

WHOSE BODY IS IT, ANYWAY?

What doctors should do when patients make bad decisions.

BY ATUL GAWANDE

THE first time I saw the patient, it was the day before his surgery and I thought he might be dead. Joseph Lazaroff, as I'll call him, lay in bed, his eyes closed, a sheet pulled up over his thin, birdlike chest. When people are asleep—or even when they are anesthetized and not breathing by themselves—it does not occur to you to question whether they are alive. They exude life as if it were heat. It's visible in the tone of an arm muscle, the supple curve of their lips, the flush of their skin. But as I bent forward to tap Lazaroff on the shoulder I found myself stopping short with that instinctive apprehension of touching the dead. His color was all wrong—pallid, fading. His cheeks, eyes, and temples were sunken, and his skin was stretched over his face like a mask. Strangest of all, his head was suspended two inches above his pillow, as if rigor mortis had set in.

"Mr. Lazaroff?" I called out, and his eyes opened. He looked at me without interest, silent and motionless.

I was in my first year of surgical residency and was working on the neurosurgery team at the time. Lazaroff had a cancer that had spread throughout his body, and he had been scheduled for surgery to excise a tumor from his spine. The senior resident had sent me to "consent" him—that is, to get Lazaroff's signature giving final permission for the operation. No problem, I had said. But now, looking at this frail, withered man, I had to wonder if we were right to operate on him.

His patient chart told the story. Eight months earlier, he had seen his doctor about a backache. The doctor initially found nothing suspicious, but three months later the pain had worsened and he ordered a scan. It revealed extensive cancer—multiple tumors in Lazaroff's liver, bowel, and up and down his spine. A biopsy showed an untreatable cancer.

Lazaroff was only in his early sixties, a longtime city administrator who had a touch of diabetes, the occasional angina, and the hardened manner of a man who had lost his wife a few years earlier and learned to live alone. His condition deteriorated rapidly. In a matter of months, he lost more than fifty pounds. As the tumors in his abdomen grew, his belly, scrotum, and legs filled up with fluid. The pain and debility eventually made it impossible for him to keep working. His thirty-something son moved in to care for him. Lazaroff went on around-the-clock morphine to control his pain. His doctors told him that he might have only weeks to live. Lazaroff wasn't ready to hear it, though. He still talked about the day he'd go back to work.

Then he took several bad falls; his legs had become unaccountably weak. He also became incontinent. He went back to his oncologist. A scan showed that a metastasis was compressing his thoracic spinal cord. The oncologist admitted him to the hospital and tried a round of radiation, but it had no effect. Indeed, he became unable to move his right leg; his lower body was becoming paralyzed.

He had two options left. He could undergo spinal surgery. It wouldn't cure him—surgery or not, he had at the most a few months left—but it offered a last-ditch chance of halting the progression of spinal-cord damage and possibly restoring some strength to his legs and sphincters. The risks, however, were severe. We'd have to go in through his chest and collapse his lung just to get at his spine. He'd face a long, difficult, and painful recovery. And given his frail condition—not to mention the previous history of heart disease—his chance of surviving the procedure and getting back home was slim.

The alternative was to do nothing. He'd go home and continue with hospice care, which would keep him com-

fortable and help him maintain a measure of control over his life. The immobility and incontinence would certainly worsen. But it was his best chance of dying peacefully, in his own bed, and being able to say goodbye to his loved ones.

The decision was Lazaroff's.

THAT, in itself, is a remarkable fact. Only a decade ago, doctors made the decisions; patients did what they were told. Doctors did not consult patients about their desires and priorities, and routinely withheld information—sometimes crucial information, such as what drugs they were on, what treatments they were being given, and what their diagnosis was. Patients were even forbidden to look at their own medical records: it wasn't their property, doctors said. They were regarded as children: too fragile and simpleminded to handle the truth, let alone make decisions. And they suffered for it. People were put on machines, given drugs, and subjected to operations they would not have chosen. And they missed out on treatments that they might have preferred.

My father, a urologist who practices in Ohio, recounts that, through the seventies and much of the eighties, when men came to see him seeking vasectomies it was accepted that *he* would judge whether the surgery was not only medically appropriate but also personally appropriate for them. He routinely refused to do the operation if the men were unmarried, married but without children, or "too young." In retrospect, he's not sure he did right by all these patients, and, he says, he'd never do things this way today. In fact, he can't even think of a patient in the last few years whom he has turned down for a vasectomy.

