Telling Life's

STORY BY
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MEDICAL STUDENTS LEARN THE IMPORTANCE OF LISTENING TO PATIENTS' STORIES AS WELL AS THEIR HEARTBEATS.

SOME RECENT MEDICAL ADVANCES ARE almost beyond imagining. Doctors routinely perform heart surgeries on premature babies barely bigger than a human hand. Marvelous electronic machines probe deep into human tissue with magnetic pulses to search out the tiniest tumors. Scientists are cracking the genetic code to build lifesaving drugs that harness our bodies' own healing power.

But in many ways, medicine is still humbled by death and disease. There never will be an easy way for a physician to tell a patient that nothing will stop the cancer in his organs. Or to explain to relatives that a family member's life will soon end. Or for a doctor to ponder in her own mind how much more pain an accident victim should bear before treatment is withdrawn.

Decisions like those can be the most difficult because there are no hard-and-fast answers, no textbook solutions. They're the sort of enduring dilemmas that sometimes make the practice of medicine an unfathomable riddle.

That's because treating a medical ailment isn't always as simple as unplugging a clogged artery or zapping a disease-causing bug with antibiotics. There's a dimension of medicine that goes beyond microbes and molecules. Knowing how a person's life story interacts with his disease can be a diagnostic tool just as important as a blood pressure reading or a white cell count.

"Medicine uses all kinds of scientific conclusions," says Bill Bondeson, Curators' Professor of philosophy, "but it applies them to the complexities and lives of particular patients. That's why medicine is an art, not a science."

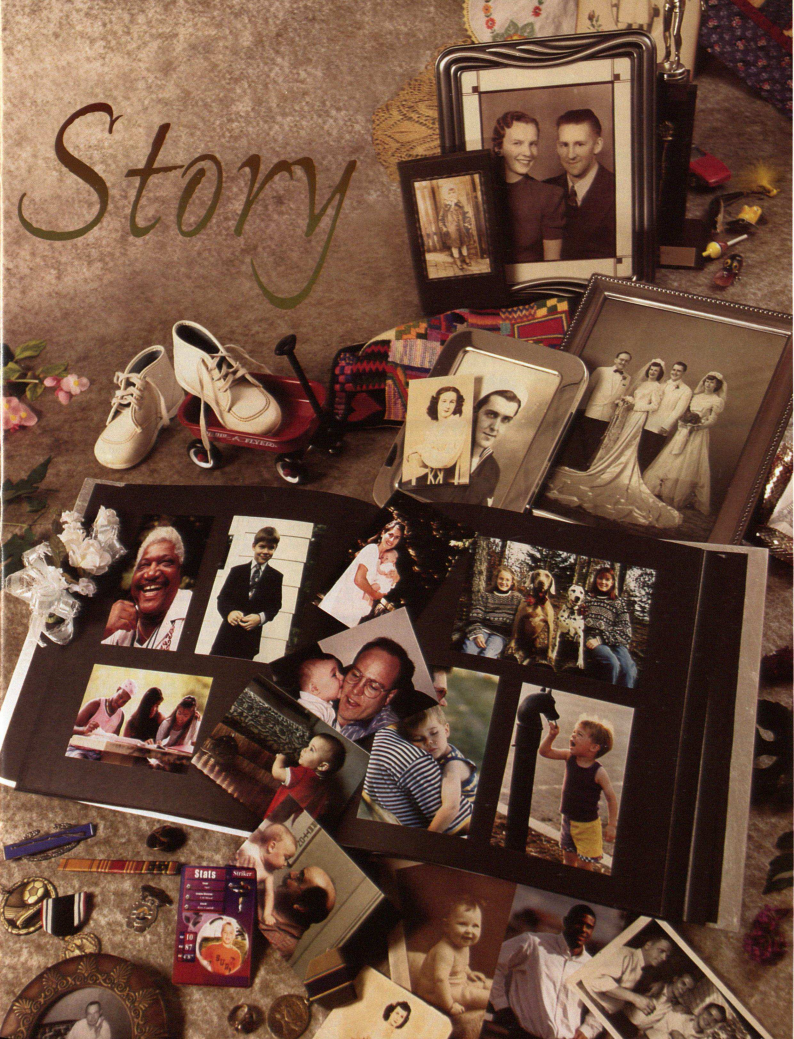
For more than 20 years, Bondeson has taught a course in medical ethics to future physicians at MU's School of Medicine. Philosophy is a discipline of logic, but it also can be a tool—perhaps not to answer, but to unravel moral questions.

