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On my mind: Being a hospital patient



Last month, I had a middle-of-the-night dream that turned out to be prophetic: there was an intruder in my house, and he wanted to do me harm. When I woke the next morning at my usual early hour, the dream was gone. The day was crisp and clear, birds were chirping, and everywhere, purple, green, and pink buds were popping open against a background of winter grays and browns: my favorite time of day during the most hopeful time of year.

But when I stood up, I suddenly felt lightheaded. I lay back down until I felt better, but when I tried getting up again, the dizziness returned, and I felt drained of energy. I felt my pulse. It was slow and irregular — a sign of atrial fibrillation. I called my son, who was in the next room, and asked him to take me to the ER. There, I was greeted with a warm “Hey, Dr. Silberstein” by Trish Bergeron, the unit administrator, with whom I’ve worked since I moved to the Vineyard in 1995. I knew or at least recognized almost all of the staff. Speaking as one colleague to another, I announced, “Bradycardia and AFib.”

They hooked me up to an EKG. “Good news,” I was told. “Normal sinus rhythm.” Michael Spiro, the nursing supervisor who always has a warm smile and engaging twinkle, came in and said, “Well, Doc, now that you’re here, we have a couple of people for you to see.” A second EKG stirred more concern. “Not AFib,” said Morris Rivera, the ER doctor on duty. “You’re now in third degree heart block,” a condition in which the electrical signals of the heart stop communicating adequately with each other, potentially causing the heart to stop completely. “The helicopter will arrive in 20 minutes.” A blood test revealed that my heart muscle was stressed, if not damaged, and after a mutually tearful hug with my son on the tarmac, I was wheeled into the helicopter.

I have never before been on a med flight, but have always loved helicopter rides. There is something magical about gracefully floating off the ground before the helicopter turns and heads off into the sky. The day was as gorgeous in the sky as it was on the ground. I felt secure and cared for by Ronnie and Joe, nurse and medic, who felt like protecting angels as we flew over green forests and blue seas. Ronnie assured me that my EKG was fine and that the chest pressure I’d felt as I was rolled in was probably run-of-the-mill anxiety. Then, mid-flight, they started to confer with concern. Ronnie was

pointing to my EKG, on which I could read “ST elevation.” Ronnie moved close to me, raised the ear protection, and drawing close to my ear said, “I am sure you know what we’re talking about.” I did: ST elevation is a potential sign of a heart attack.

Sailing through the heavens, I closed my eyes and felt a sense of the spiritual, just as I do when watching the waves or walking through a Vineyard forest. My mind landed on the transience of all life. It occurred to me that I might die that day or in 30 years, and that in the big picture, the difference was not particularly significant. I felt the richness of my life up until that day. I thought of the enormous gifts that my family, friends, and relationships with my patients have been. I savored the joy of my life’s work. I felt calm and comforted as the helicopter slowly descended until we gently landed on the roof of MGH.

Joe and Ronnie escorted me down the elevator and into a cubicle in a windowless emergency room. Doctors and nurses swarmed around as I was lifted off the stretcher onto a gurney. The pads that would have been used to shock my heart if it had stopped on the helicopter were removed and replaced by new ones that fit the defibrillators at MGH. A new IV was inserted into one arm as a needle was stuck into the other for more blood samples. ER docs and cardiologists at different levels of training and with different expertise filtered in and out. One of them told me he thought that I had not had a heart attack, but they would continue following my labs.

An hour earlier, I had been in the familiar, bright, spacious, world of the Martha’s Vineyard Hospital, surrounded by colleagues. Now I was in what felt like a bustling underground cave with bright lights, voices, and electronic sounds everywhere. The staff were professional, knowledgeable, or pleasant, but my disorientation was intensified by the fact that I was no longer “Dr. Silberstein,” but rather addressed as “Charles” by people who didn’t know me, some of whom I addressed as “Doctor.”

A young cardiologist with sharp, inquisitive eyes and a warm smile introduced himself as Danny. He explained that my Lyme test came back positive, and that Lyme may have caused the inflammation in my heart. Those little corkscrew spirochaetes apparently have an affinity for heart muscle. They immediately started me on intravenous antibiotics. After a few hours in the ER, I was transferred to the telemetry unit, where they would monitor my heart 24 hours a day.

