

WHOSE LAST WISHES DO WE HONOR?
BY ELAINE VITONE

THE MODERN DEATHBED

Statistically speaking, most of us will die like Gene Smith is now—lying in a hospital bed amid the rhythmic chirping of machines. He has a life-limiting, chronic illness—one of the usual suspects that kill Americans—and has been seeing a specialist for some time. At his last appointment, he got the news: Treatment isn't helping anymore.

Smith's nursing home transferred him here last night when he began having trouble breathing, which the hospital staff says may or may not be due to his chronic illness. Now his blood pressure is dangerously low. He gasps inside his facemask, though it's putting concentrated oxygen in his lungs. His wife, Nancy Smith, holds his hand.

Hospitalist Jane Miller walks in and introduces herself. "I'm sorry to be meeting you under these circumstances," she says, standing beside the bed. "So, what's been going on?" Her eyes bow with concern. From reading his chart earlier, she knows—as the Smiths do—that Smith has only a few months, at best. At worst, he will die much earlier—certainly within 24 hours if he isn't put on a respirator soon.

Where do we fall short of providing "the good death," and what can we do to improve?

ILLUSTRATIONS | CATHERINE LAZURE

Smith is awake and aware but tired and out of breath, so his wife explains that he has gotten worse just in the last few hours. “He’s getting scared,” she says faintly.

Miller asks about treatment for Smith’s chronic illness, and Nancy Smith nods. “We saw the doctor last week, and he said there wasn’t anything else they could do.”

Miller adjusts a knob in the wall. “I’m just gonna increase the amount of oxygen. Has anyone discussed wishes if we got to a critical point as far as whether or not you’d want to be put on a breathing machine?”

“He had a bad experience last time. He was in the ICU for weeks.”

“So is that something that you think you wouldn’t want to go ahead and ...” Miller stops herself. “We can just assist you and try to make you more comfortable and not put that breathing tube back down?”

“Is that what you’re suggesting?” Nancy Smith asks.

Miller sighs. “Well, it’s hard—we’re just meeting. I don’t have a relationship with you guys, and I don’t know if your doctors had discussed that. It seems like the situation is pretty far advanced, and I don’t know that putting in a breathing tube would help. I’m not sure what is causing this, and we may or may not be able to reverse it. But he’s gonna tire out and not be able to oxygenate his blood well enough without us assisting him soon.”

Nancy Smith pauses, confused. “What are you suggesting for us?”

“Well, I don’t know what your wishes would be. I guess I’m suggesting that we move him to the ICU if we’re thinking that,” she pauses, “he’s gonna continue to get treatment. But it seems like that may not be something you are thinking of doing.”

Meanwhile, in a narrow, darkened room at the University of Pittsburgh, on the other side of a two-way mirror facing Smith’s bed, Pitt’s Amber Barnato and her research assistant, Heather Hsu, sit on the edges of their chairs, watching Miller and the Smiths—or rather, Miller and the two actors who are playing the Smiths.

Miller (we’ve changed her name) has volunteered her time to participate in a pilot study Barnato is leading on how physicians make decisions with patients at the end of life.

“She’s skirting it,” Barnato says of Miller. Barnato’s anxious because she has instructed

the actors not to offer Smith’s wishes unless asked. At first, Miller started to ask, but didn’t give them the chance to respond. Now she isn’t technically phrasing it as a question. She’s getting warmer—definitely close—but not quite there.

Now visibly upset, Miller turns to Smith. “Are you still awake there? I’m sorry—we’re sort of talking above you.”

Smith speaks softly through his mask.

“I’m sorry? You can hear me?” Miller says, rubbing his upper arm gently. “Are you able to tell us what you would want?”

Smith raises his finger to his throat and whispers, “No tube.”

Still, as a physician whose art is diagnosis, Miller can’t help reaching for a solution, trying to do as she was trained from Day One: To heal.

“We can get him to an ICU and see if there’s something we can reverse.”

Smith lowers his head.

