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## **Sense of compassion**

Being paralyzed and totally dependent on others gave Dr. Brad Berk lots of time to think.

As chief executive of University of Rochester Medical Center, he'd led efforts to improve patient care. But rehabilitating from a bicycle accident that injured his spinal cord showed him clearly that healing is about more than science-based treatments. To put your trust in caregivers, you need a caring connection and clear communication.

Nine months after that life-changing day, Berk returns to work full time Monday determined to promote the kinder, gentler side to care, and to provide time for it at the hospitals under his watch.

"Now I really want to go back to my roots," said Berk, who relies on a motorized wheelchair to get around.

The scientist and cardiologist known for his methodical, data-driven approach to solving problems now speaks about the power of healing touch, the importance of attentively listening to patients and families, and the need to show compassion. In talks to medical residents and students, he's been sharing his experiences. He tells about losing trust in his providers when he was given an unidentified pill and about the unexpected delight of an intensive care unit nurse washing his hair.

The nurse offered the in-bed shampoo because, she told him, she'd always admired his well-kept hair and that, frankly, "It looks terrible right now."

Berk was still on a ventilator at the time, unable to feel anything but his head. "That was the most pleasurable thing I'd experienced in 10 days," he said. "That simple act was enormously restorative to my spirit."

The UR School of Medicine and Dentistry is already known for training doctors to consider the familial, psychological and societal influences when treating patients. But making this the focus throughout Strong Memorial and Highland hospitals ? so that everyone from clinicians to patient transporters views each patient as a whole person ? is difficult, Berk said. "It's about transforming a culture."

## **A different chief**

He's starting by behaving the way he'd like others to imitate. Pre-accident, Berk typically multitasked through 16-hour work days. His wife, Mary Berk, describes the Brighton native as beyond a type A personality: "double A." Now the 56-year-old former squash player has slowed down ? partly because of his injury but also as a conscious choice. Berk used to be tied to his Blackberry during family get-togethers.

"When you talk to him now, he's totally present," said his oldest daughter, Mariah DiMarco, 32, of Brighton. "You get his full attention."

Berk, a grandfather of three, plans to work shorter days, delegate more tasks and spend more time with his family. His physical and occupational therapy sessions will drop from three hours per weekday to an average of 90 minutes.

In conversation, he pays close attention to people, even strangers who recognize and greet him in the halls. Instead of taking less-traveled routes, he often rides the main red elevators at Strong, enjoying interaction with more of his thousands of employees.

"I just feel like he's connecting with people in a different way and communicates through his demeanor and his tone and his way of listening and speaking, a level of unhurried interest in the person to whom he's speaking," said Dr. Donald Bordley, director of the internal medicine residency program.

"His voice is softer as a result of his injury." But more than that, "His way of communicating is softer."

Dr. Mark Taubman, acting CEO during Berk's rehabilitation, said Berk is shifting from a quarterback, immersed in everything, to a coach.

The two men, friends since they worked together in a lab 29 years ago, have been in close contact throughout the past nine months.

One thing that hasn't changed about Berk is his optimism and dedication to the goals he sets, Taubman said. Berk's drive has helped him regain so much after the devastating injury.

Nine days ago, he started using a regular walker during rehab sessions. He still has limited sensation and must look at his legs to coordinate movement.

He's able to type with more of his fingers, but he can't lift his arm enough to comb his own hair.

He's come a long way from those initial days when he could barely nod to communicate.

### **Surprise on a curve**

On May 30, the lifelong cyclist was finishing a quick, 18-mile ride near his cottage on Canandaigua Lake. He enjoyed the view from a hilltop, looked down and saw nobody else on the road. He likes to go fast, and he leaned into a hairpin turn, like a motorcyclist, at about 23 mph. Suddenly an oncoming car appeared in Berk's path. "Obviously he'd been parked behind the hill where I couldn't see him," he said.

Berk braked. He feared hitting the guard rail and falling down the steep bank. So he tried a mountain bike move on his road bike. He leaned back and intentionally skidded, successfully turning the bike to face uphill, trying to get out of the way of the car. But when he started to pedal, he flew over the handlebars.

His rear tire had blown.

He hit the ground and struck his head, awake.

"Oh, good news, the bicycle helmet worked," he recalled thinking. "Then I realized I couldn't feel my legs."

His left arm didn't feel like it was part of his body. Then he lost feeling in his right arm.

"Oh no, this is bad," he thought. He correctly diagnosed a fracture of a vertebra high in his neck.

He was panting, which he identified as trouble breathing caused by the paralysis.

"I was worried I might die right there."

Lying on the road, he remembered the late actor Christopher Reeve and thought, "If I get out of this not being on a ventilator, I'll be happy."

Berk calmly instructed the car driver not to move him, to call 911, to dial Berk's cottage. Berk told his son, David, that he'd broken his neck. When David and Mary Berk arrived, he instructed them to make other calls, alerting a trauma team at Strong.

He was airlifted to Rochester, had surgery to stabilize his neck and spent 12 days in intensive care and 20 days on a ventilator. On June 11, he was flown to Kessler Rehabilitation Institute in New Jersey, which specializes in spinal cord injury.

After 100 days of intense rehab in a huge gym, to the tune of rock music, he was glad to get closer to home.

### **Family key to healing**

He told the story from his kitchen, as David cut waffles into bite-size pieces for his father. Berk uses special silverware with finger loops that give him more control with his still-limited but improving left hand. Berk was right-handed, but his right side is now his weakest. "Family is as important as medicine" when you have an injury with a long rehabilitation, Berk said.

