On the Other Hand...

Laura Stephenson Carter • • • Photographs by Jon Gilbert Fox

Resolving the ethical dilemmas presented by modern medicine is not for the faint of heart. As technology introduces ever more perplexing questions, medical ethics committees have stepped in to help caregivers, patients, and families chart the right course. Here’s an inside look at DHMC’s ethics committee, one of the nation’s oldest.

Text by Laura Stephenson Carter • • • Photographs by Jon Gilbert Fox

Laura Carter is the associate editor of Dartmouth Medicine magazine. After completing the reporting and writing for this feature, she made sure that her own advance directive was on file at DHMC. All of the ethical scenarios here in italic type are based on actual cases that have come before the DHMC Ethics Committee. Just the names and some identifying details have been changed in order to preserve patient confidentiality.

The excruciating headache was what tipped off the doctors that her lung problems had a neurological origin. The tumor was inoperable, the doctor explained gently. “We don’t expect her to wake up,” I recall him saying.

Not wake up? Inoperable? Wasn’t there something that could be done? The doctor shook his head sadly. “There’s nothing we can do,” he repeated.

Stunned, we filed back into her room. I don’t remember how long we stayed there, but at some point we said our goodbyes—to my mother, as well as to each other before we dispersed back across the country. My mother lived for 10 days on the ventilator. Then my father called each of us to say that she had been removed from life support and was gone. Her funeral was a few days later.

I began working on this article, and hearing stories about other deaths fraught with complex choices, I thought back to my own family’s experience. My father had made the difficult decision to take my mother off life support. I asked him recently what guidance the medical staff had offered during that trying time. Not much, he said. I can only imagine how lonely and scared he must have felt. Back then, decisions to limit medical treatment were often challenged in court. His lawyer had warned him to be careful. But my father was stoic, and my siblings and I trusted him to do what he thought was best—to make the decision that was right for our mother.

A year earlier, my mother had had a bout of pneumonia that had seemed to linger. Her lungs had never fully cleared, and she had, reluctantly, started seeing doctors again. But they had been stumped, so my mother had resigned herself to the annoyance of chronic lung congestion. It was nothing compared to her years of suffering from the crippling pain of arthritis and from the side effects of treating it—such as the stomach ulcers caused by the thousands of aspirins she swallowed. She had had headaches in the past, too, but none as bad as the one that had landed her in the hospital.

From our huddle around my mother’s bed, a neurologist ushered us into a small conference room. He explained that she had a tumor in her brain stem—the part of the brain that controls blood pressure, heartbeat, and breathing. It was the tumor that had wreaked havoc with her respiratory function, causing fluid to collect in her lungs.

Gradually, we learned what had happened. My mother—who was notorious for avoiding doctors after years of unsuccessful treatments for debilitating rheumatoid arthritis—had collapsed at home with a paralyzing headache. Terrified, she’d asked my youngest brother, who was living with my parents at the time, to call an ambulance. At some point she lost consciousness. My father rushed home from a business trip in North Dakota, and the rest of my siblings and I flew in from all corners of the country.

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I'm sure that at some point my mother had made it clear to my father that she would never want to live out her days “as a vegetable,” the way Quintanilla describes.

Since then, laws have been passed that allow end-of-life treatment decisions to be made by patients (when they’re able to play a role) and their physicians and families, without resorting to the courts. But what if the parties don’t agree? Who decides what happens in that case?

Today, at most hospitals, an “ethics consult” can be requested to objectively resolve such questions. Many concern end-of-life issues.

Dartmouth-Hitchcock Medical Center has one of the oldest hospital ethics committees in the United States. It was created in 1983 and since 1994 has been led by James Bernat, M.D., a neurologist and an internationally recognized ethicist. The 26-member committee includes physicians, nurses, social workers, administrators, a chaplain, a lawyer, and a medical student, as well as a public member—someone with no connection to Dartmouth or to medicine.

The DBMC committee not only consults on cases in which the appropriate course of treatment isn’t clear, but also educates DHMC caregivers about bioethics, develops ethics policies, coordinates the New Hampshire-Vermont Ethics Network, collaborates with Dartmouth’s Committee for the Protection of Human Subjects, and occasionally lobbies on ethics-related legislation. But it’s the ethics consult subcommittee—or “ethics SWAT team,” as some members of the group call it—that grapples directly with ethical dilemmas.

