

First, Do No Harm

The Terri Schiavo case brought end-of-life questions to the forefront of the American public, reinforcing the importance of preparing a living will. But for many New Yorkers deemed “incompetent,” such options do not apply. Medical decisions are often made by the courts, and are not always in the patient’s best medical interests.

By Renée Gearhart Levy

This article was originally written five years ago. Due to litigation against the State of New York by the Pouliot family, we were unable to run it at that time. With the litigation settled, and end-of-life issues in the national headlines, we felt the story was still worth telling.



When Sheila Pouliot died at University Hospital in 2000, there was a range of emotions expressed by her family and caregivers. “You think you’re prepared for this, but you’re really not,” her sister Alice Blouin said at the time.

Sadness and loss were evident, but overwhelmingly, there was also a sense of relief. For three months, Pouliot had been the center of a legal drama, caught between the professional judgment of her physicians and the laws of New York State.

Pouliot was a severely disabled adult who was hospitalized due to internal bleeding and an infection at the site of her feeding tube. Given doctors’ opinions that Pouliot’s death was imminent, her family requested aggressive treatment be withheld once she was stabilized. Families with dying loved

ones make similar difficult decisions every day, and typically, that’s the end of it—a private decision made between family and physician. In this case, however, it was only the beginning.

END-OF-LIFE DECISIONS

New York stands alone with Missouri and Michigan as states where courts have specifically held that family members cannot make end-of-life decisions. The New York Court of Appeals has held that life-sustaining measures can only be withdrawn based on “clear and convincing evidence” of the patient’s wishes. While many adults

never leave a health-care proxy or living will, other patients—infants, children, and mentally disabled adults—never have the ability to do so. They and their families are caught in a medical and legal limbo.

Issues at the end of life are often complicated and emotional. That was no less the case for Sheila Pouliot’s family.

Pouliot was born in 1957, a healthy baby until she contracted mumps at nine-months old, resulting in profound physical and mental disabilities. She had flexion contractures of all four extremities, was bed bound, and partially blind. She was, nonetheless, an integral part of her family, who loved her dearly. “My parents just doted over her. We all did,” says Blouin, her older sister by seven years. “To us, there was always somebody there. She was always a person.”

When Sheila was 20, however, her mother began suffering from her own health difficulties and became unable to care for her. Blouin and her brother were both starting their own young families and Sheila moved to the Syracuse Developmental Center, where she lived for the next 22 years, visited by her family every Sunday, birthday, and holiday.

That ended on December 21, 1999, when Sheila was brought to University Hospital



for treatment of gastrointestinal bleeding and aspiration pneumonia. The bleeding was caused by an infection that developed at the site of her feeding tube. Her intestine no longer functioned. Given her grim prognosis, her family elected to terminate artificial nutrition and hydration.

Concerned about the Pouliot family’s decision, the Syracuse Developmental Center contacted New York State’s Office of Mental Retardation and Developmental Disabilities (OMRDD), the agency charged with protecting the rights of the mentally retarded and developmentally disabled in New York. In turn, the OMRDD contacted the state attorney general’s office and asked them to intervene. And so the fate of Sheila Pouliot’s care—and her family’s desire that she be allowed to die—became not only a

question of medicine, but a question of law.

At issue was whether University Hospital should stop giving Pouliot nutrition and hydration, as requested by her family and agreed upon by eight treating physicians and the director of University Hospital’s Ethics Consultation Team.

New York law clearly grants competent adults the right to refuse treatment necessary to save or extend life. When patients can’t decide for themselves, and have not left advance instructions, health care professionals routinely turn to family members to consent to needed treatment, including nutrition and hydration.

In most states, family members can also refuse life-sustaining treatment for incapacitated patients. Under New York’s do-not-resuscitate law, family members and others

close to the patient can decide about cardiopulmonary resuscitation, but they have no authority to refuse nutrition and hydration unless the patient has signed a health care proxy and/or made explicit their wishes regarding nutrition and hydration. Children and adults who have never been mentally competent are not able to make that designation and their families were left without the legal right to make that decision.

Although a 1989 state law (the New York Mental Hygiene Act) required local surrogate decision-making committees to make treatment decisions for patients who can’t make them for themselves, the legislature never appropriated funds to create these committees, except in a handful of towns. In most areas of New York—Syracuse included—they did not exist at the time of the

Pouliot case. Even if the committee had been functional, it would not have been able to make a decision, because under the law at the time of Sheila Pouliot's hospitalization, there was no precedent that would have allowed even a court to make that decision. (While there is now such a committee in Syracuse, it typically handles questions such as whether a patient should be anesthetized for a procedure.)

