

Voice

Outbox

A Simple Piece of Paper

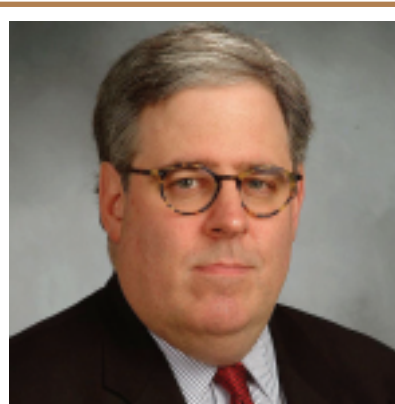
In a recently published book, ...*And a Time to Die*, medical anthropologist and University of California professor Sharon Kaufman chronicles the deaths of 27 people, describing how they pass their final days and hours. According to one review, Kaufman “debunks the cozy belief that if we just have all our paperwork in order—the living will, the DNR, the power of attorney—we can control how we die. She includes examples of seriously ill patients who decide they want to continue living, no matter what they signed earlier.”

It’s easy to forget that advance directives—a durable power of attorney, a living will, a health care proxy—are important, even necessary, tools of financial planning when the picture that a family confronts is a family member struggling for each breath. Somehow, all the legal and financial paperwork seems useless. Except it’s not—because about 75 percent of Americans will die in a hospital under a “do not resuscitate” order, a doctor’s order that comes directly from an individual’s wishes expressed in a living will. This statistic is a good thing, says **Dr. Joseph Fins**, subject of our “**10 Questions**” interview. “It means these are not unilateral decisions by doctors; these are decisions by families and conversations have been held. It’s the patient’s voice coming through.” These “negotiated deaths” include patients, their doctors, their families—and their pieces of paper that may have started those conversations.

Shelley A. Lee
Voice Editor

10 Questions with...

Joseph Fins, M.D., on Contract Versus Covenant: Lessons on Advance Directives from the Terri Schiavo Case



Who: Joseph J. Fins, M.D.

What: Chief of the division of medical ethics, Weill Medical College of Cornell University; associate professor of medicine; physician-ethicist-in residence at the HealthCare Chaplaincy in New York, New York.

What’s on his mind: “It’s an honor and an awesome moral responsibility to serve as someone’s health care agent. It goes far beyond the legal document.”

During the 13-day dying of Terri Schiavo, Dr. Joseph Fins appeared on CNN’s *Lou Dobbs Tonight* program four nights in a row. “We discussed every twist and turn,” says Fins. “The role of Congress, the different brain

states, the legacy. Fortunately, very few deaths are this public and divisive to a family. But people do make decisions for dying people every day and it’s no less difficult. It can be easier, though, if families talk about it and make their covenant.”

Sadly, Terri Schiavo became an icon for a cause, laying bare the sensitive end-of-life issues of who makes medical decisions for those who can’t, how to understand common but morally inexact terminology such as “quality of life,” whether federal laws should review disputes about a terminally ill person’s wishes, and who exactly has a stake in the outcome of those discussions or disputes.

Fins maintains that 20 years of progress on controlling one’s medical destiny is still fragile and hopes that cultural norms don’t swing too far back toward denying patients and their proxies the right to make decisions—and have them respected. Most of all, he hopes that both parties to what he calls a covenant understand their moral obligations to each other: “It’s a lot more complicated than ‘self-determination.’”

An associate professor of medicine at Weill Medical College of Cornell University in New York, chief of the division of medical ethics, and a practicing internal medicine physician, Fins was the recipient of a Project on Death in America Faculty Scholars Award. He has written numerous articles on end-of-life decisions, palliative

10 Questions continued on page 12 ➤

10 Questions *continued from page 10*

care, advance directives, and medical ethics. He serves on the board of Partnership for Caring, and was vice chair of the ethics committee of the American Geriatrics Society.

Voice recently talked with Dr. Fins on advance directives as covenants, the legacy of Terri Schiavo, and death and dying in America.

1 What do you think is the single most important theme or issue in the Terri Schiavo case?

Certainly it's important for your readers to know that it was atypical. Most families are not divided at the end of one's life. But the tensions and disagreements in that family reflect deep cultural divisions in our country. A red state-blue state phenomenon became embedded in this family tragedy, and it mirrors a broader social template. I think that's why it was so dramatic. And with many prominent people involved, not the least of whom were Governor Bush and President Bush, the ingredients for high drama were all there. If you look at it with a longer-term view, this was a tragedy in three parts: Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo.