One of the reasons for this dramatic shift in how decisions are made in medicine was a 1984 book, "The Silent World



"I thought it had a pretty good story and interesting characters, but I really didn't like the font."

of Doctor and Patient," by a Yale doctor and ethicist named Jay Katz. It was a devastating critique of traditional medical decision-making, and it had wide influence. In the book, Katz argued that medical decisions could and should be made by the patients involved. And he made his case using the stories of actual patients.

One was that of "Iphigenia Jones," a twenty-one-year-old woman who was found to have a malignancy in one of her breasts. Then, as now, she had two options: mastectomy (which would mean removing the breast and the lymph nodes of the nearby axilla) or radiation with minimal surgery (removing just the lump and the lymph nodes). Survival rates were equal, although in a spared breast the tumor can recur and ultimately make mastectomy necessary. This surgeon preferred doing mastectomies, and that's what he told her he'd do. In the days leading up to the operation, however, the surgeon developed misgivings about removing the breast of someone that young. So the night before the operation he did an unusual thing: he discussed the treatment options with her and let her choose. She chose the breast-preserving treatment.

Sometime later, both patient and surgeon appeared on a panel discussing treatment options for breast cancer. Their story drew a heated response. Surgeons almost uniformly attacked the idea that patients should be allowed to choose. As one surgeon asked, "If doctors have such trouble deciding which treatment is best, how can patients decide?" But, as Katz wrote, the decision involved not technical but personal issues: Which was more important to Iphigenia—the preservation of her breast or the security of living without a significant chance that the lump would grow back? No doctor was the authority on these matters. Only Iphigenia was. Yet in such situations doctors did step in, often not even asking about a patient's concerns, and make their own decisions—decisions perhaps influenced by money, professional bias (for example, surgeons tend to favor surgery), and personal idiosyncrasy.

Eventually, medical schools came around to Katz's position. By the time I attended, in the early nineties, we were taught to see patients as autonomous decision-makers. "You work for them," I was often reminded. There are still many old-school doctors who try to dic-

tate from on high, but they are finding that patients won't put up with that anymore. Most doctors, taking seriously the idea that patients should control their own fates, lay out the options and the risks involved. A few even refuse to make recommendations, for fear of improperly influencing patients. Patients ask questions, look up information on the Internet, seek second opinions. And they decide.

In practice, however, matters aren't so straightforward. Patients, it turns out, make bad decisions, too. Sometimes, of course, the difference between one option and another isn't especially significant. But when you see your patient making a grave mistake, should you simply do what the patient wants? The current medical orthodoxy says yes. After all, whose body is it, anyway?

LAZAROFF wanted surgery. The oncologist was dubious about the choice, but she called in a neurosurgeon. The neurosurgeon, a trim man in his forties with a stellar reputation and a fondness for bow ties, saw Lazaroff and his son that afternoon. He warned them at length about how terrible the risks were and how limited the potential benefit. Sometimes, he told me later, patients just don't seem to hear the dangers, and in those cases he tends to be especially explicit about them—getting stuck on a ventilator because of poor lung function, having a stroke, dying. But Lazaroff wasn't to be dissuaded. The surgeon put him on the schedule.

"Mr. Lazaroff, I'm a surgical intern, and I'm here to talk to you about your surgery tomorrow," I said. "You're going to be having a thoracic spine corpectomy and fusion." He looked at me blankly. "This means that we will be removing the tumor compressing your spine," I said. His expression did not change. "The hope is that it will keep your paralysis from worsening."

"I'm not paralyzed," he said at last. "The surgery is so I *won't* become paralyzed."

I quickly retreated. "I'm sorry—I meant, keep you from becoming paralyzed." Perhaps this was just semantics—he could still move his left leg some. "I just need you to sign a permission form so you can have the surgery tomorrow."

The "informed-consent form" is a relatively recent development. It lists as

many complications as we doctors can think of—everything from a mild allergic reaction to death—and, in signing it, you indicate that you have accepted these risks. It has the mark of lawyerdom and bureaucracy, and I doubt that patients feel any better informed after reading it. It does, however, provide an occasion to review the risks involved.