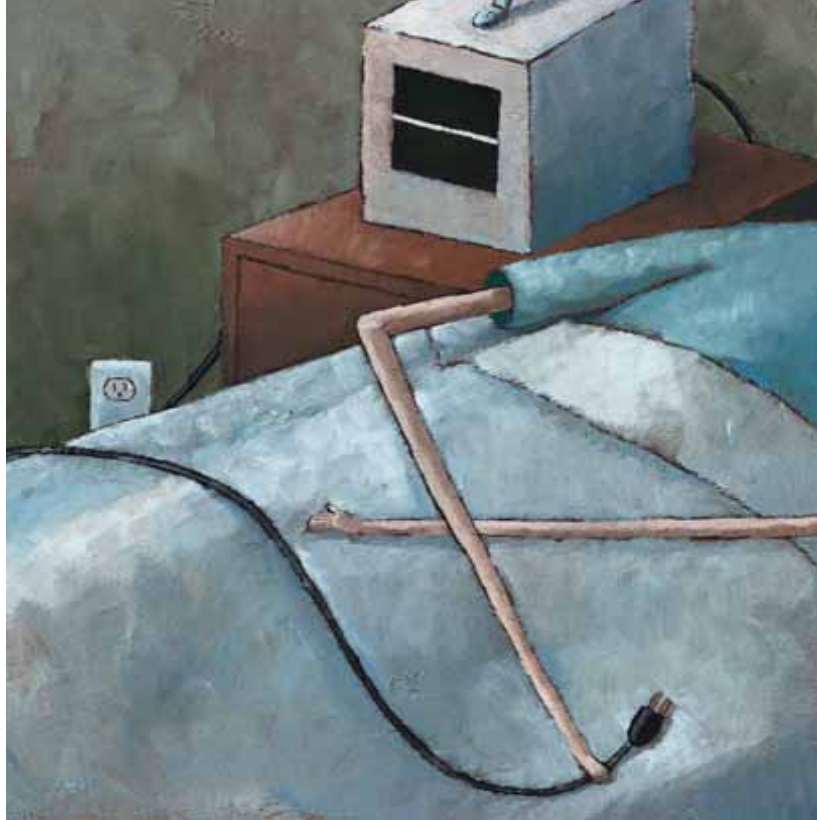
For most of her life, Pouliot had received nutrition through a feeding tube in her abdomen. Because she was experiencing gastrointestinal bleeding, and for reasons that could never be determined, her intestine no longer transferred food. She could no longer tolerate nutrition through that site. Despite the wishes of her family and the professional opinions of her physicians, the New York State Attorney General's Office insisted that the law required some form of artificial hydration and nutrition be given.

COURT-ORDERED TREATMENT

A hearing was held in early January involving all parties in the case. A compromise was reached—it was agreed that total parenteral nutrition (TPN) and other more invasive methods were not medically feasible, but that IV fluids must be restarted and efforts made to use the feeding tube.

Despite this directive, the only sustenance she could tolerate was IV hydration with D5NS—sugar water. She also received Fentanyl for pain via transdermal patches.

Over two months Pouliot's condition continued to deteriorate. Without nutrition to provide protein, Pouliot's body began consuming the protein in her body. Her physicians and hospital administration became increasingly concerned about the court-



ordered treatment.

"No one can live on sugar water, except maybe a hummingbird," says Kathy Faber-Langendoen, MD, Medical Alumni Endowed Professor of Bioethics, who chaired University Hospital's ethics committee at the time. "This was not a normal treatment plan. From a medical standpoint, I felt we were creating a situation that wasn't respectful of the person she was, only to serve some political or legal agenda. Her personal circumstance had been forgotten."



Patricia J. Numann, MD '65

"For a physician, it's very difficult when the law tries to put you in the position of having to do something you know is medically unsound and unreasonable," says Patricia J. Numann, MD '65, a surgeon and medical director of University Hospital. "Medical therapy, if it can't be curative, should be palliative. In this circumstance, palliation was difficult to achieve other than by doing what we had originally asked to do—to stop nutrition and hydration."

The attorney for the Pouliot family, Martha Mulroy, a former nurse, asked the judge to reconsider the course of action agreed upon at the earlier hearing. In an official proceeding

in early March 2000, attorneys for both sides presented their views. Drs. Numann and Faber-Langendoen also testified.

