

The Impatient Patient —

Reexamining Difficult Patient-Provider Relationships

by Marilyn Schaeffer

I didn't mean to end up on the floor.

After all, the bed was nearby and I was tired of being exposed while sitting on a commode. Besides, my sister was there to help. I thought once I stood, I could make a quick swing and land on the bed.

But I was wrong, terribly wrong. When my sister attempted to lift me, grasping me under my arms, I slithered through them, falling on the floor like a mass of Jell-O.

Now the good thing about being on the hospital floor was the dizzying amount of time for reflection. Why couldn't I stand? What was wrong with my legs that had worked just days before? My diagnosis, which held the answers to these questions, meant nothing to me, even though I had asked the neurologist to write it out — Guillain-Barre Syndrome. My being around medicine (mostly as a radiology technologist) for twenty-odd years held no clues as to what Guillain-Barre Syndrome was or how it was affecting me.

So there I lay, wondering if it was true that hospitals had a lot of germs on the floor. If so, I thought, I was now one with them and at their mercy.

Beyond the haze of my reflection, I was aware of my sister scurrying for help. When told of my dilemma, the nurse assigned to my care stood over me and could not refrain from verbally rapping me on the nose for my attempt at independence. I deserved the reprimand, I told myself, and lay silently while she gathered assistance. I was a bad girl. Almost fifty and now being shamed for disobedience. Disobeying instructions was not really my character, I wanted to call out, but such a cry was not going to get me into bed or soothe the personnel that took seconds from other tasks to lift me into it. Only one nurse squeezed my hand in sympathy at my flight from the floor and into the bed. That gesture was enough to redeem the moment from being one of total humiliation.

Was I being difficult? Was I trying to thwart the staff and the needed directives for my care? Was I intentionally adding to their day's tasks by noncompliance? Not in my mind. Until I hit the floor, I didn't know I couldn't stand. And even then, after I'd been hoisted into bed, no one told me I wouldn't be able to stand alone for awhile. So I thought it was a fluke. In my mind, I had to keep trying until someone told me I couldn't do that with Guillain-Barre Syndrome, that my illness was making it impossible for me to stand. But no one did.

My San Francisco sister tried to help by downloading articles from the Internet for me. I put them in the drawer where they stayed until after I went home. I was too tired and drug-fogged to make any sense of the words.

My Kansas City sister in turn became my advocate, and that advocacy with the hospital was crucial to my care. With rehab, I was soon able to stand, to grasp things, and to walk, the simple tasks Guillain Barre had made impossible. And in all of this, I would like to believe my desire to restore my independence was an asset to my recovery.

I wonder if anyone on the other side of the bed, the other side of the tubes and needles and wheelchairs, can really understand the needs and emotions of patients as they struggle with their illnesses. In this age of HMOs, PPOs, and the demise of the family physician, it is becoming more and more of a challenge for these two minds to meet: the healer and the person needing healing. Suddenly thrust together at the bedside there is no time to discover the history or concerns of the other. Nowhere in my chart was it noted that I had lived alone most of my adult life, that I valued my independence, enjoyed travel and adventure, and feared more than anything, burdening my sister with a long-term illness. I — who had ridden a motorcycle to Utah, white-water rafted the Green and Colorado rivers, safari-ed in Kenya, volunteered a year of my life in Quito, and had been on my own since twenty-one — feared, more than anything, dependency. Who knew this? It was at the core of my struggles and at the heart of my fear. It was, in other words, information that may have been helpful — even vital — to my recovery.

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I realize that such information-gathering chats take time and there is an urgency to treat illnesses like Guillain Barre quickly. In my case, the neurologist's quick diagnosis and treatment created a remarkable recovery. What I am suggesting, though, is that often a patient thought to be uncooperative is really at another level of consciousness. Perhaps what appears to be a lack of cooperation needs to be investigated. Perhaps before patients are labeled, tied down, or force-fed, it might be best to discover more about them. What appears to be resistance to treatment or lack of cooperation may, in reality, be something far different.

Some patient reactions might have to do with physical handicaps that existed before the hospitalization. When my friend's eighty-plus-year-old father was hospitalized a few years ago, a resident told her that he had tried to talk with her father about treatment, but the elderly man was confused and unable to comprehend. My friend reminded him that her father was hard of hearing and could "hear" better with his glasses on (only people who need glasses understand this phenomenon). After putting on his glasses and inserting his hearing aid, her father responded appropriately to questions. My friend had told this to a staff person before, but such information must have been lost in nurses' notes and hurriedness.

