For centuries, practitioners of medicine have sought to lessen pain, restore physiologic homeostasis, preserve anatomical function, and prolong life. With many of these goals realized as we enter the 21st century, it is ironic that public discussion of medical care often focuses on definitions of inappropriate death vs unnatural longevity, as they relate to the most critically ill patients.

In recent decades, physicians, loved ones, and the public have been made painfully aware of this debate while witnessing the final punctuation in the lives of Karen Ann Quinlan, Nancy Cruzan, and, more recently, Terri Schiavo. The medical, ethical, and legal issues surrounding these cases are open to numerous interpretations, many influenced by the life experiences and core values of the observers. In the final days of Mrs Schiavo’s life, perhaps these factors and naivety, not malice, formed the basis of contradictory or clearly erroneous public statements that originated from individuals with diverse and often opposing political, ethical, and religious views and were widely disseminated through the media.

It is beyond the mission of this journal to identify and correct the individual errors or proselytize on behalf of any particular viewpoint. In contrast, it is highly appropriate to use recent events as an opportunity to review end-of-life issues so that we practitioners can better serve future individuals whose care is entrusted to us. Providing educational background information on end-of-life issues is not a new activity for Mayo Clinic Proceedings. In recent years, the journal has published numerous articles on quantifying and improving the quality of life in cancer patients, including those diagnosed with terminal disease. These and related articles have helped physicians better understand the importance of optimizing pain control, nutrition, physical stamina, and mental health during a patient’s remaining life (ie, life that could sometimes persist for years after diagnosis of a terminal illness and whose quality might deteriorate absent proper attention). More recently, we reported on the relationship among family expectations, resource utilization, and outcome in gravely ill patients. The current examination of additional end-of-life issues is simply a continuum of journal activities on this important topic.

In the case of Mrs Schiavo, the public was exposed through the media to both bombastic and highly nuanced discussions of permanent vegetative states and whether these could be confused with other states of prolonged unconsciousness that might improve to some degree. To address this, in the August issue of the Proceedings, 2 experts previously unaffiliated with each other, Dr Eelco Wijdicks of the Mayo Clinic in Rochester, Minn, and Dr Ronald Cranford of the Hennepin County Medical Center, Minneapolis, Minn, collaboratively authored a review article on the clinical diagnosis of prolonged states of impaired consciousness in adults. From this article, we learned the criteria for diagnosing a permanent vegetative state and whether a patient who has had such a diagnosis for a year or more can ever recover. We also learned that the patient in a permanent vegetative state can have stimulus-associated movements that may appear purposeful but are not. Such background information had later value when readers reflected on widely publicized video footage of Mrs Schiavo appearing to recognize and respond to a loved one entering her room, well after Mrs Schiavo had been diagnosed as being in a permanent vegetative state. Autopsy would later determine that her brain lacked the structures required to generate an appropriate response to a visual stimulus.

At the April 6, 2005, Department of Medicine Grand Rounds conference, Dr Christopher Hook, of the Mayo Clinic in Rochester, Minn, and Dr Ronald Cranford of the Hennepin County Medical Center, Minneapolis, Minn, collaboratively authored a review article on the clinical diagnosis of prolonged states of impaired consciousness in adults. From this article, we learned the criteria for diagnosing a permanent vegetative state and whether a patient who has had such a diagnosis for a year or more can ever recover. We also learned that the patient in a permanent vegetative state can have stimulus-associated movements that may appear purposeful but are not. Such background information had later value when readers reflected on widely publicized video footage of Mrs Schiavo appearing to recognize and respond to a loved one entering her room, well after Mrs Schiavo had been diagnosed as being in a permanent vegetative state. Autopsy would later determine that her brain lacked the structures required to generate an appropriate response to a visual stimulus.
life and March 31 death of Terri Schiavo. A standing-room-only audience of more than 200 listened attentively, respectful of the equanimity of the presentation. Not surprisingly, when a manuscript based on this presentation was submitted to Mayo Clinic Proceedings, the manuscript was subjected to peer review and, after appropriate modification to respond to reviewers’ critiques, accepted for publication. This article, which appears in the current issue of the journal, is intended to give readers a better understanding of the exhaustive medical and legal deliberations that surrounded the final years and death of Mrs Schiavo. In their article, Dr Hook and his coauthor Dr Paul Mueller attempt to distill this experience and share 11 important and generalizable lessons that can be learned from the Schiavo case. These address the legal rights and duties of surrogate decision makers and guidelines for determining what is reasonable vs unreasonable care.