Barnato and Hsu, who can’t help but root for Miller to make the right move, squirm as she struggles.

“So that’s what you’re suggesting?” Nancy Smith says.

“It’s hard to say. It’s not clear to me from the chart that I reviewed what your wishes were to be in this instance as far as resuscitation orders.”

“We have that at home.”

“You do?”

“Mhmm.”

“What are his wishes?”

Barnato is visibly relieved. Miller has uttered a question the Smiths can answer.

For the last several weeks here at the Peter M. Winter Institute for Simulation Education and Research (WISER) in the

about how they die. Through this simulation, Barnato’s team hopes to gain a better understanding of how doctors approach these difficult conversations and how these approaches affect how patients like Smith spend their last days of life.

Barnato, assistant professor of medicine and of health policy and management as well as associate director of the clinical scientist training program, later explains what she believes was causing the confusion in the simulation room. For one, facing death can feel like defeat to doctors. For another, by the nature of their training, they have “totally different needs” from their patients. “Doctors need data to make a decision,” she says. “Patients need someone to interpret the information, gather their goals from them, and merge those with what the doctor knows about prognosis.” In the simulation, Miller didn’t know how to get the information she needed—Smith’s wishes.

After the simulation has ended, the actors take five. Barnato walks in to hug and congratulate them on a job well done. This particular run was a doozy.

“I don’t know if I did it right or not,” says Peg Wietharn, who played Nancy Smith.

“We were in a quandary,” says John Roell, who acted out the role of the patient, Gene Smith.

Barnato reassures them. “She was putting stuff out there, but she wasn’t quite asking questions.”

Relieved, Wietharn smiles, then sighs. “I think I need some oxygen now.”

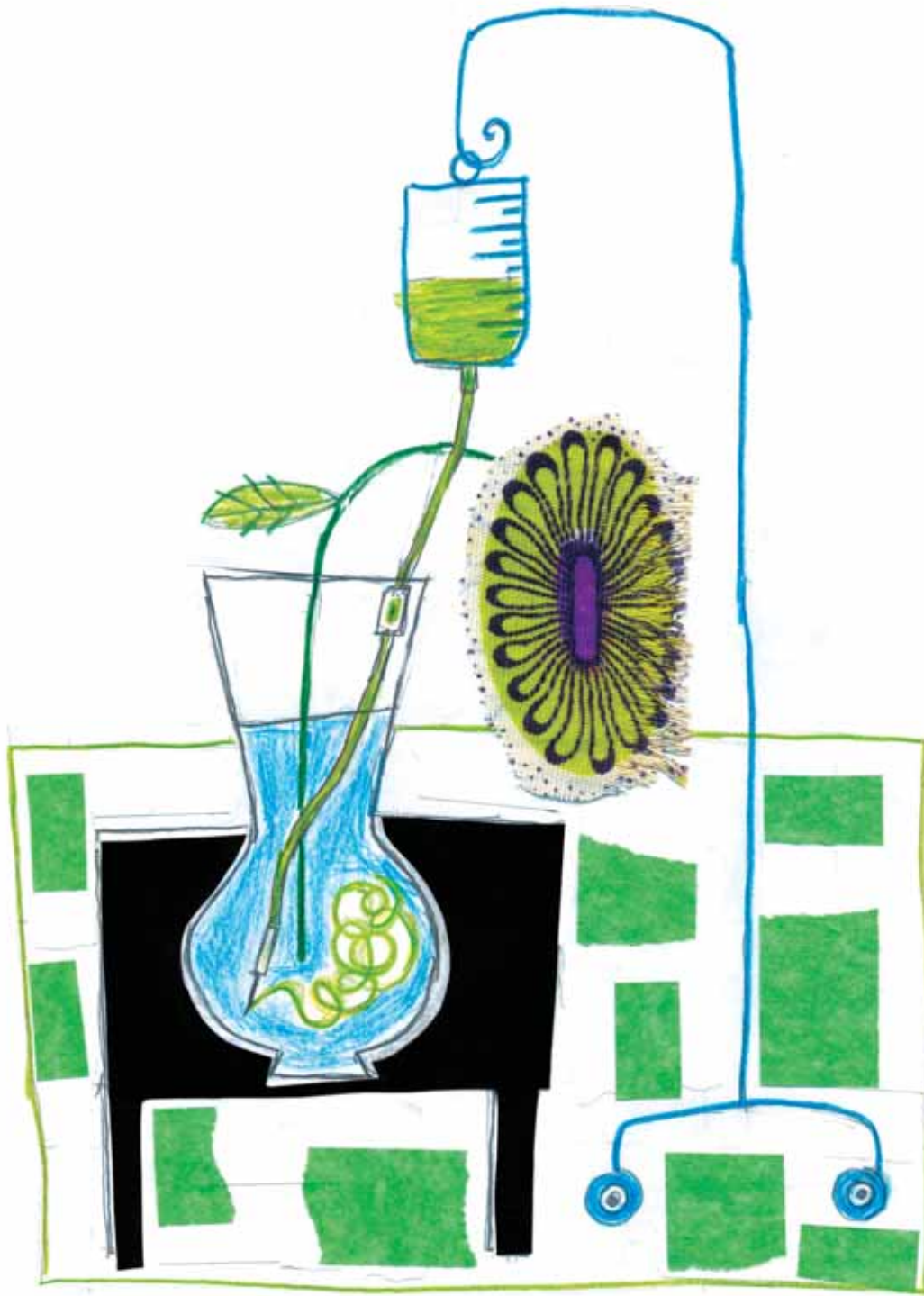
The simulation is tiring for the actors, who face the uncertainty of the contemporary deathbed as many as four times in a

