By all accounts, Daniel Joseph “Joey” Fiori was an intelligent and vigorous young man with a promising future. He played drums in his high school band in suburban Philadelphia and engaged in a variety of sports, including football at school and surfing at the beach where he spent much time during the summer as a teenager. After graduation, Joey was looking forward to furthering his education by studying nuclear physics, a goal that seemed well within his reach given his IQ of 147.

The Vietnam War intervened, however, and in 1968, rather than be drafted by the army, Joey enlisted in the navy. He served with distinction in Vietnam and was going home on leave in 1971 to marry his childhood sweetheart when tragedy struck. Just ten days before the wedding, Fiori was involved in a motorcycle accident that caused him severe brain damage (Hinds 1994).

Fiori was still severely impaired when he regained consciousness after more than a year in a coma. His vocabulary consisted of only two words—itch and eye—and his ability to interact with and understand his environment was extremely limited. He was also wheelchair-bound. Rosemarie Sherman, Joey’s mother, took her son home and cared for him with the help of home health care aides.

Joey Fiori’s medical problems were compounded in 1976 when he fell while attempting to get out of his wheelchair and walk. The fall caused a break in his leg that was serious enough to require a stay at the local veterans’ hospital. While he was convalescing there, hospital personnel failed to provide the required antiseizure medication Fiori had taken for years. As a result, he suffered a grand mal seizure that left him in a persistent vegetative state (PVS) (see Box 1.1). Mrs. Sherman brought legal action against the hospital, and the Veterans Administration ultimately agreed to compensate her fully for the cost of her own health care (as the primary caregiver) and her son’s health care for the duration of his life.

As with most patients in a PVS, the vegetative functions of Fiori’s lower brain—where heartbeat, respiration, and body temperature are regulated—
BOX 1.1 The Persistent Vegetative State (PVS)

The Multi-Society Task Force on PVS was established in 1991 to address definitional and clinical aspects of the persistent vegetative state (PVS). The task force was created by drawing two physicians from each of five medical societies (the Child Neurological Society, the American Academy of Neurology, the American Neurological Association, the American Association of Neurological Surgeons, and the American Academy of Pediatrics). The group’s findings were published as a two-part series in the *New England Journal of Medicine* (Multi-Society Task Force on PVS 1994a, 1994b).

According to the task force, the persistent vegetative state is a relatively new phenomenon, which was first identified by medical researchers in 1972 (Multi-Society Task Force on PVS 1994a: 1499). The task force went on to define the syndrome as “a clinical condition of complete unawareness of the self and environment” (Multi-Society Task Force on PVS 1994a: 1499).

Even though PVS patients may exhibit sleep-and-wake cycles, they show no evidence of response to or understanding of environmental stimuli. Patients in a PVS resulting from a loss of oxygen to the brain can reliably be considered permanently vegetative after three months; those in a PVS resulting from a blow to the head can reliably be considered permanently vegetative after one year (Multi-Society Task Force on PVS 1994b: 1575). Recoveries from a PVS after the designated time has elapsed are exceedingly rare, and they are inevitably associated with severe and permanent disability (e.g., blindness and paralysis). The life expectancy for patients in a PVS ranges from two to five years, though occasionally, patients can be sustained a good deal longer (Multi-Society Task Force on PVS 1994b: 1575). On average, the cost of caring for a patient in a PVS exceeds $250,000 the first year and runs approximately $150,000 a year thereafter (Multi-Society Task Force on PVS 1994b: 1576).

remained intact. Fiori also exhibited standard sleep-and-wake cycles, another common characteristic of PVS patients. But the thinking part of Fiori’s brain—the harbor of memory, emotion, communication, and understanding—was entirely and irreversibly destroyed. His swallowing reflex was compromised as well, so Fiori received nutrition and fluids through a gastrostomy tube that was surgically implanted in his stomach. Fiori also had a tracheostomy tube that was hooked up to an oxygen mist machine several times a day in order to make breathing a bit easier for him (see Box 1.1).

After Fiori’s condition stabilized, his mother took him home again, where she tended to him for the next fifteen years. Fiori needed to be rolled periodically (to prevent bedsores), cleaned (he was completely incontinent), and have his limbs stretched (to help forestall the muscle atrophy and limb contracture that result from complete inactivity), so private duty nurses were retained to help with these physically demanding tasks. Despite what the doctors were telling her about the permanence of her son’s vegetative condition,
TABLE 1.1 PVS and Syndromes Often Confused with PVS

<table>
<thead>
<tr>
<th>Condition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Persistent vegetative state (PVS)</strong></td>
<td>A clinical condition of complete unawareness of the self and environment. Even though PVS patients may exhibit sleep-and-wake cycles, they show no evidence of response to or understanding of environmental stimuli.</td>
</tr>
<tr>
<td><strong>Brain death</strong></td>
<td>Brain death involves the irreversible loss of all brain functions, including vegetative functions. The body can only be maintained for short periods of time (hours or perhaps days) even with aggressive treatment. Brain-dead patients can be pronounced legally dead after two electroencephalograms taken twenty-four hours apart confirm the absence of all brain activity. Typically, vegetative functions are artificially maintained only long enough to harvest organs and tissues for transplantation.</td>
</tr>
<tr>
<td><strong>Coma</strong></td>
<td>Comas are unarousable, sleeplike conditions resulting from injury to the brain stem. A coma, the condition Joey Fiori was in immediately following his accident, may last for an extended period of time, but rarely are comas permanent; many comas last only a few hours, days, or weeks. Sometimes, a coma can evolve into the more permanent PVS.</td>
</tr>
<tr>
<td><strong>Locked-in state</strong></td>
<td>The locked-in state is sometimes referred to as the state of severe and permanent paralysis. Patients in a locked-in state suffer from a complete and irreversible loss of all motor functions, making it very difficult or impossible for them to acknowledge or communicate with others even though they maintain normal levels of consciousness. The end stage of amyotrophic lateral sclerosis (Lou Gehrig's disease) is a common cause of the locked-in state. Diagnostic tests (e.g., CT scans and MRIs) can reliably distinguish between the locked-in state and the PVS.</td>
</tr>
</tbody>
</table>

**SOURCE:** Information for this table is drawn primarily from Cranford 1991a: 14-16.

she held out hope that Joey would “snap out” of his vegetative state, just as he had awakened from his yearlong coma in 1972 (see Table 1.1).

In 1990, Sherman’s health began to fail, making it impossible for her to continue caring for her son at home. So in 1991, she agreed to have Joey put in a suburban Philadelphia nursing home, where she continued to visit him daily or as often as her health would allow. During this time, Mrs. Sherman also helped do his laundry, coordinated nursing schedules, and held bedside prayer vigils with friends as she continued to hope for a miraculous recovery.

Then, on Valentine’s Day 1992, Rosemarie Sherman had a revelation. She had taken a bouquet of flowers and two plastic hearts to her son’s bed-
The Case of Joey Fiori

side, saying, “One heart is yours, Joey, and one heart is mine” (Morris 1994). At that moment, Mrs. Sherman became fully aware, for the first time, of the utter lack of understanding behind her son’s blinking eyes. “He didn’t even know I was there. All these years I thought he knew I was there,’ she said, her voice cracking. ‘He didn’t know’” (Morris 1994). It was on that day that Rosemarie Sherman accepted the fact that her son would never recover.

