

A Case for Advance Directives

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During the past 20 years, there have been several court cases across the country about the ability of family members and guardians to withhold or withdraw life-sustaining treatment to incompetent patients when there is no medical reason to believe the patient will ever recover the ability to function. Three highly publicized cases provided the impetus for advance directive legislation in many states and shaped the judiciary's analysis of many subsequent cases, often referred to as "right-to-die" cases.

On April 15, 1975, Karen Quinlan, age 21, collapsed at her home. She ceased breathing at least twice before she arrived at the hospital. During Karen's hospitalization, several neurologists with extensive experience and backgrounds examined her, and all agreed she was in a chronic persistent vegetative state, having irreversible brain damage, and that she lacked cognitive or cerebral functioning.

Karen's father petitioned for guardianship over Karen's person and authorization for her physicians to discontinue all extraordinary measures, including the use of the respirator to sustain Karen's life. Karen's mother, sister, and a friend testified that, in response to instances where friends and relatives were terminally ill, Karen told them she never wanted

to be kept alive by extraordinary means. The New Jersey Supreme Court granted the guardianship petition and approved the withdrawal of life support if Karen's physicians determined there was no possibility she would ever emerge from her comatose condition to a cognitive, sapient state and there was agreement among the guardian and family about the withdrawal of life support.¹

Some time after the New Jersey Supreme Court's decision in 1976, Karen's treatment professionals removed her from the ventilator. Karen began breathing on her own and continued to do so until she died in June 1985. Karen's parents never sought to remove her nasal-gastro tube, so the removal of nutrition and hydration was not an issue in the case. In the *Quinlan* case, Karen's physicians believed that removing her from the respirator would conflict with then existing medical standards that brain death was a precondition to removing a patient from a respirator. The court concluded that "the evidence in this case convinces us that the focal point of decision should be the prognosis as to the reasonable possibility of return to cognitive and sapient life, as distinguished from the forced continuance of that biological vegetative existence to which Karen seems to be doomed." The court noted it was not bound by the pertinent medical standards and practices that guided the decisions of the physicians in the case. The case sparked a national debate about death with dignity.

In January 1983, Nancy Cruzan, age 30, lost control of her car and sustained cerebral contusions com-

pounded by significant oxygen deprivation, ultimately leaving her in a persistent vegetative state. Nancy's parents petitioned the court for an order authorizing Nancy's treatment professionals to discontinue artificial nutrition and hydration. The Missouri trial court granted authorization for the withdrawal of life-sustaining treatment based on evidence that Nancy had a "somewhat serious conversation" with a friend at age 26 that if sick or injured she would not want her life to continue unless she could live at least halfway normally. The Missouri Supreme Court, however, reversed the trial court's decision, imposing a clear and convincing evidentiary standard regarding Nancy's desire to live or die under certain circumstances. The Missouri Supreme Court concluded that Nancy's statement to her friend regarding her desires was "unreliable for the purpose of determining her intent."²

The United States Supreme Court recognized that a competent person's right to refuse medical treatment, including artificial nutrition and hydration is constitutionally protected. The Court held that in the case of an incompetent person, a state may adopt a standard of clear and convincing proof of the person's desires regarding life and death. The US Supreme Court upheld the Missouri Supreme Court's ruling, which denied authorization to withdraw life-sustaining treatment because the evidence regarding Nancy's preferences about the withdrawal of life-sustaining treatment under the circumstances was not clear and convincing.³ The *Cruzan* case marked a notable change

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in right-to-die cases because it involved the withdrawal of artificial nutrition and hydration, resolving the question that artificial nutrition and hydration, even though fundamental to human existence, are medical treatment that a patient or patient's guardian could refuse in the same way they might refuse a respirator or other forms of medical treatment.

After the US Supreme Court's decision, the Cruzan family petitioned the Missouri trial court for a rehearing, at which time it introduced testimony from additional witnesses. One witness at the rehearing was a co-worker who testified that Nancy told her that if she were a "vegetable," she did not want to be force fed or kept alive by machines. Based on all of the evidence in the new hearing record, the court granted the parents' request for withdrawal of life-sustaining treatment. Nancy died shortly thereafter, in December 1990.