Bondeson teaches medical students that life is a narrative and a series of promises to other people. To take on a role as a physician or teacher also means taking on certain responsibilities. To understand their patients, he explains, they must understand the story of their lives and how disease fits into that story. And to treat their patients with dignity and sensitivity, doctors must understand that story. Disease means different things to different people.

Bondeson gives his medical students this advice: Try to understand the meaning of an illness or a problem in the life of this patient. "It didn't occur on its own. It didn't occur in the abstract. It occurred in the context of a life story."

One person might view his disease as a logical consequence of a lifetime of heavy smoking or drinking. Another might view his body as a machine, with rusting cogwheels gradually wearing out. Still another might see pain and disease as an obstacle that God is using to test his faith.

"There's not a single answer to any particular problem for any patient," Bondeson says. "Folks refuse treatment sometimes, or they modify it, and sometimes they just plain don't do what they're supposed to do." Usually there's a reason, a kind of story behind it. "So if you're going to treat them with respect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and with the dignity they deserve, then I think you have to find out what that story is. And of course you have to find out what, for any given patient, amounts to being healed. Again, that's not the same answer for everybody. How you treat somebody depends on how they look at those questions."

It's especially important, Bondeson says, when people are deciding how to bring their lives to an end, a time when they put together the pieces of their past and try to write the final chapter of that story. He uses his own beliefs as an example:

"If I were to become terminally ill, and if I were in unrelievable pain and suffering. If I felt that my promises and commitments to other people were coming to an end. If I had the permission of those who are close to me and who'd be taking care of me. Given all that—and that's a very complicated set of conditions—I would be in favor of asking someone to help me bring my life to an end.

"Just because I'm terminally ill doesn't mean I ought to do it. And I shouldn't do it without a lot of thought, but when my story has come to an end, when my promises have been made and kept, then I think I can say it's time for me to bring all this to a halt.

"But if someone really believes religiously that their pain and suffering is there as some kind of test, or some hurdle to jump over, and they want to keep on going, it's very hard to say no to that kind of request.

"I do believe people think of their lives as having beginnings, middles and ends—not unlike a play in three acts, and there is a final act," Bondeson says. "I think that when your story is done, when your commitments and your connections to other folks are on the decline or slowly vanishing, then I think it's time to think about withholding treatment or withdrawing it. But that's a patient's decision; it shouldn't be anybody else's."

However, there are other stages—or acts—in a person's life than the final curtain call, where understanding the life story is important, Bondeson says. "Anytime you have a medical procedure or a surgery done, it's fair to ask, 'How will I be different if this is done? How much of what I've lost because of a disease do I want to get back? How much of the help a physician offers me really fits into my own life story?' "

An active and athletic person who delights in playing a set of tennis or a round of golf might be likely to opt for the temporary discomfort and long rehabilitation of hip replacement surgery. Conversely, someone whose life story has focused on playing it safe and taking it easy might be less willing to take that step.

Sometimes, another person makes that choice for the patient—a parent or another family member. Parents might refuse medical treatment for their child because of religious convictions, for instance.

"Some people may not want to get completely cured," Bondeson says. "So at any age, even the choice of treatments fits into a life story."

And sometimes, a physician's role can be to help patients understand their own life stories—to help them see their lives as a journey.