2 It seems those two earlier cases were more about right-to-die and that this one became more of a right-to-live case, at least as viewed by some people.

Fundamentally, this was a right-to-die case. It was about Terri's wishes as they were adjudicated by court after court. The fact that she had a feeding tube removed three times and reinserted twice was incredibly invasive and a violation of her views if that's not what she wanted. In the *Quinlan* and *Cruzan* cases, you had families come together to try to have an individual's wishes respected. Those

cases—*Quinlan* to remove a ventilator and *Cruzan* to remove a feeding tube—established that people have a right to refuse treatment and therapy. The *Cruzan* case settled that a feeding tube is life-sustaining therapy. The Supreme Court said that both artificial nutrition and hydration are “medicine.” The fact that Terri Schiavo died when it was removed is proof. It's not ordinary feeding because she couldn't feed herself and it doesn't go through the mouth. Since this was settled in the *Cruzan* case—the right to remove a feeding tube—the Supreme Court refused to hear this case.

That was one basis. The other was the issue of states' rights. It was very dramatic that Congress inserted itself in a matter that historically has rested in state courts. Every case that gets adjudicated—a will, a family dispute, guardianship for health care decisions—is handled by state courts. The courts ultimately have supremacy, and by Congress intervening and asking for judicial review, that, too, undermines the standing of the courts. The legislative branch is not the ultimate adjudicator of matters of law.

As to whether it was appropriate for Schiavo's parents to continue to go to court, I think that disputes should go to court. I respect their right to seek that avenue. But ultimately the law is supposed to protect the rights of the patient and the primacy of self-determination. The courts determined that Schiavo's husband's and other witnesses' remarks about her not wanting to live that way were credible and multiple rounds of judicial review upheld that. Sometimes even elections—and sometimes in Florida—are decided by courts. After it was decided that the feeding tube was not something she wanted, it became medical treatment that was not consented to. I don't think we want to give the state the authority to force medical treatments on people.

3 What aspects of medicine in the case troubled you?

For one, there were too many doctors, including those in Congress, misrepresenting medicine and asserting a diagnosis on a patient they'd never examined. Most important, however, is that there are definitive medical criteria for what constitutes a vegetative state. It's not a values choice. It's one thing to respect others' views on whether life is worth living in a persistent vegetative state, but we can't turn the diagnostic act into a values choice. That undermines the integrity of medicine. Moral judgments should not supplant science; science should support moral judgments. We shouldn't start “spinning” the science. When we do, we impoverish the discourse. Science is meant to be interpreted and discussed, but not spun. The Schiavo case threatened to undermine both the legal process and the medical one. And the two of those in tandem can begin to fracture civil society, because in civil society we have to depend on the law and the learned professions. Both took a hit.

On a very positive note, you'd have to say that the value and compassion of hospice care was highlighted. The hospice that cared for Terri Schiavo obviously did a good job—she did not die quickly, which would have been evidence that she wasn't physiologically well cared for.

4 How might it affect 20 or 30 years of consensus on individuals' ability to control their medical destiny?

Progress on the issue of right to die, of choice and destiny, has been very fragile. It was hard to establish and it's hard to sustain, because if all of us had a choice between living and dying we'd choose to live. The reality is we're all going to die,

10 Questions continued on page 13 

10 Questions continued from page 12

and to acknowledge that means we can move forward and make it more humane and compassionate. In some ways, this is also a response to the debate over assisted suicide. In 1997, the Supreme Court was considering a case about assisted suicide, and Jack Kevorkian, not Terri Schiavo, was on the cover of *Time* magazine. Culturally, there's been a significant shift in the last seven years. I'm personally opposed to assisted suicide and I do think some members of the medical community got ahead of the cultural norms. So then we started moving back toward the center—only we never stopped at the center. You might say that the rhetoric and positions of the *Schiavo* case were payment for the excesses in the other direction in the 1990s.

5 Studies show that two-thirds of people age 65 or older have a living will and it seems that the living will is what automatically comes to mind when people think about their wishes for the end of life. Why is it not enough?

