



Opposite: Bridget, Jarrett and Wade Knyal welcome Nada Elbuluk and Matthew Meunier into their home.

Into the Home, Into the Heart

BY JAMES TOBIN • PHOTOS BY MARTIN VLOET

The Family Centered Experience fashions students' empathy and compassion into a powerful tool for healing

In the fall of 2004, identical copies of a letter from the U-M Medical School arrived in the mailboxes of two first-year students, Nada Elbuluk and Matthew Meunier. The letter said that as part of their curriculum, all first- and second-year students would work in pairs in a program called the Family Centered Experience (FCE). Each student team was assigned to learn all they could about a perfect stranger with a chronic disease. Elbuluk and Meunier were assigned to work with a volunteer named Jarrett Knyal, whose diagnosis, the letter said, was paraplegia and colon cancer. That was understating it, as the students would learn.

The student pair met Jarrett Knyal (pronounced *nile*) a few weeks later, when they rang the doorbell at his ranch house in northwest Ann Arbor. Through the front window, the two students could see a fair-haired man of young middle age, stretched out full-length on his stomach on an improvised platform — half table, half bed — in the living room. He was waving at them to come inside. They stepped through the door, and an extraordinary relationship began.

The traditional medical school curriculum teaches students to think and speak in what medical sociologists call the language of disease, which views malfunctions of the human body through the eyes of the physician. The language of disease is indispensable to healing. But in the medical subculture, it tends to drown out its counterpart, the language of illness, which interprets disease through the eyes of the patient. Disease is the metastasizing cell, the inflamed spinal cord, the atrial flutter, comprehensible only to the expert. Illness is the patient's pain and suffering, the disruption of work and home life, the disability and fear, and the ripples that flow through a family's financial and emotional resources. It's no secret that many doctors know everything there is to know about disease without paying much attention to illness. Traditionally, medical schools have had the same problem.

The Family Centered Experience, the leading program of its kind in the United States, aims to make this distinction clear to every Michigan medical student. The FCE reinforces that a doctor who understands the difference will do far more good than one who doesn't.

The program was conceived by Casey White, Ph.D., assistant dean for medical education, and founded by White, along with Arno Kumagai, M.D., who is now director of the program and associate professor of internal medicine, and Rachel Perlman, M.D., who is associate director of the FCE and assistant professor of internal medicine. Starting in fall 2003, new students began to meet several times in each of their first two years with a chronically ill patient and his or her family. The students were assigned to ask about the personal experience of illness; the effects on the family; their cultural and spiritual backgrounds; and their experiences as health care consumers. Back on campus, the students met regularly in small groups to discuss their experiences. They wrote about them, too, even created artistic works

about them — paintings, poetry, multimedia presentations.

In many cases, students and volunteers have found themselves moving deep into personal terrain, discussing aspects of illness that are seldom aired in the everyday business of dispensing health care. These discussions are then related in class, and students thereby teach each other lessons, Arno Kumagai says, that may last throughout their careers.

"Stories have enormous power to impart meaning," he says. "Sometimes they enter our souls. They may stay dormant, but then suddenly you hear something and it resonates within you. I think these stories are planting seeds of empathy, so that when the students are in a similar situation, the stories they've heard in these groups will trigger something in them, and they'll say, 'Wait a second. We need to cut through all this other stuff and look at the person behind what's going on.' That's our hope."

At that first meeting, Jarrett Knyal introduced Nada Elbuluk and Matthew Meunier to his wife, Bridget Weise Knyal, and their son, Wade, who was barely a toddler. Bridget served dinner, and the Knyals told the two students their story.

Jarrett, a native of Illinois, explained that he had been paralyzed when he was in college in Chicago. Standing on the roof of a house, he had accidentally touched a live electrical wire with a length of wood. His left hand was badly burned. He fell to the ground and broke his back. The hand was amputated, and he was paralyzed from the chest down.