Herman, a man in his eighties, is admitted to the hospital with a twisted colon. He’s incontinent, is unable to speak, and is agitated. The attending physician is concerned that the chief complication is bowel obstruction, which he tells his father in detail about his health status and explains that the only way to relieve the obstruction is to perform a colostomy. He's worried that by refusing treatment, his father would be committing suicide and dying from an underlying bowel obstruction was not an act of suicide. One thing we really don't want is people participating in these decisions walking away feeling that they made a decision to kill a person,” says Palc. “We take a great deal of pains to [emphasize] that this is nature taking its course and that we are trying to follow the wishes of the patient . . . the patient’s own values with respect to life-sustaining treatment.” Eventually everyone agreed in the case of Herman, Palc adds. “The treatment goal shifted from fixing the obstruction to allowing him to live comfortably in the time he had left.”

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One of the things that complicates end-of-life decision-making is the lack of advance directives. That’s the official term for two documents—a living will, in which patients indicate their wishes about the type of medical care they wish to receive if they become terminally ill (or permanently unconscious, in New Hampshire and some other states), and a durable power of attorney for health care, which designates someone to make medical decisions on a patient’s behalf if the patient is unable to do so. Only about 20% of U.S. adults have signed advance directives.

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The daughter felt that it was unlikely her father would do well after surgery and that he probably wouldn’t even understand what was happening to him. But it was “clear that the [son] was the decision-maker,” says Palc. It turned out he was worried that by refusing treatment, his father would be committing passive suicide and dying from an underlying bowel obstruction was not an act of suicide. “One thing we really don't want is people participating in these decisions walking away feeling that they made a decision to kill a person,” says Palc. “We take a great deal of pains to [emphasize] that this is nature taking its course and that we are trying to follow the wishes of the patient . . . the patient’s own values with respect to life-sustaining treatment.” Eventually everyone agreed in the case of Herman, Palc adds. “The treatment goal shifted from fixing the obstruction to allowing him to live comfortably in the time he had left.”

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By 1987, 60% of U.S. hospitals had an institutional ethics committee. They often will rethink their initial decisions. “One role the committee can play is being an objective outsider” in helping patients, families, and physicians make decisions, says Margaret Plunkett, M.S.N., a clinical nurse specialist in psychiatry and a member of the Ethics Committee. The committee encourages physicians to have “clear and direct conversations about . . . specific goals of care that make sense . . . [and] what kinds of treatments really match that goal of care.”

A lot of the cases that we deal with in the Ethics Committee that involve end of life could be eliminated—we wouldn’t have to have an ethics consult—if the patient had an advance directive,” explains Elizabeth Stanton, a lawyer in DBMC’s Risk Management Department and another longtime member of the institution’s Ethics Committee. “I think the plan, with Ethics Committee support, is to elevate advance directives to the status of flu shots, smoking cessation, and similar health-care initiatives.”

But some of the cases that come before the ethics teams involve patients who do have an advance directive indicating that in the event of a terminal illness they don’t want to be kept alive by artificial means. Yet doctors may be torn between honoring the directive and continuing to deliver aggressive treatment. Or family members may not have accepted the situation’s finality. An ethics consult can help everyone reach agreement on what the patient would have wanted.

“Technical advances are coming in floods now instead of just waves,” explains Kate Clay. Along with new technology has come a flood of new technical terms that patients and their families often don’t understand. It’s difficult enough to make treatment decisions when the facts are clear, but today’s plethora of arcane terms adds to the confusion. Without thinking, medical professionals toss around terms like “CPR,” “DNR,” “DNI,” and “intubate” or “extubate.”

“A lot of people have these conversations in a very rushed way,” admits medical student Emily Rubin, who recently joined the Ethics Committee. “Intubation” refers to the insertion of a tube down the patient’s trachea; the other end of the tube is connected to a ventilator that breathes for the patient. “Advance directives” to the status of flu shots, smoking cessation, and similar health-care initiatives.”

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With support from members of the ethics consult team, the father was eventually able to recognize that the treatment he was asking for would not promote his son’s comfort and that the staff truly had Jerry’s best interests at heart. When the boy was finally told the full extent of his illness, he wasn’t surprised. Instead, he had been worried about how his parents were doing and had been trying to protect them.

“Sometimes an ethics consult can break this logjam where people are stuck,” says Plunkett. The ethics consultants are careful, however, not to overwhelm patients and families with too many new faces and will sometimes spend most of their time meeting with the care team, coaching them on how to communicate effectively with patients and their families.

Ill ethics consults are also discussed by the entire committee, usually once the issue has been resolved. A few days after its resolution, Jerry’s case was presented at a meeting of the full Ethics Committee. Such discussions are viewed as educational, and committee members are encouraged to ask questions and express their own views, even though the question may be moot by then.