Sherman suffered a heart attack later that year, which increased her ever present concern that Joey would survive her and have no one to provide him with the kind of devoted, hands-on care and advocacy she had given him for over twenty years. Now, with her sharpened appreciation for the hopelessness of her son’s predicament, Sherman began to see the futility in the ongoing processes of blood testing, poking, prodding, turning, cleaning, toileting, respirating, and medicating her son. “Is there no end to the insanity?” she remembered wondering (quote is from a personal interview).

The only reasonable course of action, she concluded, was to ask that her son’s feeding tube be withdrawn. “My Joey’s between two worlds,” she explained at the time. “I want my son to die with dignity. . . . If he could speak, there is no way he would want to live this way” (Hinds 1994).

Joey’s siblings were reluctant to go along with this decision at first. But in a family meeting, their mother asked each of them in turn, “What would you want done if it were you in the situation that Joey is in?” (quote is from a personal interview). To a person, they all said that they would want life-sustaining treatment removed. “So that,” said Sherman, “is what I will do for Joey.” Mrs. Sherman conferred further with several priests and doctors familiar with the case and was reassured that withdrawal of feeding was an appropriate course of action in the situation.

The nursing home disagreed, however, and suggested that Sherman obtain a court order approving the removal of the feeding tube. As one administrator affiliated with the nursing home explained, forgoing feeding would constitute a “hospice response” to Fiori’s situation, and that was problematic for two reasons. First, technically speaking, Fiori was not terminally ill (which is a standard prerequisite for receiving hospice care); all his caregivers agreed that he could live, with continued life-sustaining medical treatment and good nursing care, for many more years. Second, even if Fiori were terminally ill, the nursing home did not have a hospice program in place: “Withdrawing feeding . . . that’s just not something we do,” explained the administrator (quote is from a personal interview). Even if the court approved Mrs. Sherman’s request, this same administrator speculated, the institution’s directors would likely ask that Fiori be transferred to another facility rather than have the nursing home become involved in the withholding of feeding.

Sherman decided to fight the institution’s decision, and the first stop in the legal battle over her son’s life and death was the Orphans’ Court of Bucks
The Case of Joey Fiori

County (Pennsylvania). A motion was filed in May 1992, and a hearing was held before Judge Leonard B. Sokolove in September of that year. Sherman was opposed in court by the office of the Pennsylvania state attorney general (AG). Two physicians, one of whom was secured by the attorney general's office, provided concurring testimony that although Fiori was in a persistent vegetative state and would not improve, he could survive for ten to twenty more years with good nursing care (Eastburn and Schaeffer 1994: 5). For her part, Mrs. Sherman testified that "I knew my son better than anyone knew him . . . he liked living . . . he would not want to live this way." She closed with the passionate request that her son be afforded the opportunity to "rest in peace and be with God" (Eastburn and Schaeffer 1994: 6).

Although not contesting either the medical diagnosis or the prognosis, the lawyers from the attorney general's office argued that judges are better and more impartially positioned than family members to make end-of-life decisions and that no decisions about terminating life-sustaining medical treatment should be made without clear and convincing evidence that forgoing treatment is what the patient would want. Louis J. Rovelli, the executive deputy attorney general, later opined that "we are talking about starving a person to death, in layman's terms" (Morris 1994). He subsequently argued that there is no reason to treat patients in a persistent vegetative state that way, for they "may be healthy, physically . . . or as healthy as one could be in a coma" and "they are provided for financially and feeling no pain" (Galewitz 1995).

In February 1993, Judge Sokolove granted Sherman's petition, but the attorney general's office filed an appeal with the state's superior court, which shortly thereafter agreed to hear the case. In a 2-to-1 decision issued in November 1993, a panel of three superior court judges reversed Judge Sokolove's trial court ruling and accepted the attorney general's position that clear and convincing evidence of a patient's wishes must be presented before life-sustaining medical treatments are either withheld or withdrawn. Failing the presentation of such evidence (and none existed in Joey Fiori's case), the panel argued that the courts should rule in favor of preserving life.

The majority opinion of the three-judge panel was not well crafted, however. In fact, the decision was so unclear and left so many questions unresolved that both Sherman and the attorney general's office filed applications for the case to be reheard en banc (before a panel of nine superior court judges). The superior court voted to accept the case for rehearing, the court's three-judge panel decision was withdrawn, and a panel of nine superior court judges was selected to rehear the case. At about this time, as stories of the decision began to appear in the local papers, right-to-life protagonists began making disturbing calls to Mrs. Sherman. "Is 'Danny' there? Can I speak with him? Is Danny hungry?" the callers asked. Mrs. Sherman was forced to have her telephone number changed. (Obviously, the callers
The Case of Joey Fiori

were not familiar enough with the family or the case to know that Daniel Fiori went by the nickname "Joey.")

The dissenting judge in the 2-to-1 panel decision, Phyllis W. Beck, found herself part of a 6-to-3 majority after the nine judges reheard the case. Subsequently, Beck was assigned the task of authoring the superior court's opinion, which affirmed Judge Sokolove's original trial court ruling and was issued in January 1995.

Once again, the attorney general's office appealed the ruling, this time to Pennsylvania's highest court, the state's supreme court. The Pennsylvania Supreme Court agreed to hear the case, but before arguments could be heard, Fiori contracted pneumonia, his ninth episode since 1976. Each time previously, antibiotics were given as a matter of course and the infection was resolved. This time, however, at Rosemarie Sherman's request, antibiotics were not administered. The pneumonia was allowed to take its natural and ultimately fatal course, claiming the life of Daniel Joseph Fiori on February 6, 1995. Fiori was forty-four and had been in a persistent vegetative state for nearly two decades. At the time of his death, his health care bill was approximately $165,000 a year. And since 1976, more than $3 million had been spent caring for this now middle-aged man.

The legal battle did not end there, however, for the attorney general's office argued that a case like this one would probably arise again. Because there was no definitive case law on the books (aside from the January ruling of the superior court), the AG's office pressed the supreme court to continue with the case and issue a ruling, even though that decision would be moot with regard to Joey Fiori. The supreme court agreed and proceeded to schedule hearings.

Meanwhile, with her son dead and with limited resources at her disposal, Rosemarie Sherman agreed to grant the Pennsylvania Medical Society (PMS) the right to continue arguing the case on her behalf. The PMS had already filed an amicus curiae (friend-of-the-court) brief in support of Sherman's position before the superior court, so the group was familiar with the case and its potential implications. As one lawyer close to the case explained, "If you do not get involved in these kinds of landmark cases, you let others make the law for you" (quote is from a personal interview). Seeing that an important question was at stake and appreciating the fact that law was about to be made, the PMS stepped quickly into the breach and took on the role of lead counsel in support of Sherman's petition.

The supreme court heard oral arguments from the PMS (Hoffman 1995) and the attorney general's office (Unger and Knorr 1995) in April 1995. In addition to the oral and written briefs supplied by these organizations, a friend-of-the-court brief in support of the AG's position was provided by the Pennsylvania Catholic Conference (Connell and Quinlan 1995). Two other amicus briefs were supplied in support of the position advanced by Sherman and the PMS: one from a New York-based right-to-die organiza-
tion called Choice in Dying (CID) (Kavolius and Fade 1995) and a second brief jointly issued by the University of Pittsburgh Center for Medical Ethics and the University of Pennsylvania Medical Center (Meisel and Adler 1995). A review of these five briefs, together with Rosemarie Sherman's brief before the superior court (Eastburn and Schaeffer 1994), the opinions rendered by the trial court judge (Sokolove 1993) and three superior court judges from the en banc decision (Beck 1995; Wieand 1995; Popovich 1995), and the final decision of the Pennsylvania Supreme Court (Cappy 1996), provides an excellent opportunity to assay the arguments on each side of the two important and closely related questions in this case: Who can make end-of-life decisions for another? And on what basis should those decisions be made?