An obvious explanation for lack of cooperation might be medication the patient is receiving. Who better to know this than medical personnel? Among my other "sins" while hospitalized was pulling out my Ng tube while heavily se-

dated. In my mind the tape around my nostril seemed messy and I imagined that the curled tape, feeling like crusted-over secretions, was an awful sight. I thought it must need to be replaced or cleaned, yet no one seemed to notice what I found so offensive. So I pulled it out. Quickly. It was a relief to take care of that problem. I didn't understand why I had needed a feeding tube in the first place. No one told me I had developed a Bell's palsy and had a problem keeping liquids out of my lungs. So I didn't think it mattered. The nurse, however, angrily reinserted the tube and threatened to tie my hands down if I didn't leave it alone. She was irked that I had created additional work for her; though in my Demerol-laced consciousness, I had simply been trying to help.

Many years ago my father, while hospitalized, was given respiratory treatments. The therapist was increasingly frustrated with him because he kept falling asleep. My mother discovered from the doctor that my father was receiving Valium "to help him sleep and reduce his anxiety." Now my father was not an anxious man, nor had he ever needed help sleeping. Once my mother convinced the doctor of those facts, the medicine was stopped and my father was able to participate in therapy wide awake. Surely the therapist had access to my father's records and the ability to inquire about my father's lack of effort during treatment that would have spared them both frustration.

Admittedly such instances are not clear-cut. But perhaps there needs to be greater attention to other possibilities before a patient is labeled difficult and then restrained. These apparent struggles may, in fact, be opportunities for both sides, healer and patient, to find goals and treatments together that will speed recovery.

Misunderstandings take place when there is a lack of respect — on both sides. My own humbling experience did not end on the floor. I also endured being called "honey" rather than by my name, first or last. This lack of identity by some caretakers pushed me to the edge of frustration and dependency. Such a small, seemingly innocuous act is, for someone sick and dependent, a big deal. Not being an individual, not being known beyond my disease, fell on me as heavily as I had fallen on the floor. I had left my dignity on the floor; I was not going to leave my name there, too. So I told the offenders to stop calling me honey, but it rang on deaf ears. One of my greatest triumphs was when a young man proceeded to call me "honey" for the umpteenth time, and I called him "Sonny." I don't remember seeing him again; nor do I recall being called "honey" again. It was a small triumph but my hospital stay was made up of such small things. I needed, as do most patients, a sense of being more than a body part or a disease. My name confirms my being recognized as an individual (not to mention being the right patient for treatment!)

A patient is allowed to make few choices in the hospital. Prodded and probed, exposed physically and feeling nakedly vulnerable, requires an abandonment that would be difficult for a healthy person. Some of my experiences in the hospital have taken almost as much time to heal as the Guillain Barre. Wellness needs to encompass wholeness. The time and energy invested in knowing a patient may, in the long run, lead to a faster recovery. And at the least, knowing

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more about a patient may confirm that the patient's seeming noncompliance is really a result of fear, misunderstanding, or from some other innocent and easily understood source.

Family members are often the most ready source for such information, though they, too, don't escape the label of noncompliant. Sometimes they are viewed as being more difficult than the patient. This is a fragile tightrope for caregivers to maneuver.

Several times during my stay, my sister challenged the system. I wasn't always aware of the issues, but after I was better I was glad for her intervention. When someone in street clothes and without an ID came to take me for a procedure, she questioned who he was and the inappropriateness of sending a stranger to transport me. My sister championed several such causes that were resolved through a patient advocate. It was difficult, however. At times I felt her interventions may have been resented and, consequently, threatened my care. I warned her to be cautious, but I knew I needed an advocate, and my sister willingly took on the task. I was grateful she was there and glad she questioned things I was too ill to pursue.

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I know at times the staff found her difficult. But was she? Was I? The answer is no. Falling on the floor and pulling my feeding tube out were not acts of rebellion. I knew the importance of following instructions and had at other times in my life been a model patient. But I was frustrated and terribly afraid of being thrown into all too sudden dependency. Some nurses and physicians understood my craving to take a shower, wash my hair, do-it-myself-if-I-can. I remember those myriad of people and their acts of kindness fondly. I certainly learned what I valued and learned to accept help when I knew I couldn't do it myself.

I can't speak for all patients. But now I can speak from my experience and share a stretched horizon. After all, my experiences are not isolated ones. And out of these experiences I ask for physicians and nurses and other hospital personnel to consider other possibilities before they assume someone is noncompliant. Patients are human, scared, frustrated, dependent.

Lots of things in a hospital go bump in the night. If patients are reduced to children, will their childish fears resurface? Is it possible that medications are making them act aggressive or squirrely? Is there a relative with insight who is an advocate or just an interloper? Did anyone even talk with the patient or just yell at them to obey directives? Spending some time answering these questions might prove valuable for both sides. In most instances, no one wants to get better and out of the hospital more than the patient. Not only is there an opportunity to reduce frustrations but also a great opportunity to gain trust and cooperation. In the end the process could lead to a transformation of both patient and healer.