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Section: PERSPECTIVE

The Schindlers' wish

THE MORALIST

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The legal battle over the fate of 41-year-old Theresa Marie "Terri" Schiavo may be close to an end. Judge George W. Greer of Pinellas County, Fla., has ruled that at 1 p.m. on Friday, Terri's husband, Michael Schiavo, "shall cause the removal of nutrition and hydration." For years, over the objections of Robert and Mary Schindler, Terri's parents, Michael has sought authorization to remove the plastic feeding tube that keeps Terri alive.

Now that Michael can legally end his severely disabled wife's life, should he do it? And should he have spent all those years seeking her death, anyway? The Schiavo case raises ethical questions about whether human life is too precious to end, but also about whether we have a moral obligation to yield to the wishes of fellow family members who want to keep helpless kin alive.

Terri Schiavo lies helplessly on a hospice bed in what doctors call a "persistent vegetative coma," fed through a tube. She lost consciousness when she was 25, after an unexpected heart attack cut off the flow of oxygen to her brain.

The Schindlers have argued in the Florida courts that their daughter is not clearly in a hopeless coma, and that she could perhaps benefit from therapy, if only Michael would allow it. Terri opens and shuts her eyes. She even responds to sounds and touch. However, medical experts have persuaded the Florida courts that Terri's grunts, grimaces and smiles - some of which have been captured on poignant video by her family- are not the products of self-aware, voluntary behavior.

The Schindlers question their son-in-law's motives for wanting their daughter dead. They have accused Michael of misappropriating Terri's share of a medical malpractice award won in the case he brought against the doctor who failed to diagnose Terri's abnormal, heart-stopping potassium level. The Schindlers have also accused Schiavo of wanting to get rid of Terri so that he can marry the girlfriend by whom he has already fathered two children. In fact, on Feb. 28, Mr. Schindler filed for divorce on behalf of Terri, arguing that Michael is guilty of adultery and abandonment.

Terri's parents have filed a flurry of court petitions aimed at prolonging her life, including requests for additional testing and medical evaluation. Fearing that their legal maneuvers will ultimately fail, the Schindlers have requested that family members or a willing nurse be allowed to attempt natural feeding when artificial feeding is discontinued. Should Terri die, the Schindlers have filed a petition demanding that Michael Schiavo bury rather than cremate his Catholic wife's body.

Displays of religiosity notwithstanding, Michael Schiavo has questioned the purity of the Schindlers' motives. In an appearance on "Larry King Live," Schiavo asserted that Mr. Schindler angered him by greedily demanding a share of Terri's money.

So far as the courts are concerned, this case is supposed to be about Terri's rights, not her family's competing wishes. In the United States, each individual has a right to refuse life-sustaining medical care. Feeding tubes, chemotherapy and respirators may not be imposed on the unwilling.

A New Jersey woman's case resulted in the first major American court decision basing a comatose individual's right to die on the right to privacy: Karen Ann Quinlan of Byram had been in a vegetative coma for a year when her father won the right in 1976 to remove her from a respirator. In another important case - Cruzan vs. Director, Missouri Department of Health - the U.S. Supreme Court held in 1990 that the 14th Amendment guarantee of liberty includes the right to refuse life-sustaining medical care.

Thus, it is Terri Schiavo's own constitutional right to privacy that explains why the Florida courts are forced to grant her husband permission to order the removal of her feeding tube over the objections of her parents. When people are unable to choose for themselves, legal guardians can choose for them. Constitutional privacy requires that legal guardians choose on the basis of what the courts deem "clear and convincing evidence" of the individual's own preferences.

Millions of Americans have executed "living wills" or "advance medical directives" in recent years. These written documents set out preferences for medical treatment. Terri Schiavo had no living will or advance directive. But her husband, along with some of her friends and acquaintances, say Terri revealed in conversation that she most certainly would not want to continue living in a persistent, brain-damaged state. This is all the evidence of choice the courts required before authorizing Terri's death.

In October 2003, the last time a court authorized Michael to have Terri's feeding tube removed, the Florida state legislature and governor hastily intervened to save her life. A statute known as "Terri's Law" was enacted. The law authorized the governor to issue a one-time executive order preventing the termination of life support over the objections of a close family member. As soon as Gov. Jeb Bush issued his order, Terri's feeding tube went back in and remains in place today.

But Michael Schiavo is set for what he hopes is a final feeding-tube removal on Friday. Right-to-life and disability activists with no personal ties to Terri are urging Schiavo to keep his wife alive. They say no innocent human being should be intentionally killed, especially by starvation.

Schiavo may be justified in ignoring the pleas of strangers. But is he justified in turning down the pleas of his wife's parents, who have formally offered through their lawyers to assume complete responsibility for Terri's care?

Students of bioethics know the true story of Lia Lee, the epileptic child of Hmong immigrants to California. As described in Anne Fadiman's 1997 book, "The Spirit Catches You and You Fall Down," 7-year-old Lia was declared brain dead after a major seizure and infection.

Her mother, Foua, and father, Nao Kao, stunned doctors when they asked to take Lia home. They saw no reason to part with their daughter just because she was unable to move about, speak or think. Fully expecting the child to die soon, puzzled physicians released Lia to pacify her angry, heartbroken family.

Lia survived. The Lees brushed Lia's hair until it shone like black satin, rubbed her skin rosy and dressed her floppy body in beautiful clothes. They fed her with ordinary utensils, not through the plastic tubes supplied by the hospital.

Perhaps the Schindlers are a bit like the Lees. Perhaps the Lees' wish to continue an intimate relationship with their daughter despite her brain-damaged state is their wish, too. Outsiders cannot pretend to know the Schindlers' actual motives. But parents in the position of the Schindlers could, in theory, find rich meaning and satisfaction in a shared existence with a person classified by others as comatose, vegetative and hopeless.

Morality, I believe, calls on people like Michael Schiavo to take account of the sincere wishes of emotionally involved close kin. But genuine moral sensitivity to in-laws will not result in yielding to them in every case. Like law, morality demands that we respect the life-and-death wishes that we can reasonably impute to

persons who cannot speak for themselves.

Based on the available evidence, it appears that force-feeding Terri disrespects her wishes and is a kind of cruelty. Michael Schiavo's efforts to let his wife die are thus morally defensible - as long as he is relying on sound medical advice and he has been truthful about the certainty of his wife's preferences.

There is still a place in the world for the Schindlers' wish, however. Where good evidence of what loved ones in long-term comas would want for themselves is lacking, erring on the side of preserving life can serve at least two worthwhile goals: expressing the special value we ought to place on human existence and respecting the wishes of family members for continued intimacy on their own terms.

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