Judge Sokolove Finds the Balance of Interests

Tipping in Sherman’s Favor

The first ruling in this case was issued on February 3, 1993, by Leonard B. Sokolove, judge of the Orphans’ Court Division of the Bucks County Court of Common Pleas, located in Doylestown, Pennsylvania. Sokolove began his analysis by reviewing the state’s interest in preserving life, an interest that is traditionally expressed as four separate but related interests: (1) the prevention of suicide, (2) the protection of innocent third parties, (3) the preservation of the integrity of the medical profession, and (4) the preservation of life. Sokolove argued that the first three goals did not apply in Joey Fiori’s case.

Sokolove reasoned that because Fiori was unaware of his circumstances, the proposed action—the withdrawal of feeding—could not be considered a suicide. Sokolove also dismissed the second state interest: There were no innocent third parties to be adversely affected because the mother was bringing the action and Fiori had no spouse or children depending on him. With regard to the third interest, Judge Sokolove contended that the medical profession would not be adversely affected since every representative of the profession involved in the case supported the petitioner's request (Sokolove 1993: 4).

Finally, with regard to the sweeping “preservation of life” role the state assumes for itself, Judge Sokolove made three points. First, he cited the only other decision in a case of this type in Pennsylvania—Ragona, another trial court case without the force of precedent. In that case, it was argued that “the Commonwealth's interest [in preserving life] weakens and the individual's right grows as the prognosis dims and the intrusiveness of the treatment increases” (cited in Sokolove 1993: 5). Second, Sokolove determined that the plaintiff was acting in good faith in conjunction with sound medical advice. And third, he argued that the rationale for withdrawing
life-sustaining medical treatment could be at least partially built on the foundation of public opinion, for “an overwhelming majority of society would, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them” (Sokolove 1993: 6, citations omitted). Sokolove bolstered this last point by referring to an influential and well-regarded federal report that endorsed the process of determining what decision was in the best interest of the patient via objective, societally shared criteria (see President’s Commission 1993: 134–135).

Summing up, Judge Sokolove argued that “the medical evidence is convincing that Daniel Joseph Fiori’s life is without content, let alone any quality. . . . The petition of Rosemarie Sherman [is] granted, and the [nursing home is] authorized to discontinue artificial feeding and all other means of life-sustaining procedures” (Sokolove 1993: 8–9).

Sherman’s Attorneys Plead Their Case
Before the Superior Court

After winning at the trial court level and seeing the original ruling overturned by a 2-to-1 panel decision in the superior court, the attorneys representing Mrs. Sherman—William Eastburn and John Schaeffer—found themselves arguing before an en banc session of the superior court. In their presentation, the attorneys reiterated what they perceived to be the relevant facts of the relationship between Sherman and her son. They pointed out that Sherman had been Fiori’s mother for forty-four years and had lived with or cared for him for all but two of those years (the years Fiori spent in the navy). She had cared for her vegetative son in her home for thirteen years and had visited him several times a day (and participated in his care) at the nursing home thereafter. She had made all decisions regarding his welfare for twenty-two years and had been the legally appointed guardian of her son for the last twelve years of his life. “Who, more than Rosemarie Sherman, was better equipped to make medical treatment decisions for Joey Fiori?” they asked (Eastburn and Schaeffer 1994: 22).

To bolster the argument that family members should be allowed to make end-of-life decisions for their loved ones without court involvement, Sherman’s attorneys cited the Connecticut Superior Court decision in the case of Sandra Foody. That court ruled that if a patient was permanently and irrevocably incapacitated and if concerned family members were present to act in good faith, those family members could make any treatment decision that the patient could have made for him- or herself, if competent:

The courts have recognized the rights of a guardian of the person to vicariously assert the right of an incompetent or unconscious ward to accept or deny medical care. To deny this exercise because the patient is unconscious or incompetent
The Case of Joey Fiori

would be to deny the right. It is incumbent upon the state to afford an incompetent the same panoply of rights and choices it recognizes in competent persons (Eastburn and Schaeffer 1994: 17–18, emphasis added, citations omitted).

Sherman’s attorneys criticized the attorney general’s suggestion that clear and convincing evidence should be required before waiving life-sustaining medical treatment. Requiring that standard of proof, they argued, would eliminate any balancing of governmental and individual interests for patients who did not have the forethought to issue explicit instructions about treatment decisions they themselves would make at the end of conscious life. The attorneys contended that such a ruling would allow the government to prevail—despite the family’s and the patient’s physical and emotional ordeal, despite the hopeless prognosis, and despite the absence of any quality of life or hope of improvement in the patient’s condition. “The Commonwealth’s proposed standard would, quite simply, abrogate Mr. Fiori’s constitutional rights to refuse treatment, a right which should only be abridged upon a showing of compelling state interest. No such interest exists in this case,” Sherman’s attorneys concluded (Eastburn and Schaeffer 1994: 20–21).

Judge Beck Puts the Ball Back in Sherman’s Court

Judge Phyllis Beck delivered the superior court’s majority opinion on January 17, 1995. Beck’s opinion focused on the key issue of whether and to what degree the right to self-determination can be exercised by surrogates after a principal has become incompetent. In finding in favor of Rosemarie Sherman, Beck noted that courts across the nation had agreed to allow the withdrawal of treatment from incompetent patients in every other case of this type, as long as the patient’s desires could be determined. That is, “the right to self-determination has uniformly been held to survive incompetency” (Beck 1995: 12). The only sticking point, Beck noted, was the level of evidence required.

Those few states that require a high degree of certainty regarding the patient’s wishes have done so for at least one of two reasons: (1) to prevent a wrong decision from leading to the withdrawal of life-sustaining treatment prematurely (the reality of medical uncertainty always leaves some sliver of hope for recovery), or (2) to prevent decisionmakers from acting in bad faith. Beck found both rationales wanting. First, she pointed out that public opinion research indicated most people would want life-sustaining treatments withdrawn if they were in a permanently vegetative state. Consequently, she said, the number of wrongful continuances of treatment that would occur if courts made presumptions in favor of life would far exceed
the number of wrongful deaths that would occur if the courts allowed the discontinuance of such treatments.

Second, Beck pointed out that there was no evidence to suggest that surrogates act in bad faith or on the basis of conflicts of interest. The state's attorneys had earlier argued that the potential for abuse in decision making was a sound reason to apply the “clear and convincing evidence” test. But Judge Beck found that no such evidence could be sustained in this specific case or more generally.

Third, Judge Beck found fault with the entire concept of judicial involvement in cases like the one at hand. “The time of the decision to withdraw life sustaining treatment is one fraught with pain and anxiety for those who love the patient,” she wrote. “To compound the suffering with a court proceeding is insensitive and unnecessary . . . overly intrusive, and violative of the individual’s right to privacy” (Beck 1995: 14–15).