On February 25, 1990, Terri Schiavo, age 26, suffered a cardiac arrest that ultimately led to a persistent vegetative state. As in the *Quinlan* and *Cruzan* cases, Terri did not have a living will or power of attorney for health care to convey her desires regarding life-prolonging treatment in the event of incapacity. Her husband petitioned the court to remove her nutrition and hydration tube, launching a public disagreement with her parents about the withdrawal of artificial nutrition and hydration.⁴

Terri's wishes regarding life-prolonging treatment and the appropriateness of withdrawing life support were debated in numerous court proceedings and the Florida legislature, and by the Florida governor, medical ethicists, and legal scholars. After the exhaustion of all appeals and legislative measures, Terri's treatment professionals removed her feeding and hydration tube in accordance with a court order. She died on March 31, 2005.

The highly publicized cases about the withdrawal of life-sustaining

treatment, commonly known as right-to-die cases, have prompted many states, including Wisconsin, to enact advance directive statutes.⁶ Advance directives are living wills and power of attorney for health care instruments that allow competent individuals to express, in writing, their desires about health care, including the receipt of artificial nutrition, hydration, and other life-sustaining procedures in the event the person later becomes incompetent and has a terminal condition or is in a persistent vegetative state. The *Cruzan* case helped to spark the enactment of the federal Patient Self-Determination Act.⁷ The Patient Self-Determination Act requires hospitals, nursing homes, hospices, and other entities that receive Medicare and Medicaid funding to provide information to patients at the time of admission about the right to make health care decisions and create advance directives, maintain policies about advance directives and inform patients about those policies, document whether or not the patient has an advance directive in the medical record, ensure compliance with state law regarding advance directives, and educate staff and the community on issues regarding advance directives.

The courts in the *Quinlan*, *Cruzan* and *Schiavo* cases recognized that the informed consent doctrine is firmly entrenched in American tort law and that the logical corollary to that doctrine is the right to refuse unwanted medical treatment, including artificial nutrition and hydration. The courts determined that a patient's right to refuse medical treatment extends to incompetent individuals. Incompetent patients are unable to exercise their right to refuse medical treatment, so surrogate decision makers such as guardians may exercise the incompetent person's right to refuse medical treatment within certain parameters imposed by the courts of the particular state. Some of the parameters that

the courts have imposed to protect incompetent patients are

- the imposition of a clear and convincing evidence standard by which a guardian/surrogate must prove that the patient would have wanted the withdrawal of artificial nutrition, hydration or other treatment under the existing circumstances.
- agreement among the family members and the guardian about withdrawing life-sustaining treatment, along with a determination by the patient's physicians that the patient will never regain a cognitive, sapient state.

Decisions in Wisconsin

The Wisconsin Supreme Court, in the case of *In the Matter of the Guardianship of L.W.*, granted Wisconsin incompetent persons in a persistent vegetative state the right to refuse life-sustaining treatment, including a refusal of artificial nutrition and hydration. In the *L.W.* case, L.W., a 79-year-old man with a long history of schizophrenia, suffered a cardiac arrest. According to the evidence, he was incompetent, had no close friends or relatives and there was no evidence indicating that he ever expressed his desires regarding life-sustaining treatment to anyone. L.W.'s treatment professionals determined he was in a chronic, persistent vegetative state. L.W.'s guardian petitioned the court for a determination of authority to withdraw life-sustaining treatment.

L.W. died of natural causes while the appeal was pending. Despite his death, the Wisconsin Supreme Court decided the case because it contained issues of first impression in Wisconsin. The Court concluded that an individual has a constitutional right to refuse unwanted medical treatment, including artificial nutrition and hydration. The Court also concluded that the right to refuse unwanted life-sustaining medical treatment extends

to incompetent individuals. Unlike the Missouri court in the *Cruzan* case, the Wisconsin Supreme Court rejected the requirement of clear and convincing evidence to demonstrate the wishes of the individual regarding life-sustaining treatment. The Court recognized that few individuals provide explicit written or oral instructions regarding life-sustaining treatment for many reasons, including "ignorance, superstition, carelessness, sloth, procrastination, or the simple refusal to believe it could happen to oneself."⁸ In the *L.W.* case, the court recognized that a person's failure to execute an advance directive or give oral instructions regarding life-sustaining treatment in the event that the person later becomes incompetent is not a decision to accept all treatment. The Court adopted a "best interests" test so that "where it is in the best interests of an incompetent person in a persistent vegetative state to refuse life-sustaining medical treatment, his or her right to refuse must be exercised by a surrogate decision maker."

