Surrogate Decision Making at End-of-Life

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PALLIATIVE CARE & BIOETHICS MANAGER

ATLANTIC HEALTH SYSTEM

Primary Focus = the patient

Best option:

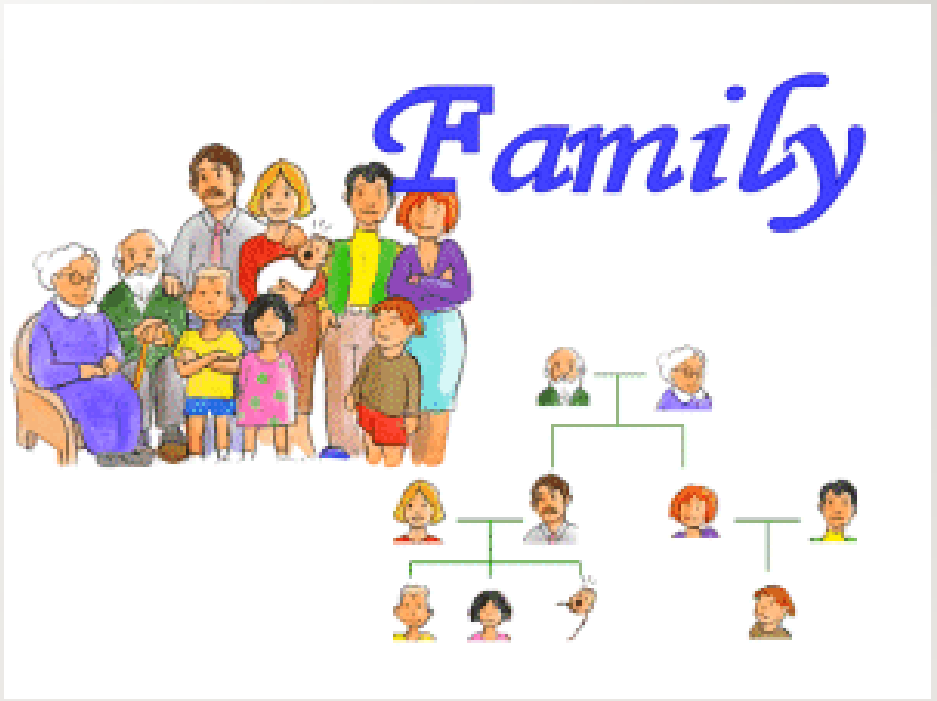
- Patient with decision-making capacity
- How do we know what she wants?

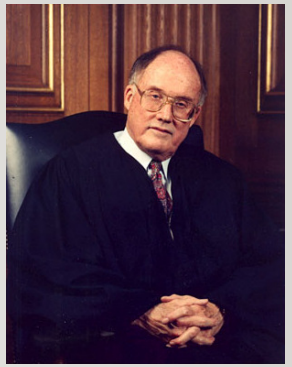
  Legal Tools (to be discussed)
- Conversation (with whom, when?)

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





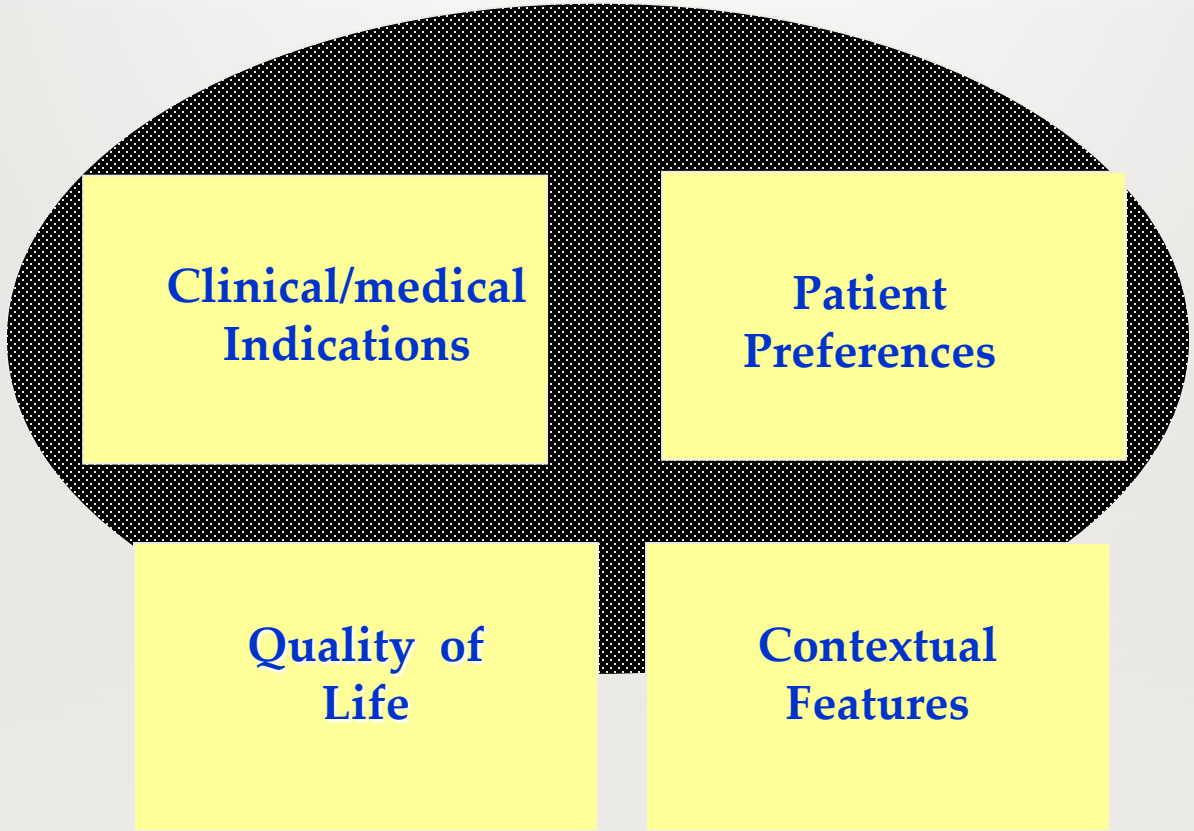
Who are the surrogate decision-makers?