The neurosurgeon had already gone over them in detail. So I hit the highlights. “We ask for your signature so we’re sure you understand the risks,” I said. “Although you’re having this done to preserve your abilities, the operation could fail or leave you paralyzed.” I tried to sound firm without being harsh. “You could have a stroke or a heart attack or could even die.” I held the form and a pen out to him.

“No one said I could die from this,” he said, tremulously. “It’s my last hope. Are you saying I’m going to die?”

I froze, not knowing quite what to say. Just then, Lazaroff’s son, whom I’ll call David, arrived, with his wrinkled clothes, scraggly beard, and slight paunch. The father’s mood changed abruptly, and I remembered from notes in the medical chart that David had recently raised the question with him of whether heroic measures were still appropriate. “Don’t you give up on me,” Lazaroff now rasped at his son. “You give me every chance I’ve got.” He snatched the form and the pen from my hand. We stood, chastised and silent, as Lazaroff made a slow, illegible scrawl near the line for his signature.

Outside the room, David told me that he wasn’t sure this was the right move. His mother had spent a long time in intensive care on a ventilator before dying of emphysema, and since then his father had often said that he did not want anything like that to happen to him. But now he was adamant about doing “everything.” David did not dare argue with him.

Lazaroff had his surgery the next day. Once under anesthesia, he was rolled onto his left side. A thoracic surgeon made a long incision, opening into the chest cavity from the front around to the back along the eighth rib, slipped in a rib spreader, cranked it open, and then fixed in place a retractor to hold the deflated lung out of the way. You could see right down into the back of the chest to the spinal column. A fleshy, tennis-

ball-size mass enveloped the tenth vertebra. The neurosurgeon took over and meticulously dissected around and under the tumor. It took a couple of hours, but eventually the tumor was attached only where it invaded the bony vertebral body. He then used a rongeur—a rigid, jawed instrument—to take small, painstaking bites in the vertebral body, like a beaver gnawing slowly through a tree trunk, ultimately removing the vertebra and, with it, the mass. To rebuild the spine, he filled the space left behind with a doughy plug of methacrylate, an acrylic cement, and let it slowly harden in place. He slipped a probe in behind the new artificial vertebra. There was plenty of space. It had taken more than four hours, but the pressure on the spinal cord was gone. The thoracic surgeon closed Lazaroff’s chest, leaving a rubber chest tube jutting out to reinflate his lung, and he was wheeled into intensive care.

The operation was a technical success. Lazaroff’s lungs wouldn’t recover, however, and we struggled to get him off the ventilator. Over the next few days, they gradually became stiff and fibrotic, requiring higher ventilator pressures. We tried to keep him under sedation, but he frequently broke through and woke up wild-eyed and thrashing. David kept a despondent bedside vigil. Successive chest X-rays showed worsening lung damage. Small blood clots lodged in Lazaroff’s lungs, and we put him on a blood thinner to prevent more clots from forming. Then some slow bleeding started—we weren’t sure from where—and we had to give him blood transfusions almost daily. After a week, he began spiking fevers, but we couldn’t find where the infection was. On the ninth day after the operation, the high ventilator pressures blew small holes in his lungs. We had to cut into his chest and insert an extra tube to keep his lungs from collapsing. The effort and expense it took to keep him going were enormous, the results dispiriting. It became

apparent that our efforts were futile. It was exactly the way Lazaroff hadn’t wanted to die—strapped down and sedated, tubes in every natural orifice and in several new ones, and on a ventilator. On the fourteenth day, David told the neurosurgeon that we should stop.

The neurosurgeon came to me with the news. I went to Lazaroff’s I.C.U. room, one of eight bays arrayed in a semicircle around a nursing station, each with a tile floor, a window, and a sliding glass door that closed it off from the noise but not from the eyes of the nurses. A nurse and I slipped in. I checked to make sure that Lazaroff’s morphine drip was turned up high. Taking my place at the bedside, I leaned close to him and, in case he could hear me, told him I was going to take the breathing tube out of his mouth. I snipped the ties securing the tube and deflated the balloon cuff holding it in his trachea. Then I pulled the tube out. He coughed a couple of times, opened his eyes briefly, and then closed them. The nurse suctioned out phlegm from his mouth. I turned the ventilator off, and suddenly the room was quiet except for the sound of his labored, gasping breaths. We watched as he tired out. His breathing slowed down until he took only occasional, agonal breaths, and then he stopped. I put my stethoscope on his chest and listened to his heart fade away. Thirteen minutes after I took him off the ventilator, I told the nurse to record that Joseph Lazaroff had died.

