They entered the ICU with serious health problems, but once home there were new problems to cope with. Here’s what happened—and how to prevent it from happening to you or a loved one.

BY KENNETH MILLER
At 87, my father was sharp and spirited—a retired middle-school French teacher who tore through crossword puzzles and yelled out the answers while watching Jeopardy! In the fall of 2014, facing radiation therapy for cancer, he put his Boston condo on the market and moved in with my younger brother Jon in Ithaca, NY. Dad sailed through the treatments, and the tumor in his neck vanished. But within a week of finishing his treatments, he landed back in the local hospital with a low white-blood-cell count and a raging infection. I flew in from Los Angeles to help out.

In the intensive care unit, I barely recognized my father. He couldn’t get through a sentence without losing his way. Overwhelmed by the choices on the hospital menu, he begged me to decide between pudding and Jell-O. Sometimes he spoke in strings of loosely related words, modulating his voice as if he were making perfect sense. One evening, he seemed more disoriented than ever. “How do I fit into your plan,” he asked me, “now that the schedule has changed?” I asked what plan he meant. “The bagel plan,” he said. “I know we can get bagels that might not be the best kind of bagels, but we can fit them into our schedule. I think this is a plan that can work.” As he went on, it became clear that he thought he was in his old condo and that my two brothers and I were bringing our families for brunch.

I asked the doctor doing rounds if Dad could be slipping into dementia. “It’s unlikely that would happen so quickly,” he assured me. “My guess is that he’s got what we call ‘ICU psychosis.’”

When I Googled that phrase, my fears grew. The formal term for what my father was experiencing is hospital-associated delirium. It’s part of a broader spectrum of mental and physical ailments called post-intensive care syndrome (PICS), often triggered by the patient’s treatment, rather than—or in addition to—the ailment being treated. Doctors have only recently recognized PICS as a serious problem deserving more study.

**INTENSIVE CARE WITH INTENSE SIDE EFFECTS**

Medical miracles routinely happen in ICUs, but the cure can sometimes be as violent as the disease. Patients in the ICU are battling severe or life-threatening illnesses or injuries. They require constant monitoring and are often hooked up to life-support or other special equipment. ICU patients are often given heavy doses of sedatives to help them tolerate having a ventilator tube jammed down their throats, and they’re put on opioid analgesics to dull their pain. They’re hooked up to IV bags and catheters and monitoring machines,
WHAT YOU CAN DO

Although hospitals are getting better at preventing and controlling delirium, family members can play a vital role. These tips from experts can help you keep your loved one moored in reality.

BRING IN PERSONAL ITEMS, such as family photos or favorite CDs, to help the patient feel connected to life outside the hospital.

MAKE SURE THE PATIENT HAS NECESSARY GLASSES OR HEARING AIDS. Being able to see and hear clearly is key to staying oriented.

ENCOURAGE PHYSICAL ACTIVITY. If possible, help the patient get up and walk a few times a day (with a doctor’s OK, of course).

KEEP THE PATIENT ENGAGED. Make conversations about current events or family activities. Play card games or do crossword puzzles.

KEEP AN ICU JOURNAL. After discharge, the patient can refer to the journal to get an accurate sense of what happened during hospitalization.

BE ALERT. If you notice worrisome behaviors or think the patient is being treated inappropriately, don’t hesitate to alert a doctor or nurse.

A growing body of research shows that these functions may take a long time to recover and in some cases never will. A 2013 study published in the New England Journal of Medicine found that 58% of ICU patients who entered the hospital with normal brain function had cognitive impairments mimicking traumatic brain injury or mild Alzheimer’s disease a year after leaving the hospital. A German study showed that 24% of ICU patients remained impaired after 6 years. Johns Hopkins University School of Medicine researchers recently reported that 20% of all ICU patients suffer from post-traumatic stress disorder—a figure comparable to the percentage of combat veterans or rape victims with PTSD. Other studies indicate that depression and anxiety affect 20 to 30% of ICU survivors. In 2010, the Society of Critical Care Medicine grouped these symptoms (along with persistent physical weakness) into the newly recognized disorder they named PICS.

