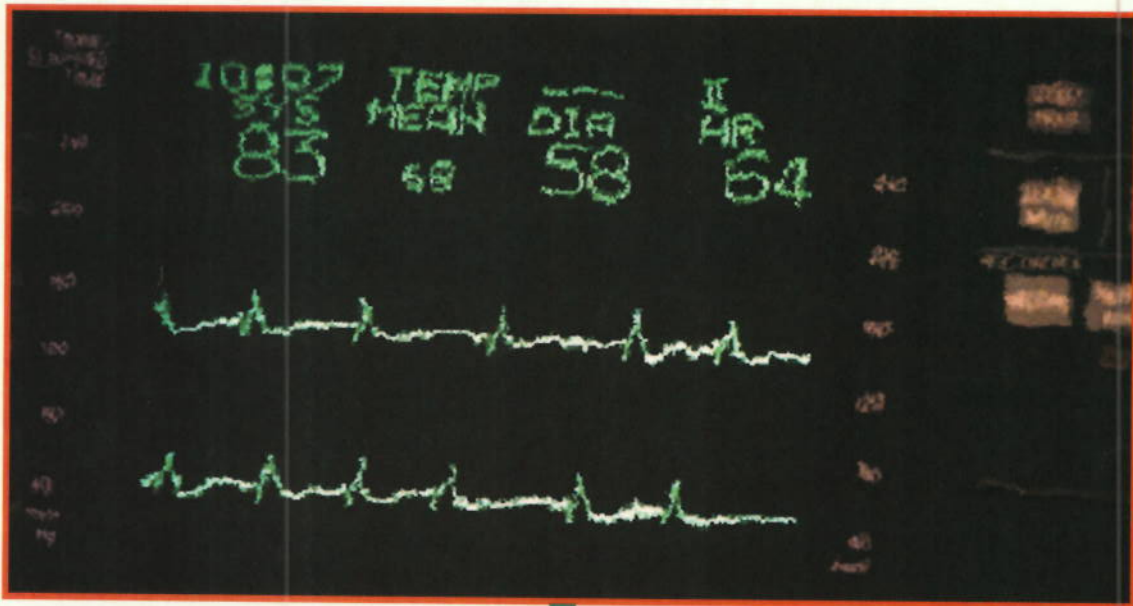




# Crossing the Line

David Myers

Medical knowledge has blurred the line between life and death, forcing families to face difficult decisions.



"Why won't you let me die?" asked my 92-year-old father-in-law of his doctor as he lay with a hip fracture in the Army's hospital near Tacoma, Washington.

This longing for release from misery—"I just want to die"—had been heard by all his friends and family during his waning months before his fall. Although life had been good to this one-time school teacher and Army colonel, he no longer could find pleasure even in the memories of his leadership of a secret World War II Army mission that put him in intimate contact with Mao and other Chinese Communist revolutionaries. Too weak to lift his legs into bed, often unable to swallow, occasionally incontinent, incapable of hearing most conversation or television, he prayed "hundreds of times" that God would claim him.

"I lie here just thinking what it's going to be like to cross that line."

## Absolute Consistency

Knowing his intense wish to be allowed to slip from this life to the next, I assist my mother-in-law in

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adding to his hospital chart a copy of his living will that requests no medical intervention in the event of a terminal condition. I add a note indicating that the family supports his wish that artificial interventions not extend his life. With absolute consistency, he reaffirms this wish in conversations with nurses and other hospital staff. Aware that his prospects are grim and that he no longer is able to swallow without taking fluid into his lungs, one sympathetic nurse even volunteers that it might be possible to disconnect the IVs.

Would he want this? He immediately responds that the Bible says suicide is a sin. Then, realizing that I am only asking about halting the artificial life support, his face brightens: "Tell them to cut it. If they did that, I wouldn't have to go to a nursing home."

With all this information relayed to his caregivers (but the IVs for now still dripping) he and we believe we have done everything possible to enable the granting of his last wish should the end approach.

The next morning, the longed-for moment does approach. The resident physician reports that a serious internal infection has the patient in septic shock, near death. His temperature is rising. His blood pressure has dropped into the low 70s. His kidney output has plummeted. His racing heart gives a 120 pulse. He





has entered a peaceful light coma. The infection, one nurse reflected, was God's gift to him—the answer to his prayers.

Alas, the young resident reports that, contrary to every expressed wish, he is “aggressively” treating the infection with massive doses of antibiotics. “This is *not* what my father would want,” my wife Carol tells him by phone from our home in Michigan (I had happened onto the scene during a West Coast trip). Although granting that stopping the antibiotics would “likely hasten his death,” the doctor reassures us that the drugs probably won't matter.

“Conservatively, there is a 75 percent chance he will not survive this day.”

