Guardianship and Surrogate Decision-making

Objectives

- Understand the principles/standards of surrogate decision-making
- Identify the roles and limits of a guardian in surrogate decision-making
- Understand the process of surrogate decision-making as a guardian using guidelines from the National Guardianship Association

Surrogate Decision-Making

- Substitute Judgment
  - The surrogate is responsible for making treatment decisions based on what the patient would choose for him/herself
  - The surrogate should use the patient’s previously expressed wishes, values, beliefs, etc.
- Best Interests
  - When the surrogate has no clear idea what the patient would choose, the decision is based on what a reasonable person would choose in the same circumstances
  - Ultimately, the decision is based on what will be most clinically beneficial to this particular patient in this particular situation
The Role of a Guardian

- A guardian is a court-appointed advocate for the patient
- A guardian is equivalent to a legal representative, which is distinct from a surrogate designated by the patient him/herself
  - The guardian may consent to or refuse treatments on the patient's behalf
  - The guardian may not withdraw life-sustaining treatment without a court order unless the patient is imminently dying or permanently unconscious as documented by the physician

The Role of a Guardian

- Guardians are called to use the least restrictive means of directing medical care for the client, including where the client lives
- The client should be included in all decision-making to extent that they are capable to do so
- The guardian should visit the client regularly and be in touch with the caregivers to monitor the client's health status

The Role of the Guardian with Family

- Some individuals who are assigned a guardian do have family with whom they are in contact
- The guardian has a responsibility to keep family informed if they (the family) so wish
- Family may become a hinderance to caring for the patient
  - The guardian may limit information given to the family
  - In extreme cases, the guardian may limit or even prohibit contact between the family and the patient
NGA Guidelines for decision-making

- Determine the person’s current wishes if possible
- Consider the person's expressed wishes prior to incapacity if possible
  - The person may have a previously executed advance directive
- Consider evidence or guidance of how the person would have made decisions
  - Reach out to previous medical providers, religious or spiritual advisors, refer to previous treatment decisions made by the person himself/herself
- Diligently seek the opinions of the person’s family and/or friends
  - The guardian should review information from family/friends to evaluate for conflicts of interest or possible distortions to the informant’s perception of the person’s situation

- Evaluate the burdens and benefits of continued treatment
  - Pain, outcomes of treatment, outlook for future functional status
- Obtain second physician opinions if needed
- Obtain opinions from nursing and other staff who are currently involved in direct care for the person
- Consider financial consequences
  - Decisions should not be based on financial concern, but finances are a real consideration especially for long term care plans
- Develop a continuing plan of care
  - Withholding or withdrawing certain treatments does not mean abandonment of care for the person

Example #1 - Ms. J

- 80yo Female, history of schizophrenia and hip fracture
- Previously lived in Texas, lived in a homeless shelter in Pittsburgh
- Ms. J has no known family
- At the time of guardianship appointment, Ms. J had times of lucidity
- She frequently refused care interventions, including medications
Ms. J

- Ms. J had several psychiatric episodes which resulted in her transfer to Western Psych clinic for adjustment of her psychotropic medication
- After routine testing, it was determined that Ms. J has hepatitis; the guardian was asked about adding medication to treat the hepatitis
- Guardian reviewed Ms. J’s history and current health status
  - Client has been eating less, sleeping more, being less active
  - Previously refused many treatments, especially medications
  - Guardian chose to withhold hepatitis medication

Example #2 - Ms. E

- 59yo female with history of diabetes, difficulty ambulating, and intellectual disability
- Ms. E lived at home with her 35yo daughter who has a history of hydrocephalus with Dandy Walker syndrome
- Ms. E was hospitalized, and staff saw signs of neglect, APS was called
- Guardianship was appointed with instruction from the judge that Ms. E could remain in her home with her daughter
- 11 days after the guardianship hearing, Ms. E was found in bed with soiled clothing and sores which appeared infected

Ms. E

- Ms. E was hospitalized with a diagnosis of cellulitis
- From the hospital, Ms. E was discharged to a nursing facility
- A second hearing resulted in orders that Ms. E remain in the facility unless/until both she and her daughter were able to establish in home services for continued care for each of them
Ms. E

- Ms. E’s daughter frequently visits the facility and causes severe disturbances.
- The daughter’s visits result in distress for Ms. E as well as staff and other residents.
- The daughter frequently contacts the guardian demanding that Ms. E be returned home.
- The guardian has informed the facility staff that the daughter should be removed by security or law enforcement if she causes disturbances.
- The guardian explains the situation and court order to both Ms. E and her daughter.

Ms. MJ

- 53yo female who is currently bed bound at home with stage 4 decubiti, right leg BKA, hip fracture, OCD and anxiety.
- APS was contacted when Ms. MJ was hospitalized for hip fracture and infection and was refusing care.
- Guardianship was appointed for both person and estate.
- Ms. MJ has two adult children, each of whom live out of state.
- Ms. MJ is legally married although her husband does not live in the home and has a long term relationship with another woman.

Ms. MJ

- Ms. MJ lives alone, her sister lives nearby and stops in frequently to offer help, home health visits 3x per week for wound care.
- Guardianship of the person is limited.
- Ms. MJ wants her husband to be excluded from all communication, she wants her daughter to be kept informed of all decisions and developments.
- The guardian has a care plan goal of having MJ approved for in home waiver services for comprehensive care at home.