Surrogate Decision Making at End-of-Life

JEANNE KERWIN, D.MH, CT
PALLIATIVE CARE & BIOETHICS MANAGER
ATLANTIC HEALTH SYSTEM
Primary Focus = the patient

Best option:

• Patient with decision-making capacity
• How do we know what she wants?
  Legal Tools (to be discussed)
• Conversation (with whom, when?)
Who are the surrogate decision-makers?  
*Defined in Case Law*

- Husbands, wives, legal partners
- Adult children
- Parents
- Siblings, cousins, aunts, uncles, nephews, nieces
- Close and caring friends
Who are the surrogate decision-makers?

*If no family/close & caring friend*

- Court appointed guardian
  - Special Medical guardian
- Office of the Public Guardian
  - Standard Request form for medical provider to request DNR, or W/H W/D LST
- Bureau of Guardian Services (BGS) – for those patients receiving services under NJ DOH Division of Developmental Disabilities
  - Required Bioethics Consultation for DNR or Withdrawal/Withholding of Life-Sustaining Treatments
  - Standard Request Form
What the decision-maker needs to know
Four Box Method

- Clinical/medical Indications
- Patient Preferences
- Quality of Life
- Contextual Features

Jonsen et al., 2010
Medical Information

- Diagnosis
- Prognosis
- Treatment Options
- Benefits vs. Burdens of each option
- Expected Outcomes
Definitions of Treatment Options

- Feeding tubes
- Intubation
- Ventilators
- Dialysis
- IV medications/pressors
- IVVH, ECHMO, LVAD, ICD,
What would patient want to do?

- **Clear and Convincing evidence**
  - Advance Directive, POLST
  - Conversation about specific preferences “She told me that if…..”

- **Substituted Judgment**
  - I know he hated to be in the hospital; he never wanted to be dependent

- **Best Interest Standard**
  - Burdens vs. benefits
What about vulnerable patients?

- Those with mental illness
- Intellectual/Developmental disability patients
- Unrepresented patients
- Homeless
- Undocumented
Case Stories

• Max
Case Stories

- Charlie

[Image of a grill with the text: EVERY HUMAN HAS RIGHTS]
Case Stories

Helen & Diane
Case Stories

- Alfonso
Role of Hospital Ethics Committee

- Required by The Joint Commission
- Interdisciplinary members: physicians, nurses, SW, chaplains, ethicist, others community members
- Roles/Responsibilities:
  - Policy review and creation
  - Education (hospital staff and community/patients/families)
  - Consultation service
Bioethics Consultation

- **Trained** bioethics consult team (select members of Committee)
- Review all aspects of case (medical, patient/family wishes, contextual issues)
- Meet with all stakeholders
- Render “opinion” and “recommendations” – *Do not make decisions*
  - Documented in medical record
- Decisions remain with doctor/patient/surrogate
Decision-Making is **Difficult** in High-tech Medical Arena
Tools to Protect End-of-Life Preferences

• #1 = *Conversations* !!
Tools to Protect End-of-Life Preferences

  - **Instruction Directive** – specific instructions for variety of circumstances
    - “If I can no longer recognize my family/friends or communicate.....I want/don’t want..”
    - “If I am in a persistent vegetative state.....I want/don’t want
  - **HC Representative Designation** – appointing one to speak for you “if” you lose
decisional capacity – appoint an alternate(s)
    - Note: Did you have an in-depth conversation with your HC Representative????
Advance Directive *Limitations*

- Must be =>18
- Must have decision-making capacity to complete Advance Directive
- Does not “stop” any interventions until:
  - Delivered to hospital and physician
  - Determined to have lost decisional capacity by MD
  - Determination of diagnosis and prognosis
  - Evaluation of expressed wishes in light of diagnosis/prognosis
- Ambiguous language – easy to mold interpretation!
  - Examples: “If no reasonable chance of my recovery” “if I have a terminal condition” “if the doctor thinks it would be helpful”
Suggestions to improve Advance Directives
from the bedside experience

• Instructional Directive: Discuss preferences in terms of “function” not diagnosis. **Examples:** “If I can no longer recognize or communicate with my loved ones…”; “If I am permanently unable to eat and taste food orally, I do not wish to be fed through tubes”; “If I cannot manage my bodily needs (eating, toileting, bathing,...)”; **Remember:** Operational criteria for AD = loss of decision-making capacity as first functional loss!

• Most important: **First…..** have the conversation with family/loved ones and health care representative!!!
POLST
Practitioners Orders for Life-Sustaining Treatments

- Legislated in NJ 2011
- Standardized (green) NJ form
- What is it? - Comprehensive Medical Order set representing patient preferences for end-of-life care completed by physician or advance practice nurse
- Who should have one? – Patients with life-expectancy of < 1 year or life-limiting illness/condition (voluntary for patient/surrogate to request orders to honor preferences or appropriate medical treatment)
- Portable, actionable and accepted/honored in all settings without interpretation
What kinds of orders are on a POLST?

Goals of Care

- Orders to reflect choices about:
  - Resuscitation attempts (DNR or Full Code)
  - Hospitalizations
  - Intubation and mechanical ventilation
  - Artificial feeding
  - Intensive care – aggressive life-sustaining treatments
  - Comfort Care only

*Allows patients to accept some & avoid other treatments.....*
Benefits of POLST orders

• Can be used for at any age for a terminal condition (child – adult)
• Does not require decision-making capacity – A surrogate can request/consent
• Portable in ALL SETTINGS!
• Actionable at “point of contact” – does not require interpretation - should be validated by MD/APN in clinical encounter
• Requires a comprehensive conversation with patient/surrogate and MD/APN
Thank you
Questions/Discussion