END OF LIFE DECISIONS IN GUARDIANSHIP CASES – A HOSPITAL'S PERSPECTIVE

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Agenda

* Overview of Types of End of Life Decisions
* Sources of Authority for Guardian Decision-Making
* Things to Know About Hospital Operations
* Perceived Issues/Potential Solutions
* Questions to Ask when Making End of Life Decisions
* Scenarios
* Recommendations
* Questions

Different types of End of Life Decisions

* DNR (Do Not Resuscitate)
* DNI (Do Not Intubate)
* Withdrawal of life-sustaining treatment (e.g., mechanical ventilation, dialysis, antibiotics, chemotherapy, artificial nutrition and hydration)
* Comfort Measures

Statutory Authority for Guardian Decision-making - Incompetency

- **N.C.G.S. § 35A-1241**
  - Describes powers and duties of guardian of the person, including consenting to medical care
  - Does not preclude consenting to end of life medical decisions

Statutory Authority for Guardian Decision-making - Incompetency

§ 35A-1241. Powers and duties of guardian of the person.

(a) To the extent that it is not inconsistent with the terms of any order of the clerk or any other court of competent jurisdiction, a guardian of the person has the following powers and duties:

(3) The guardian of the person may give any consent or approval that may be necessary to enable the ward to receive medical, legal, psychological, or other professional care, counsel, treatment, or service; provided that, if the patient has a health care agent appointed pursuant to a valid health care power of attorney, the health care agent shall have the right to exercise the authority granted in the health care power of attorney unless the Clerk has suspended the authority of that health care agent in accordance with G.S. 35A-1208. The guardian shall not, however, consent to the sterilization of a mentally ill or mentally retarded ward unless the guardian obtains an order from the clerk in accordance with G.S. 35A-1245. The guardian of the person may give any other consent or approval on the ward's behalf that may be required or in the ward's best interest. The guardian may petition the clerk for the clerk's concurrence in the consent or approval.

Statutory Authority for Guardian Decision-making - Incompetency

- **N.C.G.S. § 35A-1241**
  - Provides immunity for decisions made by the guardian relating to medical treatment
  - Prevents the guardian from being liable for damages to the ward or the ward's estate

Statutory Authority for Guardian Decision-making - Incompetency

§ 35A-1241. Powers and duties of guardian of the person.

(c) A guardian of the person, if he has acted within the limits imposed on him by this Article or the order of appointment or both, shall not be liable for damages to the ward or the ward's estate, merely by reason of the guardian's:

(2) Authorizing medical treatment or surgery for his ward, if the guardian acted in good faith and was not negligent. (1987, c. 550, s. 1; 2003-13, s. 4; 2007-502, s. 9.)

Statutory Authority for Guardian Decision-making – Abused, neglected or dependent juveniles

- **N.C.G.S. § 7B-600**
  - Describes powers and duties of guardian of a juvenile
  - The guardian can consent to necessary medical or surgical treatment

Statutory Authority for Guardian Decision-making – Abused, neglected or dependent juveniles

§ 7B-600. Appointment of guardian.

(a) In any case when no parent appears in a hearing with the juvenile or when the court finds it would be in the best interests of the juvenile, the court may appoint a guardian of the person for the juvenile. The guardian shall operate under the supervision of the court with or without bond and shall file only such reports as the court shall require. The guardian shall have the care, custody, and control of the juvenile or may arrange a suitable placement for the juvenile and may represent the juvenile in legal actions before any court. The guardian may consent to certain actions on the part of the juvenile in place of the parent including (i) marriage, (ii) enlisting in the Armed Forces of the United States, and (iii) enrollment in school. The guardian may also consent to any necessary remedial, psychological, medical, or surgical treatment for the juvenile. The authority of the guardian shall continue until the guardianship is terminated by court order, until the juvenile is emancipated pursuant to Article 35 of Subchapter IV of this Chapter, or until the juvenile reaches the age of majority.

Statutory Authority for Guardian Decision-making – Withdrawal of Life-Prolonging Measures

- **N.C.G.S. § 90-322**
  - Allows physician to withdraw life-prolonging measures in the absence of the patient's prior declaration of wishes with the concurrence of a court-appointed guardian.
  - The guardian has decision-making priority above that of family members.

Statutory Authority for Guardian Decision-making – Withdrawal of Life-Prolonging Measures

§ 90-322. Procedures for natural death in the absence of a declaration.