First let me say that if you have a living will you'll definitely be in a much better position than without one, as shown in the *Schiavo* case. I'll digress for a moment and point out that Terri Schiavo had her cardiac arrest the same year the Supreme Court decided the *Cruzan* case. Justice Sandra Day O'Connor said words to this effect: "Wouldn't it be a good idea if we could know in advance what Nancy Cruzan wanted," and suddenly there was talk about advance directives. Senators Danforth and Moynihan introduced the Patient Self-Determination Act. So although it would have been a blessing if Terri had had a living will, it should be pointed out that 15 years ago she would have been way ahead of the cultural curve and not that many people in their mid-twenties do have a living will, although they should.

I prefer the designation of an individual through a health care proxy or medical power of attorney because that person can actually represent your interests and interpret your choices in light of changing circumstances. Ideally, you can foster a deep and thoughtful conversation with that person instead of them relying on the cryptic comment, "Don't ever let them put me on a breathing machine." Well, what if you get hit by a car, are in very serious condition and need a ventilator, but your chances to recover are pretty good? The person who says "no ventilator ever" probably didn't mean that under those circumstances. What the legal document—the health care proxy or POA—should do is begin the dialogue between patients and proxies.

6 What are some of the important findings from your research on patients and proxies?

We undertook this research to delve into how well people understand their choices and their moral responsibility to each other. I'd like individuals to really know that being someone's agent goes far beyond just agreeing to their name in the POA that the lawyer or financial advisor draws up. It's an awesome responsibility. One of the most interesting findings was that self-determination comes in two flavors: asking for everything and asking for nothing. What we found was that if somebody said, "I don't want anything done for me," no really meant no. But if somebody said, "I want everything done no matter what," it was conditional and to be interpreted in the context of the situation. We did our research in New York and Missoula, Montana, a community that has studied death and dying in great depth. [Editor's note: see www.lifesend.org about the extraordinary Missoula Demonstration Project on death, dying, caregiving, and bereavement.] Another

interesting finding is this: patients are always more clear about their wishes than proxies, because proxies are always in the interpretation business.

7 You suggest that individuals doing this end-of-life planning think of the health care proxy or power of attorney as a covenant, not a contract. Can you explain?

A contract is about minimum standards and is essentially based on mistrust. A covenant is based on trust and is about fidelity, wisdom, and love. It's not about a minimum, there's no quid pro quo, but there are incredible reciprocal obligations. In other words, not only do I as your proxy have to make decisions and take care of you and prepare myself for that, you as the patient have to prepare me for that. That's why it's about dialogue. Even though we call the legal basis of this "patient self-determination," that terminology is a moral fiction. It's not about a patient; it's about you and me having obligations to each other, especially the moral burden imposed on the proxy when the patient can no longer speak for himself. So it's really "other-realized self-determination." This is not an easy job or something to agree to lightly. Incredibly, in some states you don't even have to get the consent of the person you're naming as proxy. That's awful. But writing the person's name down is just the beginning.

8 How do both parties get comfortable with terms such as "extraordinary measures" or "quality" of life? What about the gray areas, especially those that might confront people decades down the road as medicine advances?

10 Questions continued on page 14 

10 Questions *continued from page 13*

Certainly doctors have to be involved to help with the interpretation of somebody's wishes about medical treatment and medical conditions. We also found in our research that people really do trust the agents they're appointing. Of the people we surveyed, on average, the patient and proxy had known each other more than 40 years—spouse, dear friend, other relative, child. You trust them to make these interpretive choices. That's another aspect of it being a covenant—it's discretionary.

What I consider to be the most difficult of the gray areas are situations where people have serious brain injury or disorders of consciousness, but not a persistent vegetative state such as Terri Schiavo had. What we may have to grapple with is, How do we value life when there's a severely altered life of the mind? What are the burdens and benefits of continued existence in an altered state, when you're not who you were? How does it alter the nature of your relationship with your family? Bioethics has grown up with a model of withdrawing care for a terminally ill patient who may die in weeks or months, even with aggressive care. But what about the choices when confronted with a 15-year course of Alzheimer's or a 20-year lifespan after a serious car accident when you're unable to dress, feed, and think for yourself? It's very frightening to people. And it shows that this is not about "self-determination" because we're all in a web of relationships. Those are really hard choices and they'll get even harder in the future as we have more Alzheimer's patients and as medicine can easily keep alive the bodies of those with serious brain injury.