Beck went on:
The patient’s rights are adequately represented by the surrogate, in this case, the mother. She is clearly qualified to exercise substituted judgment and can express what Mr. Fiori would want. His mother, who has given her son devoted care for almost two decades, who has taken all those years to consider what should be done, who has consulted her religious advisors and her own heart, is here to tell us that at this point in time, “enough is enough” (Beck 1995: 15).

Judge Beck elaborated on the role of the family in such cases, leaving no question as to her general conclusions:

Almost invariably the patient’s family has an intimate understanding of the patient’s medical attitudes and general world view and therefore is in the best position to know the motives and the considerations that would control the patient’s medical decisions . . . because of their special bonds with him or her. . . . These decisions have been made by families, in consultation with doctors and other advisors, in privacy and without governmental interference. . . . The majority . . . believes the law should cherish and safeguard family integrity. The wisdom and decency of a family faced with life and death decisions do not need to be tested in court (Beck 1995: 17–18).³

Judge Wieand Emphasizes the “Best Interests” of the Patient

In a concurring opinion, Judge Donald Wieand agreed with Judge Beck that families should be deferred to without courts necessarily being involved. At the same time, he was concerned about cases that ended up in court because the patient’s family disagreed with the physician, because family members disagreed among themselves, or because no family or close friends
The Case of Joey Fiori

were available to help with decision making. These cases should be brought before the court, Wieand argued, and the court should be prepared to act in accordance with its *parens patriae* role.4

He explicitly rejected, however, the attorney general's contention that continued life should be the default rule for any situation in which the desire to be allowed to die had not been explicitly expressed. Rather, he argued, the *parens patriae* responsibility should be viewed as the responsibility to see that an incompetent individual's *interests* were advanced (Wieand 1995: 7–8). This approach would require the decisionmaker (in this case, the court) to carefully weigh such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained in an effort to determine whether treatment should be continued or withdrawn.

What result would this approach have yielded if applied in the Fiori case? Wieand left little doubt about his opinion on this score: "To require someone to remain in [a persistent vegetative state] for perhaps decades cannot be in the best interest of that individual. Indeed it can be argued that to keep an individual in that condition, with no hope of recovery, is not only against the best interests, but inhumane" (Wieand 1995: 9–10, citation omitted).

**Judge Popovich Emphasizes the Importance of the Court's Role as Parens Patriae**

In his dissenting opinion, Judge Zoran Popovich appeared to be much more concerned than the judges in the majority about the ability of modern American families to act in good faith when it comes to end-of-life decision making. Popovich opined that "the deterioration of the family unit has contributed to the creation of a patchwork of single-parent homes, second and third marriages, establishing a step-parent environment and a straining of family bonding among non-blood relatives brought together by remarriage and alienated by divorce." Popovich argued that all this made the appointment of a surrogate difficult. Further, he questioned the degree to which a surrogate would act in good faith (Popovich 1995: 40).

Popovich was much more sanguine about the court's ability to play a useful role in end-of-life treatment decisions than were the judges in the majority. For example, he advanced the argument that "the state, as the *parens patriae* of its citizenry, is not to be dismissed as an intrusive, uninvited participant when the life of one of its own is at risk. In just such instances, the courts (as an extension of state government) have been a reservoir of wisdom and sound reflection when a life hangs in the balance" (Popovich 1995: 1).
For those concerned about the delay and publicity associated with court proceedings, Popovich asserted that expedited hearings could be arranged for court-supervised decision making concerning the sanctity of human life; furthermore, he said, those hearings would not be an invasion of anyone's privacy. “Rather,” he suggested, “such a process would assure that all parties are truly acting with the best interests of the patient in mind and not motivated by any ulterior motive hidden from the light of scrutiny by veiled concerns for the patient's well-being” (Popovich 1995: 2).

Finally and perhaps most revealingly, Popovich confessed that “first and foremost, my actions are motivated by the desire to preserve life” (Popovich 1995: 37). As such, he advised that the court should “proceed slowly, on a case-by-case basis, while awaiting action by the state legislature” (Popovich 1995: 20). In the meantime, he advised employing procedural and substantive safeguards.

Procedurally, he recommended the court appointment of an impartial guardian to represent the patient's interests, an individual without potential conflicts of interest. Substantively, Popovich recommended that the decision to withhold or withdraw life-sustaining treatment should require clear and convincing evidence of the patient's wishes “and not merely the guesses of third parties about what he would have wanted or what was in his best interests.” He argued that such safeguards were in place when issues of less importance hung in the balance (e.g., the placement of an incompetent person's estate or the sterilization of an incompetent patient), so they should not be considered overly burdensome in circumstances where life itself was at stake (Popovich 1995: 15–16).

The Pennsylvania Attorney General's Prolife Approach

The procedural and substantive themes touched on by Popovich in his superior court dissent were initially advanced by the state's lawyers in Judge Sokolove's courtroom in 1992. Those themes resurfaced in the attorney general's arguments before the three-judge and nine-judge panels of superior court justices, and they formed the foundation of the AG's argument before the Supreme Court of Pennsylvania in a brief filed on January 25, 1995. In all four venues, the attorney general's lawyers advanced the conservative, prolife approach articulated by Judge Popovich.

Ideologically, the Pennsylvania attorney general, Ernest D. "Ernie" Preate, was a staunch prolife advocate who had previously gained attention in the state and nationally for his role in defending Pennsylvania's relatively restrictive Abortion Control Act before the U.S. Supreme Court in 1992. This prolife leaning only partially explains why the AG's office plied such a
conservative, prolife course on end-of-life decision making in the Fiori case, however. As one state official explained, although the attorney general himself was ideologically disposed to the conservative position, the stance his office adopted also flowed from an interest in facilitating the orderly development of case law.

The development of case law was important in this matter because the Fiori case had arisen in something of a legal vacuum. Pennsylvania had a living will law on the books that created an instrument to allow individuals to designate surrogates for purposes of making end-of-life decisions. But the statutory law was silent on the question of surrogate decision making when no living will existed and no surrogates had been identified. And no appellate-level decisions had been rendered in the state.

By adopting an adversarial stance vis-à-vis Rosemarie Sherman, members of the AG's team saw the opportunity to force policymakers—judges, in this case—to chart a legal course for others to follow, secure in the knowledge that the full range of issues and positions associated with such cases would be considered. Just as it was the job of Sherman's lawyers to vigorously advocate her position in court, regardless of their personal views on the issues at hand, the AG's team of lawyers advocated the exact opposite position, hoping that the weight of arguments on either side would lead judges to decide fairly and appropriately which course to take—a course that would have the force of law in later cases.

In building a foundation for rejecting the notion of substituted judgment, state attorneys Sue Ann Unger and John Knorr focused on the "liberty interest" a patient enjoys under the Fourteenth Amendment to the U.S. Constitution. The liberty interest is understood to go hand in hand with the requirement that each citizen be accorded due process. The brief authored by Unger and Knorr contended that failing to bring cases involving end-of-life treatment decisions to the courts would violate the patients' liberty interest in prolonged life without the benefit of due process.

For example, Unger and Knorr pointed out that the superior court's en banc decision left it to physicians "to decide, not just the medical facts about the patient's condition and prognosis, but whether there are 'extraordinary circumstances'—such as the bad faith of the relative seeking to terminate treatment—which require court involvement. This imposes upon physicians a responsibility which they are ill equipped to discharge, and abdicates to them a responsibility that is inherently judicial" (Unger and Knorr 1995: 13-14).