His recovery was exemplary, though he remained a wheelchair user. After rehabilitation, he returned to college, switching his major from graphic design to computer graphics, then took a job at Northwestern University, where he met Bridget several years later. They married in 1999 and moved in 2000 to Michigan, where Jarrett took a job as an



Arno Kumagai and Casey White

art director with an internet consulting firm. Their son was born in 2003.

But one door had been closed. At age 30, Jarrett had taken the MCATs and applied to medical school. He wanted to work in physical medicine and rehabilitation, where his own experience as a paraplegic would undoubtedly give him special insight into patients' lives. But he was up against an idea that played a factor in admissions — the belief that every physician needed two good hands. Jarrett ultimately was not accepted to medical school, but he chalked it up to experience and moved on. He went to work, enjoyed his hobbies, mentored other paraplegics and looked forward to having children.

Trouble came late in 2003. Jarrett began to have difficulty defecating and discovered a small pressure sore, also called a decubitus ulcer, on one of his buttocks. These are not uncommon among paraplegics. Unless one remembers to make slight shifts in seating —

an unconscious habit in the paralyzed — the continuous pressure of weight on a point of flesh can cut off the blood supply and kill the tissue. The sores can grow out of control, and dangerous infections can ensue. The paralyzed actor Christopher Reeve and others have died from complications of decubitus ulcers.

Still, Jarrett's sore seemed minor, as did his bowel problem, also a common complaint among paraplegics. His doctor suggested a colonoscopy, but Jarrett put it off. It never occurred to him that the problem could be cancer. It was. A week after his postponed colonoscopy, in early 2004, Jarrett had a tumor removed from his colon and began chemotherapy one month later.

An agonizing dilemma developed. Chemotherapy was supposed to kill the rapidly developing new cells that might appear in any new tumor. But Jarrett began to suspect that the chemotherapy was also retarding the development of new cells where he desperately needed them — in the healing of his decubitus ulcer, which had grown from the size of a pea to the size of an orange. This gaping wound was now making his normal routine impossible. He was spending 23 hours of every day lying on his stomach so as not to make the ulcer worse. He couldn't work. He couldn't take care of his son. He could cut off chemotherapy to help the ulcer heal, but if he did that, he raised the risk of the cancer coming back.

"We were very worried," he says. "The bone was infected, and if bone is infected, the body won't put flesh over it. I really thought this was never going to get better. But then I was also worried about the cancer. I thought, 'Well, the decubitus probably isn't going to kill me — for now — but the cancer might, so I've got to keep going with the chemo.' But then the surgeon finally said, 'Well, actually, you might as well have cancer, because this decubitus can get to the point where it's chronically infected and I can't cure it.'"



Nada Elbuluk and Matthew Meunier talk with the Knyal Family

This was when Nada Elbuluk and Matthew Meunier first visited the Knyals. Jarrett had been lying on his stomach for several months. She was waiting while doctors considered him for surgery; they might try to treat the ulcer by surgical means, but the outcome would be uncertain. The Knyals and the two students talked for a long time that first night. Bridget and the students sat at the kitchen table; Jarrett lay on a hospital bed in the adjacent room. They talked not only about Jarrett's dilemma and his months-long search for an effective treatment, but about the difficulties that his condition posed for their life as a family. They talked about how Bridget had to clean and pack Jarrett's wound twice each day and administer IV antibiotics several times each day. They talked about the enormous cost of his medications. Bridget told the students she was suffering from recurrent depression. The Knyals told about their pre-chemotherapy arrangements for cryogenic sperm preservation through the U-M Fertility Counseling and Gamete Cryopreservation Program; they were worried about their hopes for having another child. And they worried about the effect on their little boy, Wade,

if his father was confined to the house, permanently stretched out on his torso. Bridget spoke of times when she broke down, thinking: "We have to choose cancer or *this*?" Jarrett asked himself: "Would I want to live if I was lying in bed my whole life? Would I want to be a parent to a child?"