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School of Medicine, Barnato and her Pitt collaborators—Derek Angus, professor of critical care medicine, of medicine, and of health policy and management, Bob Arnold, the Leo H. Crip Professor of Patient Care and professor of medicine, and Cindy Bryce, research assistant professor of medicine and of health policy and management—have been testing a hypothesis that has been very close to Barnato’s passion for most of her career: That patients oftentimes do not have enough say

day. Barnato says it has been equally hard for the study’s participating doctors, who encounter situations like this throughout their careers. Even the first few volunteers, who came in more than once to help train the actors, told her they found it difficult each time.

“In a perfect circumstance, with a fake patient, they still have rocks in their mouths,” says Barnato. “They’re being asked to walk into a room and say, ‘Hi, I’m



Dr. Jones. You don't know me and have no reason to trust me, but we have to make some life-and-death decisions for your husband, and fast."

The doctors' difficulty with this simulation speaks to a larger issue. Although some medical schools now offer basic communication courses, training specific to the deathbed is hit-or-miss. A 1991 study found

that some schools offered no training in end-of-life situations at all. New doctors might be a little better prepared. In 2003, a study reported that 60 percent of fourth-year students surveyed had been trained to discuss treatment withdrawal with patients or their families. Yet 82 percent of students and residents said they'd taken no courses in end-of-life care. A recent survey found only about 5 percent of

practicing oncologists have had any form of communication training. All too often, doctors are ill prepared for the needs of dying patients and their families.

Though the details vary, research shows that dying patients consistently describe the same desires: They want to manage their pain and symptoms, feel a sense of preparedness and completion, be valued as a whole person, and remain clearheaded and able to make decisions for themselves. Without clear communication between doctor and patient, all of the above can be difficult.

Although Barnato empathizes with her study's participants, it worries her that their decisions regarding Smith's treatment have been "all over the map," from intubation in the ICU all the way over to what Smith actually wants: palliative care, a subspecialty focused on providing comfort, dignity, and control to patients with life-limiting illnesses. However, the actors are trained not to ask for it. "Even in a simplified case in which the simulated patient has underlying goals and preferences that are scripted and waiting to be unearthed," says Barnato, "the patient's treatment plan is at the whim of the physician."

