



**The A, B, C's of Transition Care:
GUARDIANSHIP, DPA's and Special
Needs Trusts
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**Midwest Region NMPRA
Meeting: May 12, 2012**

CASE 3.

K.R. is a 21 y.o. female with mild to moderate intellectual disability. She completed special education in high school and a transitional program several months ago.

She has diabetes mellitus type I and FSGS. She has stage IV chronic kidney disease, with impending kidney failure. She presents to the ER with volume overload.

ER physicians ask K.R.'s mother to step out of the room as they explain the need for admission and initiation of dialysis. K.R. refuses dialysis and team is uncertain how to proceed

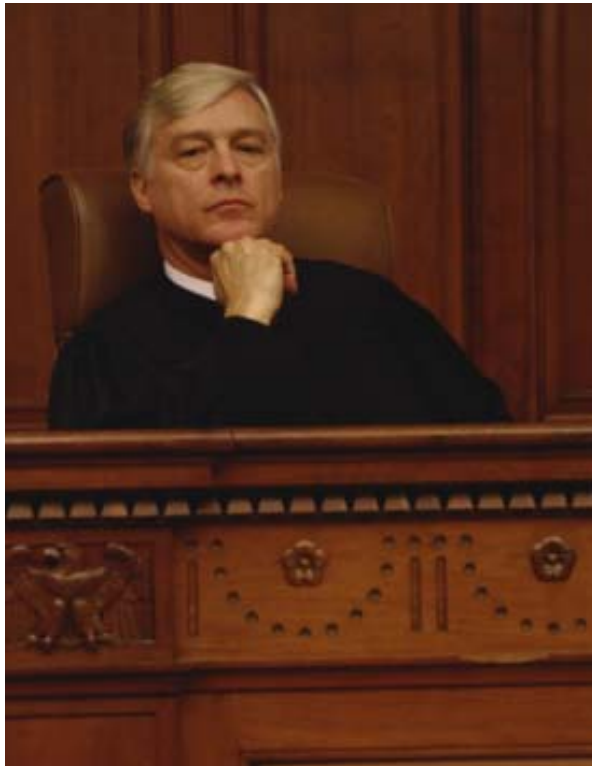


Case 3 (Continued)

- In addition to evaluating her medical issues, what other things should you discuss with the patient/family?
- Does the team have a right to speak to patient alone?
- Is her treatment refusal acceptable?
- What are the mother's rights?
- What is guardianship?
- When and how is it established?



WHAT IS GUARDIANSHIP?



- All adults ≥ 18 years have the right to make their own decisions
- People who can't make decisions because of a disability need a guardian
- Guardianship is a legal process with medical input, giving other person(s) legal authority over an individual
 - Individual loses the right to decide for him- or herself
 - Guardian becomes decision maker and ensures individual's needs are met
- Guardianship is not automatic; it is court appointed



GUARDIANSHIP

- Definition: legal relationship created when a person or institution named in a will or assigned by the court to take care of minor children or incompetent adults
 - Disability: person ≥ 18 who
 1. because of mental deterioration or physical incapacity is not fully able to manage his or her person or estate
 2. is a person with mental illness or developmental disability and who because of mental illness or developmental disability is not fully able to manage his or her person or estate
 3. because of gambling, idleness, debauchery or excessive use of intoxicants or drugs, so spends or wastes his or her estate as to expose the person with disability or dependents to want or suffering.

Illinois Guardianship and Advocacy Commission <http://gac.state.il.us/>
http://gac.state.il.us/osg/praguide2007/pg_def.html



WHO IS A GUARDIAN?



- A guardian seeks to promote interests and well-being of individual with a disability and to protect him/her from abuse, neglect and exploitation
 - Can be parent, family member, friend, agency, or institution
 - Must be 18 or older, no convictions for serious crimes
- The court gives preference to capability of guardian over relationship and gives consideration to preference of person with disability
- A guardian is a decision maker, not a caregiver, and does not have to live with ward




GUARDIANSHIPS

- ◉ Guardianships facilitate the independence and self-reliance of the ward. Wards typically allowed to do as much of their own care giving as is physically and mentally possible
 - Examples: availability and maintenance of care, making sure educational and medical services maintained and adequate



RESPONSIBILITIES OF A GUARDIAN

- Consult with and abide by person's with disability wishes to degree possible
 - Ensure proper care and supervision
 - Fulfill reporting requirements – typically, file annual report
 - Obtain court approval for:
 - Intrusive treatment (i.e., sterilization, psychotropic medication, withdrawal of life-prolonging treatment)
 - Placing person with disability in residential facility
 - Non-routine expenditures
 - Other controversial actions
- 

ALTERNATIVES TO GUARDIANSHIP

Consider legal, tax and government benefit ramifications of all decisions!
Consult an attorney who has experience with special needs law.

- **Shared bank account**

Helps person make decisions about their money

- **Representative payee**

Helps person with money from Social Security or Veteran's Administration

- **Health care proxy**

Makes decisions about person's health care if unable to make them

- **Trust**

Sets requirements about how person's money can be spent

- **Power of Attorney – Health Care or Property**

Gives legal authority to another to make certain decisions and act on person's behalf



STEPS TO GETTING GUARDIANSHIP

1. Required physician report

- Nature & type of disability, underlying diagnosis and manifestations, ability to make decisions or function independently
- Analysis and results of evaluations for person's mental, physical and educational condition
- Opinion if person is totally or partially incapable to making decisions
- Opinion as to appropriate living, treatment and rehab plan

2. Filing the petition/fee

3. Appointment of guardian ad litem

- Independent, objective attorney – meets person, family; reviews physician reports

4. Full hearing



SO... HOW MUCH DOES THIS COST?

- Petition filing fees
- Service of Process
- Surety on Bond fees
- Guardian ad Litem fees about 3 hours of legal time, more if contested
- Attorney fees about 3-6 hours of legal time, more if contested



ILLINOIS GUARDIANSHIP AND ADVOCACY COMMISSION

REGIONAL OFFICES WWW.STATE.IL.US/IGAC/

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GUARDIANSHIP CASE

- The need for guardianship was discussed with K.R. and her mother by the primary care physician.
- The lack of decision making capacity and guardianship was discussed with the inpatient team.
- After several discussions with K.R. and her mother, consent was obtained by both and dialysis was initiated two years ago.



SUMMARY: DISCUSSING GUARDIANSHIP



- Discuss guardianship with the family as soon as possible
- Connect or provide information sources
- Guardianship may be emotionally-charged issue for families
 - Need to involve the legal system
 - Recognize that disability is lifelong
- Consider framing discussion as way to be involved in young adult's safety and health
- Include young adult in discussions as much as possible

SPECIAL NEEDS TRUST

- Created to ensure that physically or intellectually disabled people will be able to inherit property intended for their benefit
 - Example: an individual inherits a parents' estate – if that exceeds their \$2,000 in assets, they could lose their SSI
- Trust money can only be used for non-essential expenses
- Important to file before 13th birthday
 - Trusts go into effect at 18 yoa and past 5 years of taxes are reviewed

