YOUR WILL: YOUR WAY

Taking Care of Business with Advance Directives

LMC Physician Lecture Series

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OBJECTIVES

- 1. Understand the value of advance directives for the individual, the family and the healthcare team.
- 2. Understand the differences/similarities between palliative care and hospice care.
- 3. Understand how you…can have it your way.

Questions

- 1. How many of you have an advance directive? living will? healthcare power of attorney?
- 2. How many of you have discussed with your family, and providers, just what your hopes and wishes are?
- 3. How many of you believe that your family will honor your wishes?

- DEATH OFTEN WEIGHS HEAVIER ON US BY ITS WEIGHT ON OTHERS, AND PAINS US BY THEIR PAIN ALMOST AS MUCH AS BY OUR OWN, AND SOMETIMES EVEN MORE.

---------------MONTAIGNE (1533-1592)----------

- DEATH IS NOT FAIR AND IT IS OFTEN CRUEL. SOME DIE YOUNG, OTHERS IN EXTREME OLD AGE. SOME DIE QUICKLY, OTHERS SLOWLY BUT PEACEFULLY. SOME FIND PERSONAL OR RELIGIOUS MEANING IN THE PROCESS, AS WELL AS AN OPPORTUNITY FOR FINAL RECONCILIATION WITH LOVED ONES.

- OTHERS, ESPECIALLY THOSE AFFLICTED WITH CANCER, AIDS, PROGRESSIVE NEUROLOGIC DISEASES OR THE CHRONIC CONDITIONS OF CARDIO-VASCULAR, RENAL AND PULMONARY ILLNESSES, DIE BY INCHES AND OFTEN IN GREAT ANGUISH.
- -------------------MARCIA ANGELL, M.D. 2004---

2 VIGNETTES

- John Cooper…50 year old man, married, two adult children. Heavy smoker for over 35 years; onset of chest pain led to x-ray, then CT scan confirmed lung lesion. Surgical biopsy reveals an invasive lung cancer (oat-cell carcinoma). Treatment options included radiation, chemo-therapy, surgical resection, or some combination. John, his wife and children choose the surgical approach.

- Day 1 Surgery goes well; Dr Ashley feels tumor was fully resected and prognosis is good.
- Day 2 Ex-tubated, breathing on his own, moved from SICU to progressive care.
- Day 3-6 High fever, respiratory problems prompt re-intubation and return to C/T ICU. Pneumonia, then progressively worsening diagnosis of adult respiratory syndrome. Dr. Ashley informs the family that the prognosis is poor.

- Day 8 No change in pulmonary status, signs of renal failure appear; dialysis is suggested. Mrs. Cooper, for the first time mentions to one of the nurses that she and John had discussed "heroic measures" should one of them develop a serious, terminal illness with little chance of full recovery and had expressed no wish for those "futile" measures. Dialysis is declined.

- Day 12 Family conference
- Advance directive
- Issues of futility
- Healthcare team concerns
- Ethical dilemmas

Pertinent Issues

- Diagnosis, Prognosis
- Communication
- Shared decision making
- Autonomy, Beneficence, Nonmaleficence

Basic Definitions

- Advance care planning…the process in which you, along with your providers, and your family come to understand the nature of your illness; the options for treatment and the prognosis. Your wishes and concerns are expressed; your choices are made known.

- Advance directive…the written record of your wishes expressed during your planning sessions. What you want to be done to you and for you, in case you cannot speak for yourself.
- Living will…a legal document outlining just which medical/surgical interventions and treatments that you wish to be performed and to specify those that you would refuse.

- Living will is often referred to as a declaration of desire for a natural death; applicable to the terminally ill or one in a permanently unconscious state. Also referred to as persistent vegetative state.
- Durable power of attorney for healthcare…you indicate in writing the individual or individuals you wish to make choices for you in the event you become unable to do so.

Basic Statistics

- ~80% wish to die at home
- Over 85% say they want spiritual needs met
- Over 90% want well-managed pain
- ~25% actually die at home
- Only ~ 6% have spoken with their religious leader
- Approximately 11% have spoken with their physician

Options and Choices

- CPR
- Feeding tubes
- Mechanical ventilators
- Chemotherapy
- Dialysis
- Antibiotics
- Palliative Care
- Organ or tissue donation
- Preferred site of death

Palliative Care

- Purest definition taken from The National Hospice and Palliative Care Organization

- "Palliative care refers to patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitates patient autonomy, access to information, and personal choice."

Hospice

- Hospice care initially the result of activities in England (Dame Cicely Saunders) in the 1960s.
- Focus on methods to improve care of the imminently dying…symptom management, emotional and spiritual support, for patients and their families.
- Typically delivered in the patient's home, possibly in a specialized hospice residence, occasionally in the hospital.

CASE STUDY 2

Mrs. K…84 year old, widowed, with 2 adult children. Long ill with chronic hypertension, chronic congestive heart failure and insulin-dependent diabetes, Mrs. K had a massive stroke and was intubated and admitted to the MICU for ventilatory and supportive care.

Her primary care physician requested consultation with a neurologist. The prognosis was grim. Ten days into the ICU stay, Mrs. K became totally unresponsive with only minimal brainstem activity.

There was not an advanced directive, but her family knew from previous discussions that she did not want life-sustaining treatments in the event of a terminal, irreversible condition; the children asked the primary care physician to discontinue mechanical ventilation and provide supportive care only.

Although she was in agreement with the family, the neurologist consultant was not; he stated, in no uncertain terms, that Mrs. K had “wiggled hers fingers” and therefore was not brain

Unilateral(one physician) discontinuation of the mechanical ventilator was against hospital policy, so the primary care physician, and the MICU nursing personnel continued treatments.

The nurses providing the care for Mrs. K, and her family members were distressed that they had to continue the aggressive care, against the patient's wishes. They expressed their moral distress over the futility of continuing what was felt to be medically inappropriate

We last saw Mrs. K in her MICU bed, tubes in every orifice, the mechanical ventilator noise and the beeping of the monitors and infusion pumps the only, lonely sounds in the room.

What were the goals of care?

For her family, her physician and the MICU nurses, to allow a peaceful, dignified, comfortable death; for the Neurologist, to use all means available to prolong the life of this

Dilemma resolution

CALL FOR AN ETHICS CONSULTATION

(3 weeks into the hospital course)

With support of Ethics Committee consult, primary care physician withdrew the death-prolonging, medically inappropriate treatments, and Mrs. K died, with comfort and restored dignity.

- "FEW ARE WILLING TO BRAVE THE DISAPPROVAL OF THEIR FELLOWS, THE CENSURE OF THEIR COLLEAGUES, THE WRATH OF THEIR SOCIETY. MORAL COURAGE IS A RARER COMMODITY THAN BRAVERY IN BATTLE OR GREAT INTELLIGENCE. YET IT IS THE ONE ESSENTIAL VITAL QUALITY FOR THOSE WHO SEEK TO CHANGE A WORLD THAT YIELDS THE MOST PAINFULLY TO CHANGE". ROBERT F. KENNEDY (1925-1968)