End-of-life Care
Meeting the Needs of Patient and Family

2017 JHS Annual Mandatory Clinical Education
Objective

• To provide knowledge enhancement in the integration of effective communication, cultural competence, and patient-family-centered care into the care delivery system at the end of life in compliance with regulatory agencies and Florida statutes.
Definitions

• "Death: is the permanent cessation of functioning of the organism as a whole" (Bernat, Culver & Gert, 1981)
  – 2,515,458 US deaths in 2010 (CDC, 2014)
  – 57 million global deaths in 2008 (WHO, 2014)

• End-of-life care: provides physical, mental, and emotional comfort, as well as social support, to people who are living with and dying of advanced illness
Definitions

- **Advance directives**: legal documents that allow the patient to make his wishes known about end-of-life care ahead of time.
- **Surrogate**: any competent adult expressly designated by a patient to make healthcare decisions on behalf of the patient upon the patient’s incapacity.
- **Proxy**: a competent adult authorized by court to make healthcare decisions for an individual if that individual has not expressly designated a surrogate.
“Palliative care: an approach that improves the quality of life of patients and their families facing the problems of life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”-WHO(2009)
Legislative Findings & Intent
(2012 Florida Statutes)

- Every competent adult has the fundamental right of self-determination regarding decisions pertaining to his or her own health, including the right to choose or refuse medical treatment.

- All health care organizations should establish a procedure to allow a person to plan for incapacity by executing a document or orally designating another person to direct the course of his or her medical treatment upon his or her incapacity to ensure that such right is not lost or diminished by virtue of later physical or mental incapacity.
Legislative Findings & Intent
(2012 Florida Statutes)

- The administration of life-prolonging medical procedures may result in only a precarious and burdensome existence.
- The need for all health care professionals to rapidly increase their understanding of end-of-life and palliative care.
- It encourages educational institutions to implement curricula to train healthcare professionals about end-of-life care, including pain management and palliative care.
What do we ask patients at point of entry?

• Do you have an Advance Directive?
  – If a patient has lost their capacity to make healthcare decisions whether temporary or permanent, a proxy or healthcare surrogate is determined or activated
What form do we use to activate healthcare surrogate or proxy?
HEALTH CARE SURROGATE / PROXY PHYSICIANS STATEMENT

I am an attending physician for ____________________________ (Patient)

In my professional opinion, this patient is presently **unable** to make informed health care decisions and he/she would benefit from the activation of his/her Health Care Surrogate or the appointment of a Health Care Proxy.

Physician ____________________________ Date ____________

Physician ID#

I am an attending physician for ____________________________ (Patient)

In my professional opinion, this patient is presently **able** to make informed health care decisions.

Physician ____________________________ Date ____________

Physician ID#
Why Palliative Care?

Offers an opportunity to discuss and plan for end-of-life care

Assures that:

– physical and mental suffering will be carefully attended to
– preferences for withholding and withdrawing life-sustaining interventions will be honored
– personal goals of the dying person will be addressed
Why Palliative Care?

Assures that:

– dignity of the dying person will be a priority
– health care providers will not abandon the dying person
– burden to family and others will be addressed
– advance directives for care will be respected regardless of the location of care
Why Palliative Care?

Assures that:

– organizational mechanisms are in place to evaluate the availability and quality of end-of-life, palliative, and hospice care services, including the evaluation of administrative and regulatory barriers

– necessary health care services will be provided and that relevant reimbursement policies are available

– goals expressed will be accomplished in a culturally appropriate manner
What are the related JHS policies?
End of Life Care (JHS Policy 400.058)

- It is the policy of JHS to assist those patients who are facing end-of-life conditions to proceed through the death process with comfort, dignity and respect.
- All efforts will be made to identify, address and positively respond to the patient’s needs, related to all primary and secondary diagnoses and symptoms, and those of their families/significant others as they relate to psychological, social, emotional and spiritual issues.
Withholding, Withdrawing & Forgoing Life Sustaining Treatment (JHS Policy 400.015)

• It is the policy of the Public Health Trust (PHT) to create an environment in which dying patients can choose a peaceful, comfortable and dignified death.

• To respect the rights of all patients to make decisions concerning their care, and to involve patients and their families or authorized representatives, as appropriate, in treatment and care decisions.

• Every competent patient has the right to determine which treatment options he or she will accept or refuse, including life-sustaining procedures and treatment.
Organizational Goal

• To improve effective communication, cultural competence, and patient-family-centered care into the care delivery system at the end of life
What can we do to address patient communication needs during end-of-life care?

- Check patient’s medical record for preferred language, any sensory or communication impairments, or any identified communication needs
- Arrange for language services if patient’s and surrogate’s language is not English
- Appropriate auxiliary aids available
- Provide alternative and/or additional communication resources for patients or surrogate’s with communication impairments
What can we do to monitor changes in patient’s communication status during end-of-life care?

- Determine any new or more severe communication impairments and contact the Speech Services department
- Anticipate the communication needs of patient who is expected to develop communication impairments from scheduled treatments
- Note any changes in medical record and communicate to staff
How can we involve the patient’s surrogate decision-maker and family in end-of-life care?

- Remind the patient of his or her right to designate a surrogate decision maker
- Ask the patient of any family members/friends he or she prefers to participate in end-of-life care
- Consider patient’s cultural beliefs in decision making
- Educate the patient and surrogate about the dying process
- Allow family to participate in end-of-life care
• Adapt existing hospital procedures to better involve the surrogate and family in care decisions
• Provide communication assistance to surrogate and family members as needed
• Encourage the surrogate and family opportunities to ask questions
How can we address patient mobility needs during end-of-life care?

- Assess if patient needs mobility assistance
- Keep call light within patient’s reach
- Observe fall precautions (Remember: policy & Morse Scale)
- Document any need for assistance in Assessment and communicate to the
How can we identify patient cultural, religious, or spiritual beliefs and practices at the end of life?

- Ask if there are any cultural, religious, or spiritual beliefs or practices that may ease his or her care at the end of life
- Consult JHS Pastoral Care as appropriate once end of life stage is identified
- Make sure that staff are aware of any garments, religious items, or rituals important to the patient during end-of-life care
• If needed, provide an area where the patient and family can pray
• Document any end-of-life cultural, religious, or spiritual needs on the medical record and communicate to the staff
How can we ensure that the patient has access to his or her chosen support system?

- Explain the purpose of the patient’s support system, including limitations
- Allow patient access to the support person at all times
- Ask the patient the degree of involvement of the support person
- Make the staff aware of the chosen support person
- Document the information in the medical record
References
