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The past twenty-five years have seen great advances in life-sustaining medical technology capable of extending life far past its natural end. With these advances, legislatures and courts have struggled with the complex legal and ethical issues associated with end-of-life decision making and refusal of life-sustaining treatment. The courts and state legislatures have generally agreed that competent persons have a right to direct decisions concerning their medical care. However, they have struggled in balancing this right against a state's interest in the preservation and sanctity of human life. The issue only becomes more difficult and complex when decisions regarding life-sustaining treatment are sought to be made on behalf of persons who lack capacity to direct their own medical care and treatment. Both state legislatures and courts at every level, including the United States Supreme Court, have struggled with determining whether such decisions should be made and, if so, where the boundaries of such authority lie.

The last twenty-five years have been witness to a number of "right to die" cases that have garnered national attention and interest, sparking the debate over advance directives and surrogate decision making with regard to life-sustaining treatment. There have also been great advances in legislation at both the national and local level on surrogate decision making and advance directives, aimed at protecting an individual's right to make

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decisions about his or her future medical care in anticipation of a time when the individual may be found incompetent. This article provides a brief history of the advances in the law over the last several decades with regard to this area—an area that involves highly personal, ethical, and moral questions.

## I. AT THE NATIONAL LEVEL

Many state courts have rendered decisions regarding whether life-sustaining treatment may be withdrawn for individuals rendered incompetent. Perhaps the most well-known state case is that of *In re Karen Quinlan*, decided by the Supreme Court of New Jersey in 1976.[1] Karen Quinlan, then twenty-one years old, remained in a persistent vegetative state after she ceased breathing for a lengthy period of time. Her father sought to become the court-appointed guardian of her person with the specific authority to discontinue life-sustaining measures. The trial court, however, refused to appoint him. The New Jersey Supreme Court ordered the trial court to appoint Karen's father as guardian of her person and determined that life-sustaining treatment may be withdrawn upon the opinion of the attending physicians that Karen lacked the possibility of recovery, and with the concurrence of the guardian and family. In so ruling, the court found that "no external compelling interest of the State could compel Karen [Quinlan] to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life."[2] Basing its decision on the right to privacy, the court found that Karen's right could be exerted on her behalf by her guardian under the "peculiar circumstances" of the case. For years, the *Quinlan* case served as guidance for many courts forced to address the same difficult questions in their state.

The issue came to the national forefront, however, in 1990 with the landmark U.S. Supreme Court case of *Cruzan v. Director of Missouri Department of Health*, 497 U.S. 261 (1990). In January of 1983, Nancy Cruzan was involved in a car accident which resulted in a comatose state and, eventually, a progressive vegetative state. After it became clear that Nancy had virtually no chance of regaining her mental abilities, her parents petitioned the court for an order authorizing termination of artificial nutrition and hydration, which would have resulted in her death. Missouri law required clear and convincing evidence of the patient's desire to forego life-sustaining treatment before a guardian could authorize withdrawal of such treatment. The evidence at trial of Nancy's wishes included a prior

1. *In Re* Quinlan, 70 N.J. 10, 355 A.2d 647 (1976).
2. *Quinlan,* 355 A.2d at 654.

statement she had made to her roommate approximately one year prior to her accident wherein she stated that she would not want to live should she face life as a "vegetable," and other similar observations. The Missouri trial court found this evidence sufficient; however, on direct appeal by both the State and the Guardian *ad litem*, the Missouri Supreme Court reversed the trial court, holding that Nancy's statements were unreliable in determining her intent and did not constitute "informed refusal" of treatment.[3]

Upon further appeal, in a 5-4 decision, the United States Supreme Court affirmed the decision of the Missouri Supreme Court.[4] The multiple concurring and dissenting opinions in the case highlight the struggle of the justices in determining the boundaries of judicial intervention with respect to issues such as the choice between life and death. Ultimately, as set forth in Chief Justice Rehnquist's opinion, the Court found that the Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment. The Court held that Missouri was warranted in its use of heightened evidentiary requirements in order to safeguard the personal element of the choice between life and death and to correctly apportion the risk of an erroneous decision on the party seeking to end life-sustaining treatment.[5] The Court declined to adopt the petitioners' alternative argument that Missouri must accept the "substituted judgment" of close family members, holding instead that the Due Process Clause does not require the State "to repose judgment on these matters with anyone but the patient herself."[6]

Justice O'Connor noted in her concurring opinion that few individuals provide explicit instructions regarding their intent to refuse medical treatment should they be rendered incompetent. She recognized, however, that delegating the authority to make medical decisions was becoming more common and several states had enacted durable power of attorney statutes authorizing an individual to appoint a surrogate to make medical treatment decisions. She noted that the *Cruzan* opinion did not address whether a State must give effect to the decisions of a surrogate decision maker, stating that such a duty may well be constitutionally required.