“Do parents have the right to tell doctors not to talk to their children about their medical care?” Bernat asked during this particular meeting. A lively exchange of views ensued.

“Is there some guidance on this?” asked another member.

There is, Bernat explained. In 1995, the American Academy of Pediatrics’ Committee on Ethics published a statement asserting the right of older children and teenagers to be involved in the medical consent process regarding their own care.

Neonatologist William Edwards, M.D., heads the infant-care arm of the Ethics Committee. Recently, he sought the full committee’s input about the breast-feeding dilemma his team had faced with Sharon. She wanted to breast-feed her baby, but he explained that the DHMC practice is to strongly encourage new mothers to breast-feed. But since it was likely that Sharon would continue to use marijuana, she should still be encouraged to breast-feed. On the other hand, Edwards pointed out, breast milk is superior to formula. But on the other hand, could it offer more harm than benefit in this case?

Edwards added that he felt Sharon wanted to do what was best for her baby. “When she’s stressed,” he said, “it’s hard for her not to smoke marijuana. Should we ever be complicit in recommending something that puts the baby at harm of illegal drugs?” He noted that the evidence is unclear regarding the effects on a baby of marijuana in breast milk, though some studies have suggested that it makes babies irritable. He also mentioned, in relation to the baby’s premature arrival, that other studies have shown an association between marijuana use and low birth weight.

“It might be good to encourage her to quit,” suggested a member of the committee. But another member worried that Sharon could be alienated from the health-care system if her caregivers were too heavy-handed about her marijuana use.

“When this mom takes her baby home, what do you have control over?” asked someone else.

“Nothing,” Edwards answered. “You can’t really evaluate if other risks are being evaluated.” The committee was full of questions for Edwards.

She might be arrested, he responded, clearly concerned. “Or she might get stoned and crash her car.”

A neonatal nurse who had accompanied Edwards to the meeting spoke up, explaining that “there’s a lot of emotions among the nursing staff if they are compelled to go along with something they’re not comfortable with.”

“Tell the mother we don’t know the harms of marijuana, but that she shouldn’t smoke it,” suggested a committee member.

“Do I send her on a path to breast-feed or not?” persisted Edwards, trying to pull the discussion back to the question of most concern to the neonatologists.

Several members noted that it was difficult to justify advocating against something with solid evidence of harm. “If you knew the mother was going to drink [alcohol] during breast-feeding, would you still set her on a road to breast-feeding?” asked a committee member.

“Yes,” Edwards admitted.

“It seems the illegality is what concerns you,” put in Bernat.

“So what did you tell her?” someone finally asked.

“We recommended she not smoke marijuana,” Edwards said, and we recommended she breast-feed.”

A few weeks later, Edwards reflects on that committee meeting. It does not surprise him that there was no clear opinion from the committee. “Almost by definition,” he says, “an ethical dilemma is a situation where there is not a clear answer.”

“That’s the nature of the beast,” agrees Bernat. “Our goal is to provide a forum for discussion, [to] help people understand the issues. We don’t have decision-making authority.”

What did surprise Edwards, however, was that “there was very little concern about the illicit drug use,” he says. “They were quite happy to go with breast-feeding and its known benefits [despite the mother]’s continued participation in an illegal activity with undefined but probably low risk medically.”

T he committee deals with many other kinds of cases, all of them heartrending for everyone involved. “There’s never an ethics consult that isn’t upsetting,” says one committee member. The cases can be tough, painful, overwhelming, emotionally charged, and even nightmarish at times. Here are a few more examples:

Betty, now in her seventies, has suffered from bipolar illness since she was a young adult. Many years ago, she had signed what’s known as a Ubyssey contract—named for the Roman hero who instructed his crew to bind him to the mast of his ship and not release him, even if he begged to be set free, while the ship sailed past the Sirens, whose beautiful singing lured sailors to their death on the rocks (his crew, meanwhile, plucked their ears with forceps to keep from hearing the enchanting song). Someone with a mental illness that occurs in predictable phases may sign such a contract during a healthy phase; it authorizes doctors to deliver the treatments they think best and gives them permission to disregard what the patient says when the
A ethics consultant helped everyone understand that continuing aggressive treatment no longer made any sense. Betty was placed in hospice care and died peacefully.

David, a 35-year-old man, died in a car accident. His wife wants to use his sperm harvested so she can use it to have a child. That would require nearly immediate harvesting, before the sperm lose viability, but it’s unclear what David’s wishes were.

The ethics consultants authorized the harvesting to preserve the option of using the sperm and then they deliberated. They ultimately decided that since David had never expressed his wishes in writing, his wife did not have a right to use his sperm. Since then, the committee has helped the ob-gyn department craft a policy that addresses such issues ahead of time.