LAZAROFF, I thought, chose badly. Not, however, because he died so violently and appallingly. Good decisions can have bad results (sometimes people must take terrible chances), and bad decisions can have good results (“Better lucky than good,” surgeons like to say). I thought Lazaroff chose badly because his choice ran against his deepest interests—interests not as I or anyone else conceived them but as he conceived them. Above all, it was clear that he wanted to live. He would take any risk—even death—to live. But, as we explained to him, life was not what we had to offer. We could offer only a chance of preserving minimal lower-body function for his brief remaining time—at a cost of severe violence to him and against extreme odds of a miserable death. But he did not hear us: in staving off paralysis, he seemed to believe that



he might stave off death. There are people who will look clear-eyed at such odds and take their chances with surgery. But, knowing how much Lazaroff had dreaded dying the way his wife had, I do not believe he was one of them.

Could it have been a mistake, then, even to have told him about the surgical option? Our contemporary medical credo has made us exquisitely attuned to the requirements of patient autonomy. But there are still times—and they are more frequent than we readily admit—when a doctor has to steer patients to do what's right for themselves.

This is a controversial suggestion. People are rightly suspicious of those claiming to know better than they do what's best for them. But a good physician cannot simply stand aside when patients make bad or self-defeating decisions—decisions that go against their deepest goals.

I remember a case from my first weeks of internship. I was on the general surgical service, and among the patients I was responsible for was a woman in her fifties—I'll call her Mrs. McLaughlin—who had had a big abdominal operation just two days before. An incision ran the entire length of her belly. Fluids and pain medication dripped through an intravenous line into her arm. She was recovering according to schedule, but she wouldn't get out of bed. I explained why it was essential for her to get up and around: it cuts the risk of pneumonia, clot formation in leg veins, and other complications. She wasn't swayed. She was tired, she said, and didn't feel up to it. Did she understand that she was risking serious problems? Yes, she said. Just leave me be.

During rounds that afternoon, the chief resident asked me if the patient had got out of bed. Well, no, I said—she had refused. That's no excuse, the chief said, and she marched me back to Mrs. McLaughlin's room. The chief sat down on the edge of the bed and, as friendly as a country pastor, said, "Hi, how're you doing," made some small talk, took Mrs. McLaughlin by the hand, and then said, "It's time to get out of bed now." And I watched Mrs. McLaughlin get up without a moment's hesitation, shuffle over to a chair, plop herself down, and say, "You know, that wasn't so bad after all."

I had come into residency to learn how to be a surgeon. I had thought that meant simply learning the repertoire of moves and techniques involved in doing an operation or making a diagnosis. In fact, there was also the new and delicate matter of talking patients through their decisions—something that entailed its own repertoire of moves and techniques.

SUPPOSE you're a doctor. You're in an examination room of your clinic—one of those cramped spaces with fluorescent lights, a Matisse poster on the wall, a box of latex gloves on the counter, and a cold, padded patient table as centerpiece—seeing a female patient in her forties. She's a mother of two and a partner in a downtown law firm. Despite the circumstances, and the flimsy paper gown she's in, she manages to maintain her composure. You feel no mass or abnormality in her breasts. She had a mammogram before seeing you, and now you review the radiologist's report, which reads, "There is a faint group of pufctate, clustered calcifications in the upper outer quadrant of the left breast that were not clearly present on the prior examination. Biopsy may be considered to exclude the possibility of malignancy." Translation: Worrisome features have appeared; they could mean breast cancer.

You tell her the news. Given the findings, you say, you think she ought to have a biopsy. She groans, and then stiffens. "Every time I see one of you people, you find something you want biopsied," she says. Three times in the past five years, her annual mammogram has revealed an area of "suspicious" calcifications. Three times a surgeon has taken her to the operating room and removed the tissue in question. And three times, under the pathologist's microscope, it has proved to be benign. "You just don't know when enough is enough," she says. "Whatever these specks are that keep turning up, they've proved to be normal." She pauses, and decides. "I'm not getting another goddam biopsy," she says, and she stands up to get dressed.