Relying on physicians to make determinations about the good faith of family members hardly constituted due process, they continued. Doctors were qualified to pass judgment on a patient's medical condition and prognosis. They were also qualified to suggest whether forgoing treatment made sense from a medical standpoint or whether it could reasonably be consid-
The Case of Joey Fiori

...ed medically futile. But in the view of the AG’s lawyers, physicians would not have the time, information, resources, skills, or predisposition needed to make judgments about the degree to which surrogates were acting in good faith. Rather, they argued, there was no reason to suppose that physicians have any special ability to “perceive” the many factors—conflicts of interest, lack of good faith, disagreements among family members, and failure to abide by the patient’s wishes—that might counsel hesitation in rubber-stamping a self-elected surrogate’s decision to withhold treatment. Such things are the proper responsibilities of guardians ad litem and courts, not physicians. . . . By excluding the court from its proper role, the Superior Court has compromised the integrity of the medical profession (Unger and Knorr 1995: 33, 34).8

The AG’s lawyers used the details of the Fiori case to illustrate just how conflicts of interest could be overlooked. In 1981, Rosemarie Sherman became Fiori’s legal guardian for purposes of prosecuting her malpractice action against the federal government after her son had suffered the seizure that put him in a PVS in 1976. The resulting settlement led to the establishment of a trust fund for Fiori’s care and provided for an annuity to be paid to Mrs. Sherman should she survive her son. Although the AG’s lawyers claimed they were not directly impugning Mrs. Sherman’s integrity or motives, they argued that the conflict of interest (and potential for abuse) was clearly manifested in this case and that this should disqualify Sherman as a guardian of her son’s interests.9

The AG’s lawyers then moved on from Judge Beck’s notion of “substituted judgment” (allowing a close family member to substitute his or her judgment for the decision of the principal, without court involvement) to critique Judge Wieand’s “best interests” proposal, which was to take effect when substituted judgment could not be rendered. According to Unger and Knorr (1995: 30), not only did Mrs. Sherman fail to provide sufficient evidence that her son would wish to forgo continued life-sustaining treatments (in accordance with the substituted judgment approach), she also failed to present sufficient evidence that the forgoing of such treatments were in her son’s best interest (as opposed to her own best interest or the interest of society). “Mr. Fiori was incapable of suffering pain or humiliation and unaware of his family,” they argued, “[and] after well over a decade in a persistent vegetative state, Mr. Fiori’s life could present no increased loss of dignity or intrusion on privacy.” They went on to suggest that “under circumstances of no physical, psychological, or economic burden for his continued existence, immediate death could not be in the best interest of a patient such as Fiori” (Unger and Knorr 1995: 31).

More generally, the AG’s lawyers argued that no one could accurately determine the value framework of an individual who had left no clear and
convincing evidence of his or her wishes, making the entire notion of the patient’s best interests suspect. Consequently, they said, “continued life” had to be the default decision rule when no clear and convincing evidence to the contrary was presented. In short, the state was bound to protect the life of one of its citizens when due process had not yielded clear evidence to suggest that the patient would prefer to die in a given set of circumstances.

The Case of Joey Fiori

The Prolife Argument of the Pennsylvania Catholic Conference

Richard Connell and Maura Quinlan, representing the Pennsylvania Catholic Conference of Bishops, filed an amicus brief criticizing the superior court’s decision on two seemingly contradictory grounds. First, Connell and Quinlan cited the 1990 case of Ruth Ragona, the only other case heard in the state of Pennsylvania to raise the same issues as raised by the Fiori case. The sixty-four-year-old Ragona had clearly expressed the desire not to be kept alive by artificial means should she become permanently incapacitated. After two strokes left Mrs. Ragona in a vegetative state, her husband asked that his wife’s nasogastric (NG) tube be removed. A panel of three Lackawanna County trial court judges agreed to apply the clear and convincing evidence standard, as advocated in that case by the attorney general’s office, and approved the withdrawal of her feeding tubes since clear and convincing evidence of her wishes was available.

Although the Ragona decision would carry no weight as a precedent in case law (only appellate court decisions can do that), Connell and Quinlan indicated that the supreme court should endorse the Ragona ruling (Connell and Quinlan 1995: 8). They then buttressed the import of the patient’s intentions by referencing Pennsylvania’s Advance Directive for Health Care Act, which states that “the intent of the patient would appear to be the controlling determination with respect to the withdrawal of basic nutrition and hydration” (Connell and Quinlan 1995: 9).

However, the contradiction in the Catholic Conference’s case became apparent when, after stressing the importance of self-determination through their citations of case and statutory law, the Catholic Conference’s lawyers turned to the Pennsylvania bishops’ definitive statement on the issue: “The patient in the persistent vegetative state is not imminently terminal. . . . The feeding—regardless of whether it be considered as treatment or as care—is serving a life-sustaining purpose. Therefore, it remains an ordinary means of sustaining life and should be continued” (Catholic Bishops of Pennsylvania 1991: 14). This latter, purely normative statement seems very much at odds with the case and statutory law cited earlier, both of which support the right of self-determination (assuming clear and convincing evidence exists).
Interestingly, the Connell-Quinlan brief did help bolster the attorney general’s case in another way. Unger and Knorr picked up on the normative statement of the Pennsylvania bishops and used it to critique Mrs. Sherman’s contention that her son would not want to be kept alive in his vegetative condition. Joey Fiori had been an altar boy through his high school years and was a devout Catholic, the AG’s lawyers accurately pointed out. In doing so, they seemed to imply that Rosemarie Sherman could not even begin to suggest that her son would want life-sustaining medical treatment withdrawn when the position of the Pennsylvania Conference of Catholic Bishops was so much at odds with the notion of withdrawing treatment (Unger and Knorr 1995: 30).

The Pennsylvania Medical Society Argues in Favor of Allowing the Withdrawal of Treatment

The Pennsylvania Medical Society position was advanced before the state supreme court, for both the society and Rosemarie Sherman, by PMS attorney Robert Hoffman. A central part of Hoffman’s argument was devoted to questioning the presumption that life should be maintained as the default rule when clear and convincing evidence of the patient’s wishes to the contrary was not available.

Hoffman drew on several sources to advance this argument. First, just as trial court judge Sokolove had done three years earlier, he cited public opinion polls and other research indicating that the vast majority of U.S. citizens would not want to be sustained in a permanently vegetative state. Second, he noted that doctors who had studied this issue closely had concluded that the use of aggressive medical therapy in such cases could be medically futile and perhaps even wasteful (see Multi-Society Task Force on PVS 1994b). Third, Hoffman noted that, in reality, most deaths today are already “managed” in some way. When considered together, he asserted, these factors showed that the AG’s argument regarding the presumption in favor of life could not be sustained.

This was not to suggest, he added, that one should presume an individual would want life support withdrawn unless there was clear and convincing evidence to the contrary (although some have made this argument—see Cantor 1989, 1996). Rather, Hoffman proposed that rules be constructed so as not to bias treatment decisions in either direction (Hoffman 1995: 28). The goal, he argued, should be
to implement, without preconception but with dignity, an individual’s right to accept or reject life-sustaining treatment. Those rules should neither assume the patient desires treatment to be maintained nor discontinued and should treat as equals the right to life and the right to refuse life-sustaining treatment.
The Case of Joey Fiori

... Accordingly, while court proceedings, when utilized, must impose a “bur­den of proof,” the selected standard should not skew the result unnecessarily in either direction (Hoffman 1995: 45).

