SPEECH: A PERSPECTIVE FROM THE BENCH

THE HONORABLE EDWARD D. REIBMAN*

It is an honor to be among such distinguished, nationally recognized participants in this symposium. In the time allotted to me, I would like to give you a sense of how some of the issues that we are discussing today present themselves in the courtroom and the kinds of decisions the trial judge is called upon to make. In doing so, I will refer to a case that came before me in February, 2010. The facts are real and unchanged.

K.K. is a fifty-five year old woman. She was adjudicated incapacitated in 2005. She has had multiple sclerosis for many years, which has caused her to become a quadriplegic. She has been on continuous tube feedings through a percutaneous endoscopic gastronomy tube that was placed in 2005. She resides in a rehabilitation center, but has had multiple hospital admissions for recurrent urinary tract infections and recurrent aspiration pneumonia. In fact, she has had respiratory failure requiring mechanical ventilation four times over the last two years, and then another bout in early February. That last episode also resulted in respiratory failure and she was placed on mechanical ventilation.

K.K. makes some vocal sounds, but it is very difficult to understand exactly what she is saying. According to the doctor, who is board certified in internal medicine, pulmonary medicine, critical care, and hospice and palliative care, there is really no ability to have interaction at all with her.

During her most recent hospital admission, K.K. seemed to recover over the course of a week. She was extubated, removed from the ventilator, and transferred from the Intensive Care Unit (ICU) to a medical/surgical floor. However, she was transferred back to the ICU within twenty-four hours for recurrent respiratory failure and placed back on the ventilator. Since that time, she has had slow improvement in her pulmonary status to the point where, during the last forty-eight hours, she was again extubated and removed from the ventilator. Her tube feeds have restarted and she is on antibiotics for her pneumonia and urinary tract infection. She is potentially able to be discharged from the hospital to her rehabilitation facility within the next twenty-four to forty-eight hours.

According to the doctor, K.K.'s overall prognosis is quite poor. He opines that we are now seeing, and will continue to see in the near future, a series of re-admissions to the hospital related to her pulmonary status, i.e. more aspiration pneumonia, mechanical ventilation and, according to the doctor, pain.

The question before the court is whether to authorize the placement of a Do Not Resuscitate order ("DNR") on K.K.'s chart.

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* Judge, Court of Common Pleas of Lehigh County, Pennsylvania.

When K.K. was adjudicated in 2005, her mother was appointed to be the plenary guardian of her person. That decision attempted to follow the Pennsylvania Supreme Court case of *In re Fiori*.[1] In that case, the Supreme Court noted the right at common law of "every individual to the possession and control of his own person."[2] The doctrine of informed consent for medical procedures has developed from that principle. And the logical corollary of that principle is that a patient then has a right "to refuse treatment and to withdraw consent to treatment once begun."[3] The Supreme Court went on to hold that the implementation of that right—that is, the ability to give consent, for an incapacitated person, in the absence of an advance written directive having been executed prior to becoming incapacitated—could be exercised by the "substituted judgment" of a close family member on behalf of the incapacitated person.[4] The Supreme Court concluded that empowering a close family member to substitute his or her decision for the incapacitated person would most likely effectuate as much as possible the decision the incapacitated person would make if capacitated.[5] In arriving at that determination, the Supreme Court assumed "[c]lose family members are usually the most knowledgeable about the patient's preferences, goals, and values; they have an understanding of the nuances of our personality that set us apart as individuals . . . [and] a special bond with the . . . patient."[6]

In K.K.'s case, the 2005 decree stated the guardian of the person was empowered to provide any required consents or approvals on her ward's behalf. As the guardian of K.K.'s person, K.K.'s mother subsequently consented multiple times to the insertion of the feeding tube and to placing K.K. on mechanical ventilation. She now refuses to authorize the DNR order.

K.K. had apparently executed an advance directive in 2004, nine months before she was adjudicated incapacitated. The existence of that advance directive was unknown to the court in 2005, and became available only recently. The document is now nearly six years old.

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1. 673 A.2d 905 (Pa. 1996).

2. *Id.* at 909 (quoting Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891)).

3. *Id.* at 910 (quoting Mack v. Mack, 618 A.2d 744, 755 (Md. 1993)).

4. *Id.* at 912. The court stated:

> We believe that where a . . . patient has not left instructions as to the maintenance of life sustaining treatment, the only practical way to prevent the destruction of the . . . patient's right to refuse medical treatment is to allow a substitute decision maker to determine what measures the PVS patient would have desired in light of the patient's prognosis.

Id.

5. *Id.*

6. *Id.* (citing THE PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 128 (1983), *available at* http://bioethics.georgetown.edu/pcbe/reports/past_commissions/deciding_to_forego_tx.pdf).