My room was quite a contrast to the elegant, large, waterview private rooms at MVH. This room was cramped, and the curtain dividing my half from my roommate’s prevented me from seeing out the window. My roommate was an older man with a hacking cough who spoke loudly on the phone in a language I didn’t understand. It was a noisy night, and I was grateful for the sleeping pill I was given. I was dressed in a “johnny” — one of those short-sleeved robes, open in the back, with no leg covering. I asked one of the passing nurses if I could put on a T shirt and pants. She said I could, and I felt much more myself in my familiar Blackwater Farm T shirt and a pair of scrub trousers. But when my regular nurse came back into the room, she had me put the johnny back on, explaining, “If you have a cardiac event in the middle of the night, we’ll want to get to your chest right away.”

Staff came in and out of the room throughout the day and night. Sometimes people knocked before entering, but usually it was perfunctory at best. Doors were left open more often than not. Vital signs were checked. Blood was drawn sometimes two or three times a day. Tests were administered. I took occasional showers with great care and caution. I spent most of my time in bed, with nowhere else to be, unless pacing the floor. (Twenty-four rotations equal a mile.) Medicaese was spoken with great simplicity to the uninitiated and with breathtaking depth to people in the know. I found myself subtly urging its speakers to speak to me as an initiate, and then asking for repetition and explanations as the language of cardiology was spoken more fluently than I could always understand. I was seeking a delicate balance between needing to be cared for as a patient and wanting to be treated with the respect and collegial engagement I was accustomed to, having spent most of my life as a clinician.

Since arriving at Mass General, I had been thinking about Erving Goffman's early studies of institutionalization. Goffman enumerated several key concepts about institutions, including the fact that they exist in every society and are set up to control and regulate individuals' behaviors and attitudes. Institutions tend to have hierarchies, their own dress codes, languages, rules, symbols, procedures, and customs, all of which contribute to how members are taught to behave. Institutional rules become particularly important in densely packed environments where the stakes are high, such as hospitals. There, life and death stakes make behavioral control essential. Countless rules and customs govern patient behavior, often including restricting or prohibiting patients from leaving their rooms or units without authorization.

Goffman believed that we use "impression management" to present ourselves to others as we hope to be perceived." When I first arrived in my room, my name was listed on the wall as "Charles" in two places. My nurse asked how I wanted to be addressed. Seeking congeniality, I said, "Anything is fine." But then strangers came in and called me by first name, doctors who didn't know I was a colleague talked with me in simplistic language, and I longed for my title back. Nervous that I was breaking a rule, I changed my name on the white board to "Dr. Silberstein."

In hospitals, patients lose their clothes, privacy, freedom of movement, sleep schedule, usual diet, access to the outdoors, and in the days of COVID, easy access to family and friends. In my case, there was also a loss of the sense of certainty about what tomorrow would bring, because my diagnosis kept changing, and no one could tell me how long I would be in the hospital. In addition, I felt I was losing my identity as a healthy, vigorous, knowledgeable man and doctor. When I changed my name on the white board, it was in part because I hoped for special treatment, wanted to be seen as a colleague, and wished to be spoken to with familiar medical shorthand. But the biggest reason was that I wanted to hold onto my identity. I wanted to be seen and heard for who I am, rather than as an anonymous body to be poked and prodded. I wanted to restore the symmetry that exists and should be acknowledged between any two human beings.

Almost as difficult was the pervasive uncertainty about almost everything — what was causing my heart irregularity, when tests and procedures would be scheduled, when someone would show up if I buzzed for assistance, when I'd be permitted to go home. I never knew how far into the future I'd have to cancel my appointments with patients, and every day I was struggling to — yet again — rearrange my calendar. The constantly changing assessments of my current condition and prognoses about my future health were particularly unsettling. As I often comment to others, uncertainty is a disturbing state of mind. Knowing is almost always better than wondering.