Do you let her go? It's not an unreasonable thing to do. She's an adult, after all. And a biopsy is not a small thing. Scattered across her left breast are three raised scars—one almost three inches long. Enough tissue has already been taken out

that the left breast is distinctly smaller than the right one. And, yes, there are doctors who biopsy too much, who take out breast tissue on the most equivocal of findings. Patients are often right to push for explanations and second opinions.

Still, these calcifications are not equivocal findings. They often do indicate cancer. Now, if having control over one's life is to mean anything, people have to be permitted to make their own mistakes. But when the stakes are high, and the bad choice may be irreversible, doctors are reluctant to sit back. This is when they tend to push.

So push. Your patient is getting ready to walk out the door. You could stop her in her tracks and tell her she's making a big mistake. Give her a heavy speech about cancer. Point out the fallacy in supposing that three negative biopsies proves she's different. And in all likelihood you'll lose her. The aim isn't to show her how wrong she is. The aim is to win her over.

Notice what good doctors do. They don't jump right in. They step out for a minute and give her time to get dressed. Then they take her down to the office. It's more congenial there—comfortable chairs, a throw rug, family pictures all around. They sit her down. And, typically, they don't stand or assume the throne behind the big oak desk but pull up a chair and sit close beside her. As one surgical professor told me, when you sit close by, on the same level as your patients, you're no longer the rushed, bossy doctor with no time for them; patients feel less imposed upon and more inclined to think you're both on the same side of the issue.

The curious thing is that the doctors I've observed won't fuss or debate, even at this point. Instead, they have these strange, almost formulaic conversations with the patient, repeating, virtually word for word, what she tells them. "I see your point," they might say. "Every time you come in, we find something to biopsy. The specks keep coming up normal, but we never stop biopsying." Beyond this, these doctors say almost nothing until they're asked to. Oddly enough, nine times out of ten this approach works. People feel as if they've been heard, and have had an opportunity to vent. At this point, they finally begin to ask questions, voice doubts, even work through the logic themselves. And they come around.



A few still resist, and doctors will turn to other tactics. They enlist reinforcements. "Should we call the radiologist and see what he really thinks?" they might ask, or "Your husband's been out in the waiting room. Why don't we ask him to come in?" They might give her time "to think it over," knowing that people commonly waver and come around (though they don't let it go on too long). Sometimes they resort to subtler dynamics. When she says she's sticking to her decision, they might simply fall silent, letting their disappointment show. The seconds become a full minute. Then two. Before a thoughtful, sympathetic, and, yes, crafty physician, few patients will not eventually "choose" what the physician desires.

BUT it's misleading to view all this simply as the art of doctorly manipulation: when you see patients cede authority to the doctor, something else may be going on. The new orthodoxy about patient autonomy has a hard time acknowledging an awkward truth: patients frequently don't want the freedom that we've given them. That is, they're glad to have their autonomy respected, but the exercise of that autonomy means being able to relinquish it.

That's something I came to understand earlier this year. My youngest child, Hunter, was born five weeks early, weighing barely four pounds, and when she was eleven days old she stopped breathing. She had been home a week and doing well. That morning, however, she seemed irritable and fussy, and her nose ran. Thirty minutes after her feeding, her respiration became rapid, and she began making little grunting noises with each breath. Suddenly, Hunter stopped breathing. My wife, panicked, leaped up and shook Hunter awake, and the baby started breathing again. We rushed her to the hospital.

Fifteen minutes later, we were in a large, bright emergency-department examination room. With an oxygen mask on, Hunter didn't quite stabilize—she was still taking over sixty breaths a minute and expending all her energy to do it—but she regained normal oxygen levels in her blood and held her own. The doctors weren't sure what the cause of her troubles was. It could have been a heart defect, a bacterial infection, a virus. They took X-rays, blood, and urine, did an electrocardiogram, and tapped her spinal fluid. They suspected—cor-

rectly, as it turned out—that the problem was a simple respiratory virus that her lungs were too little and immature to handle. But the results from the cultures wouldn't be back for a couple of days. They admitted her to the intensive-care unit. That night, she began to tire out. She had several spells of apnea—periods of up to sixty seconds in which she stopped breathing, her heartbeat slowed, and she became pale and ominously still—but each time she came back, all by herself.

