

## ON THE BRAIN

## A Bowl of Oranges

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**For the past 4 months**, the wallpaper on my phone has been a drawing of oranges in a brightly colored turquoise and blue bowl. The image has depth and texture and light, although the edges are a bit shaky, and the color that fills the bowl has patches missing. The oranges recall a childhood song my father sang in Gujarati, "Round, round oranges! Mommy buys the oranges, Daddy cuts the oranges, Sheela eats the oranges!" ("*Gol, gol, musambi! Mummy laave musambi, Daddy kaape musambi, Sheela khai musambi!*") My father, a lover of fruit, took time selecting pieces by scent and color for their ripeness, peeling, cutting, and feeding his family, before eating any juicy morsels himself.

The drawing is the final picture my father drew in a pastels class he took at a neighborhood art school—an image of serenity for me to hold on to through the tumultuous months that followed. We would walk to the art school together some Friday mornings, usually in a bit of a hurry, hand in hand, me pulling my father forward slightly as I tried to speed walk. He was not walking slowly out of obstinacy or weakness; he had a parkinsonian shuffle that slowed his stride.

In our family, illness had always been an obstacle to overcome without the help of medication or intervention but rather with tenacity. My father had been going to the gym daily, working with a trainer to shake his shake and shake his shuffle and uncoil his neck. All the while, he and my mom reduced his dose of carbidopa/levodopa, the main medicine physicians rely on for symptomatic treatment of Parkinson disease. They could see that his efforts were effective, while the medication at higher doses caused hallucinations, a menacing adverse effect that threatened his grasp on reality and ability to function.

In the long process of becoming a physician and surgeon, I have seen humans fight with courage and determination and still fail to beat illness. I have witnessed many of these illness episodes in a world separate from my family, often not sharing the stories or the effect they have had on my understanding of healing. I have come to believe in medication somewhat and in surgery sparingly. But when I am in my home, I know that my parents are not interested in what they see as the crutches of Western medicine to achieve health. Our different approaches clashed when deciding about diagnostics and medication adjustments for my father. I thought carefully about my recommendations; they were received with love and a lot of skepticism.

My father enjoyed the pastels class. He had signed up as part of his strategy to overcome Parkinson disease. In the months prior to the class, he began to realize that he could not concentrate for long periods on reading; he was also having a harder time understanding the online religious lectures that he and my mom listened to regularly. His handwriting had become so

small that it was illegible. He had always loved art as a youth, and now he thought it might keep his mind sharp. I had helped him sign up for the next session of the class, which was to start after the holiday break.

The holiday break: on December 21, he was holding a couple pieces of fruit as he walked up a few stairs into our kitchen. One of them rolled out of his hands; he turned his head, lost his balance, and fell down the stairs head first. Then he got up on his own and walked up the stairs. He and my mom decided not to go to the hospital, in keeping with their avoid-the-physician mentality. We observed him over the next day, and he seemed fine. When he went to his routine neurology appointment 5 days later, he was still asymptomatic. As a precaution, he was sent for a cervical radiograph and a head computed tomographic scan. He had broken 2 bones high in his cervical spine and was at risk for quadriplegia.

In the days that followed, it felt as if my father's body was turned over to the medical establishment. After a contentious consent for surgery, he was taken for a spinal fusion, and, as he was being awakened, he had a cardiac arrest. To keep him alive, physicians pumped his chest, slit his throat, and placed a breathing tube. His heart recovered immediately, but he remained in a coma.

Teams of clinicians from various specialties filed in and out of his room in the intensive care unit, prodding and pinching this body connected to so many tubes and lines that were keeping him alive. His limbs were limp, his skin bruised, and his face expressionless. We, his family, were standing at the periphery, shouting in, "That body is Hansraj Champshi Maru, the respected elder of the Maru clan, descended from rural Kutch in India, born in poverty, educated at Indian Institute of Technology Bombay, recipient of a doctorate in chemical engineering, pioneering fuel-cell researcher, and Jain spiritual leader in America, now contending with Parkinson disease." In his belief, he is a soul housed in a body, but what we were seeing appeared to be a soulless body running on machines and fluids. To us, his family, this condition felt so far from what he would have wanted. But there was no way for him to speak up. There was no way for us to know what he was experiencing, if this was temporary, and what he would be like if he awakened.

It seemed impossible to reconcile my family's beliefs in a pathway to health with the workings of the intensive care unit. I wanted to be the bridge between these disparate worlds, because I do in fact embody that bridge. But somehow the medical approach felt unreasonable. Small things gave us peace: my mother's continuous presence by his side, my father's sister providing acupressure to his nonresponsive body, many family members

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participating in a near-continuous recitation of his most cherished prayers, and our success in declining a number of tests and procedures that seemed to have little therapeutic value. Each of these things required a battle with the medical team. We were asking for things that did not fit into their evidence-based model of therapy, and we were declining things they had little evidence for but believed in. The multiple tense conversations, the condescending glares, the frequent interruptions were all emotionally exhausting. However, winning those battles gave me some sense of autonomy and control when I otherwise felt like I was spinning into a black hole.

I will never know what caused my dad to wake up one day and start his slow recovery, his journey from the intensive care unit to a hospital room and onward to a medical acute-care facility. An eerie refrain began in the hospital, when he was still delirious and bedbound; "I want to put my feet on the ground and walk out of here," he would say softly. After a 3-month stay in rehabilitation, he walked independently up the porch and through the door to our house.

During that time, our family continued to advocate persistently. After we insisted, they told us they would "allow" him to get up to use the bathroom instead of wearing a diaper. We were forced to go up the chain of command to the attending physician to obtain permission to leave the unit to get some sunlight. We were labeled as a demanding family when we requested to know when and why blood was drawn and the results of every test per-

formed. After we made the complex decision to decline a feeding tube and choose more therapy for swallowing despite risking aspiration, our choice was documented as going against medical advice. The words stung, because I felt his dignity burn with each instance.

Yet I felt the sting for another reason, one that took me time to acknowledge: I knew that I too had used these same words with my own patients. With my father home, I could reflect on how my medical perspective had matured with the bridging of my worlds. I know now that I should never presume to be the expert of my patient's body or illness. They will always have a more complete knowledge of themselves. People's identities and what they value need to be at the center of determining a treatment plan. The treatment plan we arrive at might resolve aspects of the illness, but healing involves a great deal more than the closing of physical wounds.

To understand my father as a patient, we need to look at the context of his injury. The cause was not simply a fall. It was a circumstance of freedom—to walk freely in his own home, cut and eat fruit on his own, and share it with those he loved. Curtailing that freedom for so-called safety may not make him healthier; it may erode his humanity. Recovery from his injuries, and walking through life again, requires more than surgery and medication. It requires resilience built over a lifetime, persistence, prayer, accompaniment, and love. It requires adapting to strive under new conditions, trying pastels in your seventies.

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**Published Online:** September 4, 2018.  
doi:[10.1001/jamaneurol.2018.2520](https://doi.org/10.1001/jamaneurol.2018.2520)

**Conflict of Interest Disclosures:** None reported.

**Additional Contributions:** I thank my father, mother, and father's sister for granting permission to publish this information.