Speaking of medical terminology, it's also important to point out that a "do not resuscitate" (DNR) order is technically a doctor's order based on your wishes expressed in a living will. About 75 percent of Americans will die in a hospital

with a DNR order. Keep in mind that emergency medical personnel are trained and obligated to resuscitate, so if a patient goes home from the hospital with a DNR, it needs to be posted in the home so that paramedics can take it as a doctor's order. The leading cause of hospital readmission for a person in the process of dying is shortness of breath. It's a hard symptom to control at home, and the family often panics and calls 911. You have to think about this scenario too, because emergency medical professionals will work to save your life if somebody calls them.

9 In your medical ethics classes, what are the young doctors' concerns? Did the Schiavo case unsettle them?

There's great enthusiasm about the topic of medical ethics, but it only becomes more important and more real to them after they get a lot of experience. That's when they "get it." The Schiavo case certainly shook up some assumptions and what we considered "settled issues" in medicine and in law. I was teaching the required course in clinical ethics and palliative care during the time the *Schiavo* case was going on and the students kept asking, "Tell me more about *Quinlan*, about *Cruzan*, about the difference between vegetative state and minimally conscious state." They want to know. And if they're untrained in these situations, that's where you'll see an enormous amount of stress and even burnout. So we have an obligation to train our medical students well so they can *engage* these issues, not avoid them. There's an avoidance of death in our society and of other complicated issues where there isn't always a "right" answer. What's that saying—"Americans don't die, they just over-achieve." Hospice care has certainly helped us make progress about death and

dying but still we hold on to every last hope to live. That's human nature.

10 Is there an obvious legacy on end-of-life planning that we can take from Terri Schiavo's situation?

I hope as a society we don't miss an opportunity to have deep family discussions and prevent the discord that tore this family apart. The other lesson we can take is from the death of Pope John Paul II, just after Terri's death. He didn't go to the hospital; he died at home. Whoever his proxy was recognized the futility, the burdens, the disproportionality of aggressive care and let him die in peace. If there's a silver lining, it's that people may talk more about their own mortality, get their advance directives done, try to prepare their families for a time when they won't be there. At the societal level, I'd love to see more resources from the government spent on better care for people with brain injury. They receive woefully inadequate care now and often are relegated to nursing homes. That would be really advancing a culture of life.



10 Questions continued on page 16 

10 Questions *continued from page 14*

Making It Legal

Attorney Bernard Krooks, managing partner of Littman Krooks LLP, an elder-law and estate planning firm in New York City, has seen a surge since Terri Schiavo's death in



clients seeking to prepare their advance directives. That's the good news. The bad news, says Krooks, is that some state legislatures are

now proposing "disturbing" new laws. About a dozen are percolating, says Krooks, including the Alabama Starvation and Dehydration Prevention Act, which would bar the withdrawal of a feeding tube without explicit written instructions, and one in Michigan that would prevent an adulterer from making medical decisions for an incapacitated spouse. "Some of these proposed new laws are getting very narrowly specific, which I don't think is good," says Krooks. "These situations should be about personal choice on the right to control your own medical destiny."

Krooks is a past-president of the board of directors of the National Academy of Elder Law Attorneys, past chair of the elder law section of the New York State Bar Association, and currently serves on the New York United Hospital Medical Center's Bioethics Advisory Committee. He offers some specific points about the legal issues to consider in discussions between financial advisor and client on end-of-life planning:

- **The advance directive documents shouldn't be overly specific.** Krooks says clients are now coming in and

“Too often, advisors bypass the often-difficult discussions on death and ignore the psychological aspects of it.”

wanting very specific language that covers some of the horror-story aspects of Terri Schiavo—even about who might be allowed to visit them. But too much specificity can be restrictive, says Krooks, and might not cover every situation in the future. "And keep in mind that a living will is something that has to be interpreted by medical professionals, while an agent appointed in a medical power of attorney can make any and all decisions on your behalf," he says. "If you have both documents, you have evidence of your own wishes and an agent to make decisions when you can't."

- **Avoid combining the health care proxy or medical power of attorney with a broader power of attorney that covers financial matters.** Krooks advises separate documents. The financial power of attorney can cover all manner of financial decisions, including selling a home, paying taxes, liquidating investment portfolios, and incurring debt. Remind clients that a power of attorney is "springing," meaning the authority for an agent to make decisions goes into effect only when the person can no longer make their own. "There's often confusion by clients on that, and it's why many people delay creating the documents. They think it takes away their right to make their own decisions while *not* incapacitated."
- **An Alzheimer's diagnosis doesn't mean you can't sign legal docu-**

ments. As long as there are periods of lucidity where the client can understand what she or he is signing, a health care proxy is valid. When in doubt, get the person's doctor to attest to the fact.

