Decisions on life-sustaining treatment for the never-competent adult patient or for the formerly competent patient whose wishes are unknown are among the most troubling decisions healthcare providers face. Who should make treatment decisions for these patients, especially those having no known family or intimates? What criteria should the decision makers use? What role should the healthcare facility play in making the decision?

In Guidelines for State Court Decision Making in Life-sustaining Medical Treatment Cases (1992), the National Center for State Courts discusses medical decision making for adult and minor patients. The guidelines, written for use by state courts, are meticulous in presenting variations in state law. (Copies are available for $9.15 from the National Center for State Courts, 300 Newport Ave., Williamsburg, VA 23187-8798.)

The last item in the 1992 guidelines (and in an earlier edition published in 1991) is a “Decision Tree for Life-sustaining Medical Treatment Cases.” In early 1992 I modified the decision tree to reflect the process of decision making we were already following at St. John’s Regional Health Center, Springfield, MO (see Figure, pp. 50-51). I believed that such a resource could be helpful to members of St. John’s Institutional Ethics Committee and other staff who consult on patient cases. I extensively altered the branch dealing with adult patients who were never competent, did not appoint a healthcare agent, did not execute a living will, or never expressed wishes on life-sustaining treatment. The original tree only covered the court’s role in cases involving the use of life-sustaining medical treatment. The tree I developed gives the court the status of forum of last resort.

The following two cases, which occurred at St. John’s, illustrate how the decision tree can help facilities and surrogates make life-sustaining medical treatment decisions on behalf of patients who have never been competent or formerly competent.

Summary Whether to provide life-sustaining treatment for never-competent adult patients or formerly competent patients whose wishes are unknown is one of the most difficult decisions healthcare providers face. To help address this problem, in 1992 the National Center for State Courts published Guidelines for State Court Decision Making in Life-sustaining Medical Treatment Cases. The publication contains a decision tree to help judges determine whether decisions to continue or discontinue life-sustaining treatment is within the law.

A modified version of the tree has been developed for members of the institutional ethics committee and other staff who consult on patient cases at St. John’s Regional Health Center, Springfield, MO. The revised decision tree grew out of center staff’s extensive experience in making life-sustaining medical treatment decisions and essentially reflects St. John’s practice in this area. Persons who wish to use it should first run some of their own cases against the model to see if it fits their needs. They should also realize that no consensus exists in state laws regarding standards for making decisions in this area.

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Anne, with the support of her parents, has been undergoing dialysis three times each week because of insufficient kidney function. Her injury is so extensive and her condition so unstable that physicians question whether she will live no matter what treatment she receives.

If Edna’s condition stabilizes, she must undergo a craniotomy to clip the aneurysm. If she survives the craniotomy, she will probably have major neurological deficits. Edna left no advance directives; she had never spoken to her six adult daughters about her wishes. The daughters are evenly split on whether they believe Edna would want cardiopulmonary resuscitation withheld in the event of cardiac or respiratory arrest. They are also divided on whether they believe Edna would consent to the craniotomy. Repeated attempts to help them reach consensus fail.

The decision tree advises the facility to seek a court-appointed guardian in this case. The facility must inform the daughters that Edna must have made timely decisions on her behalf. If one of the daughters does not seek guardianship within a reasonable time (determined by the patient’s condition), the hospital will petition the court to have a public guardian appointed. The facility is not asking the court to decide on a treatment, but on who will speak as surrogate.

Although one daughter agreed initially to become Edna’s guardian, she decided her relationship with her sisters would suffer. So the facility ended up seeking a court-appointed public guardian.

A Wife’s Ambivalence Bill, a 38-year-old man with diabetes, has been bedridden for three years after a series of disabling strokes. He receives peritoneal dialysis three times each week because of insufficient kidney function. His mental status has steadily deteriorated, and he has been unable to make his own healthcare decisions. Bill’s wife, Anne, with the support of her parents, has been making Bill’s treatment decisions.

Anne’s mother helped Anne care for Bill at home for more than two years. Bill’s care became too much for Anne, and she was worried about how his presence would affect their five-year-old son. Although her mother opposed the decision, Anne moved Bill to a nursing home. Anne and her mother visited Bill regularly.

In the past month, Bill’s condition deteriorated, causing his body temperature to rise. He sweats copiously and continuously. The bed clothes and his pajamas must be changed many times each day. Still, he complains of feeling cold.

Bill is now hospitalized because of an open sore on his leg. The nephrologist, observing Bill’s discomfort, suggests to Anne that Bill’s dialysis be suspended. Bill would be allowed to die.

