COMMENTARY

by Ginny Morrison, JD and Debra Gerardi, RN, MPH, JD
Health Care Mediations, Inc.

Terri Schiavo's story focused the health care community anew on the great pain and many nuances of making life-sustaining treatment decisions on behalf of another. For many, the public debate held echoes of what we have faced or will face, when deciding for those we love. We were also reminded of our own disability and mortality. Health care professionals and organizations also worried about their roles in a family firestorm and how to strike a balance, exercising ethical professional judgment, not subjecting patients to unnecessary treatment, and honoring the patient—all this under the threat of being drawn into ugly court proceedings and harsh media attention.

Amidst the tragedies of Schiavo's story was the potential damage done by turning to the courts and legislature to make the most personal of decisions. After Schiavo's 1990 collapse and subsequent medical treatment (that may have involved error), her family endured an 11-year series of court proceedings—with no fewer than 23 separate actions and appeals—aimed at deciding which of them had legitimate decision-making authority and whether the decisions made were in her best interest. Florida then passed a law allowing the governor to exercise the power, customarily belonging only to the courts, to put a hold on removing life-sustaining interventions in specific circumstances like Schiavo's.

In these forums, our loss becomes blame, our uncertainty becomes fury. The most private emotions and ethical quandaries are laid open for public view and harden into simplified legal positions and sound bites. With each new legal procedure, the opportunity to come to terms with our own range of emotions is deferred. Rage mounts and is channeled into false certainty and righteous indignation and is then directed as attacks that harm the accused and deplete the accuser. Helping the loved one merges with punishing the other, which is a hollow substitute, and our suffering is prolonged.

A question then arises: Are there ways to reduce this suffering? If patients and families defer to the courts and legislatures for decisions they can live with in peace, and conflict results instead, what else can be done to meet their needs?

There are many conversations needed at such crucial times, but they seldom occur. While family members certainly have the patient's welfare in mind, the effects of poor communication can be destructive.

We can only speculate, but there are several predictable layers of experience for the people surrounding Terri Schiavo. Those close to her are likely to see their primary roles as taking care of someone they love. When there is nothing they can do, the powerlessness robs them of a piece of their identity. The dissonance and frustration often get redirected into driven attempts to control

something, which may mean challenging and trying to control caregivers and other family members.

Facing sudden loss, especially of those young and healthy, makes people struggle to make sense of the unexplainable. Schiavo's family may have hoped that if her tragedy had a reason, this would bring comfort. With such an injury to fairness, families often feel compelled to create something that restores their belief that the world is just, and they may lose sight of the fact that some things cannot be made right.

Mistrust comes from seeing others as keeping us from these efforts that now feel so crucial—protecting, taking care, regaining control, making sense, restoring justice. We see ourselves as noble and the other as demonized; a two-dimensional symbol of what is wrong replaces a complex human being. We are blind to whether the other is motivated as we are, but using a different method. And this escalates with each fresh disagreement and wound. In this context, for example, Terri's parents, Bob and Mary Schindler, reportedly continued to believe that Michael Schiavo wanted to stop nutrition and hydration to gain access to Terri's malpractice verdict award, even after he offered to donate it to charity.

Of course, many experience guilt—guilt for being unable to control natural forces to protect a loved one and guilt for the failures and omissions in our earlier relationship, with regret that we may never be able to undo that. Guilt over paying attention to the event's impact on ourselves, rather than thinking only of the patient, may prevent self-examination. But absent self-reflection, those unstated emotions may dominate how we act even more.

Many people need the chance to recognize these various effects and to have their reactions validated. Few have the skills to do this on their own, especially in a time of crisis. Health care and conflict resolution professionals can offer this kind of support through facilitated conversation. It is an element of care when ethicists, health care professionals, and clergy with the knowledge and skills—or mediators when needed—help families examine these issues. Only then can each hear the impact on the others, understand hopes and motives, and consider that different choices may be different means toward the same end. Often this can reduce hostility and help people begin to make peace with human loss. Reconciliation may be possible, and, at the very least, families can allow opposing views to co-exist without continuing battle.

Had Michael Schiavo and Bob and Mary Schindler had this opportunity, chances are greater that they would not have lived out their personal tragedy in the glare of publicity and remained in heightened conflict for 14 years. When we provide patients and families with options for managing such trying circumstances without going to court, it is a component of our mission to heal.