Mulroy and Gerard Neri, the lawyer assigned to represent Pouliot, argued that the state was violating Pouliot's civil rights by not having surrogate decision-making committees (mandated by the 1989 legislation) in place. New York Attorney General

Eliot Spitzer countered that the status of the committees was irrelevant, because the legislation did not allow those committees to make decisions about terminating life-sustaining medical treatment. While Mulroy and Neri contended Pouliot's hydration was medical treatment, the state argued it was life support and that withholding it was equivalent to assisted suicide.

Before announcing his decision, New York State Supreme Court Justice James Tormey did something highly unusual. He visited Pouliot at University Hospital. Later that afternoon, Tormey ordered hydration ended. In handing down his decision, he asked the attorney general not to appeal the decision without first paying a legal "house call" to Pouliot at the hospital. The state did appeal, however, obtaining a stay that blocked Tormey's order from taking effect.

Two days later, Justice John Lawton of the Appellate Division temporarily lifted the stay until the full court in Rochester could address the issue. Lawton based his stay on medical testimony that "hydration was doing more harm than good." Judge Lawton was also sufficiently convinced that Sheila Pouliot would not die prior to the full court being able to consider the issue.

Sheila Pouliot's hydration was stopped the following morning. She died two nights

later, her sister at her side, less than 12 hours before her case was to be heard by a full Supreme Court Appellate Division panel.

HEALTH CARE DECISIONS ACT

Had the Appellate Court heard Pouliot's case and decided in favor of ending hydration at the family's request, it would have altered case law in New York and set a precedent for giving families more ability to make health-care decisions for mentally incapacitated patients, including those at the end of life. Because the case went unheard, the law remained unchanged.

But that has not been the end of it. Dr. Faber-Langendoen and Upstate's Center for Bioethics and Humanities received a \$25,000 grant from the Greenwall Foundation to examine the gap between health care policy recommendations and existing legislation.

In 2002, the Center held a two-day conference to discuss the issue, including representatives from bioethics programs at nine New York medical schools, the American Bar Association, leaders of patient advocacy groups, health care institutions, and physicians. The outcome was an official statement in support of the Family Health Care Decisions Act, legislation first proposed in the early 1990s that would expand the authority of family members and others close to the patient to make decisions about life-sustaining treatment and provide one of the most comprehensive policies in the nation for patients without family or friends able and willing to decide about treatment on their behalf. Despite widespread support from a cross section of health care, religious, and social service organizations, the bill has remained deadlocked.

At the end of 2002, another bill, the Health Care Decisions Act for Persons with Mental Retardation, was passed and signed by Governor George Pataki. While not a perfect law, Faber-Langendoen believes it's a start.

"It's very narrow. It only covers adults



Kathy Faber-Langendoen, MD

who were never competent because of mental retardation or developmental disability. It doesn't cover someone who became incapacitated later on due to stroke or Alzheimer's disease or an accident," she says.

The law, which went into effect in May 2003, allows a family member, by going to court and getting appointed legal guardian, the right to make health care decisions on behalf of a mentally retarded or developmentally disabled relative, based on their best interests. If this law would have been in effect in 2000, a guardian, acting on behalf of Sheila Pouliot, would have been authorized to make a decision to withhold arti-

ficial nutrition and hydration.

According to Dr. Numann, the law needs to be broader, but it needs to be changed carefully. "The reality is, when you have patients who can't speak for themselves, you have to be very, very careful who you let speak for them, so you really are acting in their best interests," says Numann. "Despite my anger over this individual case, I really understand where the Attorney General was coming from."

The major drawback, according to experts, is the time and legal costs involved (at least six months and between \$5,000 and \$10,000, depending on the locale). "This is something families need to plan for in advance," says Faber-Langendoen. "It's not something that you can do on the spur of the moment in the face of a medical emergency."

Is your paperwork in order?

High profile cases such as with Terri Schiavo, or in Central New York with Sheila Pouliot, illustrate the need to plan for difficult health-care decisions.

According to Dr. Kathy Faber-Langendoen, Medical Alumni Endowed Professor of Bioethics and Director of Bioethics for University Hospital, only about 20 to 30 percent of adults in the United States have a living will or health care proxy in place.

"People think they're too young, or they're optimistic they're never going to need it, or they say they're too busy," says Faber-Langendoen. "But it's a conversation every mentally competent adult should have. If there is anyone in your life that you trust more than the state to make a decision on your behalf about medical care, they should be appointed your health care proxy."

Health care proxy forms that meet the requirements of the New York State Department of Health are available online at the Upstate Center for Bioethics and Humanities website, www.upstate.edu/cbh. A wallet-sized health-care proxy card is also available from the Center by calling (315)464-5404.

