

**G**eorge is a twenty-three-year-old young man with Down's syndrome. Until three years ago, he lived at home with his parents and had a part-time job washing dishes at a restaurant. When George turned twenty, he and his parents decided that living in a group home would be a good experience for him and he entered into his new life enthusiastically. George and his parents have a good relationship and they have always encouraged him to be prudently independent. George has often brought his good friend, Stan, home for supper. They both live at the home for developmentally disabled young men, and his parents are happy that he has found a friend.

But one Saturday, George and Stan were waiting for a bus and in the course of some horseplay, Stan accidentally pushed George too hard and he fell in front of the bus. He suffers from severe brain injury, has no swallowing reflex and has had a feeding tube placed. A year has passed. The parents visit George each day at the rehabilitation hospital, but he has shown no signs of consciousness. Stan is devastated by George's condition and the parents permit him to visit once a week, although the young man would prefer to be there every day.

The doctor has requested a Do Not Resuscitate Order for George and the parents have signed it although they are not legally declared his guardians. But now they are talking to the doctor about removing the feeding tube. It is not instrumental in restoring him to any quality of life and they realize that it would be better that George simply be allowed to die.

George and his parents live in a state that requires "clear and convincing evidence" for withholding/withdrawing nutrition and hydration, and they are feeling hard pressed to provide such evidence. They have not talked with George about dying; in the beginning, it was not relevant; now they wish they had helped him make his advance directive. Even if they have themselves declared his guardian they live in a state that does not permit guardians to withhold or withdraw life-sustaining treatment.

They ask you for advice.

## Case Study

### What Should We Do?

Case compiled and questions posed by Rosemary Flanigan, director of ethics committee education and training, Midwest Bioethics Center, Kansas City, Missouri.

## Discussion

### QUESTIONS

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- The conflict in this case is between law and ethics. Address first what is the ethical thing to do here.
- Is it ethically appropriate to remove the feeding tube? What is your argument?
- Should the parents ask Stan and the other boys at the group home if George has ever expressed an opinion on the subject of end-of-life?
- Is the ideal here that the parents use a substituted judgment or a best interest judgment?

(Substituted judgment is one in which the surrogate or proxy decision maker can speak the judgments previously articulated by the patient; best interest judgment is one in which decision makers do not know the patient's wishes but choose to do what reasonable people would decide under like circumstances or in similar positions.)

- Distinguish between competency and decisional capacity. Even if George has been declared incompetent, could he still have decisional capacity to make out an advance directive?
- What kind of ethical reasoning are you using — virtue, principles, consequences?
- If the Disabled Advisory Group for Brain Injury protests your position, can you defend it?