Caroline, a 67-year-old woman, is dying of cancer. Her caregivers have recommended stopping aggressive treatment and providing only comfort care. Caroline had signed both a durable power of attorney for health care and a power of attorney for financial matters, naming her husband as her proxy in both. Her husband understands her status but would like to have her kept alive a few more days so she can finish some financial transactions.

The ethics team ended up advising Caroline’s husband that it wasn’t in her best interest to be kept alive for such a purpose. Her husband agreed, and aggressive treatment was discontinued.

Simon, an 85-year-old man, has had a major stroke and is unconscious. He has “DNR” tattooed on his chest. His caregivers aren’t sure whether that serves as an adequate reflection of his wishes.

The ethics team, too, felt it was unclear, in case Simon had changed his mind since getting the tattoo. So, because Simon had a durable power of attorney for health care and a power of attorneys for financial matters, naming her husband as his proxy in both. Her husband understands her status but would like to have her kept alive a few more days so she can finish some financial transactions.

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Lynn Peterson, M.D., a retired surgeon who is a member of DHMC’s Ethics Committee, admits that he was once skeptical of the value of ethics committees. “It’s very hard, I think, for a patient or a family to directly disagree with a doctor who’s going to take care of them,” says Peterson, who headed Harvard Medical School’s Division of Medical Ethics from 1989 to 1997 and the Ethics Service at Harvard’s Brigham and Women’s Hospital from 1997 to 2004.

But a third party like an ethics consult team, Peterson came to realize, can let “the family express their concerns and their point of view without having to necessarily directly confront the caregivers.”

Although ethics consults have helped many people, the team isn’t called in as often as it might be. Part of the problem is that some caregivers and many families aren’t aware of its existence.

Another problem is that some health-care providers are so focused on curing illness and fixing injury, at any cost, that they can’t face offering less than the most aggressive treatment. “Doctors have been trained to save life,” says Rosemary Evans, the public member of the Ethics Committee. “It’s . . . very hard for them to let go.”

Critical-care nurse Sarah Stableford agrees. “As a society,” she says, “we’re very comfortable bringing [people] into the world, and very uncomfortable letting them leave the world. Prolonging life is a great thing to do. Prolonging death is unconscionable, [yet] we do an awful lot of prolonging death.”

A further problem is that some families resist the idea of a meeting with a group of medical professionals. “So many times, I think, people go to an ethics committee consultation thinking of the ethics committee as some kind of a tribunal,” says the Reverend Patrick McCoy, a chaplain at DHMC and a member of the ethics consult team. “It’s really a chance to problem-solve and to resolve conflict.

“I think the leaders of [the consult team] are really very good at acknowledging the emotional charge that’s there,” McCoy continues, at “trying to help the whole story unfold . . . the medical story of what the illness is, what the treatment process has been like, what the options are, what the consequences of the options are . . . so that all of the different layers can be teased out and the family can be helped to articulate what the patient’s wishes would be for decisions if the patient could participate.”

Despite the committee’s success at resolving thorny ethics problems, the number of formal consults has decreased over the years—partly because palliative care is beginning to fill the role that ethics consults used to. Palliative care often involves an ethics-oriented discussion, says Palac, to help patients decide whether to refuse or accept further medical intervention. And more and more patients are seeking assistance from the Center for Shared Decision Making, and so coming to decisions without requiring an ethics consult.

While the Ethics Committee continues its work, there’s one problem it has not yet addressed—what Bernat calls the “collision between the financial and the ethical.” Others share his concern that limited resources for health-care services could one day play a role in decision-making.

“In the best of all possible worlds,” says Bernat, “if money weren’t an issue, you could identify an ethical course of action” without thinking about cost. “But the costs are crashing down on us,” he continues. “In the future, we are not going to have the luxury that we’ve had in the past, which is to not pay that much attention to how much things cost. . . . The way we operate is going to have to take [cost] into account.”

“There’s just no way we’re going to be able to keep on doing what we’re doing,” agrees Paul Manganiello, M.D., an ob-gyn who’s been on the Ethics Committee since its inception in the 1980s. Part of what’s driven the escalation of medical services, he feels, is that “people just have too much faith in technology.”

Bernat and his colleagues recognize some other issues that need to be addressed, too, such as the ethical implications of a dysfunctional health-care system and of millions of uninsured patients. But those may be problems too big for an individual hospital ethics committee to tackle.

So for now, the DHMC Ethics Committee will continue to help caregivers, patients, and families grapple with ethical dilemmas—one case at a time.