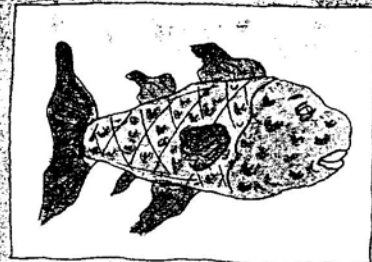
A decision needed to be made. Should she be intubated and put on a ventilator? Or should the doctors wait to see if she could recover without it? There were risks either way. If the team didn't intubate her now, under controlled circumstances, and she "crashed"—maybe the next time she would not wake up from an apneic spell—they would have to perform an emergency intubation, a tricky thing to do in a child so small. Delays could occur, the breathing tube could go down the wrong pipe, the doctors could inadvertently traumatize the airway and cause it to shut down, and then she might suffer brain damage or even die from lack of oxygen. The likelihood of such a disaster was slim but real. I myself had seen it happen. On the other hand, you don't want to put someone on a ventilator if you don't have to. Serious complications, such as pneumonia or the sort of lung blowout that Lazzaroff experienced, happen frequently. And, as people who have been hooked up to one of these contraptions can tell you, the machine shoots air into and out of you with terrifying, uncomfortable force; your mouth becomes sore; your lips crack. Sedation is given, but the drugs bring complications, too.

So who should have made the choice? In many ways, I was the ideal candidate to decide what was best. I was the father, so I cared more than any hospital staffer ever could about which risks were taken. And I was a doctor, so I understood the issues involved. I also knew how often problems like miscommunication, overwork, and plain hubris could lead physicians to make bad choices.

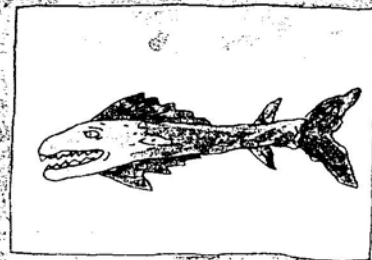
And yet when the team of doctors came to talk to me about whether to intubate Hunter I wanted *them* to decide—doctors I had never met before. The ethicist Jay Katz and others have disparaged this kind of desire as

REVISED NAMES OF VARIOUS FISH

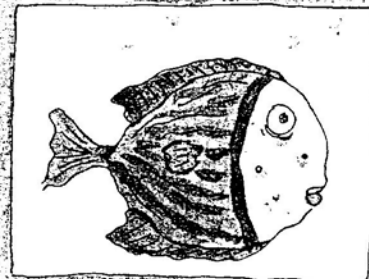
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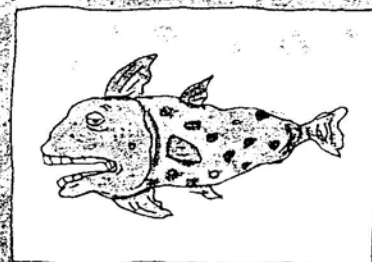
OLD NAME: SHINGLEFISH
NEW NAME: NEPTUNE'S PRIDE



OLD NAME: GREEN SLUDGY
NEW NAME: WAVEMASTER



OLD NAME: SEA CRISTLE
NEW NAME: OCEAN BOY



OLD NAME: GREASYMOUTH BLEB
NEW NAME: FILET DE MER

"childlike regression." But that judgment seems heartless to me. The uncertainties were savage, and I could not bear the possibility of making the wrong call. Even if I made what I was sure was the right choice for her, I could not live with the guilt if something went wrong. People like Katz believe that patients should be pushed to take responsibility for major decisions. But that would have seemed like a kind of harsh paternalism in itself. I needed Hunter's physicians to bear the responsibility: they could live with the consequences, good or bad.

I let the doctors make the call, and they did so on the spot. They would keep Hunter off the ventilator, they told me. And, with that, the bleary-eyed, stethoscope-collared pack shuffled onward to their next patient.

It turns out that patients commonly prefer to have others make their medical decisions. One study found that although sixty-four per cent of the general public thought they'd want to select their own treatment if they developed cancer, only twelve per cent of newly diagnosed cancer patients actually did want to do so.

