Walking each other home

Conversations about end of life decisions

"One conversation can make all the difference"

Marianne Rockett Williams Memorial Symposium on Pastoral Care

Framing our conversation in faith, hope, and love.

“It’s not about death, it’s what matters most in your life.” Atul Guwande

Sharing faith

In God

In each other

In friendship

In being present to walk each other home.

Why are we here today?
Because talking matters.

90% of people say that talking with their loved ones about end-of-life care is important.

27% have actually done so. (The Conversation Project National Survey 2013)

80% of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.

7% report having had this conversation with their doctor. (Survey of Californians by the California Healthcare Foundation, 2012)

Fear of flying, fear of dying?

- Most people are less afraid of death than they are of the dying process.
- Talking about it eases fear.
- Developing a plan is proactive rather than reactive.
- Planning for the end of life allows you to live your best life until the very end.
- Making your wishes known is a gift to those you love.

Barriers to talking about the end of life:

- Death is a taboo subject.
- It makes us uncomfortable.
- Unsure about how to initiate the conversation or what tools to use.
- It makes us think of our own death.
- May cause conflict if family members have different beliefs or opinions.

Objectives:

1. Discuss the importance of conversation about end of life care.
2. Define and differentiate terms used in end of life care planning.
3. Describe physical and psychological changes which occur during final stage of life.
4. Facilitate a basic understanding of the terms: cardio-pulmonary resuscitation, intubation, mechanical ventilation, and artificial nutrition and hydration.
5. Explain the importance of establishing goals of care for the final stage of life.
6. Develop strategies to initiate conversation about, and assist with, end of life care planning.

Goals:

- To increase our comfort level in talking about the dying process.
- To consider our own goals of care at end of life.
- To encourage caring conversation with loved ones about their end of life wishes.

Confronting Mortality

We may not be able to choose exactly how we die, but we may choose how we live until we die.

Signs that life is winding down:

May be due to old age, or a life-limiting diagnosis

Decreased strength and endurance

Less interest in usual activities

Changes in appetite

Increased need to sleep—frequent naps

Desire to be at home, in familiar surroundings

Cont’d:

Less interactive with others

Falls

Weight loss

Frequent visits to the doctor

Repeated hospitalization

Frailty

Options:

Continue to pursue **aggressive medical care** and treatment, which may include:

Cardiopulmonary resuscitation—CPR

Intubation/Mechanical Ventilation

Artificial Nutrition and Hydration

CPR

Healthy patient with acute illness, i.e. heart attack, trauma

20-40 % survival; unpredictable risk of neurological disability.

Acute on chronic or advanced illness/not imminently dying

5-20% survival; high risk of neurological disability.

Imminently dying

0% chance of survival

Stratification to Aid Physician Decision-Making Regarding DNR Discussions and Advance Care Planning, Taylor, RM, et al J Support Oncology 2010

Intubation/Mechanical Ventilation

Life support--helps people breathe when they are not able to breathe enough on their own.

Doesn’t fix primary disease.

Supports patient until other treatments become effective.

Often requires heavy sedation.

For patients who are very sick, at times the ventilator only postpones death.

--American Thoracic Society, *Patient Information Series*

Artificial Nutrition and Hydration

Fluids administered intravenously (IV) for short duration.

Nutrition given through a tube through the nose (NG) or directly into the stomach (PEG tube).

Appropriate uses—cancer, surgery, post CVA.

Not appropriate for difficulty swallowing (dysphagia) due to dementia.

The time for Dr. to ASK, TELL, ASK

What is your understanding of the situation?

Do you think your loved one will survive CPR/Intubation/ANH?

What do you think will happen AFTER CPR/Intubation/ANH?

Time for you to ponder:

Will treatment make a difference?

Do burdens of treatment outweigh benefits?

Is there hope of recovery?

    If so, what will life be like after?

What do I value, what are my goals of care?

HOPE

Being hopeful is a human condition. We are hopeful until our final breath.

Let’s talk about the spectrum of hope.

“It’s not about death, it’s what matters most in your life.”

Atul Guwande

Goals of Care

- What matters to you now?
- How do you envision life from this point on?
- What can you live with; what makes life no longer worth living?
- How do you determine goals of care for someone who can no longer communicate?

Alternative Choices

Palliative Care:

A change in focus from curative to supportive medical care. The goal is to manage symptoms to provide comfort, not necessarily to prolong life.

(May continue to pursue aggressive medical intervention, i.e. chemotherapy.)

Allow Natural Death

Like natural childbirth, natural dying is a way to cope with one of the great milestones in life, and to help us appreciate that all of life is about connections, relationships, and unconditional love.

--Marilyn Webb, *The Good Death*

Hospice:

Care provided to a person in the final months of life. Focus is on comfort and support for the person and their family. No further aggressive pursuit of curative medical intervention. All medical care is aimed at symptom management to allow for a peaceful death.

Must be ordered by a physician who certifies life expectancy of six months or less.

Hospice Diagnoses (2014)

- Cancer-37%
- Non Cancer Diagnoses-63%

  Dementia-15%

  Heart Disease-15%

  Lung Disease-9%

  Other-8%

  Stroke-6%

  Kidney Disease-3%

  Liver Disease-2%

  Non-ALS Motor Neuron Disease-2%

  Debility (unspecified)-2%

  Amyotrophic Lateral Sclerosis (ALS)->1%

  HIV/AIDS->1%

How do we know the end is nearing?

