Hospice, Palliative Care, and Advance Directives

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Hospice
History of Hospice

- Same root as “hospitality”
- Referred to place of shelter for travelers, back to medieval times
History of Hospice

- First applied to specialized care for dying by Dame Cicely Saunders
  - Created first modern hospice, St. Christopher’s, in London, 1967

- Florence Wald, Dean of Yale School of Nursing
  - Founded first US Hospice in Branford, CT, 1974

- Hospice benefit made permanent by Congress in 1986
Hospice

- Medicare benefit
- Life expectancy of 6 months or less
- Elect to forego further curative treatment
- Benefit periods: 90 days, 90 days, 60 days, 60 days, 60 days...
  - Can be recertified indefinitely if continue to meet hospice criteria
Hospice Locations/Levels of Care

- **Home (95%)**
  - Includes assisted living facilities and nursing homes

- **Inpatient**
  - Dedicated inpatient hospice unit (Philip Hulitar Center), contracted beds at a hospital or nursing home
  - Active symptom management, unsafe home environment, or imminent death
Hospice Locations/Levels of Care

- **Respite Care**
  - Short-term inpatient care to relieve family/primary caregiver
  - Limited to 5 consecutive days

- **Continuous Home Care**
  - Intends to support patient and caregiver through brief periods of crisis
  - Provides 8-24 hrs of care per day
  - Care must be provided primarily (>50%) by an LPN or RN
Hospice – Covered Services

- Case oversight by the physician “Hospice Medical Director”
- Nursing care
  - Symptom assessment, skilled services/treatments, and case management
  - Nurse visits routinely
  - 24-hour/7-day per week emergency contact available
- Social work
  - Counseling and planning (living will, DPOA, funeral)
- Chaplain
  - Spiritual support
Hospice – Covered Services

- All medications and supplies related to the terminal illness
- Durable medical equipment
  - Hospital bed, commode, wheelchair, oxygen, etc.
- Home health aide and volunteer services
- Bereavement support to the family after the death of the patient
Hospice – Not Covered

- Medications for conditions not related to terminal diagnosis
- Continuous nursing/aide assistance
- Nursing home room and board charges
Myth – “Hospice is Where People Go to Die”

- Hospice vs. non-hospice patient survival
  - Mean survival was 29 days longer for hospice patients

- Possible explanations
  - Avoid risks of overtreatment
  - Psychosocial support tends to prolong life
  - Often see patients “rally” on hospice

"He's our new Palliative Specialist!"
Palliative Care

- Specialized medical care for people with serious illnesses
- Focuses on providing patients with relief from the symptoms and stress of a serious illness - whatever the diagnosis
- Goal is to improve quality of life for both the patient and the family
Palliative Care

- Appropriate at any age and at any stage in a serious illness
- Can be provided along with curative treatment
Palliative Care

- Improves quality of life
- Focuses on symptom management
  - Pain, SOB, fatigue, constipation, loss of appetite, nausea/vomiting, insomnia, depression, anxiety
- Improves communication
- Helps patients/families better understand treatment options
Palliative Care

- Team approach
- Partnership of patient, specialists, and family
- Help with “goals of care”
Palliative Care

- Has increased greatly in past 20 years
- Associated with improved outcomes and significant cost savings
- In the US, 55% of hospitals with >100 beds, and nearly 1/5 of community hospitals have palliative care programs
- Most often provided in acute hospitalizations
- Expanding in home, nursing home, and outpatient setting
Gray area under the curve equals 100% of all health care expenditures over a life span.
Prevalence of U.S. Hospital Palliative Care Teams 2000–2009

Source: Center to Advance Palliative Care, March 2011
Palliative Care

Rhode Island was one of 8 states in the US to receive a grade of “A” for access to palliative care (88% of hospitals have palliative care services)

- Other states were Vermont, District of Columbia, Nebraska, Maryland, Minnesota, Oregon, and Washington
Do Patients Getting Palliative Care Die Sooner?