(b) If a person's condition has been determined to meet the conditions set forth in subsection (a) of this section and no instrument has been executed as provided in G.S. 90-321, then life-prolonging measures may be withheld or discontinued upon the direction and under the supervision of the attending physician with the concurrence of the following persons, in the order indicated:

(1) A guardian of the patient's person, or a general guardian with powers over the patient's person, appointed by a court of competent jurisdiction pursuant to Article 5 of Chapter 35A of the General Statutes; provided that, if the patient has a health care agent appointed pursuant to a valid health care power of attorney, the health care agent shall have the right to exercise the authority to the extent granted in the health care power of attorney and to the extent provided in G.S. 32A-19(b) unless the Clerk has suspended the authority of that health care agent in accordance with G.S. 35A-1208(a);

(2) A health care agent appointed pursuant to a valid health care power of attorney, to the extent of the authority granted;

(3) An attorney-in-fact, with powers to make health care decisions for the patient, appointed by the patient pursuant to Article 1 or Article 2 of Chapter 32A of the General Statutes, to the extent of the authority granted;

(4) The patient's spouse;

(5) A majority of the patient's reasonably available parents and children who are at least 18 years of age;

(6) A majority of the patient's reasonably available siblings who are at least 18 years of age; or

(7) An individual who has an established relationship with the patient, who is acting in good faith on behalf of the patient, and who can reliably convey the patient's wishes.

Statutory Authority for Guardian Decision-making – Withdrawal of Life-Prolonging Measures

- **N.C.G.S. § 90-322**
  - The statute gives a statutory defense to those acting pursuant to the statute.
  - It prevents those acting pursuant to the statute from civil or criminal liability.

Statutory Authority for Guardian Decision-making – Withdrawal of Life-Prolonging Measures

§ 90-322. Procedures for natural death in the absence of a declaration.

(d) The withholding or discontinuance of such life-prolonging measures shall not be considered the cause of death for any civil or criminal purpose nor shall it be considered unprofessional conduct. Any person, institution or facility against whom criminal or civil liability is asserted because of conduct in compliance with this section may interpose this section as a defense. (1977, c. 815; 1979, c. 715, s. 2; 1981, c. 848, s. 5; 1983, c. 313, ss. 2-4; c. 768, s. 5.1; 1991, c. 639, s. 4; 1993, c. 553, s. 29; 2007-502, s. 12.)

DSS Policy Manual

NC Division of Aging and Family Services
Family Services Manual
Vol. V. Adult and Family Services
Chapter VIII. Guardianship, § 6620; pp. 11-17

(f) Although the guardianship statute does not specifically address the issue of the withholding or discontinuing of life-prolonging measures, it does offer general guidance. The guardian may give any consent or approval needed to enable the ward to receive medical care, or "any consent or approval needed on the ward's behalf that may be required or in the ward's best interest". [G. S. 35A-1241(3)]. Decisions concerning life-prolonging measures, such as:

(1) entry of "do not resuscitate" orders or

(2) removal of life support should not be made without the approval of the guardian.

If consenting to the withholding of or discontinuance of life-prolonging measures is in the ward's best interest, there is nothing in the statute that precludes guardians from consenting.

Things to Know About Hospital Operations

* Resources are limited.
* Competition for beds at SNFs or other long term facilities is very stiff, especially for Medicaid patients.
* Hospitals see patients from many different counties and work with many different DSS agencies.
* Health care providers are very sensitive to ethical issues and providing care that is in a patient's best interests.
* "Social hold" problems.

Perceived Issues & Potential Solutions

DSS Concerns	Hospital Response
We don't know what the patient would want.	Your charge is to make a decision in the patient's best interests, not to substitute their judgment for yours.
We are worried that the family will sue us if they disagree with our decision.	There is statutory protection for guardian decision making, including the decision to withdraw life-prolonging measures.
We feel like we are causing the patient harm.	Our providers feel like they are prolonging a patient's suffering when he/she has no hope for any quality of life.
We feel like we are being bullied to make a certain decision.	Ask questions, use our resources – we want to help you make a decision in the patient's best interests.

Questions to Ask When Making End of Life Decisions

General rule of thumb –

What kind of questions would you ask if this was one of your family members?

Suggestions:

1. Ask to speak to the attending physician, not the resident, to get the patient's current status, prognosis, and best care options. You want to speak with the attending who has the overall picture of the patient's status, and not just a peripheral service provider.
2. Ask for an ethics consult when there are questions about the patient's or the family's wishes.
3. Ask for a palliative care consult.

Questions to Ask When Making End of Life Decisions

4. Ask about the patient's level of functioning, quality of life, level of pain, and hope of recovery. If the patient survives, what ongoing treatment will he/she need?
5. Ask if further care is futile, and if so, why. Will further care impact the quality of life and lead to improved outcomes, or will it just prolong life?
6. Ask whether the risks or potential discomfort of interventions outweigh any perceived benefits.
7. Ask whether the patient is actively dying.

Questions to Ask When Making End of Life Decisions

8. Ask whether the patient has any visitors.
9. Don't be afraid to ask questions of the physicians and caregivers directly – you do not have to handle conversations through social work or case managers.
10. If the physicians can't answer all your questions initially, don't be afraid to keep asking. Sometimes it takes a while for the physicians to have a full clinical picture of a patient's condition.