### Why?

This bizarre argument—that we should accept the aggressive treatment because it might not be effective—begins our cram course in real-life medical ethics. Over the ensuing several days he does not die. We therefore are caught up in hours of dialogue with doctors, nurses, and family members—dialogue that raises difficult issues and sensitizes us to why some people are driven to Dr. Kevorkian. The nursing staff uniformly offers—sometimes behind a closed door—support for the patient's wish: “We want you to know we support what you are doing.” The physicians resist, offering arguments such as these:

- *The living will does not cover this particular life-threatening ailment, because the infection might be reversible, allowing the patient to survive a few more weeks or months in a nursing home.*

But that “best case” outcome would be the patient's long-expressed worst-case nightmare. Moreover, what is “terminally ill”? Is it only having a disease that will cause death? Or is it also being a mortal human who by virtue of age and infirmity is destined soon to die?

- *The 1988 living will is too old for us to be sure it represents his wishes today.*

Actually, it understated his recent feelings. He had, for example, repeatedly told family members not to call 911 should he collapse with an apparent stroke or heart attack.



- *The treatment regimen of maintenance IVs, antibiotics, and blood thinners is routine hospital procedure, not a heroic effort to sustain life.*

The line that defines *heroic* is arbitrary and shifting across time, culture, and changing technology. The only meaningful alternatives to the patient are assisted suicide, artificial life support, and a natural end—com-

## Lessons of Life and Death



In the aftermath, we reflect on issues raised and lessons learned:

- In cases involving potential life-extension questions, shouldn't physicians and families discuss advance directives that put everyone on the same page in the event of a crisis?

- Could medical ethics courses better counsel physicians to respect patients' faith and values? Seeking a word to describe the physicians' death-averting act I settle on “arrogance.” It was doctors playing God. Or is my judgment harsh? After all, the resident's orders, supported by the attending physician, were grounded not only in legal concerns but in his own moral convictions about the sanctity of life.

- Do young doctors have difficulty appreciating how death acceptance changes across the life cycle? Do they presume that how they feel about life extension is how a 92-year-old person should feel? For every

forted but not accelerated or impeded by the hospital staff. Short of writing a document that covers every conceivable life-threatening scenario, we cannot imagine a patient whose preference for the third option could be clearer.

To verify his wishes again, I ask as the antibiotic



drips whether he would want to receive a drug that would fight an infection that has him sliding downhill. He shakes his head no, then rallies his strength to whisper, "I just want to die."

- *This is a hospital—a medical system whose purpose is saving lives. Allowing someone to die when routine medical care might prevent the death is nearly unthinkable. If you didn't want his life protected, why did you bring him here?*

Explaining the obvious, we remind them that he came because he broke his hip. Death was not imminent.

We wonder: why can't hospitals be death-accepting, like hospices? If to everything there is a season, a time to be born and a time to die, what better time to die than after a full life with a failing body at age 92?

- *He has been depressed, so we do not feel comfortable taking seriously his expressed wish to die.*

But this is Catch-22. His utter misery in recent months over his losing control of his body led to an understandably depressed condition and a wish to die. His wish to die—the chief symptom of his depression—then gets used to discount his wish to die.

- *If God intends this patient to die, then nothing we*

older person with whom we discuss the case, the antibiotic rescue illustrated what they would not want for themselves.

- Are we too intimidated by physician authority? Why on the fateful day did I only gently plead and reason with the physicians. Had I asked more questions, I would have learned that the hospital had previously failed to offer the patient its "right to self-determination" form, that a hospital patient advocate was available to us, that my father-in-law had at home a signed power of attorney that gave his wife and daughter untapped legal powers, and that under state law an incapacitated patient's spouse has the power to consent to health care in the absence of power of attorney.

- Why do we devote such enormous resources to extending unnaturally the life of miserable 90-year-olds, while allowing 22 percent of America's children to live in poverty?

*do can make a difference. That, of course, cuts both ways.*

If God intends for a patient to live then he will, and doing nothing won't matter.

- *We try to think about what we'd want if this were us or one of our loved ones.*

"But this is *us* and *our* loved one," I reply, "and he has made his wishes abundantly clear to us all. If he wakes up in a nursing home, he is going to be angry—angry at you for not honoring his desire and angry at us for not making you do so."

We wonder why these doctors aren't as patient-centered as the nurses. A recent survey of 852 ICU nurses published by the *New England Journal of Medicine*



confirms that many nurses feel a keen responsibility for alleviating patient suffering, even to the point of intentionally hastening death, such as with morphine overdoses.

"Physicians are sometimes inadequately responsive to a patient's suffering," reported the lead researcher, Dr. David Asch of the University of Pennsylvania Medical Center.