- Patients with metastatic lung cancer
- Early palliative consult led to:
  - Better quality of life
  - Less depressive symptoms
    - 16% vs. 38%
  - Less aggressive care
  - Longer survival
    - 11.6 months vs. 8.9 months

“You’ve got six months, but with aggressive treatment we can help make that seem much longer.”
Advance Directives
Advance Directives

- Written or verbal instructions for patient’s care if he/she is unable to make decisions
Durable Power of Attorney for Health Care

- "Health Care Proxy"
  - Document that allows patient to appoint someone to make medical decisions on their behalf when they can no longer make them
  - Important to discuss wishes with HCP
  - If no proxy designated, surrogate decision maker
    - 1. spouse, 2. adult child, 3. parent, 4. adult sibling, (5. close friend)
Durable Power of Attorney for Health Care

- Form must be signed by 2 witnesses or 1 notary public, lawyer not necessary
- Witnesses must be adults, but not:
  - The agent or alternate agent
  - A health care provider
  - An employee of a health care provider
  - The operator of a community care facility
  - An employee of an operator of a community care facility
Living Will

- Document that specifies type of medical treatments patient would or would not want if unable to communicate
- May include resuscitation, mechanical ventilation, and artificial nutrition and hydration
Living Will

- Usually too narrow to apply to many common situations
  - Use language such as “incurable or irreversible condition with no reasonable expectation of recovery”
POLST/MOLST

- Standardized document completed by health care professionals together with patient or surrogate decision maker
- Transferred with patient across care settings: hospitals, home, nursing homes, hospice, etc.
- Includes sections on CPR, medical interventions, artificial nutrition
Physician Orders for Life-Sustaining Treatment (POLST)

Follow these orders until orders change. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written.

Guidance for Health Care Professionals:
http://www.ohsu.edu/polk/program/documents/guideline.pdf

Patient Last Name: Doc
Patient First Name: John
Middle Init.
Date of Birth (mm/dd/yyyy): 1/23/1975
Gender: M ✔ F
Last 4 SSN: 1234
Address: 123 S. Main St., Anywhere, OR 97123

A  CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and is not breathing.
☐ Attempt Resuscitation/CPR
☐ Do Not Attempt Resuscitation/DNR
When not in cardiopulmonary arrest, follow orders in B and C.

B  MEDICAL INTERVENTIONS: If patient has pulse and is breathing.
☐ Comfort Measures Only (Allow Natural Death). Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management.
☐ Limited Additional Interventions: In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: Provide basic medical treatments.
☐ Full Treatment: In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. Treatment Plan: Full treatment including life support measures in the intensive care unit.
Additional Orders: Waive blood transfusions

C  ARTIFICIALLY ADMINISTERED NUTRITION: Offer food by mouth if feasible.
☒ No artificial nutrition by tube.
☐ Defined trial period of artificial nutrition by tube.
☐ Long-term artificial nutrition by tube. Additional Orders:

D  DOCUMENTATION OF DISCUSSION:
☐ Patient (Patient has capacity)
☐ Parent of minor
☐ Court-appointed Guardian
☒ Health Care Representative or legally recognized surrogate
☒ Surrogate for patient with developmental disabilities or significant mental health condition (Note: Special requirements for completion. See reverse side.)
☐ Other

Signature of Patient or Surrogate
Signature: recommended
Name (print): Doc
Relationship (write "self" if patient): self

This form will be sent to the POLST Registry unless the patient wishes to opt out, if so check out box

E  SIGNATURE OF PHYSICIAN / NP / PA
Print Signing Physician / NP / PA Name: required
Physician / NP / PA Signature: required
Print Signing Physician / NP / PA Phone Number: 94.555.1234
Signer License Number: required
Date: 4/1/2013
Office Use Only