In her many years as a pediatrician at the University, Eleanor Shaheen Braddock has helped patients and their families cope with illness and death. After she retired, Braddock, MS '78, continued that role in a new way. Guided by her strong religious faith, she embarked on a rigorous clinical pastoral education program to become a hospital chaplain. "It is an extension of what I was doing, but now I am looking at spiritual issues." As a chaplain, Braddock now works with patients in mid-Missouri hospitals. She often is involved in those end-of-life decisions.

Her new role can be every bit as impor-

tant as the life-nurturing skills she practiced as a physician, Braddock says. "When you're told you have cancer, when you're told you no longer can walk, that's the biological impact, but it doesn't take care of the psychological, spiritual or social impacts to a patient."

One of the things chaplains do is listen to life stories of patients they visit, Braddock says. "Our bottom line is to learn who they are as persons. Listening to people's stories helps validate them and affirm them. Some of the patients I visit are depressed, thinking they haven't accomplished much in their lives. Some feel that they have unfinished business. By telling their stories, these patients can reflect on their lives, what their hopes and dreams were in other years."

As both a physician and a chaplain, Braddock has been involved in many gatherings when family and friends come to say a last farewell. She assures them that tears are all right. Sometimes they'll sing songs—hymns from the past. And sometimes, she says, that last visit can be a way to let a dying family member know that he doesn't have to fight so hard, that he has permission to let go, and that the family will be OK.

"Life is a journey. We come from the womb, from these genes. I think it's an exciting journey, and I think sometimes we waste a lot of the journey by not recognizing our self-worth, by not seeing the dignity of another person and pulling worth from it. We need to make our journey hopeful.

"In encouraging them to tell their story, you give them respect, you give them dignity. When you tell your story you realize that somebody worthwhile existed in this body."

Coming to terms with one's own life story sometimes can help a person make tough decisions about medical treatment. Bondeson works with physicians, patients and their families to sort out some of the most difficult issues that people can face.

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He remembers one case in which a desperately ill patient had given his daughter a durable power of attorney—the authority to make medical decisions for him if he wasn't able to. Other family members objected to the daughter's sole authority for life-and-death decisions.

Although well intentioned, the family's objections ran counter to the father's expressed wishes, Bondeson says. "He wanted his daughter to make this decision. That's what we had right there on the chart in front of us. He wanted to end his life under her control, and we better respect that kind of request.

"What we try to help the family figure out—if you can't talk to the patients themselves—is 'What do you think grandma or grandpa would want? What basic information could we get that would help us figure out what she or he would like to have done?' Because you want to respect patients' wishes, they have a right to decide what happens to themselves. I think we all have a right to say what counts as our story."

Physicians face the same sort of perplexing questions. At what point may a doctor unplug the ventilator that could keep a comatose—but brain-dead—patient breathing? "There are ways to keep people going forever and ever, and we're getting better at it daily," Bondeson says. Those wonderful medicines and technologies can have downsides.

"People often say that if we make decisions to take patients off life support, or if we put them on, then we're 'playing God.' Well, playing God is the most empty concept in all of medicine. Most days I don't have a clue as to what it means, though people trot it out all the time.

"Some people will say, 'Well if we keep a patient going, that's playing God.' All right, maybe it is. And if we take them off the support, that's playing God. It sounds like any time you're making a decision about yourself, you're playing God. And at that point the concept becomes empty; you really haven't said anything.

"In a certain sense, we may not create our stories, but surely by our choices we make that story unfold in one way or another. By our personal choices, by our professional choices, we write that story for ourselves."

Bondeson points to the growing number of people who are writing living wills—legal documents that detail the limits of medical care that person would like to receive if he or she is incapacitated. "The reason why I think people want to sign living wills is that they want more and more to be their own author of the final chapter in their story. Often what they worry about is somebody else writing that final chapter for them, and they don't want that to happen.

"People want to control what those last days or months are like; they don't want to spend their last six weeks on the planet as a prisoner of medical technology. If that isn't deciding the final chapter of your life and the final chapter of that story, I don't know what is." ❋