

Book Review

Colby W. *Long Goodbye: The Deaths of Nancy Cruzan*. Carlsbad, CA: Hay House, 2002.
Reviewed by Cameron Bopp, MD

In early 1987, 31-year-old William H. Colby was a new lawyer at a prestigious Kansas City firm when he was asked to take on a *pro bono* case by a senior partner with a strong civil rights interest. A blue-collar family in small town southwestern Missouri was seeking to have the feeding tube removed from their 28-year-old daughter, who had been in a persistent vegetative state for four years following an auto accident. The state rehabilitation hospital where she was a patient had refused to comply without a court order. In *Long Goodbye: The Deaths of Nancy Cruzan*, Colby provides us with a remarkable, very personal account of this family through his eyes as their attorney during the four legal battles that finally allowed Nancy Cruzan to die peacefully with her family at Christmas in 1990.

While the US Supreme Court opinion in *Cruzan v Director, Missouri Department of Health (1990)* was a landmark in clarifying what has come to be known in the US as the right to die, the Supreme Court was only the third of the four court proceedings that the Cruzans endured in their long ordeal. Colby balances the dry legal record with a rich narrative history that portrays the Cruzan family's experience in human terms of their hope, suffering, love, and desire to do the right thing for Nancy. He uses his intimate first-hand knowledge of the details of the case and the people involved to give life and voice to this particular family, at this specific place and time. At the same time he provides an inside account of the legal system, the legal and media strategies that emerge, the political forces that play out through the courts—and through the emotions of the Cruzan family's intensely personal involvement in them. His access to transcriptions and his notes detailing the actual words used by protagonists during planning sessions, depositions, and court proceedings allows him to move large sections of the story along through dialogue that commands the reader's attention.

As first person narrator, Colby finds the right tone to describe the "snapshot memories" of participants, those vivid clear moments that persist through hazes of confused emotion and pain and have significance long afterward—the words spoken by an ER nurse, the odor in a room, the tone of voice of an expert witness. Colby does not skimp on his own observations and emotions, such as his shock at first seeing Nancy Cruzan in her hospital room at the Missouri Rehabilitation Hospital. While he gives us enough information about each important character, including himself, to make them come alive, for the most part he keeps the information relevant to their role in the drama. As a native Missourian, I found his sympathetic portrayal of small town, Midwestern character and life to be wonderfully accurate.

But the real focus of the story is the Cruzan family, especially Nancy's father. Joe Cruzan emerges as a complex character, an archetype of the intelligent working man whose curiosity, strong sense of

values, and tenacious determination to think complex issues through himself, sometimes idiosyncratically, are life-long traits, as are his civic sense and enjoyment of being in the public eye. When the family finally realizes the hopelessness of Nancy's recovery, he researches the family's rights and recent court decisions, corresponds with other families who had been through similar proceedings, and once on track never veers from his determined course, even as the family is increasingly buffeted by forces played out on a national legal and media stage.

The Cruzans' initial hearing was in county probate court, where they were opposed by the State of Missouri (under then-Governor John Ashcroft). Although the 1976 Quinlan case had ushered in an era of court activism and public and professional discussion on end-of-life issues, individual states continued to show wide divergence in their interpretations of the right to die over the next decade. Missouri, for example, argued in the Cruzan case that only patients meeting the criteria of brain death could be allowed to die, and that withholding "ordinary" treatment like artificial nutrition and hydration (as opposed to "extraordinary" treatment like mechanical ventilation) was equivalent to killing. Similar arguments were being made nationally at the time by conservative religious groups.

The probate court hearing, which ends with the judge granting the Cruzan's request, marks the end of the first half of the book and is by far its strongest section in terms of character development and page-turning drama. Especially engaging are the sympathetic professional characters of the distinguished, conscientious small-town lawyer who is appointed by the probate judge, his long-time friend, to serve as Nancy's *guardian ad litem*, and of the judge himself, who agonizes for weeks over his decision, finally making one that he knows will doom his chances for judicial advancement in conservative state political circles. Colby maintains a tactful and respectful objectivity when dealing with his legal adversaries from the state, but their portrayals lack the sense of nuanced realism other characters achieve. The only time he shows real impatience is when describing state medical witnesses whom he obviously considers to be intellectually and emotionally mediocre and dull.

Despite the probate judge's favorable ruling in 1988, the State of Missouri predictably did appeal the decision, leading to the second Cruzan trial in the Missouri Supreme Court in 1989. Not unexpectedly, the state high court confirmed the State's position, setting the stage for appeal to the US Supreme Court the following year. The massive preparations for the case, from the lobbying of prestigious groups to weigh in with friendly briefs, the strategy for obtaining support or at least decreased opposition from Solicitor General Kenneth Starr, to the mock court proceedings that the legal team engages in with legal experts, are aspects of the legal drama that are unknown to most of us. Understandably, the Cruzans recede into the background at this stage of the book, which becomes more of lawyer Colby's story, although their emotional ordeal continues to be documented. The Supreme Court appearance itself, with only a relatively short and strictly monitored time for presentation and questions, is anticlimactic; the final hundred pages of opinion come by fax weeks later.