SEND FORM WITH PATIENT WHenever TRANSFERRED OR DISCHARGED, SUBMIT COPY TO REGISTRY

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Comfort One Bracelet

- RI program that allows EMS to not attempt resuscitation
- Order signed by a physician
- EMS personnel will not:
  - Initiate CPR, intubate, provide ventilatory support, apply cardiac monitor, obtain IV access, administer cardiac resuscitation drugs, defibrillate
- EMS personnel can:
  - Suction airway, provide O2, position for comfort, splint, control bleeding, provide emotional support, transport to hospital
Advance Directives

- Unfortunately, most people don’t have advance directives
- Conversations often occur in acute hospital setting in times of crisis
- Physicians tend to avoid discussions about end of life or poor prognosis
  - Tend to overestimate prognosis
  - Poor documentation
WHEN do we have proper conversations about death?

ME!? I’m way too young to talk about death!

Me too! . . . It’s all such a long way off!

50 today!

21 today
Why do Physicians Avoid Discussions?

- Feel uncomfortable delivering bad news
- Don’t want patient/family to feel upset
- Uncertain/lack skill or knowledge about prognostication
- Think there is no time
Why do Physicians Avoid Discussions? (cont.)

- Don’t recognize opportunities
- Difficult to face own vulnerability to illness/mortality
- Afraid of burnout/distress
- Sense of failure
- Want to maintain hope
Advance Directives

- In a recent survey, 94% of people felt it was important to discuss wishes for end of life care with loved ones
  - Fewer than 1/3 had actually done so
- Women and those >55 y/o more likely to have had discussion

Advance Directives

- Why put off the discussion?
  - 25% “weren’t sick yet”
  - 20% “didn’t want to upset loved ones”
  - 20% “never seems like the right time”
  - 17% “didn’t know how to start conversation”
Advance Directives

- Of those who had a conversation prior to loved one’s death:
  - 2/3 “felt better knowing I was honoring my loved one’s wishes”
  - >1/3 “able to focus energy on spending quality time with loved one in dying days because care already figured out”
  - 40% “loved ones were able to die according to their own wishes”
Physician-Assisted Suicide
Physician-Assisted Suicide

- Currently legal in Belgium, Germany, Luxembourg, Switzerland, and the Netherlands
- In the US: Montana, Oregon, Vermont, and Washington
- Recent article in NEJM, 67% of physicians in the US disapprove
Physician-Assisted Suicide

- President of AAHPM, R. Sean Morrison
  - Focus should be on ensuring high quality palliative care at the end of life
  - Relieving pain and suffering can make the end of life comfortable and dignified
  - With high quality palliative care, people are comfortable, live longer, spend time with their families
Physician-Assisted Suicide

- President of AAHPM, R. Sean Morrison
  - In Oregon and Washington, many people request prescriptions to end their life, but few actually go through with it
  - Patients provided high quality palliative care tend to change their minds
Physician-Assisted Suicide

- President of Compassion & Choices, Barbara Coombs Lee
  - Unacceptable that people should be forced to endure suffering against their will
Physician-Assisted Suicide

- The American Medical Association strongly objects
  - Fundamentally inconsistent with physician’s professional role
  - Should be signal that patient’s needs are unmet and further evaluation to identify contributions to suffering is necessary
Summary

- Hospice is a Medicare benefit for people with life expectancy of 6 months or less.
- Palliative care is care focused on improving quality of life and is appropriate at any point during chronic or life-limiting illness.
- Advance directives are written or verbal instructions for patient’s care if he/she is unable to make decisions.
- Physician-assisted suicide is controversial and currently only legal in 4 states.
- We can do better!
References

- www.capc.org (Center to Advance Palliative Care)
- www.eperc.mcw.edu/EPERC/FastFactsandConcepts (End of Life/Palliative Education Resource Center)
- www.getpalliativecare.org
- www.health.ri.gov
- www.nhpco.org (National Hospice and Palliative Care Organization)