Scenario #1

* Patient in her 90s, in the ICU and intubated.
* No real life expectancy and the attending physician believes further treatment is futile because the patient cannot recover.
* Physician believes that comfort care is in the patient's best interests. "Comfort care" would not include aggressive treatments.
* The patient has no family or friends, and DSS appointed as guardian.

WHAT SHOULD THE GUARDIAN DO?

Scenario #1

WHAT REALLY HAPPENED:

* Refused to consent to a DNR or comfort care because unaware of the patient's wishes

THE RESULT:

* The patient remained full code, meaning she would receive CPR if her heart stopped, resulting in potentially cracked ribs, internal injury to organs, and significant pain with no hope of recovery.

Scenario #2

* Patient with DSS guardian needs either SNF or LTAC and is difficult to place, in part due to Medicaid status.
* Only one bed available in the state; time sensitive response required.
* The hospital is notified the bed is open and asks DSS guardian to sign the paperwork to place the patient.

WHAT SHOULD THE GUARDIAN DO?

Scenario #2

WHAT REALLY HAPPENED:

* Because of delays, the paperwork is not signed and the bed is lost.

THE RESULT:

* The patient must remain at the hospital, a less desirable location for the patient's needs.
* This situation affects lower income patients who have Medicaid more often than it does other patients.

Scenario #3

* Patient is an undocumented immigrant with family in South America, but no family in the U.S.
* DSS is appointed guardian.
* The hospital sets up a contract with an agency who will find a facility close to the patient's family in South America.
* The hospital will pay to transport the patient and for 240 days of care in the facility, which should be enough time to set up guardianship in the patient's home country.

WHAT SHOULD THE GUARDIAN DO?

Scenario #3

WHAT REALLY HAPPENED:

* DSS is concerned about liability. As a result, the hospital and DSS are unable to reach agreement on the arrangements.

THE RESULT:

* The patient is forced to remain at the hospital, which is not appropriate for his needs, and is in a different country from his family.

Scenario #4

* Child has been starved by his parents and is so emaciated that the child is in a coma and near death. DSS is appointed guardian.
* Health care team recommends DNR and withdrawal of support because there is no chance the child is going to recover.

WHAT SHOULD THE GUARDIAN DO?

Scenario #4

WHAT REALLY HAPPENED:

- DSS guardian would not consent to withdrawal of care or DNR due to pressure by parents – death of child raises parents' charges to murder.

THE RESULT:

- The health care team is deeply troubled because the best interests of the child were not kept paramount.
- Child remains full code, even though CPR would fracture the child's fragile ribs and damage internal organs.
- The child eventually died after transfer to a SNF.

Scenario #5

- Toddler who is very ill, bed-bound, and has spent his entire life since birth in the NICU.
- Child is full code, cannot be placed in a LTF because he is on TPN.
- Father is deceased. Mother lives across the state with her other children, some of which have special needs, and has her own health problems. She visits only occasionally; hasn't been to visit in three months, even though the hospital has set up transportation for her.
- The only clothes the child has are those that the hospital nurses have purchased for him with their own money.
- The hospital has contacted DSS for help.

WHAT SHOULD DSS DO?

Scenario #5

WHAT REALLY HAPPENED:

* DSS refused to take custody because the child "is in a safe place."

THE RESULT:

* The child is abandoned, with no quality of life.
* At one point the child coded and was resuscitated after a protracted period of time, which further impacted his medical status.
* No one is available to make medical decisions or to consider the option of palliative care.

Scenario #6

* Elderly man was mauled by a relative's dogs. He has essentially no skin left on his body and death will inevitably occur soon.
* Another relative has health care power of attorney, but is refusing to make end of life decisions because she is trying to avoid criminal charges being filed against the other relative.
* The family is constantly fighting over the patient's care and being disruptive in the hospital. The HCPOA relative is also trying to keep other friends and family from visiting.
* The hospital and police have contacted DSS for help.

WHAT SHOULD DSS DO?

Scenario #6

WHAT REALLY HAPPENED?

* DSS refused to take custody because the patient was going to die.

THE RESULT:

* The hospital is forced to rely on the decisions made by an individual who is being distracted by another's best interests.
* Patient eventually dies after receiving treatment that served only to prolong his life and not to improve his irreversible and extremely painful condition.

Recommendations

* Stay in regular contact with the health care team and keep the lines of communication open.
* Become familiar with hospital resources and use them.
* Either you or your attorney (or both) can contact the hospital's legal department if you aren't getting what you need from the health care team.
* Keep the handout list of questions and review regularly in end-of-life situations
* Remember your charge to act in the patient's best interests.

Questions?

* Contacts:
  UNC Hospitals Ethics Committee – (919) 843-1470
  UNC Hospitals Operator (can direct the call) – (984) 974-4131
  UNC Hospitals Police – (919) 966-3686

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