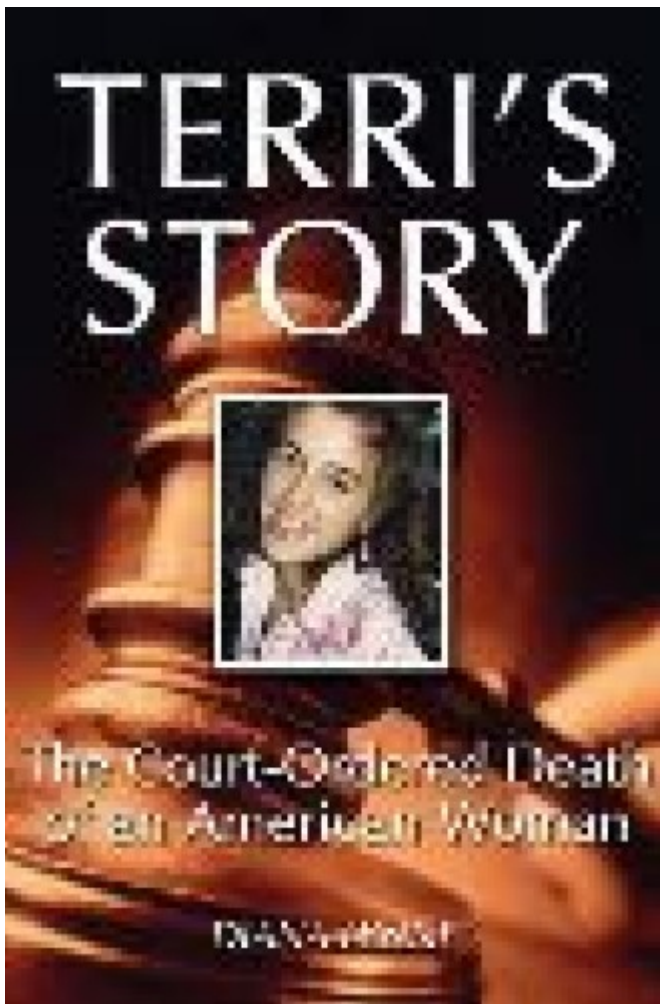


# **A Life That Matters/Terri's Story/Fighting for Dear Life/The Case of Terri Schiavo**

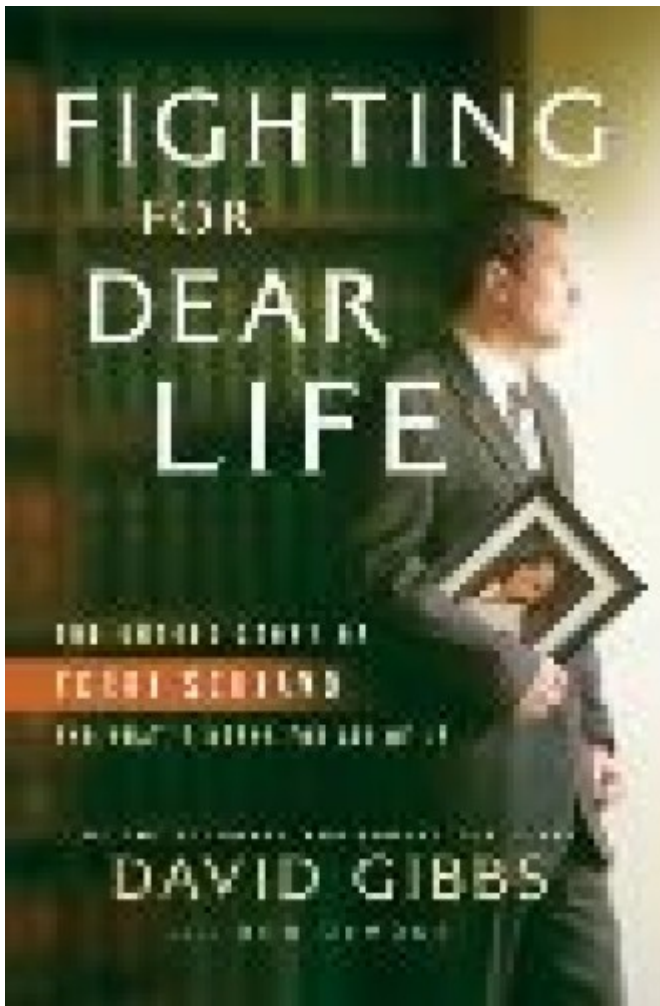
reviewed by [Stephen E. Lammers](#) in the [September 4, 2007](#) issue