The *Cruzan* decision drew national attention and highlighted the use of advance directives as a means for competent individuals to clearly state their wishes with regard to life-sustaining treatment in advance of an unforeseen crisis. In the wake of the *Cruzan* decision, the United States

3. Cruzan v. Dir. of Missouri Dep't. of Health, 497 U.S. 261, 268 (1990).

4. Chief Justice Rehnquist authored the opinion of the Court. He was joined by Justices White, Kennedy, O'Connor and Scalia. Justices O'Connor and Scalia both authored concurring opinions. Justices Brennan, Marshall, Blackmun and Stevens dissented. Justices Brennan and Stevens both authored dissenting opinions.

5. *Cruzan*, 497 U.S. at 281.

6. *Id.* at 286.

Congress passed the Patient Self Determination Act, 42 U.S.C. § 1395cc(a) (PSDA).[7] Signed into law by President Bush as part of the Omnibus Budget Reconciliation Act of 1990, the PSDA serves as a strong statement in favor of educating the public about advance directives in order to prevent cases such as Nancy Cruzan's from recurring.

Among other things, the PSDA requires many hospitals, nursing facilities, and certain other health care providers to provide written information to adult individuals receiving medical care concerning their rights under State law to make decisions concerning their medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives. The Act defines "advance directive" as a written instruction, such as a living will or durable power of attorney for health care, recognized under State law, whether statutory or as recognized by the courts of the State, and relating to the provision of medical care when the individual is incapacitated.

The PSDA requires the health care provider to document in the individual's medical record whether or not the individual has executed an advance directive. In an effort to encourage the use of advance directives, the PSDA requires health care providers to provide education for staff and the community on issues concerning advance directives. Furthermore, it called for the Secretary to implement a national campaign within six months of the Act's enactment to inform the public of advance directives and of the patient's right to participate in and direct health care decisions.

While the PSDA encouraged the execution of advance directives by a competent individual prior to being rendered incompetent, it did nothing to address the situation of life-sustaining treatment for an incompetent individual who had not previously executed a valid advance directive. Decisions regarding the latter situation have been left to individual states to tackle.

## II. AT THE ILLINOIS LEVEL

There have been great strides in Illinois law regarding advance directives and surrogate decision making in the last twenty-five years. As with most states, Illinois has had its share of controversial cases, such as *In re Estate of Longeway*, wherein the Illinois Supreme Court held that a court-appointed guardian was authorized to exercise a ward's right to refuse life-sustaining treatment based on a "substituted judgment" standard.[8] Illinois has also passed broad legislation providing for advance directives and

7. Bills for passage of the Patient Self Determination Act were already being considered at the time of the *Cruzan* decision. However, the *Cruzan* decision served as the impetus for passage of the PSDA in Congress.

8. *In re* Estate of Longeway, 133 Ill.2d 33 (1989).

substitute decision making. For example, the Illinois Living Will Act, effective January 1, 1984, recognizes the "fundamental right to control the decisions relating to the rendering of [ ] medical care, including the decision to have death delaying procedures withheld or withdrawn in instances of a terminal condition."[9]Accordingly, the Act allows individuals to execute a document directing that if they suffer from a "terminal condition," i.e. an incurable and irreversible condition which is such that death is imminent and the application of death delaying procedures serves only to prolong the dying process, then death delaying procedures shall not be utilized to prolong their life.[10] Similarly, the Illinois Power of Attorney Act, effective September 22, 1987, recognizes an individual's right to control all aspects of his or her medical treatment, including the right to direct that it be withdrawn, "even if death ensues."[11] The Act therefore allows an individual to delegate to an "agent" all health care powers that the individual may have, including the power to withdraw life-sustaining treatment.[12]

