Legal mechanisms to protect dialysis patients’ end-of-life decisions

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The moral and ethical battles surrounding the Terri Schiavo case continue even after her death. And they have brought renewed attention to the legal mechanisms available to ensure that all individuals have the right to make voluntary, informed choices about the course of their health care.

Schiavo case background

The long road leading ultimately to the death of Terri Schiavo began in 1990 when Mrs. Schiavo suffered a heart attack. Although she was only 27 years old at the time, a dramatically reduced potassium level in her body brought on her heart attack. She was kept alive in a persistent vegetative state by receiving nutrition and hydration in a hospice facility.

This case has an extensive legal history, beginning in February 2002 in a Florida courtroom. Following an extensive trial, the court concluded, based on clear and convincing evidence, that Mrs. Schiavo herself would have elected to forego further use of a feeding tube.

The legal precedent followed by the trial court was not new. The Supreme Court of Florida previously set the standard under the Florida Constitution, which gave both competent and incompetent persons the right to forego life-prolonging procedures. In a 1986 case, a Florida Appellate Court interpreted the constitutional protection to apply not only to persons who have the foresight to prepare a living will, but also those whose wishes have not been put in writing. The courts’ right to make that decision is available when family members cannot agree or when the person’s guardian believe it more appropriate for a neutral judge to make the decision. In one of its decisions, the Florida Court of Appeals said Mr. Schiavo asked the court to make this decision “in his capacity as legal guardian of his wife … in light of the bitter conflict within this family.”

Despite the clear directives of the Florida courts and their interpretation of the state constitution, determined far before the Schiavo case, neither the Florida legislature nor the United States Congress would leave this decision to be settled by the courts. In October 2003, the Florida legislature passed, and the governor signed into law, a bill ordering the continuation of the supply of nutrition and hydration that had been removed from Mrs. Schiavo following an earlier court order. Mr. Schiavo challenged the bill. The Florida Supreme Court then held that the bill signed by the governor was unconstitutional.

This led to further legislative intervention, this time by the United States Congress, in March 2005, which provided federal court review of the decisions reached by the Florida courts. Appeals taken from the Federal District Court in Tampa, Fla. up through the 11th Circuit, and finally the U.S. Supreme Court, upheld the decision of the lower Florida courts. This ultimately led to the removal of feeding tubes and Mrs. Schiavo’s death.

The clear lesson that can be drawn from the Schiavo case is that the federal and state efforts, to ensure that a patient’s wishes are known before an end-of-life decision is imminent, should be followed whenever possible. The Patient’s Self-Determination Act in 1990 and the state directive legislation are steps to ensure that lesson is learned.

Federal legislation

Congress passed the PSDA in 1990 and since then many states have enacted legislation to allow individuals to plan for end-of-life health care decisions. Federal law requires certain health care entities to provide individuals with information regarding their right to direct health care decisions in the event they are unable to make such wishes known. The vehicle for such decision making is the “advance directive,” which is defined as a written instruction, such as a living will or durable power of attorney for health, recognized under state law, and relating to the provision of medical care in the event an individual is incapacitated.

The goal of the PSDA is to broadly disseminate information regarding an individual’s right to make health care decisions and to encourage people to discuss and document their wishes regarding medical care well in advance of an incapacitating event. Accordingly, the PSDA requires health care providers to give adult individuals, at the time of patient admission or enrollment, certain information about their rights, under state laws, to advance directives, including:

• the right to participate in and direct their own health care decisions.
• the right to accept or refuse medical or surgical treatment.
• the right to prepare an advance directive.
information on the provider’s policies that govern the utilization of these rights.

The PSDA also prohibits institutions from discriminating against a patient who does not have an advance directive, and requires institutions to document patient information and provide ongoing community education on advance directives.

Although dialysis facilities were not explicitly mentioned in the federal legislation, the provisions apply to health care providers who treat individuals at all stages of wellness. Moreover, it is of particular importance that dialysis patients, like other patients with terminal conditions, articulate their desires regarding treatment at the end of life. Dialysis patients should be aware that their dialysis facilities are obligated to inform them of the above information. Dialysis patients should also make sure the facility includes documentation of their wishes in their medical record.

Common advance directives

A proper and instructive advance directive describes what type of treatment an individual would desire (or not desire as the case may be) depending on the illness. Advance directives can take many forms and the laws regarding advance directives differ from state to state. Patients and providers should be aware of their state-specific laws. Below are several common advance directives recognized by many states.

Living will

A living will only comes into effect when an individual is terminally ill, typically defined as having less than six months to live. A living will generally describes the type of treatment an individual desires in certain situations. However, a living will does not let an individual select someone to make a decision on his or her behalf upon losing the ability to make decisions independently. All 50 states and the District of Columbia have living will statutes, sometimes referred to as “right to die” legislation or “natural death” acts. Each state statute varies. For example, in some states any person may execute a living will at any time, while others require a waiting period, and their wishes may not be executed during a terminal illness. It is important to carefully examine the statutes to ensure that a living will, once executed, is valid.

Durable power of attorney for health care

A durable power of attorney for health care is another type of advance directive. An individual may execute a DPA designating a spokesperson that will have the right to make medical decisions and act on behalf of the individual for purposes that are described and limited in the DPA. The DPA becomes active any time the individual is unconscious or unable to make medical decisions. A DPA is generally more useful than a living will and the vast majority of states have now adopted statutes that formally authorize the execution of durable powers of attorney for health care decisions. Again, the statutes vary by state so it is important to review them.

Do not resuscitate order

In some states, a do not resuscitate order is part of the advance directive statute. A DNR is a request not to have cardiopulmonary resuscitation if an individual’s heart stops or the individual stops breathing. (Unless given other instructions, health care providers will try to help all patients whose heart has stopped or who have stopped breathing.) A patient can use an advance directive form or inform the health care provider that he or she does not want to be resuscitated. If this is the case, the physician puts a DNR order into the patient’s medical chart. DNR orders are accepted by physicians and health care facilities in all states.

Final thoughts

An individual’s right to autonomous choice in matters concerning the treatment of his or her own body has been a theme throughout many legal decisions involving end-of-life cases. These cases, and the political battles that have ensued, led to the enactment of federal legislation and state statutes setting forth various legal mechanisms to preserve an individual’s autonomy even when incapacitated. Cases like that of Terri Schiavo bring to the forefront the importance of documenting an advance directive so there is no ambiguity about a person’s end-of-life wishes. Dialysis patients and providers need to be aware of these legal mechanisms and discuss end-of-life treatment decisions through the end of life.

The authors would like to acknowledge the assistance of Elissa Koch, an associate of McGuireWoods LLP, for her assistance in preparing this article.