## **In Review**



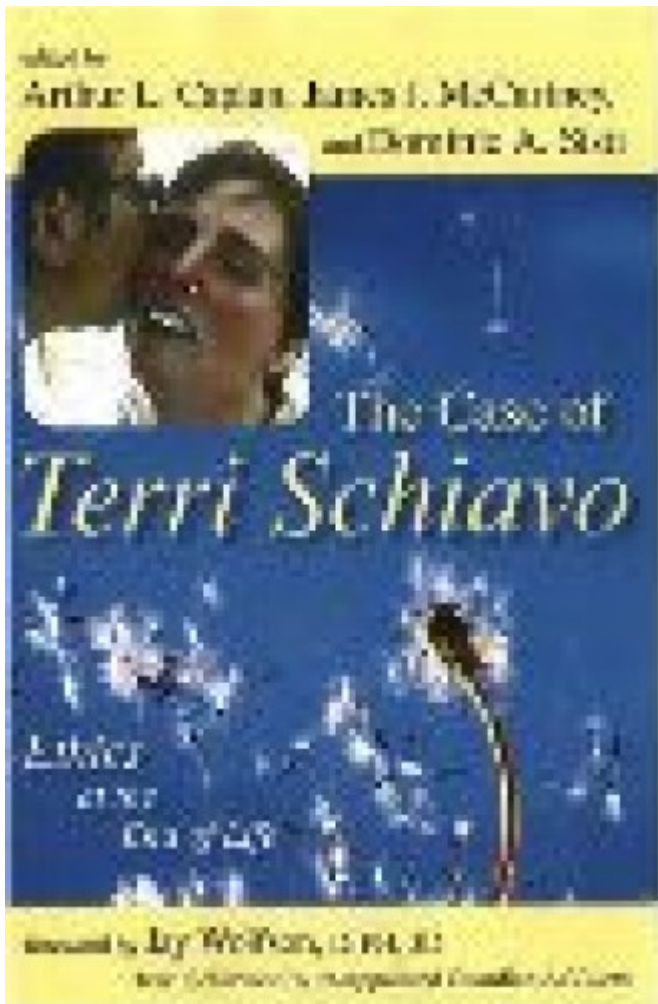
## **Terri's Story: The Court-Ordered Death of an American Woman**

Diana Lynne  
WND



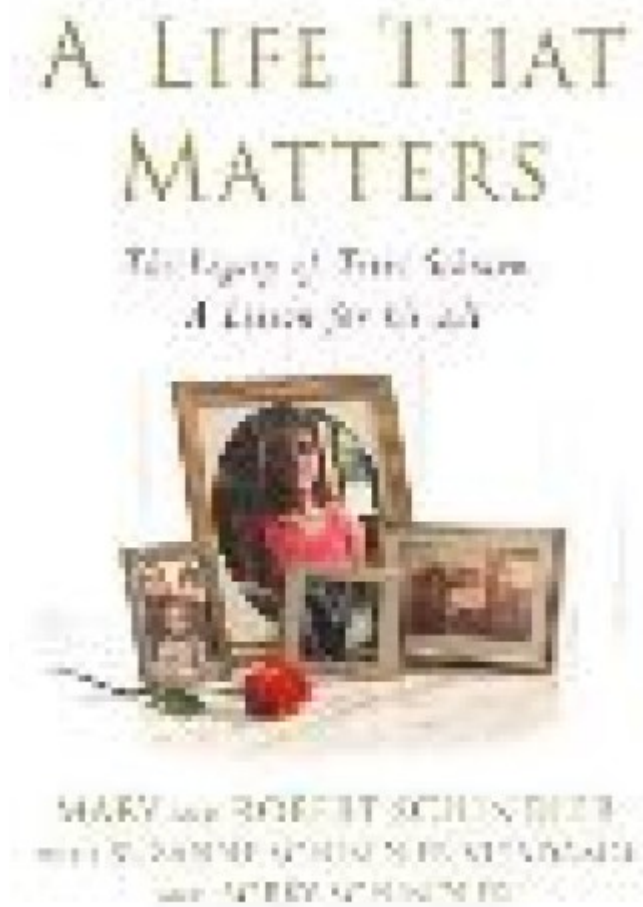
**Fighting for Dear Life: The Untold Story of Terri Schiavo and What It Means for All of Us**