Bill had never expressed wishes about treatment if he became incapacitated, and he had stoically borne his illness. Anne believes allowing Bill to die would be the right thing to do—the best for Bill and their son. Anne’s mother is appalled by the idea. Because Anne depends on her parents for emotional support, Anne feels unsure of her decision.

All of Bill’s caregivers, including Anne’s mother, recognize Anne’s moral right and responsibility to make healthcare decisions on Bill’s behalf. Anne decides it would be best to discontinue dialysis. Is there a basis for challenging this decision? Yes, because of Anne’s expressed ambivalence about her decision. Bill’s physicians and hospital staff would like Anne and those who provide her with emotional support (her parents) to be at peace with the decision. A review is indicated to resolve these issues.

At the facility’s suggestion, Anne met with the persons she believed could help her address her concerns. At the meeting her parents, siblings, mother-in-law, minister, a social worker, two of Bill’s physicians, and an ethicist voiced their concerns, affirmed Anne’s right and responsibility as chief surrogate, and said they would support the decision Anne believed was best. Two days after the meeting, Anne, with her family’s support, asked that Bill’s dialysis be discontinued.

A Good Tool Staff at St. John’s find the decision tree to be a worthwhile basic reference tool, one that has grown out of the staff’s extensive experience with making life-sustaining medical treatment decisions. The tree essentially reflects St. John’s practice in this area.

Persons who wish to use this tree should first run some of their own cases against the model to see if it will serve their needs. Additionally, they should realize that no consensus exists in state laws regarding the standard for decision making for incompetent adult patients, according to Thomas L. Hafemeister, JD, PhD, project director for Decision Making Regarding Life-sustaining Medical Treatment Project of the National Center for State Courts. Any reader wishing to use the tree I have developed should check with his or her facility’s legal counsel.

See decision tree on next page
DECISION TREE FOR LIFE-SUSTAINING MEDICAL TREATMENT (LSMT) FOR ADULTS

**What is patient's current decision-making capacity?**

- Patient does not have capacity.
  - Did patient, while competent, appoint a healthcare agent, write a living will, or otherwise express explicit wishes?
    - Patient appointed healthcare agent.
      - What is healthcare agent's informed decision?
        - Do not forgo LSMT
          - LSMT not forgone
        - Forgo LSMT
          - LSMT forgone
    - Patient wrote living will or otherwise expressed explicit wishes.
      - What is nature of those explicit wishes?
        - Forgo LSMT
          - LSMT not forgone
        - Do not forgo LSMT
          - LSMT not forgone

**What are patient's current informed wishes?**

- Do not forgo LSMT
- Forgo LSMT

**Any overriding state interests?**

- Yes
  - LSMT not forgone
- None
  - LSMT forgone

**Is there an intimate of the patient who can infer patient's wishes for treatment from consistently held other wishes, beliefs, values, and goals? Or, if multiple intimates, do they agree on what patient would wish for treatment? Or, do multiple intimates agree to defer to the judgment of one? Or, if patient's wishes cannot possibly be inferred, does surrogate(s) indicate concern for patient's best interests?**

Continued
Seek court appointment of a guardian. (Ask an intimate of patient to pursue this. If none is willing, or if they are slow to respond, the health center may petition the court.)

**What is surrogate's informed decision?**

- Do not forgo LSMT
  - Is there a basis for challenging this decision?†
    - Yes
      - Is this decision upheld on review?†
        - Yes
          - LSMT not forgone
        - No
          - LSMT forgone
    - No
      - LSMT forgone

- Forgo LSMT
  - Is there a basis for challenging this decision?‡†
    - Yes
      - Is this decision upheld on review?‡†
        - Yes
          - LSMT forgone
        - No
          - LSMT not forgone
    - No
      - LSMT not forgone


* Overriding state interests could be the preservation of life, the prevention of suicide or homicide, the need to uphold the conscience (integrity) of the healthcare providers, or the interests of minor children. Note that the "conscience" of a healthcare facility would be found in its mission and philosophy statements and in its policies.

† In addition to state interests, other bases for challenging a decision would include evidence of conflict of interest on the part of the surrogate(s), questionable capacity of the surrogate(s), questions about the commitment of the surrogate(s) to this decision, or concerns that conflict among the surrogates is insufficiently resolved.

‡ Review should first be sought among the key decision makers. Any or all of these persons may request the assistance of other healthcare providers (e.g., nurses, physicians, psychologists), other friends of the patient or surrogate(s), other resource persons (e.g., social workers, chaplains, ministers), hospital administrators, an ethicist, or an ad hoc committee composed of any of these persons. As a last resort, if the issue remains unresolved, recourse may be made to the courts.