Barnato says that for the doctors participating in the study, it's all a matter of perspective. Do they see the big picture or the immediate problem—the forest or the trees? If they are focused on the trees, they're looking at the numbers, adjusting Smith's oxygen, concentrating on getting him through the next 24 hours. If they see the forest, they recognize that there is much more at stake, and now is the time to address his wishes directly. The longer this discussion is put off, skirted, or derailed by talk of vitals and treatment options, the less likely it is that Smith will die the way he wants to.

Palliative care began in the United States in 1974, when the country's first hospice was founded (the Connecticut Hospice). However, it only became formally recognized as a subspecialty in October 2006. In 2005, the American Heart Association included palliative care recommendations in its guide-

lines for the first time in the organization's history.

At the state level, a new Pennsylvania law covering decision-making procedures for terminally ill patients took effect this February. Incidentally, that was just days before Governor Ed Rendell's administration released a 40-page report of recommendations for improving end-of-life care. The document's 160 recommendations aim to improve research, outreach, advance-directives policy, healthcare-finance structures, professional education, sensitivity to the needs of special populations, and palliative care standards—especially in acute-care hospitals, where most Pennsylvanians die.

On February 9, scholars from around the world gathered on Pitt's campus for a seminar on end-of-life issues, hosted by Pitt's Cultural Studies Program and School of Medicine. The springboard for the discussion was *The Contemporary Deathbed*, a book by emergency-medicine specialist and cultural historian John Tercier of the University of California, San Francisco. The book focused on the iconic image of death in the media—the heroic CPR attempt that often takes place after a patient's last breath. Tercier questions

why CPR has been so central to resuscitative procedures across a gamut of cases, even though it has been proven effective only when administered immediately after certain types of cardiac arrest. "For a number of years now," he writes, "medical personnel, while pumping on the chests of the dying, have been asking themselves, 'Why are we beating a dead horse?'"

Perhaps the question now is: How do we stop?

It's not news that few Americans want to end their time on earth in a hospital, with intensive—not to mention expensive—life-sustaining treatment. Yet that's exactly what most get. In the last three decades, 27 percent of the total Medicare budget has been spent on treatment during Americans' last year of life and, of that, about 40 percent in the last month.

Given that so many doctors are uncomfortable even asking patients about their wishes, it's not surprising that the contemporary deathbed still has more than a few bugs. For all our dollars spent and efforts made, and all our talk of living wills and other advance

directives, we're often still missing the mark. Where do we fall short of providing the good death, and what can we do to improve? Barnato and others at Pitt are starting to answer these questions.

Pitt's Bob Arnold, a former president of the American Academy of Hospice and Palliative Medicine, says the good death has remained elusive for a variety of reasons. To name a few: Patients and families don't know to expect good palliative care, healthcare providers haven't traditionally been trained to provide it, and health care in this country is financed with an emphasis on acute rather than chronic illness.

To address these issues, Family Hospice and Palliative Care—one of the first hospice programs in Pennsylvania—and Pitt's health sciences schools jointly established the Institute to Enhance Palliative Care in 2003. The institute educates healthcare providers about palliative care, raises public awareness about palliative care availability, advances public policy supporting better care for seri-

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ously ill patients, and conducts research into best practices.

"Twenty or 30 years ago there would have been no one looking at this stuff," says Arnold. "Now there's a whole group of junior investigators and researchers at Pitt who are all really interested in focusing on these issues."

David Barnard, who directs the Institute to Enhance Palliative Care and palliative care education at Pitt's Center for Bioethics and Health Law, says one of the bigger problems with the contemporary deathbed is the way prognosis is often communicated. Studies show that doctors tend to paint a brighter picture to patients and their families than the doctors themselves perceive—either consciously because they're uncomfortable or unconsciously because the better doctors know their patients, the more likely they are to be overly optimistic in their predictions. This leads to problems once a patient really starts to decline.

As a member of the UPMC Ethics Committee, Barnard has seen it countless times: The patient has multisystem failure and has been on a ventilator for two weeks.

