

What Terri Schiavo has taught us, 10 years after death

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The grave marks the spot in Clearwater where Terri Schiavo was laid to rest. Schiavo collapsed into a coma and eventually went into a vegetative state, igniting a firestorm of debate over her fate and sparking heightened interest in leaving end-of-life instructions. CHRIS URSO/STAFF

CLEARWATER – Terri Schiavo, who lived her life quietly, died amid a public storm of court hearings, moral and ethical debates about the right to live and right to die, and even controversy regarding the boundaries and authority of a governor.

On March 31, 2005, 13 days after her feeding tube was removed by a court order, and 15 years after she collapsed in a coma, Terri Schiavo died at age 41 at Woodside Hospice House in Pinellas Park. Her death followed a bitter, seven-year dispute between her husband, Michael, and her parents, Bob and Mary Schindler.

Michael Schiavo wanted the life support removed, arguing Terri had told him she would not want to be kept alive artificially. Her parents doubted that claim and fought to keep her alive, arguing she could improve with therapy, despite the contrary opinions of medical doctors.

The Schindlers appealed to then Gov. Jeb Bush, then President George W. Bush, the Florida Legislature and Congress to intercede, but the courts repeatedly affirmed her husband's right to let his wife die.

Terri Schiavo had no written advance directive – a so-called “living will.” There was nothing to document legally what she would or would not choose in an end of life situation, or who would speak on her behalf, that might have put the question to rest.

Now, 10 years later, there continues to be a growing effort among hospitals, hospice workers and teams of care providers to help patients and families prepare for life-ending decisions and head off the emotional stress and conflict that marked Terri Schiavo's death.

In the year following her death, the U.S. Living Will Registry, which stores advance directives to make them accessible at any time, saw hits on its website jump from 500 a day to 50,000. It eventually would level off at about 2,500 a day, but Terri Schiavo's death raised public awareness of the importance of living wills, said physician Joseph Barmakian, president of the Living Will Registry in New Jersey.

Overall, Barmakian said last week, about 30 percent of adults in the United States have a living will — still low but about 10 percent more than a decade ago.

He said Schiavo and other high-profile cases cause people to question what they would want for themselves in a similar situation. "But a lot people we see and hear from do it mostly for their families — they don't want to put their families through that process," he said.

Barmakian said there also is a trend toward supporting advance directives with a written physician's order to make sure those wishes are carried out, "so you're not making those decisions in the emergency room, for instance," he said.

Additionally, because wills can't predict every medical eventuality, people are encouraged to appoint a surrogate or a proxy — someone they trust and legally authorize to speak on their behalf if questions arise regarding medical treatment. "That's where the controversy always occurs. When there is a difference of opinion, and when the courts get involved," he said.



That lack of clarity fueled the debate regarding Terri Schiavo's death that reached the governor's mansion, leading to charges that Gov. Jeb Bush overstepped his authority in trying to prolong her life.

After Pinellas-Pasco Circuit Judge George Greer ruled in 2003 that Michael Schiavo could remove his wife's feeding tube, the governor pressed the Florida Legislature to pass Terri's Law, which sidestepped the court and allowed the governor to order the feeding to resume.

The law was overturned in court in 2004 and the Florida Supreme Court, ruling on an appeal by the governor, said it was unconstitutional and violated the separation of powers.

"What we can learn from Terri is we should all have conversations with our loved ones about our end of life care and issues. How, as individuals, we would like our end of life to look," said Deidra Woods, chief medical officer for Empath Health, an umbrella organization that operates Suncoast Hospice and Choices for Care.

"Your best chance of having your end of life choices honored is to make them known and have them recorded in writing," she said.

Woods, a hospice and palliative care physician, consults with the palliative care teams at Morton Plant Mease hospitals that pull together diverse experts who help patients with difficult illnesses and their families.

The teams typically include physicians, nurse practitioners, social workers, counselors and chaplains to meet a variety of needs for patients and families. “It’s not a purely medical discipline,” she said.

She said the teams are formed to help manage treatment for patients, but they include discussions about end of life issues.



Margie Atkinson, director of pastoral care, ethics and palliative care for Morton Plant Mease hospitals, said full-time palliative care teams began in 2008 to meet with patients and families. The practice has grown from 1,000 consultations in the first year to about 3,000 in 2014.

“It is a fast growing area of medicine,” she said.

The hospitals, which include Morton Plant, Mease Dunedin and Mease Countryside in Pinellas and North Bay in Pasco County, work with patients at various stages of illness and until a patient is diagnosed as terminal and referred to hospice.

The teams have in-depth meetings with families and patients to discuss treatment plans and wishes, and to provide emotional, spiritual and physical support. “Most physicians don’t have that kind of time,” Atkinson said.

Team members talk to patients and families about end of life wishes, to prepare them, even if patients are expected to recover.

“We bring that up early on,” Atkinson said. “We believe the best time for people to have that conversation is before end of life. So when the time comes to make decisions about withholding or withdrawing treatment, they’ve already been through it.”

They emphasize the need to make advance directives and to appoint a surrogate who knows their wishes and can speak for them if, for instance, “something ever happens, and I’m in a vegetative state and I don’t want treatment,” Atkinson said.

Still, she said, people often are hesitant to discuss those issues.

Tracy Christner, executive director for Empath’s Choices for Care in Pinellas, said it’s a struggle to persuade people to prepare end of life plans and advance directives — even the same people who would go into extraordinary detail to plan weddings or graduation celebrations.

“We are kind of a death denying nation,” she said. “We don’t like to think about these things or plan for these things.”



Choices for Care, formed in 1999, does community outreach programs to explain living wills, and to discuss things such as ventilators, dialysis machines and other advanced medical efforts “so people can make educated and informed decisions” on what they would prefer, Christner said. “That’s a big piece of what we do.”

It also works with medical professionals, chaplains and social workers to discuss ways to encourage people to make plans.

Christner said she and her two-person staff contact up to 5,000 people a year in person or by providing educational materials to prepare advance directives. “But we have no way of knowing how many actually complete them,” she said.

“We promote it as a gift to your family,” she said. “It changes the whole thing for them, so that now I’m not making a decision to take my father’s life by taking him off life support, I’m honoring the wish already made.”

She said it reduces stress and the potential family infighting about what to do. The group encourages families not only to document their choices, but to share them with anyone who might be at a person’s bedside.

“It just makes it a whole lot easier when the time comes to make those decisions,” Christner said. “I always say, you want to be a daughter, not a decision maker when that time comes. You want to be a son, not arguing over (the decision).”

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