

Excerpt from Caring Connections:

***Private Conversations and Public Discourse:
The importance of consumer engagement in end-of-life care***

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1975:

Karen Ann Quinlan

At the age of 21, Karen Ann Quinlan lost consciousness while at a party and was rushed to the emergency room of a local hospital in Newton, New Jersey. When her parents arrived on scene, their daughter had lapsed into a coma and was placed on artificial life support – both a respirator and a nasogastric tube for artificial nutrition and hydration. After several months of waiting and hoping for a change in medical status, Quinlan’s parents asked the hospital to turn off the respirator and allow their daughter to die in peace. The hospital refused, on the grounds that doing so was immoral. “You have to understand our position,” the hospital administrator told Quinlan’s father, “in this hospital, we don’t kill people.”¹



This was 1975 – a time when advancements in the medical community were helping to save and extend lives. The first direct-current defibrillator had been invented in 1961, followed by the establishment of the first hospital coronary care unit; the 911 emergency system had been launched in 1968; and the first school program to train ambulance attendants in CPR had begun in 1969. What’s more, medicine had only just named the condition to which Quinlan had fallen victim – the persistent vegetative state – in 1973.² The medical community and the American public were still very much enraptured by such advancements and wanted to do “everything possible.” No one was yet prepared to deal with the negative repercussions of these advancements.

Following a legal battle with Quinlan’s physician and the state attorney general, the case was brought before the New Jersey Supreme Court in 1976. The court ruled that Quinlan had a constitutional right to privacy that her father could exercise on her behalf. While the court granted him the right to discontinue all life support, Quinlan’s father chose only to wean her off the respirator. To the medical community’s surprise, she started breathing on her own. Quinlan lived on in a persistent vegetative state, kept alive with artificial nutrition and hydration, and died from pneumonia 10 years later.

The Quinlan case paved the way for several proactive steps in this still unfamiliar, uncharted territory. The U.S. Congress established a President’s Commission to examine the ethical issues arising from advancements in medicine and published two reports by 1983: *Defining Death and Deciding to Forego Life-Sustaining Treatment*. More notably, the California Legislature passed the nation’s first living will law to protect a person’s rights concerning his/her medical treatment. The first living will document was created in 1969 and was followed by three failed attempts to pass living will laws in Florida and

¹ Colby, William H. (2006). *Unplugged*, New York: AMACOM, p. 97; ² *Ibid.*, p. 96; ³ *Ibid.*, p. 18

California. It took the Quinlan case – and public interest in the issue – for the law to pass in California. While other states followed suit, state living will laws varied in their provisions, resulting in a fragmented national ethos. In Missouri, for example, feeding tubes were excluded from medical technology considered medical treatment – the very issue that forced Nancy Cruzan’s parents to wage a four-year legal battle.



1983:

Nancy Cruzan

In 1983, 25-year-old Nancy Cruzan swerved off the road and was thrown from her car while en route to her parent’s home in Carthage, Missouri. Paramedics found her with no vital signs, but they were able to resuscitate her. By the time she reached the hospital, she had fallen into a deep coma. After several weeks of hospitalization, she was diagnosed, like Quinlan eight years before, as being in a persistent vegetative state. As a result of the accident, Cruzan had suffered anoxia, or lack of oxygen to the brain, that caused her

bodily functions to shut down. She was placed on a respirator until hospital staff was able to get her to breathe on her own. Because she could not eat or drink, surgeons inserted a feeding tube.

For several years, her family waited in vain for any signs of recovery. Then, in 1986, they asked medical officials to remove her feeding tube after they jointly agreed that’s what she would have wanted. The medical officials refused to comply unless a specific Order of the Courts of Missouri was furnished. The family’s request was at odds with the Missouri living will law that had been enacted following the Quinlan case. After battling with the medical establishment, the Cruzan case was brought before the Missouri Supreme Court in 1988. The Court found that unless Cruzan had left clear instruction or convincing evidence that she did not want a feeding tube, it could not be removed.

