

# The Washington Post

## 5 years after Schiavo, few make end-of-life plans

By MATT SEDENSKY

The Associated Press

Tuesday, March 30, 2010; 5:43 PM

MIAMI -- Five years after the court fight over allowing Terri Schiavo to die, most Americans still don't draft the legal documents that spell out how far caregivers should go to keep them alive artificially.

Schiavo's life and death captivated the country and fueled conversations about the necessity of the documents, known as advance directives or living wills. Even though millions witnessed a worse-case scenario, there's no indication it had a lasting impact on getting more people to make their wishes known.

"The gap is so big," said Paul Malley, president of Aging With Dignity, which advocates advance directives and which saw an increase in interest during the Schiavo case. "Even a significant impact from the Schiavo case doesn't put a dent in the need that's out there."

The protracted family fight over keeping Schiavo alive, and her ultimate death March 31, 2005, plastered her story in headlines and prompted an immediate spike in Americans filling out advance directives. But while Schiavo's struggle remains in the minds of many, the momentum it created for writing the instructions appears to have ebbed.

End-of-life experts estimate 20 percent to 30 percent of U.S. adults have advance directives, the same as before the Schiavo case. Even in polls of older Americans, who fill out such forms at higher rates, there is little if any change from 2005.

"Awareness is up," said Kathy Brandt, a vice president of the National Hospice and Palliative Care Organization. "But I don't know that people understand any better and I don't know that we're ever going to get better than a third of Americans."

Much of the problem with advance directives is people aren't entirely sure what they do, or fear they mean they'd be forced to forgo lifesaving treatment. In fact, they can be changed by the patient and would only be used in limited grave circumstances, typically in which they can no longer communicate their wishes.

Living wills spell out desires regarding the use of respirators, feeding tubes and other life-support efforts, and to what lengths a person wants to be kept alive in the face of brain damage, comas and other conditions.

Schiavo, who collapsed at her St. Petersburg, Fla., home in 1990, had no such instructions in writing. Her heart stopped and she suffered what doctors said was irreversible brain damage that left her in a permanent vegetative state.

Her husband said his wife would not have wanted to live in a vegetative state; her parents wanted her kept alive. The result was an epic legal battle that involved dozens of judges in numerous jurisdictions, including the U.S. Supreme Court.

In the end, her feeding tube was ordered removed two weeks before she finally succumbed.

Still, while the paperwork on end-of-life wishes is vital - particularly in cases such as Schiavo's, when family members disagree - family discussions that precede such documentation can be even more important.

"It's an ongoing conversation," said Sally Hurme, who works on consumer health education for AARP. "Your views may change, your health circumstances may change and you need to keep your family up to date."

Malley says advance directives should be part of a broader conversation about what an individual wants out of their final years, how they want to be cared for, where they want to live and so on. Even when someone does have a living will, they often haven't had such a conversation with their loved ones.

"When people are asked what's important for them at the end of life they talk about being at home, with family, not in pain," he said. "A lot of times we only ask the question about life support treatment and tubes and ventilators."

Even for those who deal with death daily, though, thinking about one's own can be difficult.

Dr. Gail Cooney, a 57-year-old neurologist who is medical director at the Hospice of Palm Beach County and president of the American Academy of Hospice and Palliative Medicine, had spent more than 20 years preaching to patients and family alike the necessity of having advance directives. She knew full well the importance and had seen what could happen without something in writing.

But, still, it took a diagnosis of ovarian cancer and subsequent major surgery before she took her own advice.

"I knew what I wanted but I had never written it down until I was sitting there waiting for surgery in that stupid little hospital gown," she said.

© 2010 The Associated Press