Learning to prevent and treat the kind of delirium that my father experienced may be a key factor in reducing or preventing PICS. Patients who suffer from delirium while in the ICU are at highest risk of having cognitive impairment or psychiatric problems after discharge. “Delirium may fuel the syndrome,” says Wes Ely, a professor of critical care at Vanderbilt and the Nashville VA Medical Center. “It’s like pouring gasoline on a fire.” A study by Ely’s ICU Delirium and Cognitive Impairment Study Group showed a direct correlation between the duration of delirium and the severity of cognitive impairment. An increase from 1 day of delirium to 5 days, for example, was associated with significantly worse memory, attention, concentration, and mental processing speed a year after discharge.

The good news is that hospitals across the country are beginning to recognize the risk of ICU-induced delirium. The bad news, according to Ely and other experts, is that only about half of US hospitals have implemented protocols—such as minimizing sedation and getting patients moving sooner—aimed at detecting, preventing, or treating the condition. “We’ve gotten better at helping people roll out of the ICU alive, but we haven’t paid enough attention to what happens after they leave,” says Brenda Pun, a critical care nurse and researcher at Vanderbilt University Medical Center.

RECOGNIZING THE SIGNS

There’s still a lot to learn about how ICU-induced delirium can lead to full-blown PICS. Ely points to studies showing that delirium is associated with cerebral inflammation, which can shrink brain regions responsible for memory and executive function. Behaviors stemming from delirium may also play a role in PICS, making it harder to recover both physically and mentally. “If you’ve got delirium, you’re more likely to pull out your IV line or catheter,” explains Malaz Boustani, a professor of aging research at Indiana University School of Medicine. “You’re more likely to fall or need to be physically restrained.” According to a 2004 study published in JAMA, each day of delirium brings a 20% increased risk of prolonged hospitalization and 10% increased risk of death.

Complicating efforts to prevent delirium in the ICU is the fact that the condition can be difficult to recognize. ICU patients may be withdrawn or agitation, for instance, but the red flags for delirium are reduced awareness and ability to focus, impaired memory and problem-solving skills, disorganized thinking, and perceptual disturbances—sometimes including hallucinations or delusions. Although elderly patients in the ICU are at highest risk of developing delirium, it can strike at any age and during non-ICU hospital stays, too, when some of the same risk factors, like lack of sleep, are present. According to various studies, delirium affects 10 to 30% of all hospitalized adults, up to 56% of hospital patients over 65, and up to 80% of patients in the ICU.

Some cases are relatively benign, as with my father’s bagel obsession. “My mom kept seeing a purple cannon in her hospital room,” recalls Jill Adams, a writer in Albany, NY, whose 87-year-old mother was hospitalized for congestive heart failure last year. “She’d point to...
a white wall and say, ‘Oh, look at the patterns! Aren’t they beautiful?’

Often, however, the delusional images are horrific. “A lot of people think they’re being imprisoned, tortured, or raped,” says Joe Bienvenu, a professor of psychiatry at Johns Hopkins University. It’s not hard to understand how a sedated or semiconscious patient might interpret being stuck with needles or fed through a tube as a form of torture.

Those are the kinds of images that plagued Mario Guzman during his hospital stay. Guzman was 42 in 2013 when he injured an ankle while jogging near his home in San Jose, CA. An undetected bone infection led to full-blown septic shock, and he wound up spending 19 days in the ICU—7 of them on a ventilator—in a medically induced coma. When he awoke, recalls his wife, Ludmila Parada, “he was fearful of his surroundings. He’d whisper, ‘They’re trying to kill me.’

It wasn’t until Guzman was discharged, after more than 4 months in the hospital, that he confessed the source of his anxiety: He’d had recurring hallucinations in which the doctors subjected him to Nazi-style medical experiments or forced his father to unplug his life-support equipment, then waited eagerly for him to die in order to harvest his organs. Although Guzman’s delusions vanished on their own, the terror they unleashed left a permanent imprint. “My husband is a very stoic man,” Parada says, “but he still breaks down crying when he talks about that time.”