The doctor calls and says, "The family doesn't get it." Barnard explains: "Too much time is spent deciding which treatments to do, rather than getting to know the patients and what they want. The important question they should be asking patients is: 'What characteristics of life make it worth living?'"

In 2001 and 2005, Barnard secured four-year National Cancer Institute (NCI) grants—totaling about \$1.75 million—to incorporate new palliative care offerings into the curriculum. Palliative care training is now available at all levels of instruction, from classroom to residency to fellowship.

In one course, Barnard pairs first-year students with patients with life-threatening illnesses. They spend time together throughout the semester. Medical student Yohko Shinozawa (Class of '08), who took the class two years ago, was assigned Mike Kolansky (not his real name), a bearded, tattoo-clad motorcycle enthusiast in his 60s. Kolansky had undergone a liver transplant, and, as a result of his immunosuppressant medications, his kidneys began

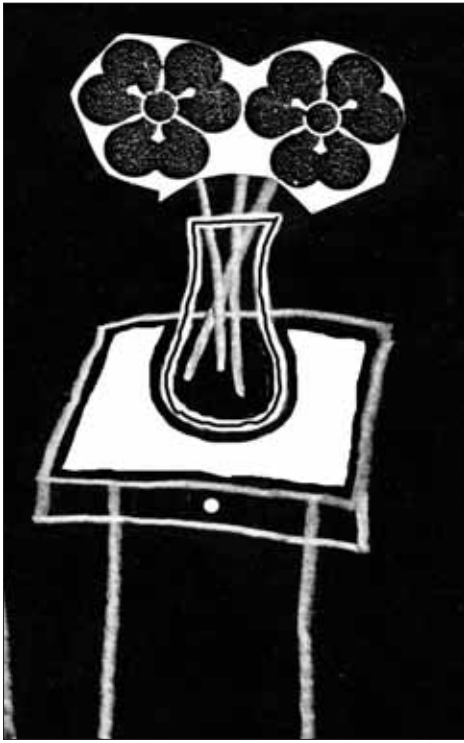
failing 10 years after the surgery.

Each Saturday, Shinozawa sat with him for one hour of his 12-hour weekly dialysis regimen at the VA hospital.

To Shinozawa's surprise, the two didn't discuss his illness much. "He was laid-back, always joking around," she says. "He was very focused on living and making the most of his life." Since her semester in Barnard's class, she has volunteered regularly for the palliative care program.

The institute also offers a two-year palliative care fellowship that combines research with clinical care. First-year fellow Elizabeth Weinstein (MD '02, Res '05) notes that while many palliative care fellowship programs are run through oncology or geriatrics divisions, Pitt's is part of the Division of General Internal Medicine. "One of the things I love about Pitt is that we see such a broad range of patients."

Weinstein says that a feather in the program's cap is Arnold himself. "A couple of weeks ago we were at a national meeting. Everyone was grabbing for five minutes of Bob Arnold's time. ... But he always down-



plays what he does. You wouldn't realize he's one of the heads of this new field."

Arnold worked with colleagues at the University of Washington, Seattle, to create Oncotalk, a four-day retreat funded by the NCI to train oncology fellows in communication skills. (Oncotalk was featured in *The New York Times* in January.) In spring 2008, Arnold will begin a new retreat, funded by the Jewish Healthcare Foundation of Pittsburgh, to train pulmonary and critical care fellows to conduct family meetings.

Arnold says facilitating conversations with groups of people in the middle of a highly emotional situation is an acquired skill. "You have to practice. ... Often people will focus more on the cognitive material rather than the emotional."

Barnato, who interned in general surgery before pursuing her career in research, can relate. "We'd tell you about every aspect of your mom's physiology, every organ system, and then we'd just end with a 'We're doing everything we can.' That was our form of a family meeting."