David Gibbs, with Bob DeMoss  
Bethany House



## **The Case of Terri Schiavo: Ethics at the End of Life**

Arthur L. Caplan, James J. McCartney and Dominic A. Sisti, eds.  
Prometheus



## **A Life That Matters: The Legacy of Terri Schiavo—A Lesson for Us All**

Mary and Robert Schindler, Suzanne Schindler Vitadamo and Bob Schindler  
Warner Books

It has been over two years since the death of Terri Schiavo. Three of these books offer personal stories of her last years of life: from the perspective of her family (the Schindlers), a reporter (Lynne) and an attorney for the family (Gibbs). The fourth, edited by Caplan, McCartney and Sisti, is a collection of primary documents as well as commentary on the case.

Most readers recall the outline of the story, which began with the 911 call that was placed in 1990 when Terri suffered cardiac arrest. She was successfully resuscitated but suffered hypoxic brain injury. Her husband, Michael, subsequently brought a lawsuit on her behalf, won the suit and, with the assistance of her family,

endeavored to care for Terri. Later, Michael and the family disagreed about what should be done for her.

Terri did not have a living will and could not speak for herself. Eventually she was judged to be in a persistent vegetative state. Her husband reassessed what should be done for her in these circumstances. According to one of the court-appointed guardians, Michael remembered that Terri had said that she never wanted to live in a condition such as the one she was in, and he sought permission from the courts to stop the nutrition and hydration that was being supplied through a feeding tube. The Schindlers thought that this was contrary to what their daughter would have wanted and opposed Michael every step of the way. After a prolonged court battle, Michael's view prevailed in court. Terri was taken off the feeding tube and died within two weeks, in March 2005.

The Schindlers rejected Terri's diagnosis, arguing that she had been denied good physical and speech therapy that might have made a significant difference. Their lawyer argues that she was responsive to her environment, contrary to the assessments of the court-appointed physicians. Lynne issues a long critique of what she takes to be the shortcomings of the legal system in Florida, which permitted Terri's death. The Caplan volume includes documents relevant to the continuing debate, including a disagreement among Roman Catholics over what is required in terms of medically supplied nutrition and hydration.

If this were simply a story about a family dispute, the case would not have achieved the notoriety that it did. But it is also a story about the proper use of legislative and executive power. Furthermore, the Schiavo case highlights some powerful currents in American culture that sometimes run contrary to one another. I will show this by speaking of two intuitions and three narratives.

The first intuition is that, generally speaking, our considered judgments about how we should die should be respected. What counts as a considered judgment is important for this case. Evidence was given about two discussions at different points in Terri's life, one before she was married and one after. Her remarks during those discussions differed, and it is not surprising that the interpretations of the remarks differ as well. The potential for contradictions such as these does not mean that we should reject our intuition about respecting a person's wishes; it does mean that following up on it may sometimes be complicated.

The second intuition is that human beings whose lives are vulnerable because of circumstances beyond their control should be supported by all of us. We should not take human life. For some, that is what happened in this case.

