

Terri Schiavo's brother working to help others

by [Sandy Bauers, Inquirer Staff Writer](#), Posted: April 4, 2013 - 3:01 AM



SANDY BAUERS / STAFF

Bobby Schindler, brother of Terri Schiavo, before a redone wedding photo of her. Family took out a bouquet, added a cross.

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By now, eight years later, after so much debate over his sister's situation - her diagnosis, her prognosis, her wishes, her autopsy - one thought remains dominant for Bobby Schindler: Terri Schiavo deserved to live.

Schindler now heads a growing foundation to help others in similar situations. Every year since her death, they've held a "Terri's Day" of remembrance.

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At 5 p.m. Friday, Archbishop Charles J. Chaput will celebrate a Mass dedicated to Terri Schiavo at the Cathedral Basilica of SS. Peter and Paul. Sarah Palin will speak afterward at a fund-raising dinner at the Philadelphia Marriott Downtown. A ticket is \$150, and 350 have been sold; \$25,000 gets you a visit with Palin, but no takers so far, Schindler said.

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Terri Schiavo died March 31, 2005, after 15 years in what doctors termed a persistent vegetative state. Her case was marked by an excruciating public family battle that traversed the courts, prompted an unprecedented session of Congress, drew the attention of the Vatican, and inspired countless Americans to complete "living wills" spelling out what care they did - or did not - want in the event of severe injury or illness.

Her husband, Michael, said she would not have wanted to live this way. Her parents and siblings said she would have chosen life, no matter what.

It is a decision that daily is facing many families, although rarely in such a public arena. Mostly, it's in a hospital conference room with a box of tissues on the table.

'Strong obligation'

Most people - 85 percent to 90 percent - say they would not want to be kept alive in a persistent vegetative state. But when they're deciding for another family

Often, the simple act of a finger that moves or an eyelid that flutters gives them hope, however faint.

But fiscal concerns are real. "If you ask the question, 'Do you want your money to go to this?' most people say no," Hansen-Flaschen said. "But if you ask the question about individual rights, people say yes."

He thinks most people don't have a problem with a family caring for a patient in a persistent vegetative state at home. But if the patient is in an acute-care hospital like HUP, where the beds are always full, that amounts to a person who likely will not get better blocking access for a person who likely will.

In the extreme cases where the family wants a persistently vegetative patient who is dying revived, Hansen-Flaschen dislikes the often-invasive measures necessary - "poking holes in people, breaking ribs, causing bruises. It feels very unnatural and wrong to be doing violence to such a person."




Meanwhile, in the nearly 25 years since Terri Schiavo first collapsed, this area of medicine has "changed dramatically," said John Whyte, director of the Moss Rehabilitation Research Institute.

Recovery of consciousness is happening more often than long believed. "There is significant long-term disability," Whyte said. "But in general, the prognosis is more positive than many people thought."

New treatments also are showing promise. Zolpidem, a sleep drug, has helped some in vegetative states regain consciousness, if only for hours. It's no magic bullet, Whyte said. "But it shows us that not everyone who is vegetative," even for a long time, "is irreversibly vegetative."

Schindler, 48, a former math and science teacher in Florida, thinks many patients are being warehoused. Last year, the foundation established a Center for Disability in the Public Square - a data-gathering and information-sharing network. In his office, he has a sketch of a rehab facility he would like the foundation to build, although he concedes it is likely a long way off.



That year, contributions were bolstered by a \$100,000 prize from the Gerard Health Foundation, a pro-life philanthropy in Natick, Mass., that praised the Schiavo network for helping 1,000 families, and giving them "safe haven amidst the pressure of the so-called 'right to die' movement."

One of them is Sara Harvey, of Horseheads, N.Y., just north of the Pennsylvania line. She has been battling officials over her husband, Gary, who has been in a persistent vegetative state for nearly seven years, after falling down steps and suffering a traumatic brain injury.

A judge had named the county Gary Harvey's guardian in 2007, and in 2009, officials planned to remove his feeding tube. Sara Harvey contacted Schindler, who has petitioned the court to name him a legal guardian.

No decision has been made, but Sara Harvey credits Schindler with saving her husband's life so far. "Bobby's like an angel over my husband."

Schindler said the foundation often can steer people to legal help and other resources. But "sometimes it doesn't work out."

"People call us, and they think that all we have to do is pick up the phone and stop something," he said. "I have to remind people, we lost. We weren't able to defend Terri."

An analysis by the nonprofit clearinghouse GuideStar shows that in 2010, the network dedicated only 40 percent of its spending to program services. Nearly half of expenditures went just to fund-raising, a percentage that dismays Schindler.

'Always a struggle'

"I wish there was more to show for it," Schindler said. "Fund-raising is always a struggle, because of the apathy out there. . . . I hate the amount of time I spend to raise funds."

In 2011, the foundation spent nearly \$46,000 on travel. Schindler said he often attended 20-plus events a year.

Terri's father, Robert, died in 2009 - brokenhearted that he was unable to save his daughter, Bobby Schindler said.

Schindler believes that questions about the value and quality of a life will only grow, given medicine's increasing ability to keep people alive, despite serious injury.

When the autopsy came out, showing the extent of her injury, he thought people used it as a justification for her death.

"To justify ending the lives of these individuals, we focus on the extent of the injury," he said. "Where in that continuum of brain injury does it become OK to kill them?"

He thinks people like his sister are "blessings." How we care for them "is a way of testing us, a reflection of our culture."

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