The advance directive states that in a time when K.K. is in a terminal condition or a state of permanent unconsciousness, she did not want tube feeds or any other artificial or invasive form of hydration or nutrition, or be transfused with blood or blood products. The hospital where K.K. is now being treated is sufficiently concerned about the apparent conflict between the "substituted judgment" of the "close relative"—in this case, K.K.'s mother—and the nearly six-year-old advance directive of the patient, and has asked this court for direction.

Specifically, the doctor believes the mother is not being faithful to K.K.'s wishes as expressed in her advance directive. He believes decisions are being made outside of what K.K. would have wanted for herself. He bases that on his reading of K.K.'s advance directive and the many conversations he has had with other members of K.K.'s family, who have said that given K.K.'s values and how she lived her life, she would not have wanted tube feeds or a return to mechanical ventilation.

The doctor has another concern about the mother. The mother denies K.K. has multiple sclerosis. She believes K.K.'s problem is an esophageal infection that is treatable. She thinks there is a conspiracy among the physicians to protect a neurologist who was once involved with K.K.'s care and for that reason the medical providers are not treating the esophageal infection. The doctor has no doubt whatsoever that K.K. has multiple sclerosis, and he also has no doubt that the mother, the close relative, substituting her judgment for K.K. is inappropriate.

So now we have a number of issues to address: *In re Fiori* instructs us to follow the clearly stated wishes of the patient before becoming incapacitated. At some point, however, does a nearly six-year old advance directive become stale or dated, entitling the court to modify or disregard it? And if so, on what basis? Are the wishes of other family members relevant to this inquiry?

Next, K.K.'s advance directive is premised upon her being in a state of permanent unconsciousness or in a terminable condition. Although she had difficulty communicating, she clearly is not in a permanent state of unconsciousness.

Is her condition "terminal"? In the case of *In re DLH*, a fifty-year-old male who was profoundly mentally retarded since birth, became ill with aspiration pneumonia, the same problem confronting K.K.[7] D.L.H.'s physicians determined his medical condition required he be placed on a mechanical ventilator to assist him in breathing.[8] D.L.H.'s court-appointed guardians attempted to decline the treatment stating mechanical ventilation was not in D.L.H.'s best interest.[9] The hospital, nonetheless, placed D.L.H. on a mechanical ventilator for approximately three weeks, at which time his aspiration pneumonia subsided to the point where he no longer required ventilation treatment.[10] The court concluded that, in at least D.L.H.'s case,

7. 967 A.2d 971, 973-74 (Pa. Super. Ct. 2009).
8. *Id.* at 974.
9. *Id.*
10. *Id.*

there was no evidence his aspiration pneumonia was a serious, permanent medical condition, but was, instead, "a curable medical condition that required temporary mechanical ventilation."[11]

Isn't that K.K.'s situation? Remember, she seems to have stabilized, was taken off the ventilator and may be discharged from the hospital within the next day or two and be returned to her rehabilitation facility, which has been her permanent home.

At what point is something "end-stage" or a "terminal condition"? Can we consider K.K.'s multiple sclerosis as "end-stage" or a "terminal condition," or because she had it for so long, was that her natural state of being? At what point does a progressive disease, such as multiple sclerosis, no longer be one's "natural state of being" but, instead, become so advanced that it is terminal? As to this issue, there is apparently no agreement within the medical profession.

Assuming we should modify or disregard the advance directive, how appropriate, under the circumstances here, is it for the mother to substitute her judgment for that of K.K., her daughter? Would it make a difference if instead of being the court-appointed guardian, the mother had been designated some years earlier by K.K. to be her agent under a health care power of attorney?

Toward the end of the hearing, K.K.'s sister stepped forward. She said she is a speech pathologist and trained to communicate with eye blinks. She said when she told K.K. what the situation was and asked her specifically whether she wanted the tube feedings to be stopped, K.K. blinked her eyes twice for "no", and when asked if she wanted to continue receiving the tube feedings, she blinked her eyes once for "yes".

From that testimony, can we conclude K.K. has changed her mind, and is now repudiating her own advance directive? Is she competent to do that?

These cases are fact-specific and extremely nuanced. As they are difficult for the family and for the healthcare providers, they are difficult for the court as well. The evidence upon which such decisions are based is often dated, circumstantial, collateral or ambiguous, and the law is not particularly well developed.

So, the question before the court—or for our purposes today, before the house—is this: Do we authorize the hospital to withhold mechanical ventilation upon any readmission of K.K.?

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11. *Id.* at 984-86. The court went on to state that "the state's interests in preserving life and maintaining the ethical integrity of the medical profession are substantial" and "[o]n balance, D.L.H.'s personal right to refuse medical treatment, as maintained through Appellants, carries little weight because Appellants failed to establish that death was (or would be) in D.L.H.'s best interest." *Id.* at 986. The court further noted that *In re Fiori* did not alter these conclusions. *Id.*