The first of the three narratives about what should have been done for Terri concerns a husband's fidelity to a promise he had made to his wife regarding her previously expressed wishes not to be kept alive in a persistent vegetative state. Respecting Terri meant stopping the nutrition and hydration supplied by medical means.

A second narrative states that Terri would have wanted to be kept alive (or at least that there was no certainty that she would not have wanted this) and that her life was valuable. She needed to be heard over against those who stated otherwise. From this perspective, one of the tragedies of this case is that many of the persons called upon to evaluate her refused to "hear" what Terri herself was trying to say. This was the story taken up by many evangelicals and some sectors of the Roman Catholic community, and it is well represented in the Schindler, Lynne and Gibbs volumes. According to this point of view, the law should err on the side of life, and we need to learn to care for those among us who cannot care for themselves.

The third narrative did not show up much in the news reports. Formally it represents the view of the disability community, which insisted that the diminution of Terri, the assumption that she was better off dead, is precisely the problem with the American medical and legal systems and much of American bioethics. The disability community insisted that the problem was not with those who wanted to do what Terri wanted; it was with the assumption that the only rational thing to want in such a circumstance is to die. Indeed, some people with disabilities insisted that it is arrogant to assume that anyone can know how they will think about these matters before they are actually disabled. Too often, according to this community, people change their minds and find that they are willing to live with conditions that they thought intolerable when they were well. Advocates for people with disabilities are able to relate many such stories. They say that we and the instruments of the law should open ourselves to these voices.

These narratives highlight how difficult it is in some cases to affirm both of our intuitions about caring for people who have such severe disabilities.

Another dispute highlighted by the Schiavo case has to do with nutrition supplied by means of medical intervention. Terri was being fed through a tube. She was not on a ventilator, but she did require skilled nursing care. She had lived a long time in this condition and might have lived many years more. In this context, was the nutrition supplied through the tube a medical intervention like other medical interventions, or was it a form of the ordinary care that is owed every human being? If it is the latter, then many would argue that such care should not be withheld or, once started, withdrawn.

There is a related matter. Too often Americans give medical treatment not for the benefit of the person treated but in order to assure themselves that they are doing everything that can be done. That attitude leads to circumstances in which treatment continues long past the time when it might lead to good effects or when the person would have wanted the type of care being provided.

This is particularly true with cases of persistent vegetative state and with many forms of dementia. In conversation with European colleagues, I am reminded that one of the differences between U.S. health care and that of other countries is the number of persons in this country with dementia who are on feeding tubes. In the past, patients with dementia often died of starvation because they could not feed themselves or even be fed. We seem to think that interrupting this dying process by feeding the patient through a tube is the only reasonable choice. I do not think that the only thing to do in such cases is to discontinue medical care, but it is true that there are multiple options in these situations, and all too often some of these options go unexplored.

Various measures could have been taken at various times during Terri Schiavo's long years of disability. Possibilities that were bypassed before 2005 might have led to a different kind of outcome. For example, in a guardian report filed with the court in 1998, the guardian argued that Terri's husband and her parents had conflicts of interest in her case. He suggested that the court appoint a neutral third party to make decisions regarding her medical treatment, but the court declined to do this. If a third party had been appointed, it might not have changed the outcome with respect to the nutrition and hydration being discontinued, but it might have changed the public perception about the neutrality of the decision makers.

So how should we respond to such a long dying? Too often we merely default to the first narrative and prepare advance directives of one sort or another. That is a start,

but it is not enough. More needs to be done. We need to become involved in conversations about dying and about how care for the dying must be changed in our culture.

Churches could begin and sustain these conversations. These do not have to be grand events; an annual sermon about dying and a workshop on practices that the congregation can put in place to support the ill and their families would be a place to start. So too would a lecture on how we die in the United States and what that means for us. Will we be hospice volunteers or supporters of the families of people who are ill? Any of these practices could be a beginning. Some communities knit prayer shawls for the sick; others train hospital visitors. We cannot know where such conversations and the resultant practices would lead, but we never know where interesting journeys will take us. That uncertainty is no excuse for failing to begin.