All the aforementioned cases, Quinlan, Cruzan, and Schiavo, involved intricate interactions among the courts, state legislatures, and family members. However, in the Schiavo case, decision making on behalf of the patient became even more complicated by divergent views among family members: Mrs Schiavo’s parents petitioned for her life to be sustained beyond the years that had passed since her catastrophic hypoxic brain injury of February 25, 1990, but Michael Schiavo, the husband, had a differing view. Among the various arguments for resolution was a suggestion by those wanting to prolong Mrs Schiavo’s life that her husband could simply divorce her and turn guardianship over to her parents. From the reporting and analysis of Hook and Mueller, the reader is able to gain insights into the courts’ views on selecting guardians or proxies for patients who cannot represent themselves. Specifically, the reader will learn whether Terri Schiavo’s parents would have been next in line to serve as guardians had her husband abdicated guardianship by divorce or other legal intervention.

Much of the controversy surrounding Mrs Schiavo’s care involved the decision to continue to use or remove a feeding tube that was intended to provide hydration and nutrition. Some viewed the feeding tube as basic medical care, whereas others viewed it as extraordinary medical care. Readers are assisted in their evaluation of this issue not only by Drs Hook and Mueller, who speak to the specifics of the Schiavo case, but also by Dr Molly McMahon and colleagues, who provide a general overview of long-term enteral tube feeding in the current issue of Mayo Clinic Proceedings. The latter article discusses the various forms of tube feeding, including the indications for beginning tube feedings, the benefits and risks of this intervention, and the medical, legal, and ethical implications of discontinuing tube feedings. In the course of reading the latter article, readers may become more sympathetic with the lay public’s misunderstanding of this intervention when it becomes apparent that health care practitioners are often mistaken about the benefits and indications for tube feedings. Specifically, survey research has determined that health care practitioners are erroneously optimistic about the benefits of tube feedings and additionally have differing standards for using tube feedings in their patients vs themselves (should both become similarly incapacitated).

Throughout the writings of Hook and Mueller and McMahon and colleagues, it is clear that common sense and legal precedent place priority on the wishes of the patient in determining which treatments are appropriate. In this regard, documentation of an individual’s wishes, before the end of life, eg, through living wills and advance directives, provides our best defense against recreating the tragedies of Quinlan, Cruzan, and Schiavo. However, even with these measures in place, uncertainties will still persist, simply because of complexities of decision making as we contemplate the finality of somatic death. I hope the following example will prove enlightening.

Some years ago, I was called late at night to the emergency department of the hospital—in my role as the attending anesthesiologist—to perform a preoperative evaluation on an elderly gentleman who had a leaking abdominal aortic aneurysm. Clinical data clearly indicated hemodynamic compromise, for which he was being treated. Although not unusual, the patient had a history of coronary artery disease, and an electrocardiogram obtained immediately on hospital admission showed myocardial ischemia, likely in response to blood loss and pain. As I approached the patient, a nurse handed me his chart, which documented previous medical center admissions. I quickly learned that the patient had undergone resection of a primary lung cancer a few years earlier, and his chest radiograph had evidence of residual scar tissue vs the early stages of recurrent cancer. I was impressed by the exhaustive documentation within the chart stating that, after the earlier lung resection, the patient desired no heroic lifesaving measures at any future point. I inferred that he thought such documentation was needed to direct his final care if his lung cancer recurred and threatened his viability.

During my interview, the patient was lucid. He told me that he knew his aneurysm was leaking and he was possibly having a heart attack, and he had been informed by his surgeons that he would almost certainly die within the next few hours without aortic surgery. I informed him of my desire to help but politely asked him to clarify for me his feelings on the intended surgery, given the extensive documentation in his chart for no future heroic measures. He confirmed that he wanted the potentially lifesaving operation. I told him I understood.
As I turned to depart to make additional preparations, the patient again addressed me: “Doctor,” he said, “regarding my choices, everything that has happened to this point has been theory; this is the real thing.”

One would hope that when our patients, their loved ones, and we confront end-of-life issues, preparatory theory and “the real thing” will be in agreement. In the instances in which this is not the case, we owe it to ourselves and those within our care to best understand the options available to us.

It is the sincere hope of this journal that the many reports we have published on end-of-life issues during the past several years have provided a mature, balanced, and honest representation of information relevant to the care of patients and to their loved ones. We are indebted to the authors who have shared their writings with us and the many reviewers who have helped improve the quality and relevance of the messages. Throughout, the articles shared with our readers reflect traditional author/journal/peer-review interactions and are not intended to represent any consensus opinions of the Mayo Clinic Proceedings editorial board or the faculty of its sponsoring institution, Mayo Clinic. If such opinions exist, they are unknown to me, and no attempt has been made to introduce them into the ongoing discussion.

William L. Lanier, MD
Editor-in-Chief


