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# Many Still Seek One Final Say on Ending Life

By [JOHN SCHWARTZ](#) and JAMES ESTRIN

Interest in living wills - the documents that let people specify what medical measures they want or do not want at the end of life - has surged in the aftermath of the fierce nationwide battle over the fate of Terri Schiavo, lawyers and other experts on all sides of the issue say.

While interest peaked around the time of Ms. Schiavo's death on March 31, it is still strong, these experts say.

Many people are filling out the forms for the first time. Others are taking a new look at forms they filled out some time ago. Most living wills describe the conditions for withdrawing life support, but others demand the fullest extent of treatment.

The results of Ms. Schiavo's autopsy, released on Wednesday, underscored the need to make one's wishes known, said Dr. Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania. He noted that politicians had been eager to intervene in her case even though it was now evident that her brain was irredeemably damaged.

"The movement to say, 'You've got to have Tom DeLay act as a third-party surrogate witness before you can have medical treatment stopped' seemed to be irrefutably silenced by the autopsy report," Dr. Caplan said.

Since March, Aging With Dignity, a nonprofit group in Florida devoted to supporting end-of-life wishes, has received requests for more than 800,000 copies of its do-it-yourself form, known as Five Wishes, which blends the statement of wishes and the appointment of a medical proxy, a relative or friend with the power to make life-or-death decisions.

That is a 60 times the normal number of requests, said the group's president, Paul Malley. "Mail is coming to us by the truckloads," he said.

Christina Lesco of Long Beach, N.Y., said that as she watched the television coverage of the final days of Ms. Schiavo - the brain-injured Florida woman who spent 15 years unable to express her wishes about treatment or end-of-life care - she felt sadness for the family and determination that the same thing

should never happen to her own family.

So Ms. Lesco, a 45-year-old jewelry executive, went to see her lawyer and filled out the forms she needed to describe her wishes and to name her brother as her representative for making tough medical decisions if she is incapacitated.

"They explain in detail what all the words mean," she said. "Some of the words are scary for you. It's a scary thing to go through, to write about. But you have to do it."

Dr. Cecil B. Wilson, an internist in Winter Park, Fla., who is a board member of the American Medical Association, said many of his own elderly patients had already filled out such forms but added that recently they were pressing him to go over the forms and make sure they were clear and binding.

The number of visitors to the part of the association's Web site devoted to end-of-life issues jumped to 25 times the usual during the Schiavo controversy, Dr. Wilson said - though he added that it was hard to say how many people would act on their interest. Any rise in the actual use of the forms is not likely to be felt any time soon, since people filling them out today may not need them for years to come.

Bill Saunders, a senior fellow in bioethics at the Family Research Council, a Christian group that vigorously opposed the removal of Ms. Schiavo's feeding tube, said, "In various forums across the country, I have seen heightened interest" in living wills and proxy forms.

Donna R. Bashaw, a lawyer in Laguna Hills, Calif., who is vice president of the National Academy of Elder Law Attorneys, said the living will, long "almost a throwaway" document slipped into the folder of estate papers for clients to fill out, was now being asked for specifically.

For people who do not want to be kept alive in a greatly diminished state, there is a new sense of urgency, said Barbara Coombs Lee, president of the Compassion in Dying Federation, a group in Portland, Ore., that favors greater latitude for people to make end-of-life choices, including doctor-assisted suicide.

"People are afraid if they don't document their wishes in the most unambiguous way, some politician will try and thwart them," she said.

There are two main types of the forms known broadly as advance directives. Living wills describe kinds of medical treatment, including life-support measures like machine-assisted breathing and feeding tubes, and allow people to say what they find acceptable or unacceptable.

The second form, the durable power of attorney for health care, appoints a family member or friend as a proxy to make medical decisions if the patient cannot. Because no one can anticipate every situation, many experts say the proxy is more important than the living will.

The Schiavo case has encouraged people to talk about advance directives, said Mr. Malley of Aging With Dignity. The Schiavo case and the interest in forms like living wills have led to increased openness to having talks on death and dying, Mr. Malley said.

"People used to think this conversation was only relevant in the emergency room or the lawyer's office," he said. "Today those end-of-life conversations are happening around dining room tables and in living rooms."

The Rev. Dr. Paul Smith, senior minister at the First Presbyterian Church in Brooklyn Heights, whose own living will calls for withdrawal of food and fluids if his medical case is futile, says that is as it should be.

"Death isn't the grim reaper - we live, we die. It is a normal process," he said. "The more we talk about it, the more comfortable we get with the topic."

Marilyn Saviola, a polio survivor who is the director of advocacy at Independence Care System, a long-term-care program, said, "My advance directive says that I want heroic measures."

She went on, "We're a very disposable society, and I don't want to be considered disposable."

So her form says, "I want everything to be done as long as I'm not brain-dead and there's a chance that I would have full or partial recovery," she said. It gives instructions to stop treatment if she is in a persistent vegetative state for five years.

Because death is as varied as life, a range of organizations now offer or recommend forms that reflect their philosophies. Mr. Saunders of the Family Research Council suggests the use of a durable power of attorney instead of a living will, which "locks you in."

The Islamic Medical Association of North America offers an advance directive that balances the Islamic prohibitions against suicide with a sense of not wanting life to be prolonged at all costs.

Under the Koran, "euthanasia, assisted suicide, all those things would be totally out of line," said Dr. Shahid Athar, a physician on the faculty of Indiana University School of Medicine and chairman of the Islamic Medical Association. But at the same time, "nothing is to be done to prolong the dying process." His own living will is based on those beliefs, he said.

Andrea Albanese, a 27-year-old employee of the Catholic Diocese of Arlington, Va., recently filled out the form offered by the diocese because she wanted to ensure that loved ones would not take steps to end her life, even if she was in pain.

"There is value in suffering," Ms. Albanese said. "In the Catholic perspective, we can offer up our sufferings to Christ. And it will be a benefit to us, our souls, in the next life."

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