In *Cruzan*, the Supreme Court explicitly extended the constitutional right to refuse medical treatment, established in 1900, to include decisions to stop life-sustaining treatment, and clarified that artificial nutrition and hydration were medical treatments like any other, and therefore could be stopped like any other treatment. In so doing, the justices clarified that there is no rational difference between "extraordinary" measures, such as ventilators, and "ordinary" measures, such as artificial

nutrition and hydration.* The Court upheld the right of families to make decisions to forgo treatment for their incapacitated loved ones so long as that decision was based on an understanding of what the patient herself (himself) would have wanted. The Court also affirmed, however, that states could set their own standards for the level of proof that was necessary to feel confident that the decision to forgo treatment was consistent with the patient's wishes. Since Missouri wished to have an exceptionally high standard of "clear and convincing evidence," and since the Cruzans could not meet that high standard, the Supreme Court decision upheld the state's argument and, in effect, impeded the Cruzans' ability to order discontinuation of Nancy's treatment. Thus, while acknowledging the right of families to make decisions to stop treatment on behalf of incapacitated loved ones, the Court allowed that states could set the evidentiary standards by which families could effectuate that right.

This ruling, along with the intense national publicity surrounding the trial, led to Congress passing the 1990 Patient Self-determination Act, mandating hospitals to offer information on advanced directives and patient rights to patients on admission, and to the concern regarding better advance medical planning that continues currently and is the subject of these special issues of *Innovations*.

Ironically, and fortunately for the Cruzans, the publicity of the Supreme Court proceedings led two new witnesses to come forward. They had been Nancy's co-workers years earlier, during a month that she spent working in Oklahoma with severely handicapped children. Their descriptions of conversations with Nancy regarding her wishes in conditions such as a persistent vegetative state were specific and detailed enough to satisfy the Missouri court's criteria. With this new evidence, the Cruzans and Colby returned once again later in 1990 to the county probate court, this time unopposed by the state. This time, the proceedings led again, in an appropriately local and intimate setting, to the final repetition of the family's entire case, and the judgement by the same probate court judge to allow removal of Nancy's gastrostomy tube in late December.

The description of Nancy Cruzan's peaceful death at Christmas at the hospital with her family is a touching scene familiar to all of us involved in care at life's end. By now, however, the Cruzan family had forfeited their ability to escape the public eye. Outside the hospital, poorly informed fundamentalist protesters try to storm the hospital to feed her, a scene that is at once surreal and emblematic of our polarized society.

In an epilogue, Colby finishes his account with the suicide of increasingly morose Joe Cruzan in 1996—yet another human tragedy in the life of this beset family. One is left with the feeling that Joe Cruzan used himself up to protect and sustain his family, in the process sustaining an emotional exhaustion so deep that there just was not enough left to sustain him. By the end of this 400-page book, the reader is emotionally exhausted as well, left with the hope that in the years since the Cruzan decision, hospice and bereavement intervention, which the circumstances of this case precluded, have helped to prevent similar tragedies for other families.

On the whole, Colby is successful at paying homage to the cohesion, courage, and determination of this family of everyday heroes. He makes us appreciate the enormous personal toll that can be

* For an excellent summary and analysis of the legal issues, see Gostin LO. Deciding life and death in the courtroom: From Quinlan to Cruzan, Glucksberg, and Vacco—A brief history and analysis of constitutional protection of the "right to die." *Journal of the American Medical Association*. 1997;278(18):1523-1528.

exerted on families who take on the role of social spearheads through the legal system for a cause they believe in. He is somewhat awkward in entwining his own professional exhilaration as a young lawyer involved in a momentous case, but it is after all his story, too, and he emerges as a sympathetic figure who has sincerely done his best for his clients, both as an attorney and an author. One is left wondering about what advice the family received in agreeing to become involved in telling their story so publicly in the media, and how much extraordinary support the "friends" of the case, including professionals involved in end-of-life issues, should be vigilant in providing those who subject themselves to such legal ordeals on society's behalf.

The book is very worthwhile reading for anyone wanting a first-hand account of the human side of the legal process, especially of so important a case. The story certainly provides a potent incentive testimonial for proponents of better advance medical directives and care planning. In this regard, it should be especially useful for those wishing to enlist the better understanding and crucial support of the legal community in their own locales through a riveting story told by "one of their own."