## More Pain, No Gain

After a day and a half of drug treatments, the doctors agree to discontinue the drugs. Who holds the trump card when the physicians disagree with the patient and family about discontinuing the maintenance IVs? "The case would go to the hospital ethics committee," the uncomfortable physicians reply, asking that we instead continue the conversation at 9 o'clock the next morning after their staff meeting.

At 4 o'clock the next afternoon, after repeated inquiries from nurses embarrassed by doctors making a stressed 86-year-old woman with Parkinson's wait for seven hours, the doctors finally arrive with an oncologist-ethicist. For the first time, we encounter a physician bent on asking my mother-in-law questions that discern her husband's will: What was his quality of life before the fall? ("He

—David Myers

- Finally, might the demand for assisted suicides fade if patients felt more assured of having their wishes honored? "Today, people dying from a terminal illness are denied the fundamental right to choose a peaceful, dignified death," warns a Hemlock Society solicitation letter, also apprising us that a recent Robert E. Wood Foundation study "found large gaps between what patients wanted and what they actually received."

By shrinking the possibilities of unhindered deaths, do physicians unwittingly help explain why people over 75 are—Dr. Kevorkian or no—the most suicide-prone? And by ascertaining and respecting patient's wishes, might physicians further humanize their profession by viewing people not merely as bodies to be kept inhaling but also as deserving solace, dignity, and self-control?



was miserable.") How would he react to extended life in a nursing home? ("He'd hate it—he's always said that's what he wanted to avoid.") How consistently did he express the wish to die? ("About fifteen times a day.")

Having retrieved him from the brink of death, the physicians now agree to discontinue the life supports. Alleviating our concern about dehydration discomfort, the oncologist reveals that terminating fluids actually increases the comfort of IV-bloated terminal patients. The attending physician also reassures us that the ward, which has many empty beds, can care for him an indeterminate number of days.

Although he continues to be arousable only to semi-consciousness, his vital signs begin to recover. The IVs put "a lot of fluid on board," a nurse tells us, so he may live awhile. Day by day, his blood pressure rises into the 80s, then 90s, then crosses the 100 line. With all family activities canceled, the watch continues and the tears escalate. Saying her goodbyes, my wife, Carol, tells her father she loves him and feels his inaudible response—a squeeze of her hand.

"You can go home to Jesus now," she says. And she sings some of his favorite hymns: "Swing low, sweet chariot, comin' for to carry you home" and "Softly and tenderly Jesus is calling...Ye who are weary, come home." Each time she sings, he relaxes and his eyes close, suggesting a comfortable inner peace.

## A Band of Angels

Though the spirit is willing, the body is strong. Three days after the life supports are dis-



connected, the physicians, evading moral responsibility for creating this extended suffering and with death still not in sight, evict their patient to the more nominal care of a nursing home. A nurse speculates that the resident physician is uncomfortable with the visible presence of this untreated semi-conscious person, lying motionless with gaping mouth awaiting the sweet chariot.

Our visits continue. We talk to him. We swab his dry mouth with wet sponges. We ask a few questions, which by Day Five after the discontinued life supports, his weakened body but alert mind can only answer with eyeblinks.

## Patient Advice

Some advice for medical patients and their families:

1. Give a trusted family member or friend a designation of patient advocate or durable power of attorney with health care decision-making. Such a document, drawn by an attorney, gives this person the legal power to make decisions on your behalf should you become incapacitated.

2. If you have a living will, recognize that it may not cover all the situations you intend. The applicability of a living will depends on how terms like *incurable* or *irreversible* are understood. For example, pneumonia—the old person's friend—may be treated aggressively against your will. Initial and date the living will regularly to show that it expresses your current intent.

3. Inform family members of your wishes. Make sure your patient advocate designee fully understands your intentions.

4. Discuss with your physicians what you would want in the event of a life-threatening medical crisis.

5. Request a patient representative or advocate immediately if treatment isn't what the patient wants. This person will represent the patient's interests in working with the hospital and physicians.

6. Ask to meet with the ethics committee when dialogue with physicians doesn't quickly resolve differences.

—Carol Myers

Returning from dinner, I find Carol standing beside him, her face strangely aglow minutes after "a holy moment." As she had prepared to leave after three hours at his side, she swabbed his mouth again and said, "Don't worry about mother—we're taking care of her. You've been a good dad. You've had a good life. Dad, it is time for you to say good-bye."

While his eyes still gazed at her, she again began to sing. "Swing low, sweet chariot, comin' for to carry you home." His breathing hesitated, then began again. So over and again, she sang "Swing low, sweet chariot...a band of angels coming after you, comin' for to carry you home," until, in utter peace, he was carried home.

"I sang him across the line," she marveled, her tears now replaced by a quiet joy. "And then I said, 'Dad, you're free at last, Lord God almighty, you're free at last.' " An extraordinary, immaculate end to an awful week. ■