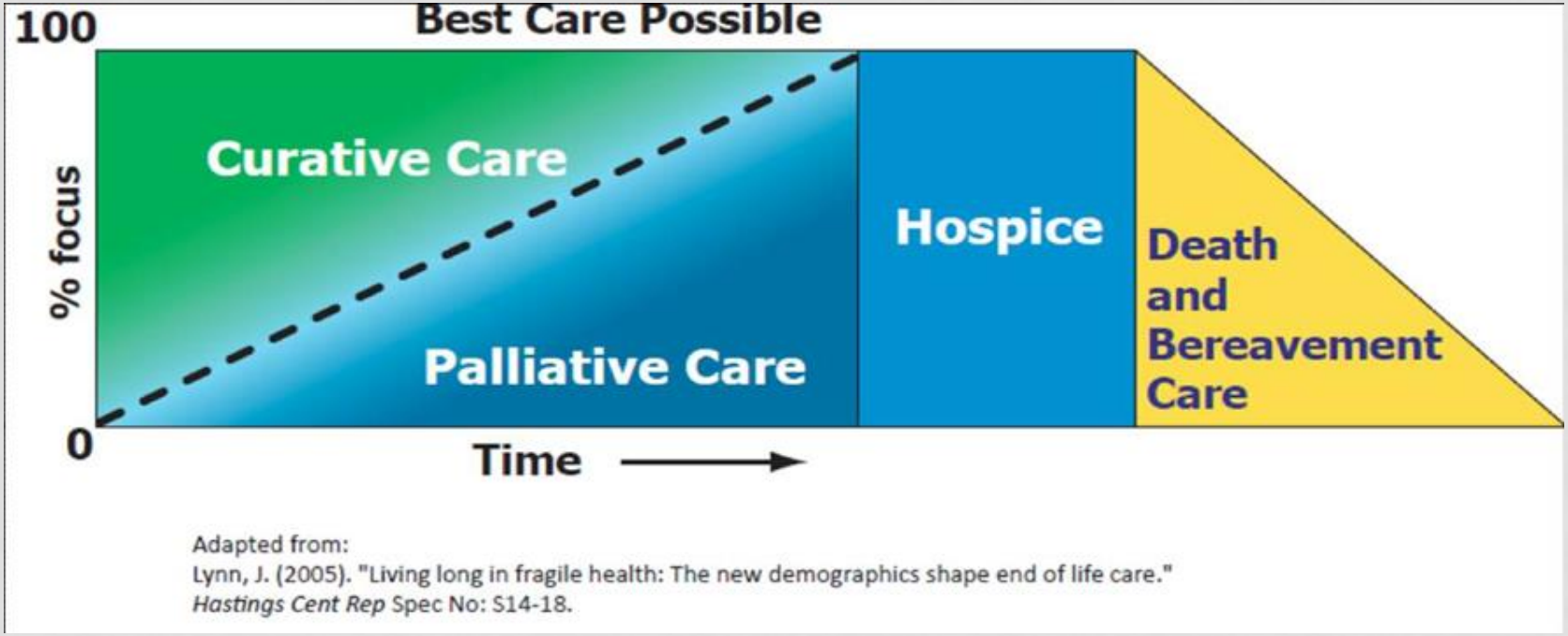
TREATMENTS POSSIBLY ASSOCIATED WITH SERIOUS ILLNESSES:

- Blood transfusions
- Chemotherapy
- Dialysis
- Invasive tests
- Pacemaker or implanted defibrillator
- Radiation therapy
- Sedation
- Surgery
- X-rays, PET/CT/CAT scans, MRIs

PALLIATIVE CARE

- Care to help people get relief from pain, distress, suffering, psycho-social and spiritual distress, and other symptoms that can occur during an illness
- A person can receive palliative care at any stage of a chronic illness, including while getting treatment
- Palliative Care is NOT hospice care

HOSPICE – PALLIATIVE CARE
HOW DO THEY DIFFER?



Adapted from:
Lynn, J. (2005). "Living long in fragile health: The new demographics shape end of life care."
Hastings Cent Rep Spec No: S14-18.

HOSPICE CARE

- Care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness.
- Hospice provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.

BARRIERS TO HOSPICE CARE

- Studies show it is often not started soon enough.
- Doctor, patient, or family member may sometimes resist hospice because they think it means "giving up" or that there is no hope.
- Can sign off or graduate from hospice services if patient's condition changes.

WHY TALKING MATTERS

- Sharing your wishes for end-of-life care can bring you closer to the people you love.
- It is critically important.

- YOU CAN DO IT!

- ONE CONVERSTION CAN MAKE ALL THE DIFFERENCE

WHERE I STAND

? What do you feel are the three most important things that you want your friends, family, and/or health care team to understand about your wishes and preferences for end-of life care?

STEP 1 - GET READY

? What do you need to think about or do before you feel ready to have the conversation?

? Do you have any particular concerns that you want to be sure to talk about?

STEP 2 – GET SET

- What is most important to you as you think about how you want to live at the end of your life?
- What do you value most?
- Finish this sentence: What matters to me at the end of life is…….

STEP 3 - GO

- **? WHO do you want to talk to?**
  - Mom, Dad, Child/Children, Partner/Souse, Sister/Brother, Faith leader, Friend, Health care provider, caregiver…
- **? WHEN would be a good time to talk?**
  - Next holiday, before my child goes to college, before my next trip, before I get sick again, before the baby arrives, the next time I visit my parents/adult children, next family gathering…
- **? WHERE would you feel comfortable talking?**
  - At the kitchen table, favorite restaurant, in the car, on a walk, sitting in a park, at my place of worship…
- **? WHAT do you want to be sure to say?**

STEP 4 – KEEP GOING

- ? Is there something you need to clarify that you feel was misunderstood or misinterpreted?
- ? Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who tend to disagree)?
- ? How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?
- ? What do you want to make sure to ask or talk about next time?

BEGIN THE CONVERSATION BECAUSE…

"It's always too soon…until it's too late."

The Conversation Project