The AG’s lawyers erred, according to Hoffman, by presuming that life would be desired when the patient had left no explicit instructions either way. That “improperly converts silence into affirmance,” Hoffman argued. He went on to characterize the attorney general’s contention—that life­sustaining treatment should be continued—as “a very odd presumption indeed, given that most people when asked, indicate that they would not want to be sustained under these conditions with this prognosis” (Hoffman 1995: 44).

Hoffman also noted that

the decision maker must make a decision either to continue or to withdraw treatment; in either event, the patient’s subjective views must be ascertained and applied as best they can. That the evidence as to personality, philosophy, value system, and life style may not always be definitive does not explain why it must be disregarded. ... The Attorney General’s complaint that this information was subject to “multiple interpretations” may be accurate as to persons who did not know Mr. Fiori. To Mrs. Sherman, who did, they were crystal clear. That is the fundamental point of this proceeding. Thus, Mrs. Sherman understood as others might not that the position of the Pennsylvania Catholic Conference would not control her son’s views, even though he was Catholic (Hoffman 1995: 45).

Hoffman also criticized the attorney general’s contention that the courts must always be involved in such cases (an idea that was also expressed in Popovich’s dissent):

The Attorney General’s position does not merely bring all such matters to court but relegates family members and their physicians to the periphery. ... Thus, concerned family members are converted into overanxious heirs. This transformation is as insulting as it is erroneous, both in general and egregiously so under the facts of this case and Mrs. Sherman’s incredible and long­standing devotion to her son. ... Under the approach advocated by the Attorney General, these difficult and personal decisions will, of necessity, become adversarial proceedings, attracting the attention of the public, and will make family members and physicians participants, not decision makers. The surrogate decision maker, whether a court or guardian, will be someone with no established relationship to the patient and none of the understanding that relationships establish. Such a procedure makes no sense, invades the privacy of the patient and family, and should be soundly rejected by this Court (Hoffman 1995: 31-33, citations omitted).11

Lastly, Hoffman challenged the attorney general’s argument regarding the lack of pain and awareness experienced by patients in a vegetative state.
If such patients did not feel pain and were unaware of the dire circumstances in which they continued to exist, then what, if any, burdens of continued life could be attributed to them? Hoffman dismissed this concern by citing the President’s Commission report on end-of-life decision making:

First, the few patients who have recovered consciousness after a prolonged period of unconsciousness were severely disabled [which] commonly included inability to speak or see, permanent distortion of the limbs, and paralysis. Being returned to such a state would be regarded as of very limited benefit by most patients. . . . Second, long-term treatment commonly imposes severe financial and emotional burdens on a patient’s family, people whose welfare most patients before they lost consciousness, placed a high value on (Hoffman 1995: 48, citing President’s Commission 1983).

“Choice in Dying” Cites Trends in the States Favoring the Right to Choose

The amicus brief filed by Choice in Dying, drafted by attorneys Anna Moretti Kavolius and Ann Fade, pointed out that the clear and convincing evidence standard had been accepted in only three states (Missouri, in Cruzan; New York, in O’Connor; and Kentucky, in DeGrella).12 It had been rejected everywhere else, they argued, because the test had been viewed as disadvantaging those who did not have the foresight, sophistication, or access to information about advance directives necessary to make their wishes known. The CID attorneys pointed out that when families could not meet the clear and convincing evidence standard, they were forced to disregard the patient's lifestyle, ethical and religious beliefs, and general life preferences and accept the state’s decision—that life should be maintained (Kavolius and Fade 1995: 6–7).

In fact, the CID lawyers pointed out that twenty-six states and the District of Columbia had already enacted surrogate decision-making statutes that authorized the kind of family and surrogate decision making being advocated by Mrs. Sherman’s representatives (Kavolius and Fade 1995: 9).13 Kavolius and Fade also echoed Hoffman and Sokolove’s point regarding public opinion. They cited a 1991 Boston Globe–Harvard School of Public Health survey that found that 53 percent of the respondents thought families, in consultation with doctors, should be allowed to make treatment decisions for their incompetent loved ones and an additional 30 percent thought family members should make such decisions unilaterally. Overall, 83 percent of the survey respondents thought families should be making or helping to make end-of-life decisions for their loved ones without the interference of the courts. Significantly, only 2 percent of the respondents thought that such decisions should be left to the courts (Kavolius and Fade 1995: 9).
Kavolius and Fade referred to the clear and convincing evidence standard as unworkable. They indicated that a high percentage of the many requests for assistance received via Choice in Dying's hot lines came from family members in New York who were having trouble getting a loved one's treatment wishes honored (New York is the home of CID and one of the three states that use the clear and convincing evidence standard). Apparently, institutions (especially New York institutions)—concerned about liability for withholding or withdrawing treatment—were regularly sending the family to court rather than reviewing the evidence and developing a consensus on treatment with members of the incompetent patient's family. The CID lawyers noted that even expedited proceedings were both expensive (in legal and medical terms) and taxing (emotionally and in terms of lost privacy). Certainly, they said, these were added reasons for rejecting the suggestion that the courts be routinely involved.

University Hospitals Cite Clinical Realities in Support of the Right to Choose

Alan Meisel and Betty Adler, attorneys for the University of Pittsburgh Center for Medical Ethics and the University of Pennsylvania Medical Center, joined the CID lawyers and PMS lawyer Robert Hoffman before the Pennsylvania Supreme Court to support Rosemarie Sherman's right to make an end-of-life decision for her son. Like their colleagues, Meisel and Adler questioned the sagacity of requiring court proceedings in such cases on a number of grounds.

First, they cited the issue of costs. Even short delays caused by court proceedings—and there had to be some delays if the proceedings were to be substantive—would be expensive in medical terms, they argued. By way of example, they noted that the charges for services rendered in the medical intensive care unit (ICU) were running approximately $2,500 a day at the hospital of the University of Pennsylvania, where many end-of-life decisions were made on a regular basis, without court involvement (Meisel and Adler 1995: 28).

Every day of delay caused by court proceedings, the attorneys asserted, added these medical and other legal charges to the bill of the family (or some third-party payer). And at the same time, the emotional turmoil was extended and the loss of privacy felt by those having to grapple with what was inevitably a very tragic and privately painful situation was exacerbated. Meisel and Adler (1995: 26) cited the Florida Court of Appeals on this point, which noted that courts often delay the process so long that the patient expires long before the case is ever settled (as happened in the Fiori case). The inescapable fact, they said, was that judicial proceedings, even
expedited ones, made the patient’s condition and the family decision-making process public, robbing them of their right to privacy in making such intimate choices (Meisel and Adler 1995: 12–14).

Next, the attorneys brought up the clinical reality—that end-of-life decisions were made in U.S. hospitals every day without clear and convincing evidence of the patient’s wishes and without the involvement of the courts. In support of this claim, Meisel and Adler (1995: 29) noted that decisions not to further prolong the dying process are made by families in consultation with the attending physician at least five to ten times per week in the intensive care units of both the University of Pennsylvania Medical Center and the University of Pittsburgh Medical Center. Additionally, similar decisions are made daily throughout hospitals in this Commonwealth and elsewhere.