Having never before spent a night in the hospital, I found many surprises during what wound up being a five-day stay. Most significant was what I learned about the healing power of friends. I was enormously comforted by the love that was extended to me by my children, wife, friends, colleagues, and patients. It was the antidote to anxiety and despair. Each email, text, and call reminded me of a different world where I was known, a world in which I felt loved and accepted; a world in which I felt free and healthy and vigorous. In the past, when a friend or patient went into the hospital or into surgery, I had no idea of how challenging an experience it would be for that person. Someone once said to me, "Minor surgery is surgery that is administered to someone else." I now know that there is no minor surgery, no minor diagnosis, no minor hospitalization. I left Mass General feeling healthy and reassured about my future, but also with a deeper empathy for my patients, friends, and strangers whose illusion of unlimited health and security can be fractured so easily.

Addendum: I wrote the above when I had come home from five days at MGH. Due to a procedure gone awry, I was rehospitalized five days later, for another 11 days. I come away from my more than two weeks at Mass General with the following practical advice for anyone facing time in a hospital.

- Make friends with nursing staff. They are 24/7 allies, and want to be helpful. The second time around, I left my name as “Charles.” Symmetry in relationships is important, and bucking the system can backfire.
- A friend who has been both a hospital board chairman and a long-term hospital patient wrote this advice to me: “Hospitals are extremely frustrating places because you’re working within the changing timeframes of half a dozen departments ... I think it’s an interesting exercise for control-oriented types ... there comes a moment when you realize that there isn’t a damn thing you can do besides just being pleasant ... I think that helps ... you’re totally at the mercy of THEIR systems, not yours ... I do think that this kind of knowledge, if you let it percolate, makes you a bit more sensitive and empathic.”
- If you can get or move to a window bed, do it. The second time at MGH I had a glorious view of the Charles River and Cambridge. It gave me a sense of freedom and escape, and something interesting and beautiful to watch.
- Don’t underestimate how frightening, disorienting, and even traumatic a hospitalization can be. Acknowledging and accepting the psychic pain made it less frightening and more manageable, and left me more room for the love and gratitude that filled so much of each day.
- Ask for what you need. Hospital staff want to feel helpful — it’s why most of them go into these professions. Warm blankets, a different diet, a sleeping pill, and a chaplain are easy to provide.
- As for sleeping pills, the most commonly used is lorazepam (Ativan). I had almost never taken lorazepam before. The common dose in hospitals is 1 mg. I only needed half of that. Start low. Take more if you need it. Too much can make you foggy the next day.
- Hospitals are bright and noisy places. Get a really good total blackout face mask and a pair of ear plugs. The Mindfold is amazing, and comes with ear plugs.
- I found that a supportive neck pillow — the kind you get in airports — made the time in bed much more comfortable.
- Welcome gifts from loved ones. A friend sent me the most gorgeous flowers. They were a constant source of joy.
- Family and friends brought and sent me meals. Hospital food is institutional. Home-cooked food made me feel healthier, tasted better, and reminded me that I was loved by people who really knew me.
- Immobility is debilitating. As soon as I was able, I started walking the halls. At times it was tiring, but it made all the difference to my well-being.
- Iatrogenic Illness (illness caused by medical treatment) is common. My second hospitalization was entirely iatrogenic. As a doctor, I have certainly recommended treatments that have had bad consequences. Much of medicine is trial and error, so mishaps are inevitable. Every medication and procedure has risks. Even so, when it happens to you, it can feel like a betrayal. As a patient, I felt frustrated and even angry to find my life upended by a mistake made by someone whose job it was to take care of me. I requested a meeting with the doctor who made the error. It was enormously helpful. Hearing his regret about what had happened to me gave me relief and a sense of closure.
- As mentioned earlier, hearing from family, friends, and my patients was a big source of comfort, particularly during my first hospitalization. It was tremendously heartwarming, at a time when my very identity was shaken, to be in contact with people who really knew me as I knew myself. On the other hand, it was important that my community understood that I might not respond, and above all, that I needed time to heal. Sometimes, I just needed solitude.
- Sometimes being a patient is boring. Having sources of entertainment (books, movies, music, games) really helps.
- In our complicated medical system, every patient needs an advocate. Having my wife present for meetings with my doctors gave me an important second set of eyes and ears. On at least one occasion, her wise observations changed the course of my treatment for the

better. The doctors and nurses were great about explaining things to her and reaching out to her after procedures. I had a great team, and it was phenomenal that she was part of it.

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