David Berk lives in New Jersey and visited his father at Kessler a couple of times a week. There, the 26-year-old fed and shaved his father, following the senior Berk's step-by-step shaving instructions: "He's very particular about things."

If there's a silver lining in the crisis, it's the time together and the reconnecting, the son said. The parents and three grown children were all busy and had drifted apart. "I don't think we've ever been closer than we are now," David said.

Daughter Sarah Berk, 23, of Washington, D.C., ran her first marathon in November in New York City as part of Team Reeve. She raised \$16,025 for spinal cord injury research and enjoyed tackling something physically difficult as her dad faced his own long haul.

Meanwhile, daughter DiMarco was gathering and delivering hundreds of cards dropped off weekly at a collection point in Brighton. The good wishes from the community cheered the whole family.

Mary Berk brought her own skill as a social worker to the crisis. She had even written a book on caregiving. Before the accident, she worked at UPMC, training health care providers on issues such as how to have difficult conversations.

But it's different when your own spouse is seriously injured, in pain daily, and you are figuring out your new role. She assumed a noted rehab center would provide all the support a family would need, but there was a lot she was left to figure out on her own.

"I was struck by what a difficult time people had coping with my emotions," she said. "All I needed was someone to say: 'Anything I can do today?'"

As a patient, Berk realized that if his wife's concerns weren't addressed, his own mindset and healing were affected. "If she's upset, that's upsetting to me," he said. When he is under stress, his muscles tighten and he

can't move as well.

He said health care providers need courage to confront difficult situations, to address the emotional needs of patients and their families. Likewise, patients and families need courage, and providers can help them find that path.

Mary Berk has joined her husband in speaking to groups at the UR medical school. "My role is really to represent the family, to help providers understand both how family is a huge resource to them and how they can assist the healing process by helping the family."

She made her husband's return home possible by selling their 1929 Tudor home in Brighton and getting a more handicapped-accessible condo in Pittsford, having the bathroom redone with a roll-in shower and finding an accessible van. She's tackled new tasks, including getting her husband dressed ? which at first took an hour and left her in a full sweat.

They are settling in to their new routines, in the new place, with their dog and a recently adopted cat that Brad Berk named after the 19th century biologist Gregor Mendel. Mary Berk said life is much better than those scary days in the hospital.

### **Opportunities for change**

Improving care requires taking a few minutes to sit down, listen to patients and hear their concerns, Berk said. Spending time upfront can save time in the long run. A patient who resists an X-ray before going home may be worried that his pet is home alone, unfed. Maybe the solution is to schedule the X-ray for the next day, as an outpatient, Berk said.

One way he hopes to provide more time for those conversations is the switch to electronic medical records. The average provider spends more than an hour a day finding paper charts, which are kept in different places on each floor, he said.

Reaction to Berk's patient-centered message varies.

"We definitely try to put ourselves in the patient's shoes," said Dr. Benjamin Greene, a resident in otolaryngology, head and neck surgery, who's heard the Berks speak. "Having him tell us what it's actually like hits a little harder."

Several patient transporters were more skeptical whether change will really happen.

Cynthia James, who cleaned rooms for five years before becoming a patient transporter last year, also expressed hope: "I'm glad that he saw that something needs to be done. It has to start at the top." Sometimes aides and nurses are short-staffed and overworked, making it hard to give patients appropriate, timely care, she said.

### **Rehab continues**

Berk will continue to be a patient, trying to regain all the function he can in the critical first year post-injury.

At a table in Strong's rehab department recently, occupational therapist Simon Carson instructed Berk to remove the lids from various containers. Berk couldn't pop off the top of a small can of shaving cream.

"This one's in the evil category," Berk said calmly, setting it aside. But he successfully pried the top off a film canister, pressed and released the lid from a bottle of pain reliever, unscrewed a toothpaste cap, and twisted the lids off two other bottles.

"I'm five for six," he concluded. "Not bad."

That's been his approach. Work to improve. Don't dwell on what you can't accomplish today.

Berk also brings that practical determination to fighting with his insurance company over his coverage. Yes, even a hospital CEO who's involved with setting up employee health insurance plans runs into hassles over his care, which he estimates has cost about \$200,000 so far.

His insurer initially wouldn't cover a special mattress to prevent bed sores. He successfully argued, with the help of a wound care nurse, that renting one for \$400 a month was cost-effective, since a bed sore can result in a \$30,000 hospital stay and can lead to a fatal infection.

His injury affects so much of his body that it's expensive to treat. His motorized wheelchair alone cost \$25,000, but he can't use a manual one because his arms are so limited.

He tries to keep costs down, such as by refusing certain tests. He's looking into creating a pilot project someday to refurbish certain used durable medical equipment ? like his wheelchair ? and provide it with a warranty at lower cost, without deductibles, to UPMC employees experiencing injuries or illness.

His outlook on health care reform has not changed. He believes that reform should be guided by the providers of medical care, not politicians.

### **Lessons learned**

Mary Berk said she wants people to find hope in their story and that it's a reminder to live in the moment. "Cherish all the moments," she said.

As tough as their road has been, she said she thinks of people who've lost someone or who have a fatal illness. "Then I think, what can you complain about?"

Her husband said his message is that challenges can be opportunities.

He wants to regain physically as much as he can. But he also can live with his handicaps as they are: "This is a perfectly reasonable life."

Berk said he would want to bicycle again, but that his doctor isn't so enthusiastic.

Then again, he said with a smile, "If you listen to everything the doctors say... ."

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