Meisel and Adler also noted that, according to the National Center for State Courts (NCSC), 70 percent of all deaths that “occur daily in the United States are somehow timed or negotiated with patients, families, and doctors quietly agreeing on not using death delaying technology. . . . It is obvious that there is a generalized society sanctioned practice that most of these life-sustaining medical treatment decisions are made without a [legally appointed] guardian or any court intervention” (NCSC 1992: 17–18; see also Lipton 1986: 1164). The same point, they added, was widely acknowledged by courts in a variety of states (see Meisel and Adler 1995: 19–20).

Meisel and Adler pointed out that 70 percent of the 2.2 million deaths in the United States every year (that is, over 1.5 million deaths) were, in reality, managed in some way. Yet, they said, the only empirical study of court involvement in such cases estimated that, on average, only 200 to 450 such cases were argued in the trial courts in any given year. Put another way, at most only 450 of the 1.5 million cases per year in which life-sustaining medical treatment was either withheld or withdrawn at the end of life ever wound up in court. That meant that courts were involved in only 0.03 percent of all such cases annually and that 99.97 percent of life-sustaining medical treatment decisions were made without judicial assistance.

If the courts were actually involved in all such decisions, as the AG lawyers suggested, the courts would need to gird for an increase in their workload of more than 200,000 percent! In addition, Meisel and Adler noted that requiring routine involvement of the courts would “disrupt the work of doctors in ways that will detrimentally affect the treatment given to patients generally” (Meisel and Adler 1995: 28, citing In re Cloyer, 660 P. 2d 738, 745, 1983).

The simple fact, according to Meisel and Adler, was that it was already an accepted custom in medicine to turn to the next of kin when treatment decisions had to be made for an incompetent patient. Furthermore, this common practice had, in recent years, acquired legal recognition as something akin to common law. The slew of legal-medical manuals, handbooks,
and articles advising physicians to obtain consent from the next of kin when considering which treatments, if any, a patient should receive testified to that reality (Meisel and Adler 1995: 19).

Meisel and Adler also took issue with the attorney general’s contention that families and physicians could not be trusted to operate privately, beyond the glare of judicial scrutiny. They pointed out that, though several courts had raised this issue, there simply was no evidence that abuse would occur if the courts were not routinely involved (Meisel and Adler 1995: 4). In fact, although family-based conflict of interest problems were regularly raised in the cases that did end up in court, a finding of “bad faith” had never been sustained by an appellate court in the twenty-year history of right-to-die litigation.

Turning to the AG’s argument that physicians were poorly equipped to act as a check on family decision making, Meisel and Adler contended that health care professionals “have a strongly inculcated professional bias in favor of continuing treatment [and] are also extraordinarily worried about potential civil or criminal liability and bad publicity. When these factors are combined, it is the experience of the amici [representatives from institutions filing this friend-of-the-court brief] that they sometimes serve as too strong a check on family members, rather than too weak a check.” In other words, it is extremely difficult—not too easy—to get life-sustaining treatment stopped in many of today’s hospitals and nursing homes. Of course, it should be difficult to terminate life-sustaining treatment—but not so difficult as to be impossible. According to Meisel and Adler (1995: 5–6), the fact that the Fiori case was litigated in the first place was stark testimony that it was, in fact, often impossible.

Families, not lawyers and judges, should make end-of-life decisions if at all possible, argued Meisel and Adler: “Our common human experience teaches us that family members and close friends care most and best for a patient. They offer support and concern, and have the best interests of the patient at heart. The importance of the family in medical treatment decisions is axiomatic” (Meisel and Adler, citing In re Farrell, 529 A. 2d at 414).

Meisel and Adler also suggested that surrogates wanted—and expected—family members to make such decisions. They cited public opinion polls and medical studies of patient preferences (Cohen-Mansfield et al. 1991; Gamble, McDonald, and Lichstein 1991) and the President’s Commission report (1983: 128) in support of their claim:

The family is typically most concerned about that patient’s well being and most knowledgeable about the patient’s wishes; the family deserves recognition as an important social unit—allowing family participation in decision making validates and bolsters that all-important social unit while protecting the privacy and preserving the autonomy of the patient who is no longer able to protect or preserve these things for him- or herself (Meisel and Adler 1995: 15–16).
Of the twenty-four jurisdictions in which decisions on the termination of treatment had been made at the appellate level, Meisel and Adler noted that courts in only three states had ever experimented with any form of routine judicial review: Massachusetts (the *Saikewicz* decision in 1977, which seemed to imply that courts would make all the final calls in life-sustaining treatment decision cases); New Jersey (*Quinlan* in 1976 and *Conroy* in 1985, both requiring incompetency and guardianship hearings); and Washington (*Cloyer* in 1983, requiring court involvement only for purposes of designating a guardian, who would be free to make decisions without court approval thereafter). In each case, appellate courts later reversed themselves and abandoned the notion of requiring routine court involvement as unworkable.

The medical center attorneys also pointed out that court review requirements were rejected both by the Uniform Law Commissioners (ULC) (see Chapter 2) and the National Center for State Courts (see Chapter 2; Meisel and Adler 1995: 32). The courts in all cases were urged to make themselves available to resolve irreconcilable disputes among family members and between the family and caregivers or when evidence suggested that the surrogate was motivated by concerns other than the best interests of the patient. But routine involvement of the courts was rejected as both unwise and impractical.

In sum, Meisel and Adler argued that the parens patriae power of the state, properly understood, did not require the state to preserve the life of an incompetent patient. Rather, it required the state to support decisions made in the patient’s best interests, and those decisions often could be advanced best if the court was not involved directly in the proceedings. This is the way decision making works for the vast majority of patients who die in hospitals and nursing homes today, and it is the way the vast majority of Americans prefer that decisions be made for themselves. Because there was no evidence that this arrangement had led to abuse, the case for dramatic change, as proposed by Popovich and the attorney general, was weak indeed, according to Meisel and Adler.

Meisel and Adler wrapped up their presentation with a summary of what had become a widely shared consensus opinion among state court judges, common to at least twenty-four of the thirty or so appellate-level decisions on related cases that had been issued to date (Meisel and Adler 1995: 8). This consensus consisted of the following principles, all of which would support Sherman’s contention and all of which ran counter—to one degree or another—to the position taken by Pennsylvania’s attorney general (Meisel and Adler 1995: 9–10):

- Incompetent patients have the same common law and constitutionally protected rights as competent patients have to refuse life-sustaining treatment;
The interests of the state in preserving life are virtually nonexistent when weighed against a competent individual's liberty interest in refusing life-sustaining treatment, and the state's interests are only a little less weak when weighed against an incompetent patient's rights to forgo life-sustaining treatment when the prognosis for recovery is very dim;

- The decision-making process should generally take place in the clinical setting among caregivers and family members (while courts remain available to assist when irreconcilable conflicts arise);
- Surrogate decisionmakers should attempt to make an informed substituted judgment for the incompetent patient; if unable to do so, they should resort to making a decision that would best serve the interests of the patient;
- Artificially supplied nutrition and hydration is a medical treatment that may be withheld or forgone like any other; and
- The decision to forgo life-sustaining medical treatment does not constitute active euthanasia or assisted suicide, both of which remain illegal.