One case from her internship working in an ICU in another state stays with her. It reminds her how patients and their families can be cut out of the decision-making process. After inserting bilateral chest tubes—an aggressive surgical measure known to help in some cases of respiratory arrest—Barnato was able to bring an 85-year-old woman back from a code blue. The patient was then transferred to a long-term, acute-care facility,

where she died a few months later.

"We had amputated her feet and parts of her lower legs," says Barnato. "She was bed bound and on a ventilator. Her favorite thing to do was watch TV, and she wasn't going to be able to do that because she was now almost blind because of her diabetes."

While the patient awaited her transfer, Barnato approached her and asked about her wishes. Though she couldn't speak, through notes and gestures the patient told Barnato that this wasn't what she wanted.

Barnato was nervous about bringing it up but ultimately decided she had to. "Do you know what my resident did?" she says. "He ordered a psychiatry consult. The psychiatrist came, saw her, and decided she was depressed. And he started her on—I'm not kidding—Prozac. ... It was very demoralizing, to say the least."

In a study published in *Critical Care Medicine* in 2004, Barnato looked at the final hospitalizations of deceased patients across the country, comparing the aggressiveness of treatment. She found that in some geographic regions, the average ICU stay was much longer than others. Since then, she's found a lot of variation from hospital to hospital, ICU to ICU, and doctor to doctor. Recently, she interviewed staff members at 11 Pennsylvania hospitals, asking them about end-of-life decision-making. She heard statements like, "This doctor tends to do this, but that doctor tends to do that"—unsettling for Barnato. "You'd hope these decisions would be made by the patient and the family [rather than the doctor alone]," she says.

A few hours after Miller's simulation, Arnold enters Smith's room, introduces himself, and squats beside the bed so that he's almost looking up at Smith. If this were more than role-playing, he would have roamed the halls looking for a chair—meeting the patient at eye level is that important.

Through a series of open-ended questions, Arnold gets the couple talking. They tell him all they know, including what's going on with the chronic illness they've been fighting all these months.

Arnold repeats it all back to them. "And so some of this may be because of [the illness]. Or it could be pneumonia. Or it could be a blood clot. And the problem right now is it looks like he's gotten a fair amount worse, and it could be because of any of those things. And I guess the question is, Where do we go from

here?" He pauses, then begins again, his pitch higher, his timbre softer. "After you found out that [the illness] was worse, had you guys ever talked about where you'd go?"

They explain that they have a living will at home that says Smith "doesn't want anything extraordinary."

Arnold clarifies that they all agree on what *extraordinary* means.

Then he addresses Smith directly, asking him if anything besides the shortness of breath is making him uncomfortable, what his wishes are, and whether or not he wants to be part of the conversation in the first place. "Some people when they're sick don't want to hear a lot about the medical details," he says, "and other people want to hear what's going on."

He suggests medication that will ease Smith's discomfort. He turns off the noisy machines that distract the couple from each other, assuring them that Smith is still getting his oxygen. He asks if any loved ones or clergy need to be there, and what kind of support Nancy Smith has. Again and again, he asks them, "Questions?"

Arnold is a palliative care specialist who helped design this study, so he knows exactly what to do in this simulation. Still, listening to him is inspiring—a reminder of what's possible as American doctors become comfortable adding palliative care to their broader definition of healing.

For Shinozawa, the definition of the good death has become more nuanced as she volunteers for Pitt's palliative care program.

Some patients want somebody to talk to. Some like the silence but still want companionship. Some can't tell you what they want, because they're unable to speak or write, and it takes a lot of yes-or-no questions to understand their desires.

And then there are the patients who simply want to focus on *living* with an illness—like Kolansky the biker. "Don't take life so seriously," he told Shinozawa the day they met. "Take it as it comes."

Once, she asked, "Is there any one thing you want to do before you die?"

"Go on one last ride," he said. He added that he didn't want to burden his family with a funeral. "Sprinkle my ashes on my Harley," he said, joking. "Take me cruising one more time."

"Death isn't easy to talk about," says Shinozawa. "It's not like after we take this course we become experts on this. But I think it's a good start." ■