

TALKING TO PATIENTS ABOUT END-OF-LIFE PLANNING –THE COURTS AND CONGRESS HAVE LONG SAID: IT’S A GOOD THING TO DO!

By Jeanine Freeman, JD

In January of 1983, 24-year-old Nancy Cruzan lost control of her car as she traveled down a road in Jasper County, Missouri. When discovered, Nancy was lying face down in a ditch without detectable respiratory or cardiac function. Paramedics restored her breathing and heartbeat at the accident site. At the hospital, an attending neurosurgeon determined she sustained probable cerebral contusions compounded by significant lack of oxygen for an estimated 12-14 minutes. She remained in a coma for three weeks then progressed to an unconscious state. A gastrostomy feeding and hydration tube was implanted. Rehabilitation efforts did not help. For six years, Nancy remained in a persistent vegetative state in a Missouri state hospital with the state bearing the cost of her care. Her cerebral cortical atrophy was found to be irreversible, permanent, progressive and ongoing. Her parents requested the removal of Nancy’s gastrostomy tube but the hospital refused absent a court order.

In court, Nancy’s family and friends testified to her prior stated wishes to forego medical care in circumstances such as these; a guardian appointed by the court also concluded that removal of the gastrostomy tube would be consistent with Nancy’s wishes. The state trial court authorized removal but the Missouri Supreme Court disagreed, saying that Nancy did not have a living will directing the removal of such care and that her parents could not stand in her shoes to make this decision absent clear and convincing evidence of Nancy’s wishes.

Nancy’s parents appealed to the U.S. Supreme Court. In 1990, on a 5-4 vote, the Supreme Court ruled that it was constitutionally permissible for the state of Missouri to refuse to authorize the

withdrawal of life-supportive treatment from an incompetent patient absent clear and convincing evidence of that patient’s wishes. The Court said that “clear and convincing” means proof sufficient to show that Nancy held a “firm and settled” commitment to the termination of life supports under circumstances like those she was experiencing. Upon return of the case to Missouri, additional evidence of Nancy’s wishes was presented sufficient to warrant a state court order authorizing removal of Nancy’s gastrostomy tube under the Missouri standard.*

Many court cases addressing a patient’s right to refuse care have been studied, analyzed, and relied upon to support outcomes one way or the other. The *Cruzan* case particularly focused on evidence of an incompetent patient’s wishes. In a separate opinion written in support of the majority’s decision, Justice Sandra Day O’Connor emphasized the increasing role of proxy decision makers in directing an incompetent patient’s medical care. Even so, most people had never executed living wills giving written direction regarding the ongoing use of life sustaining treatment in the event of an irreversible coma. Looking to AMA polling data, 56% of respondents indicated they had told family members of their wishes regarding the use of life sustaining treatment if they were to experience an irreversible coma, but only 15% had filled out a living will expressing those wishes; another AMA survey indicated that only 9% of Americans had executed advance directives regarding treatment in the event of incompetency. Justice O’Connor cautioned that a failure to give proper credence particularly to a patient’s designated agent for medical decision making threatens to thwart the incompetent patient’s intent.



Jeanine Freeman, JD, is Deputy Executive Vice President of Legal Affairs and Policy Development for the Iowa Medical Society.

Congress took note of the *Cruzan* decision and in that same year passed the Patient Self Determination Act of 1990. To help assure that patients know of their medical decision making rights, Medicare-certified hospitals, skilled nursing facilities, home health agencies and hospice programs must provide written information to patients about their rights under state law to make decisions concerning their medical care, including the right to refuse medical or surgical treatment and to formulate advance directives. Affected facilities also must provide patients information regarding their own policies in implementing such rights; document whether the patient has an advance directive; not condition care or otherwise discriminate against a patient because the patient does or does not have an advance directive; ensure compliance with state laws with respect to advance directives; and provide education for staff and the community on issues concerning advance directives. Upon passage of this federal law, the Iowa Hospital Association, the Iowa Medical Society, and the Iowa State Bar Association cooperated in the development of a pamphlet on patient rights under Iowa law for facility use in meeting their new federal obligations; revised versions of that pamphlet continue to be used today.

In 2009, Congress again took up the gauntlet of facilitating patient understanding of advance medical care planning. H.R. 3200, an early House version of the federal health reform bill, proposed Medicare payment to physicians for “advance care planning consultation” at the initiation of the Medicare patient. Such consultation included discussion of living wills and durable powers of attorney, physician orders regarding life sustaining care, and end-of-life care services such as palliative care and hospice.

The proposal met with substantial resistance from those who believed the design behind such consultations was to withhold care from elderly patients at the end of their lives. The Patient Protection and Affordability Care Act (PPACA) passed in March of 2010 with no mention of advance medical care planning.

CMS, however, took one last run at Medicare payment for physician consultation with patients regarding end-of-life care planning in the final 2011 Medicare physician payment rule by including voluntary advance care planning as a specified element of the newly-coded Medicare annual wellness visit. Again, resistance was raised and advance care planning was removed as a facet of the wellness visit. Physicians can still visit with Medicare patients regarding advance medical care decision making but such consultation is not a separately payable service under Medicare.

**Please note: Neither Iowa law nor the Iowa courts require a “clear and convincing” evidentiary standard of proof before life-sustaining care can be removed from an incompetent patient upon authorization of a recognized substitute decision maker. Standards of medical care govern whether a patient’s medical condition warrants such removal. Decision makers on behalf of the incompetent patient are governed, first, by the wishes of the patient but, if not known, then by the patient’s best interests in light of the patient’s medical situation.*