The Pennsylvania Supreme Court Leaves No Doubt: “Sherman Was Right”

On April 2, 1996, the Pennsylvania Supreme Court issued a unanimous ruling in favor of Rosemarie Sherman and the Pennsylvania Medical Society. Justice Ralph J. Cappy, author of the court's opinion, argued simply that "the right to refuse medical treatment has deep roots in our common law" (Cappy 1996: 6) and that when the patient is no longer able to decide for him- or herself what treatments to accept or refuse, "a close family member is well-suited to the role of substitute decision-maker" (Cappy 1996: 13).

Cappy's opinion echoed Judge Sokolove's trial court decision in dismissing the four traditional state interests in such cases. With regard to the state's interest in the prevention of suicide, Cappy (1996: 7) wrote that withdrawing treatment could not be considered suicide because "in removing life-sustaining measures, the natural death process is allowed to continue." With regard to the protection of innocent third parties, Cappy (1996: 7) wrote that "the patient [Fiori] has no dependents who would be left emotionally and financially bereft."

When it came to preserving the integrity of the medical profession, Cappy (1996: 8) noted simply that "the medical community supports the withdrawal of life-sustaining treatment" in such cases. Finally, on the issue of the state's interest in the preservation of life, Judge Cappy (1996: 8)
wrote that “the state’s interest in maintaining the PVS individual in an end­less twilight state between life and death is so weak that it cannot overcome the individual’s right to self-determination.”

The court was unswayed by the attorney general’s argument that clear and convincing evidence had to be present before a decision to forgo life-sustaining treatment from an incompetent patient could be carried out. Instead, Judge Cappy (1996: 11-12) adopted the Choice in Dying position, arguing that “were this test [the clear and convincing evidence test] to be applied, all of those patients who did not have the prescience or the sophistication to express clearly and unmistakably their views on this precise matter would not be able to have life support removed. . . . The only practical way to prevent the destruction of the PVS patient’s right to refuse medical treatment is to allow a substitute decision maker to determine what measures the PVS patient would have desired in light of the patient’s prognosis.”

Cappy went on to note that “in addition to the great knowledge of the PVS patient’s personal views, close family members have a special bond with the PVS patient.” Again parting ways with the attorney general, Cappy concluded that when physicians and close family members were in agreement on the course of action to take, there was no need for court involvement (Cappy 1996: 14).

Summary

The basic argument of the attorney general and those on the AG’s side of the issue was straightforward: Because the state has an unqualified interest in preserving life, we should err on the side of life when it is not abundantly clear what the individual in the persistent vegetative state would want in terms of life-sustaining medical treatment. By contrast, Joey Fiori’s mother, her attorney, those filing friend-of-the-court briefs on her behalf, and the superior and supreme courts of Pennsylvania held that although life may be sacred, the state’s interest in preserving life does not automatically trump the right of a patient to have someone exercise on his or her behalf the right of self-determination, a right that flows from the common law right of privacy that protects one’s body from unwanted intrusion. All parties agreed that this zone of privacy could not be violated without consent of the patient, but only those who supported Sherman’s position agreed that someone very familiar with the patient should be able to decide what an incompetent patient would have wanted if competent.

The attorney general’s approach to this issue, which is not widely supported in legal or medical circles, was not original. Lawyers representing the nursing home that cared for Nancy Jobes unsuccessfully adopted the same line of argument during the court fight to keep Jobes alive after an automobile accident and subsequent surgery left her, like Fiori, in a persistent
“Mrs. Jobes requires extensive care. While numerous medications, nutrition and hydration were initially provided through the use of a nasogastric tube, as a result of increasing difficulties with that tube’s frequent removal and reinserter, a gastrostomy tube was surgically inserted into Mrs. Jobes’s stomach in December 1980. A life-threatening failure of this gastrostomy tube in June 1985 led to the closing of the gastric fistula, [and] a new cutting in her abdominal cavity [was created for] the establishment of a jejunostomy tube in her small intestine. Mrs. Jobes has been hospitalized at least three times since the performance of the jejunostomy for complications arising from its insertion and employment. It is through this tube that many medications, nutrition (a commercially produced synthetic, pre-digested nutritional formula) and hydration are provided. An automatic electrically driven pump provides a constant slow rate of liquid to the bowel where it is digested. Mrs. Jobes is incontinent and requires a catheter to continuously irrigate her bladder. She receives routine enemas for bowel evacuation. Mrs. Jobes also has a tracheostomy, which is covered with a plastic shield to which a flexible tube is attached. Through this tube she receives air from a compressor in order to afford moisture to the tracheotomy. The mist is driven by a mechanical air compressor. There is a suction machine adjacent to the bed available if necessary to remove her saliva. Mrs. Jobes cannot swallow. She is given antibiotics when necessary, as well as medication intended to prevent seizures. Mrs. Jobes’s muscles have atrophied and her limbs are rigidly contracted. Her extremities cannot move. Her closely clenched fingers are padded to prevent the skin between them from breaking down.

“To summarize, Mrs. Jobes’s physical condition is extreme: major organs and systems have failed; she is profoundly comatose; her body has atrophied, contracted, and deteriorated; she is totally incontinent. Her treatment is overwhelmingly burdensome and intrusive; she has been repeatedly hospitalized for more extended, extraordinary medical treatment; she requires two surgically implanted devices; she must be evacuated and irrigated; she must be handled constantly and prevented from self mutilation. Her prognosis is hopeless; she cannot live without massive, extraordinary medical and health care measures. One may fairly and reasonably ask whether these bodily intrusions and invasions upon a person in such dire condition and so close to death, undertaken for the best motives, have not reached a point that it is not possible to perpetuate her life without destroying her dignity and denigrating her humanity .... When cherished values of human dignity and personal privacy, which belong to every person living or dying, are sufficiently transgressed by what is being done to the individual, we should be ready to say: enough” (In re Jobes 529 A. 2d at 458–459).
vegetative state. In 1985, after Nancy Jobes had spent five years in a PVS, her husband and parents asked for and were granted the right to have artificial feeding terminated. The detailed characterization of Jobes’s desperate clinical circumstances provided by Judge Alan B. Handler, author of a concurring opinion in the case, illustrated just how far medical technology is sometimes extended to save some individuals from death. These circumstances, presented in Box 1.2, are not uncommon for anyone in a PVS, Joey Fiori included.

Abstract reasoning cannot be separated from these clinical realities. When those who advocate the state’s interest in preserving life fail to consider the medical and personal conditions of patients such as Jobes and Fiori, their pronouncements have the hollow ring of irrelevant platitudes. The condition of both Fiori and Jobes was nothing short of hopeless. And when loving family members stepped forward to ask that treatment be withdrawn, rejection of those reasonable and well-intentioned requests led to a continuation of treatment that was both degrading and dehumanizing.

When all agree that the patient is severely and irreversibly ill and someone who clearly has the patient’s interest in mind makes a decision to prevent further “invasions of privacy,” the state should step aside unless it intends to place its own interests above the interests of the individual. To do otherwise would be overly protective, paternalistic, and even oppressive, according to most medical, ethical, and legal organizations (see Chapter 2). Furthermore, forcing continued treatment would not resonate well with current religious pronouncements or popular opinion on this subject (see Chapter 3).

The fact is that, although the attorney general’s arguments had some merit in the abstract, they simply did not play out well in reality. It is not simply the philosophical heft of the arguments made by those on Rosemarie Sherman’s side of the case that makes this so. It is the concurring and broadly based body of literature, court decisions, statutes, professional association statements, and religious pronouncements that have been generated on the subject since the mid-1980s that help tip the balance clearly in Sherman’s favor.