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

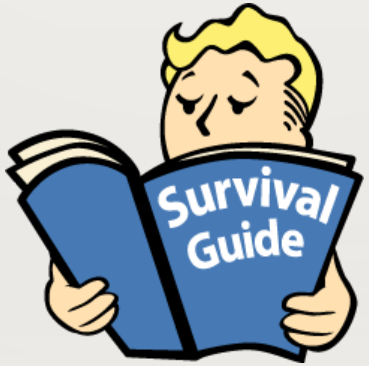
Four Box Method



Jonsen et al., 2010

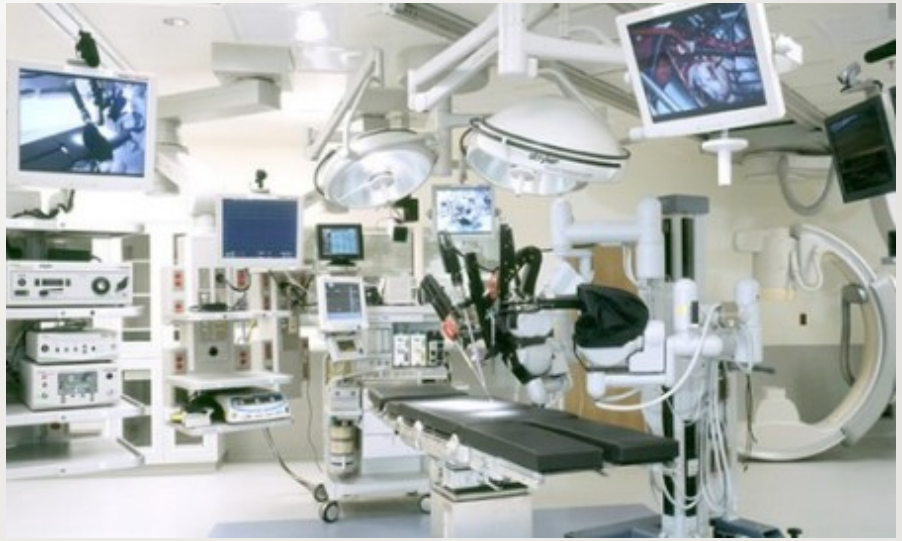
Medical Information

- 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?

- **<u>Clear and Convincing evidence</u>**
  - Advance Directive, POLST
  - Conversation about specific preferences "She told me that if….."
- **<u>Substituted Judgment</u>**
  - I know he hated to be in the hospital; he never wanted to be dependent
- **<u>Best Interest Standard</u>**
  - Burdens vs. benefits

What about vulnerable patients?

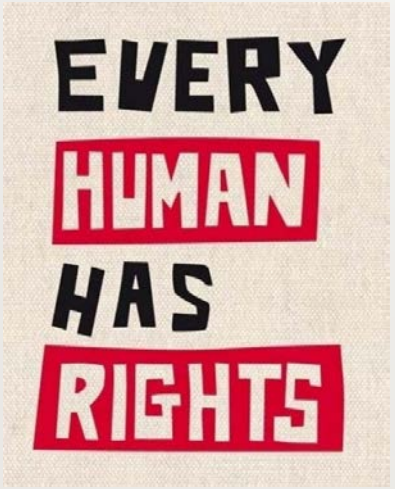
- Those with mental illness
- Intellectual/Developmental disability patients
- Unrepresented patients
- Homeless
- Undocumented

Case Stories

- Max

Case Stories

- Charlie



Case Stories

Helen & Diane

Case Stories

- Alfonso

Role of Hospital Ethics Committee

- Required by The Joint Comission
- 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

- Advance Directives (NJ Advance Directive for Health Care Act– 1991)
  - **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