Still, there was the nagging question: If I wanted the best decision for Hunter, was relinquishing my hard-won autonomy really the right thing to do? Carl Schneider, a professor of law and medicine at the University of Michigan, recently published a book called "The

Practice of Autonomy," in which he sorted through a welter of studies and data on medical decision-making, even undertaking a systematic analysis of patients' memoirs. He found that the ill were often in a poor position to make good choices: they were frequently exhausted, irritable, shattered, or despondent. Often, they were just trying to get through their immediate pain, nausea, and fatigue; they could hardly think about major decisions. This rang true to me. I wasn't even the patient, and all I could do was sit and watch Hunter, worry, or distract myself with busywork. I did not have the concentration or the energy to weigh the treatment options properly.

Schneider found that physicians, being less emotionally engaged, are able to reason through the uncertainties without the distortions of fear and attachment. They work in a scientific culture that disciplines the way they make decisions. They have the benefit of "group rationality"—norms based on scholarly literature and refined practice. And they have the key relevant experience. Even though I am a doctor, I did not have the experience that Hunter's doctors had with her specific condition.

In the end, Hunter managed to stay off the ventilator, although she had a slow and sometimes scary recovery. At one point, less than twenty-four hours after the doctors had transferred her to a regular floor, her condition

deteriorated and they had to rush her back to the I.C.U. She spent ten days in intensive care and two weeks in the hospital. But she went home in fine shape.

JUST as there is an art to being a doctor, there is an art to being a patient. You must choose wisely when to submit and when to assert yourself. Even when patients decide not to decide, they should still question their physicians and insist on explanations. I may have let Hunter's doctors take control, but I pressed them for a clear plan in the event that she should crash. Later, I worried that they were being too slow to feed her—she wasn't given anything to eat for more than a week, and I pestered them with questions as to why. When they took her off the oxygen monitor on her eleventh day in the hospital, I got nervous. What harm was there in keeping it on, I asked. I'm sure I was obstinate, even wrongheaded, at times. You do the best you can, taking the measure of your doctors and nurses and your own situation, trying to be neither too passive nor too pushy for your own good.

But the conundrum remains: If both doctors and patients are fallible, who should decide? We want a rule. And so we've decided that patients should be the ultimate arbiter. But such a hard-and-fast rule seems ill-suited both to a caring relationship between doctor and patient and to the reality of medical care, where a hundred decisions have to be made quickly. A mother is in labor: Should the doctor give hormones to stimulate stronger contractions? Should he or she break the bag of water? Should an epidural anesthetic be given? If so, at what point in labor? Are antibiotics needed? How often should the mother's blood pressure be checked? Should the doctor use forceps? Should the doctor perform an episiotomy? If things don't progress quickly, should the doctor perform a cesarean section? The doctor should not make all these decisions, and neither should the patient. Something must be worked out between them, one on one—a personal *modus operandi*.

Where many ethicists go wrong is in promoting patient autonomy as a kind of ultimate value in medicine rather than recognizing it as one value among others. Schneider found that what patients want most from doctors isn't autonomy *per se*; it's competence and kindness.



"Just don't come crawling back to me when I start becoming visible."

Now, kindness will often involve respecting patients' autonomy, assuring that they have control over vital decisions. But it may also mean taking on burdensome decisions when patients don't want them, or guiding patients in the right direction when they do. Even when patients do want to make their own decisions, there are times when the compassionate thing to do is to press, hard: to steer them to accept an operation or treatment that they fear, or forgo one that they'd pinned their hopes on. Many ethicists find this line of reasoning disturbing, and medicine will continue to struggle with how patients and doctors ought to make decisions. But, as the field grows ever more complex and technological, the real task isn't to banish paternalism; the real task is to preserve kindness.

ONE more case, again from my internship year. The patient—I'll call him Mr. Howe—was in his late thirties, stout, bald, and with a muted, awkward manner. I wanted to turn the sound up when he spoke, and pictured him as someone who worked alone, perhaps as an accountant or a computer programmer. He was in the hospital following an operation for a badly infected gallbladder. Whenever I saw him, he wore the sad look of someone caged and he asked no questions. He could not wait to leave the hospital.

Late Saturday afternoon, maybe three days after his surgery, his nurse paged me. He had spiked a high fever and become short of breath. He didn't look well, she said.

I found him sweating profusely, his face flushed, eyes wide. He was sitting bent forward, propped up on his thick arms, panting. He had an oxygen mask on, and, even with the flow turned up to the maximum, the pulse-oximeter readings showed barely adequate oxygen levels in his blood. His heart was racing at well over a hundred beats a minute, and his blood pressure was much too low.