In 1989, the U.S. Supreme Court agreed to hear the case, marking the first right-to-die case to reach the hallowed chambers. The case generated national headlines and captured public attention for the next 18 months. On June 25, 1990, in a 5-4 decision, the Cruzan family lost the case: the federal court stated that the Missouri ruling did not violate the federal constitution and, “unless Nancy Cruzan had left clear and convincing evidence of her wish to remove the feeding tube, it had to stay in place.” Ultimately, the Cruzan family prevailed when two witnesses came forward, testifying that Nancy had indeed expressed those wishes during conversations with each of them. On December 15, 1990, the tube was removed. Nancy Cruzan died 11 days later.

While the Cruzans were finishing their long journey of caring for Nancy, the ordeal of Terri Schiavo’s family was just beginning.

1990:

Terri Schiavo

On the morning of February 25, 1990, 26-year-old Terri Schiavo collapsed in the hallway of her apartment in St. Petersburg, Florida. Her husband, Michael, dialed 911. By the time the paramedics arrived, she was not breathing and had no pulse. They attempted to resuscitate her: she was defibrillated several times and was hospitalized, placed on a respirator and had a feeding tube inserted. The long period without oxygen led to profound brain injury that eventually, upon autopsy, was termed

“anoxic-ischemic encephalopathy,” a disorder characterized by a reduction in oxygen supply combined with reduced blood flow to the brain.



While Terri’s medical condition turned out to be very similar to Nancy Cruzan’s, the Schiavo family disagreed on what they perceived to be her true cognitive state and on whether she would have wanted her life prolonged through artificial means. Terri’s husband believed she was in a permanent vegetative state and would not have wanted artificial means to prolong her life. Conversely, Terri’s parents and siblings were convinced that she was in a “minimally conscious state” and that removing her life support was tantamount to murder. The ensuing initial legal battles between 1993 and 2000 involved the husband’s role as legal guardian and his request, beginning in 1998, to remove Terri’s life support.

In 2000, the case changed dramatically when the media entered the picture: a lone reporter from the *St. Petersburg Times* was assigned to the case and seated in the courtroom. While Michael Schiavo’s attorney objected to the reporter’s presence, the judge ruled to permit the media coverage, absent of any case law to support doing otherwise. It is worth noting that the judge had offered an extended recess to allow both attorneys to research the issue, but both decided to proceed.³

With the advent of 24-hour cable television, the local story soon reached epic proportions, transforming a personal legal matter into national tabloid news. The coverage incited demonstrations among pro-life and disability rights activists and prompted politicians, including then-Florida Governor Jeb Bush and House Majority Leader Tom Delay, to take unprecedented moves to pass legislation granting Terri’s parents more time to argue their case.

In 2000, the judge ruled that Michael Schiavo could stop tube feeding Terri and allow her to die. Shortly after this decision, Michael had Terri moved from a nursing facility to Woodside, a residential facility operated by The Hospice of Florida Suncoast (now Suncoast Hospice). On April 24, 2001, Terri’s artificial nutrition and hydration was stopped – but not for long; Terri’s parents filed a new lawsuit, leading to an emergency order to resume feeding.

In all, the Schiavo case involved 14 appeals and numerous motions, petitions and hearings in the Florida courts; five suits in federal district court; Florida legislation known as “Terri’s Law” (later struck down by the Supreme Court of Florida); and the fast-track passage of the federal law, “For the relief of the parents of Theresa Marie Schiavo,” sponsored by House Majority Leader Tom Delay. Ultimately, the decision to discontinue life support fell back to the Florida courts, which ruled in favor of her husband. On March 18, 2005, Terri was disconnected from life support. She died on March 31.

During the final weeks of Schiavo’s life, media attention to the story, fueled by around-the-clock protestors outside Woodside, resulted in unprecedented attention to the issue of advance care planning. During the week before Terri Schiavo’s death, NHPCO received hundreds of phone calls each day – including more than 1,200 in a single day – as well as thousands of emails and web hits from people seeking advance directives.