These Acts reflect a consensus among states that a competent individual has the right to direct future decisions regarding his or her health care, including the decision to forego life-sustaining treatment. However, in 1991, Illinois went one step further by creating legislation to specify the circumstances under which life-sustaining treatment could be withdrawn on behalf of an incompetent individual *in absence of an advance directive.* The Illinois Health Care Surrogate Act reflects the view of the legislature that decisions to forgo life-sustaining treatment are private and may be made "without judicial involvement *of any kind.*"[13]

Among its strongly-worded legislative findings, the Act states that "lack of decisional capacity, alone, should not prevent decisions to forgo life-sustaining treatment from being made on behalf of persons who lack decisional capacity and have no known applicable living will or power of attorney for health care."[14] The legislature goes on to state that "uncertainty and lack of clarity in the law concerning the making of private decisions concerning medical treatment and to forgo life-sustaining treatment, without judicial involvement, causes unnecessary emotional distress to the individuals involved and unduly impedes upon the individual right to forgo life-sustaining treatment."[15]

9. Ill. Living Will Act, 755 ILL. COMP. STAT.ANN. 35/1 (2009).

10. *Id.* at 35/2, 35/3 (2009).

11. Ill. Power of Attorney Act, 755 ILL. COMP. STAT.ANN 45/4-1 (2009).

12. Powers of Attorney for Health Care, 755 ILL. COMP. STAT.ANN 45/4-3 (2009).

13. Health Care Surrogate Act, 755 ILL. COMP. STAT.ANN 40/5(b) (2009) (emphasis added).

14. *Id.*

15. *Id.*

Accordingly, under the Act, decisions whether to forgo life-sustaining treatment on behalf of a minor or an adult patient without "decisional capacity"[16] are lawful, *without resort to the courts or legal process*, if the patient has a terminal condition, permanent unconsciousness, or incurable or irreversible condition, as defined under the Act.[17] Decisions must be made by the surrogate decision maker in consultation with the attending physician. The surrogate decision maker must conform as closely as possible to what the patient would have done or intended under the circumstances, taking into account evidence including the patient's personal, philosophical, religious, moral and ethical values relative to the purpose of life, sickness, medical procedures, suffering, and death. If the patient's wishes are unknown, the surrogate decision maker is to make the decision in the patient's best interests, taking into account the views of family and friends that the surrogate decision maker believes the patient would have considered.[18]

The Act applies only when a patient does not have a valid advance directive, such as an unrevoked living will or an authorized agent under a power of attorney for healthcare. The Act sets forth a hierarchy of surrogate decision makers as follows: (1) the patient's guardian of the person; (2) the patient's spouse; (3) any adult son or daughter of the patient; (4) either parent of the patient; (5) any adult brother or sister of the patient; (6) any adult grandchild of the patient; (7) a close friend of the patient; (8) the patient's guardian of the estate.[19]

When the last several decades are reviewed, it is fascinating to consider the evolution of the law with respect to decisions regarding life-sustaining treatment—from the creation of state statutes allowing for advance directives to legislation not only allowing for a surrogate decision maker to make decisions regarding life-sustaining treatment in absence of advance directives, but also allowing such decisions to be made in certain cases based on the surrogate's determination as to the "best interests" of the

16. Decisional capacity is defined as the ability to understand and appreciate the nature and consequences of a decision regarding medical treatment or forgoing life-sustaining treatment and the ability to reach and communicate an informed decision in the matter as determined by the attending physician.

17. Notably, after its passage, the HCSA was amended to allow a surrogate to make certain other medical decisions in addition to decisions regarding life-sustaining treatment. As to the former, the patient must lack decisional capacity, but no qualifying condition is required.

18. 755 ILL. COMP. STAT.ANN 40/20 (2009).

19. *See* 755 ILL. COMP. STAT.ANN 40/25(2009).When two or more surrogates in equal priority disagree about a decision, the majority in that category controls, unless the minority initiates guardianship proceedings. Although the HCSA aims to avoid court intervention, in the event there is no controlling majority, the assistance of the court may be, and often is, sought.

person rendered incompetent. A review of the law also provides an interesting look at the struggle of the legislature and the courts in determining the boundaries of their authority to intervene in areas of the law that have such personal, ethical and moral roots. As individual cases such as the *Terry Schiavo* matter continue to garner national attention, it is likely that these debates will continue in the decades to come despite increasing legislation to address such situations.