His wife, a small, thin, pale woman with lank black hair, stood to the side, rocking on her feet and hugging herself. I put on my decisive, confident-surgeon look, examined him, drew blood for tests and cultures, and asked the nurse to give him a bolus of intravenous fluid. Then I went out into the hall and paged S., one of the chief residents, for help.

When she called back, I filled her in on the details. I think he's septic, I said.

Sometimes a bacterial infection gets into the bloodstream and triggers a massive, system-wide response: high fevers and dilation of the body's peripheral blood vessels, causing the skin to flush, the blood pressure to drop, and the heart to speed up. After abdominal surgery, a common cause of this is an infection of the surgical wound. But his incision was not red or hot or tender, and he had no pain in his belly. His lungs, however, had sounded like a washing machine when I listened with my stethoscope. Perhaps a pneumonia had started this disaster.

S. came right over. She was just past thirty, almost six feet tall, with short blond hair, athletic, exhaustingly energetic, and relentlessly can-do. She took one look at Howe and then murmured to the nurse to keep an intubation kit available at the bedside. I had started antibiotics, and the fluids had improved his blood pressure a bit, but he was still on maximal oxygen and working hard to maintain his breathing. She went over to him, put a hand on his shoulder, and asked how he was doing. It took a moment before he managed to reply. "Fine," he said—a silly answer to a silly question, but a conversation starter. She explained the situation: the sepsis, the likely pneumonia, and the probability that he would get worse before he got better. The antibiotics would fix the problem, but not instantly, she said, and he was tiring out quickly. To get him through it, she would need to put him to sleep, intubate him, and place him on a breathing machine.

"No," he gasped and sat straight up. "Don't . . . put me . . . on a . . . machine."

It would not be for long, she said. Maybe a couple of days. We'd give him sedatives so he'd be as comfortable as possible the whole time. And—she wanted to be sure he understood—without the ventilator he would die.

He shook his head. "No . . . machine!"

He was, we believed, making a bad decision—out of fear, maybe incomprehension. With antibiotics and some high-tech support, we had every reason to believe he'd recover fully. Howe had a lot to live for—he was young and otherwise healthy, and he had a wife and a child. Apparently, he thought so, too, for he had cared enough about his well-being to accept the initial operation. If not for the terror of the moment, we

thought, he would have accepted the treatment. Could we be certain we were right? No, but if we *were* right could we really just let him die?

S. looked over at Howe's wife, who was stricken with fear and, in an effort to enlist her in the cause, asked what she thought her husband should do. She burst into tears. "I don't know, I don't know," she cried. "Can't you save him?" She couldn't take it anymore, and left the room. For the next few minutes, S. kept



trying to persuade Howe. When it was clear that she was making no headway, she left to phone his attending surgeon at home, and then returned to the bedside. Soon

Howe did tire out. He leaned back in his bed, pale, sweaty strands of hair sticking to his pate, oxygen levels dropping on the monitor. He closed his eyes, and he gradually fell into unconsciousness.

That was when S. went into action. She lowered the head of Howe's bed until he lay flat. She had a nurse draw up a tranquilizing agent and administer it in his I.V. She pressed a bag mask to his face and squeezed breaths of oxygen down into his lungs. Then I handed her the intubation equipment, and she slipped a long, clear plastic breathing tube down into his trachea on the first try. We wheeled Howe in his bed to the elevator and took him down a few floors to the intensive-care unit.

Later, I found his wife and explained that he was now on a ventilator in the I.C.U. She said nothing and went to see him.

Over the next twenty-four hours, his lungs improved markedly. We lightened up on the sedation and let him take over breathing from the machine. He woke up and opened his eyes, the breathing tube sticking out of his mouth. He did not struggle.

"I'm going to take this tube out of your mouth now, O.K.?" I said. He nodded. I cut the ties and deflated the balloon cuff holding the tube in place. Then I pulled it out, and he coughed violently a few times. "You had a pneumonia," I told him, "but you're doing just fine now."

I stood there, silent and anxious for a moment, waiting to see what he would say. He swallowed hard, wincing from the soreness. Then he looked at me, and, in a hoarse but steady voice, he said, "Thank you." ♦