Based on the decision of the Wisconsin Supreme Court in the *L.W.* case, a guardian may consent to the withholding of life-sustaining treatment of a person even if the person has not previously indicated his or her desires regarding life-sustaining treatment, under the following circumstances:

- (1) the incompetent patient's attending physician, together with 2 independent neurologists or physicians, determine with reasonable medical certainty that the patient is in a persistent vegetative state and has no reasonable chance of recovery to a cognitive and sentient life; and
- (2) the guardian determines in good faith that the withholding or withdrawal of treatment is in the ward's best interests, according to the objective factors

outlined below

- In making the best interests determination, the guardian must begin with a presumption that continued life is in the best interests of the ward. Whether that presumption may be overcome depends upon a good faith assessment by the guardian of several objective factors. Objective factors the guardian may consider include the degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options.⁸

The Wisconsin Court noted that the "best interests" standard could apply to patients who are born incompetent, to prevent medical technology from unnaturally prolonging the dying process in a manner that is likely to transgress human dignity and personal privacy.

The decision in the *L.W.* case is a major step toward resolving right-to-die cases in Wisconsin. However, the *L.W.* case does not resolve all right-to-die issues. In 1997, the Wisconsin Supreme Court decided the case, *In the Matter of the Guardianship of Edna M.F.*, in which it held that the guardian could not direct the withdrawal of life-sustaining treatment because Edna was not in a persistent vegetative state and the evidence of her desires regarding life-sustaining treatment was unreliable⁹. Edna M.F. is a 71-year-old woman with dementia related to Alzheimer's disease. She is bedridden and has a permanent feeding tube in her body. Edna breathes without a respirator, but receives artificial nutrition and hydration via her feeding tube. Edna's treatment professionals believe her condition is unlikely to improve. The only evidence regarding Edna's desires about

life-sustaining treatment was testimony from her sister that during a conversation in 1966 or 1967, Edna told her, "I would rather die of cancer than lose my mind." The Court concluded that the statement that Edna made approximately 30 years earlier was not a clear expression of what her desires would be in 1997, under her current conditions. The Court in the *Edna M.F.* case refused to extend the "best interests" standard to cases involving incompetent patients suffering from incurable or irreversible health conditions that do not meet the medical definition of a persistent vegetative state.

Conclusion

The few publicized right-to-die cases discussed in this article are merely a small sampling of the many court cases across the country involving the issue of withholding or withdrawing life-sustaining treatment. Despite the vast number of cases, many people do not have an advance directive. The *Edna M.F.* case demonstrates the complexity of the right-to-die cases. Although the courts have been forced to decide some issues regarding the withdrawal of life-sustaining treatment, they are ill equipped to decide the vast array of issues that surround the ethical, medical, and legal debates about the relationship between quality of life and continuing or discontinuing all life-sustaining measures in the myriad of circumstances where the patients ability to function or have a normal life cannot be restored.

The Wisconsin Medical Society, Wisconsin Hospital Association, the State Bar of Wisconsin, and others jointly developed an educational campaign to provide information about planning ahead for future health needs, including producing the consumer guide entitled *A Gift to Your Family*.¹⁰ Educational efforts are clearly important. However, it is also

important for medical ethics committees to discuss the issues, including the implications of the Wisconsin Supreme Court's refusal to extend the "best interests" standard to incompetent patients who are not in a persistent vegetative state, but suffer from conditions that render them unable to recover the ability to comprehend their surroundings or function. Ultimately, the many unresolved issues surrounding the withholding or withdrawal of life-sustaining treatment might be appropriate for legislative consideration.

Endnotes

1. See *In the Matter of Karen Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).
2. See *Cruzan v. Harmon*, 760 S.W.2d 408 (1988).
3. See *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261; 110 S. Ct. 2841; 111 L. Ed. 224 (1990).
4. The Florida Appellate Court in upheld the trial court's decision authorizing the termination of life support in the case of *Schindler v. Schiavo (in Re Schiavo)*, 780 So. 2d 176 (2001).
5. Terri Schiavo's "story," along with statements, videos, autopsy reports, and other information about her life and death appear on a Web site maintained by her family at www.terrisfight.org. Accessed on September 17, 2007.
6. Wisconsin Statutes Chapter 154 outlines the living will and Chapter 155 establishes the criteria for the power of attorney for health care instrument.
7. 42 United States Code § 1395cc(a).
8. See *In the Matter of Guardianship of L.W.*, 167 Wis. 2d 53, 482 N.W.2d 60 (1992).
9. See *In the Matter of the Guardianship of Edna M.F.*, 210 Wis. 2d 557, 563 N.W.2d 485 (1997).
10. The publication can be viewed on the State Bar of Wisconsin Web site at: <http://www.wisbar.org/AM/Template.cfm?Section=LifePlanning&Template=/CM/ContentDisplay.cfm&ContentID=38082>, and purchased directly from the State Bar for a nominal fee.

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