Nada Elbuluk remembers that she had gone into the meeting thinking only that Jarrett was a paraplegic recovering from cancer; she knew nothing about the ulcer. She came away moved by the complexity of the Knyals' situation.

"It really put everything in life in perspective," she says. "What you think is difficult to deal with really pales in comparison. Some people would go insane in that situation, but the most amazing part about him is that he's so optimistic. He doesn't let anything get him down."

A few weeks later, Knyal was approved for surgery, and the students attended a pre-surgery clinic appointment with him. Both remembered being surprised when they saw him at the clinic. He was sitting in his wheelchair, looking so much more independ-

ent than when he had been laid out on his stomach at home. "He just looked different," Elbuluk said. "He seemed more like an everyday guy. He didn't seem like a person who was dealing with a health condition."

The students sat in as Jarrett went through a long exam with a physician's assistant. His surgeon came into the room for a brief talk — "not even a minute or two," Meunier remembers — and the students expressed surprise at how short the talk had been. That was nothing, Jarrett said. He told them he'd been operated on by doctors he had never even met.

Then a nurse came in to talk to the Knyals about what they would need to do when Jarrett went home after the surgery. But the exam room was needed, so the group had to move into a corridor, with other people passing by. The nurse began a detailed explanation.

"It was incredibly complex, and of course they had a lot of questions about it," Meunier recalls, "toileting and all sorts of sensitive issues that they were talking to the nurse about — *in the hallway*. I found that really kind of ... not what I expected. I was kind of taken aback."

But the surgery went forward — three surgeries, in fact — and when Elbuluk and Meunier visited the Knyals in the spring of 2005, Jarrett greeted them at the door in his wheelchair. The ulcer had healed. The students were jubilant.

"It was pretty incredible to see the transformation," Elbuluk says, "to see their new hope and how it changed their life. To them it meant everything for the surgery to work."

There were more long talks over dinners that spring and the following year, with long reflections on the course of Jarrett's care.

"When they'd come over," Jarrett says, "I'd try to tell them it's important not to focus just on the science. They're both good that way, I think. Their heads are in the right place. The training can dehumanize people. Maybe it's getting better. But I think there are good people who



The Knyal Family

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start out with a positive outlook, and for a lot of reasons lose it. I saw plenty of tired and cranky doctors.

"A big reason why I wanted to be a doctor was that I had some really horrible interactions with doctors, and I had some really great ones, too. I saw the difference that it could make. Maybe just five minutes more, or just the expression on someone's face. Just the little things, you know? And even if you don't care about treating someone really well from an emotional standpoint, happy people get better quicker than sad people. That's clear."

For Elbuluk, learning to know the Knyals has transformed her study of medicine.

"If the whole experience had been in a doctor's office, it would have been completely different," she says. "You'd just be seeing them as a patient with a condition, and thinking about how best to treat that condition. Getting to meet this family and be in their home so many times really helped me see things from a unique perspective. Had I just met them in a doctor's office, I wouldn't know what they went through trying to have their child. I wouldn't know about her depression, about his having to lie in bed all those hours and what that actually means.

"It's looking at the patient beyond the disease. It's a person who has a family, who is a son or a daughter or a father or a mother, and they have attachments and feelings and things that they're dealing with. And I think that being in medicine, you want to maintain that compassion and empathy. You don't want to just treat the disease. You want to be able to treat the person."

This, of course, is precisely what the designers of the FCE hoped the students would take from the experience.

"There are studies that show or suggest that the outcomes are better when people feel that they are being understood and listened to by the doctors," Kumagai says. "But the question isn't just whether the outcomes are better. It's also of human worth — to feel as though you're being listened to when you are suffering.

"We are not teaching empathy or compassion. We are taking the empathy and compassion and idealism that students come to medicine with, and we are helping them, through the patients' stories of illness, to fashion that empathy and compassion into a tool for healing. And it's a powerful, powerful tool." [m](#)

For other student stories from the Family Centered Experience, visit www.medicineatmichigan.org/magazine