- **Understand who your client really is.** Although Krooks' firm wants to advise the entire family, it's the individual—typically the "senior"—who's the client. When clients come in with an adult child, Krooks asks for time alone with each. It is, after all, the senior individual's money, health, wishes, and documents, he says. "But we want to make sure the family is together on this."
- **Understand your own role.** The financial advisor must understand end-of-life issues, educate clients about them, and encourage and facilitate dialogue about death, dying, and preparing for it. "Financial advisors can be a comforting resource on these issues," Krooks says. "Too often, advisors bypass the often-difficult discussions on death and ignore the psychological aspects of it."

Krooks' April 2005 Virtual Learning Center presentation on advance financial and medical directives can be accessed at the Financial Planning Association's Web site: www.fpanet.org. For more information on locating a certified elder law attorney, visit the National Academy of Elder Law Attorneys: www.naela.org.



10 Questions *continued from page 16*

Fidelity, Wisdom, and Love

In the interactive workbook and video *Fidelity, Wisdom, and Love: Patients and Proxies in Relationship*, Dr. Joseph Fins and his co-author, Barbara Maltby, used several years of research as the basis to help people decide on the kind of end-of-life care they want, choose someone to speak for you when you can't make your own decisions, think about and discuss some common medical situations to help your agent make better decisions, and talk comfortably about your wishes. The book discusses the difference in a living will and a health care proxy or medical power of attorney, suggests dialogue between the patient and proxy, and provides suggested discussion for situations when guidelines aren't clear. Four medical conditions are described that allow the patient and the proxy to engage in meaningful discussion on choices: congestive heart failure, cancer, stroke, and Alzheimer's.

"In each scenario, you can role-play as the patient and the proxy," says Dr. Fins. "Ideally, people will buy two books and each person can have their own. But, of course, they should come together and talk about it." Two workbooks and the companion video can be ordered for \$33 at www.fidelitywisdomandlove.org or \$8 for a single workbook at Amazon.com. All proceeds go to the Division of Ethics at Weill Medical College of Cornell University.

Other end-of-life planning resources:

- Aging With Dignity's "Five Wishes" document (www.agingwithdignity.org)
- The National Hospice and Palliative Care Organization (www.nhpco.org)
- The National Academy of Elder Law Attorneys (www.naela.org)
- The *Caring Conversations* workbook from the Center for Practical Bioethics (www.practicalbioethics.org)
- Partnership for Caring (www.partnershipforcaring.org)
- Choice in Dying (www.choiceindying.org)



Coming Soon...

Be sure to look for these upcoming "10 Questions" interviews in the pages of the *Journal*:

- Should the role of business today include a serious commitment to corporate social responsibility, or is that beyond the requirement for business to act as a vehicle for economic progress? **David Henderson**, a London-based economist,

thinks that corporate social responsibility is misguided, dangerous, and based on a set of false and dangerous beliefs about the nature of capitalism.

- Wharton professors **Dan Hunter and Kevin Werbach** discuss blogs and blogging—they're here to stay, but where are they headed? Should you blog? What legal protections do you have in a blog? Is there a blogger business model?

Talking Point

Advancing the Case of Advance Directives

According to a recent article in *USA Today*, "lingerie, Tupperware, and murder mystery parties have been the rage for years. Now add a new one to the list: living-wills parties." These "parties with a purpose" were the brainchild of Leslie Piet, a registered nurse who's also on the board of Aging With Dignity, and who uses Aging With Dignity's "Five Wishes" document to get people started with their advance directives. People are taking the opportunity during discussions after Terri Schiavo's death to get some plans into place.

We can't let the opportunity pass, either—there are important discussions that financial advisors should be having with their clients and clients' families about end-of-life planning. We'd like you to share yours with us:

- What kind of conversations are you having with your clients about living wills, powers of attorney, the agent they want to appoint?
- How do you handle sensitive family dynamics that come up?
- How general or specific do you make your clients' advance directives?
- How involved should financial planners be in helping clients understand and discuss illness, death, dying, laws, and ethics?
- What resources or tools do you find particularly helpful?

Discuss it here: www.journalfp.net and go to the July Talking Point.