One to three months before death:

Withdrawal from the world and people

Decreased food intake

Increase in sleep

Going inside self

Less communication

One to two weeks before death:

Mental changes:

Disorientation

Agitation

Talking with the unseen (vivid dreams)

Confusion

Picking at clothing or bedding

Days or hours before death:

Intensification of physical changes of recent days

Surge of energy

Not eating, taking little fluids

Eyes glassy, tearing, half open

Irregular breathing pattern

Restlessness and/or no movement

Purplish, blotchy skin coloration of hands, feet, limbs

Pulse weak and difficult to feel

Decreased urine output

Complains of body feeling tired and heavy

Decreased blood pressure

Pulse increase or decrease

Skin color changes: pale, bluish

Increased perspiration

Respiration irregularities

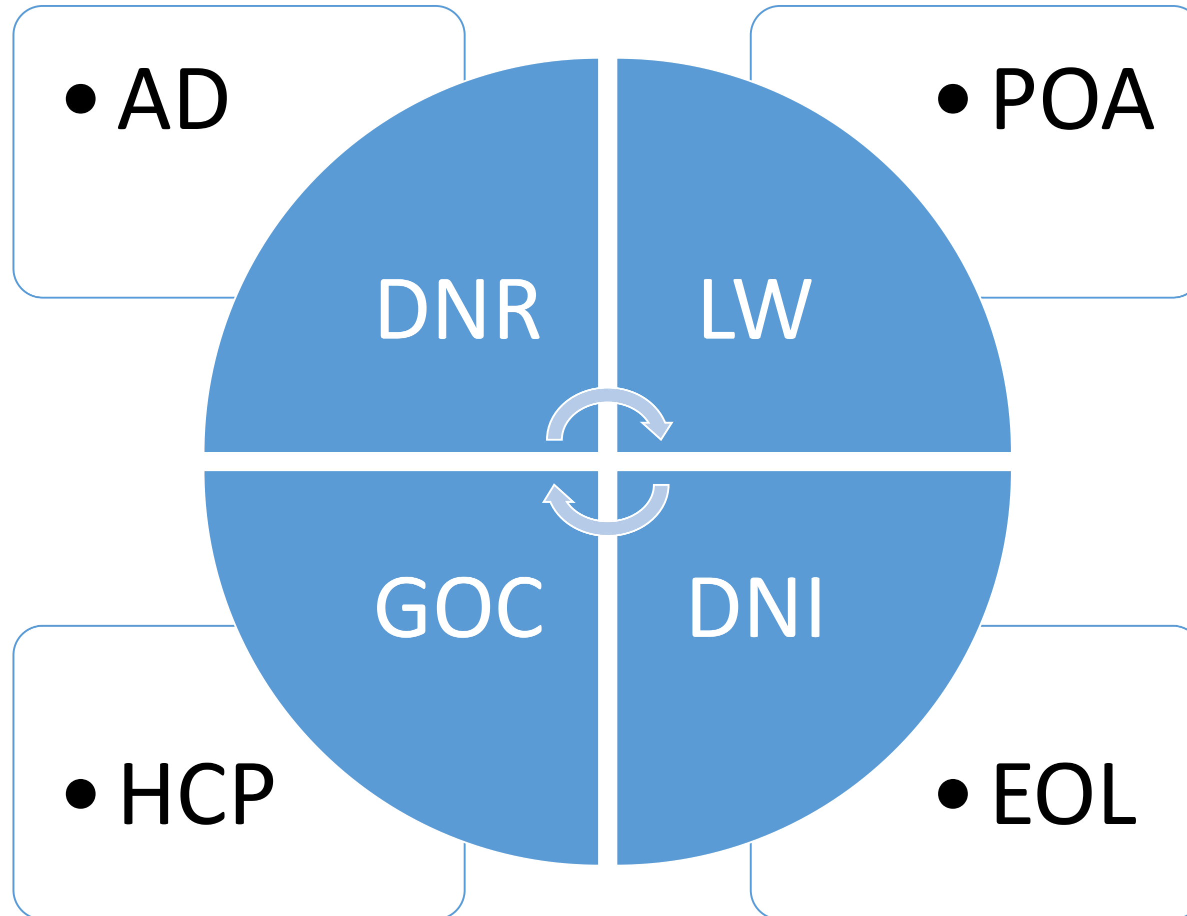
Congestion (increased secretions)

Sleeping but not responding

Poorly regulated body temperature

"Gone From My Sight" Barbara Karnes RN

Decision Making:
Goals of care for the end of life.



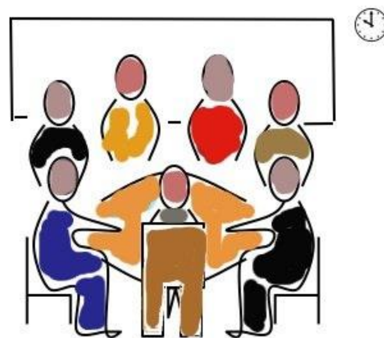
Mapping the journey home.

- AD-Advanced Directive is the written expression of a person's wishes regarding medical treatment.
- LW-Living Will, legal documentation of a person's wishes regarding medical treatment, often part of other legal documents such as a will.
- HCP-Health Care Proxy, the person chosen/designated to make medical decisions if a person lacks capacity.

Medical Orders: GPS guidance for the journey

- DNR-Do Not Resuscitate
- DNI- Do Not Intubate
- MOLST-Medical Orders for Life Sustaining Treatment

Time for small group discussion.



Faith Hope Love

Faith supports us, hope sustains us, love draws us together.

Be present for each other on life's journey.