Rob Rainer, 54, is another former patient who experienced horrific hallucinations while in the ICU and afterward. In 2015, he spent 2 months in two different New Hampshire hospitals with a rare and often deadly strain of pneumonia. While on a ventilator, he experienced an alternate reality in which his father had bought the hospital with a dishonest business partner who was abusing the patients and trying to defraud Rainer’s family. He also became convinced that he was being sexually molested by the nursing staff. His hands had to be tied down to keep him from ripping out his tubes. “I was locked in this strange world,” he says. “It was so vivid and real—much different from a dream.” Rainer realizes he will never know what really happened, and that, to him, is the scariest part. After a year of cognitive-behavioral therapy (a technique that helps patients overcome harmful thought patterns), as well as support-group sessions with other ICU survivors, Rainer has finally learned to stop focusing on his ICU stay and concentrate instead on his good fortune in having survived a deadly disease.

Both Guzman and Rainer are still
suffering physical and mental effects from their illnesses. Guzman, a former design engineer, lost a foot, an arm, two fingers, and five toes and is partially paralyzed. Rainer, a lawyer, was left with scarred lungs, cataracts, and hearing loss, among other problems. But the repercussions of delirium added greatly to their woes. Rainer had to have a procedure to repair a disk in his neck that was believed to be damaged while he was delirious and struggling against his restraints.

PREVENTING PICS

Until about 10 years ago, intensive care doctors did not pay much attention to patient miseries like these because the long-term impact of delirium hadn’t been recognized. “When I was in training, in the 1980s and ’90s, we thought of it as an inconvenience,” says Gerald Weinhouse, a pulmonary and critical care physician at Brigham and Women’s Hospital in Boston. “We’d tell family members, ‘It’s disturbing, but it gets better. Don’t worry about it.’”

Back then, many of the clinical practices now known to trigger or exacerbate delirium, such as keeping ventilator patients deeply sedated, were starting to become routine. Doctors believed it was more humane to keep patients sedated when such invasive medical procedures were being done. Around the same time, critical care became an independent specialty. “As a result, it was possible for the physicians who were taking care of these patients to never really know them as individuals, not before, during, or after their illness,” explains Daniela Lamas, a critical care physician at Brigham and Women’s.

Eventually, however, a few doctors began connecting the dots. “Patients would come back to my clinic after a stay in the ICU saying they couldn’t go back to work,” Ely recalls. “It seemed like something had changed for them in the ICU, but we didn’t know what.” In the early 2000s, he and other researchers began investigating the links between patients’ experiences in intensive care and their later problems. As they tracked populations of ICU survivors, they found that delirium was a key factor in all the disorders later grouped together under PICS. They also realized that in many cases—more than 40%, according to an analysis by Harvard Medical School researchers—the syndrome could be at least partially prevented.

Over the past decade, a growing number of hospitals have begun taking steps to do that—and to ensure that if delirium does arise, it’s caught early and extinguished quickly. Researchers have developed assessment tools to help doctors and nurses check for symptoms in ICU patients. Many intensive care units now limit sedatives and opioid painkillers to the minimum necessary for comfort. Patients are encouraged to start sitting, standing, and walking as soon as possible. At night, nurses make a point of dimming lights and minimizing noise and intrusive procedures; after sunrise, they open the blinds and switch on the TV morning talk shows. They remind patients what day it is and where they are. To help those who develop PICS after discharge, a handful of hospitals have established post-ICU clinics or support groups (aftertheicu.org).

But thousands of hospitals have yet to adopt antidelirium measures, and even those that have can’t prevent every case. That’s where family members come in. “My advice is to be an active participant in your loved one’s care,” says Pun. “Your nurses and physicians are there to work with you. You know this patient best—her likes, her dislikes, her normal patterns. You’re an important member of the team.” Pun urges family members to ask questions and point out troubling behaviors.

She also recommends keeping an ICU diary, with a record of daily events and descriptions or photos of the patient and her surroundings. “The idea is to have a record you can use to help the patient interpret memories and debunk false ones,” Pun explains. “If the patient says, ‘These yellow people kept coming into my room,’ you can show her that visitors had to wear yellow gowns over their clothes to avoid spreading bacteria.”

My father’s delirium began to dissipate after his fifth day in the hospital, and he was released to my brother’s care 3 days after that. Within a month, he was well enough to move into his own place at a senior living complex a few miles away. It was several more months before his old sharpness returned, but by his 88th birthday, he was back to shouting at Jeopardy! and finishing several crosswords a day. On the day he turned 89, he flew to LA to visit my family—on his own.

I asked him recently what he remembered from that week when he lost his mind. “Nothing at all, to be honest,” he told me. “Maybe I’m lucky that way.”