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## Hospitals Foreign Soil for Those Who Don't Work There

**F**or many of you, the hospital has by now become your home away from home. You spend a great deal of time there. You know your way from the ER to the ICU and the morgue. You've learned the hierarchy of who can tell whom what to do, and when it's your turn to do so, you can rattle off an impressive string of acronyms and "medspeak" in rapid fire. And then, there's that white coat that gives you added stature and authority.

We, the patients, family members, and other concerned visitors, are babes in the woods in this setting. If we've been lucky in life heretofore, we find that visiting a hospital can be like stepping off a hijacked plane into a foreign country we never planned to visit. Few things look familiar. We don't fully understand what we're being made to do. We don't speak the language well enough to communicate with those surrounding us, and we're not certain how friendly they are or what might provoke them into hurting us or our loved ones.

The signs we see don't mean much to us—the few words we recognize tend to scare us more than anything else. We don't know how to interpret the various "uniforms" people are wearing, other than the white coats we're all familiar with. Quite a few of the busy people moving with confidence around us have the aura of authority figures, no matter what they're wearing. When it's our turn, they focus on us or our loved ones, freely taking samples of blood, attaching instruments, probing private body parts, and asking intensely personal questions. But they don't really say much at all directly to us, and they don't seem interested in a lot of what we try to tell them. We're left feeling confused, humiliated, and somewhat stupid. Obviously, we're not astute enough to figure out what they want us to tell them. Why couldn't we remember everything we'd eaten or taken in the last 24 hours? We failed the test, and the consequences could be life threatening.

I am not exaggerating the situation. Last winter, my husband—who had some chronic health issues but was still able to hold down a demanding job and carry on a fairly normal life—was taken down by a nasty anonymous virus that attacked several major organ systems. We thought it was a bad case of the flu. I only took him to the emergency room because his weakness failed to pass in a few days and listening to him struggle to breathe scared me badly. It was the doctor's answering service (not the doctor on call, who never returned my call) that advised me to take him to the ER.

Within the first 24 hours at the hospital, I lost all ability to communicate with my husband when he was sedated and hooked up to a ventilator. For the next three and a half weeks, he lay unconscious, struggling for survival, and I lived on what his doc-

tors and nurses chose to tell me. And they weren't saying a lot that I could make sense of.

For one thing, as his condition worsened he was in the care of eight specialists. Each would tell me something different, and I wasn't equipped to put all these pieces of information together in a meaningful way. For example, early on, I heard the following statements from different doctors all in the same day: "He has a virus." "His lungs are in really bad shape, and he could die." "There are some indications he had a heart attack." "His kidneys are failing, and he's going to need dialysis."

I knew that viruses can kill people. I knew that my husband was considered a high risk for heart attacks and that his lungs had been compromised by years of smoking. But I could not fathom how all of these things were related, let alone what was causing the kidneys to fail at this particular time. It took a very long time—days, maybe a week or more—before I had both the courage and opportunity to pester my husband's infectious disease specialist with so many questions that he explained that the virus had attacked the heart, lungs, and kidneys and that most of what we were seeing was the aftermath of that battle.

This same doctor also helped me by shedding light on why the brief reports I was receiving from different specialists often seemed, to my layman's ears, to contradict each other. (One day the cardiologist told me, "His heart's basically in pretty good shape." Yet, a scant hour later, the pulmonary specialist informed me, "He's getting worse. He could die.") Each specialist, he told me, tends to focus on the area of the body he or she specializes in, not the patient's overall condition, and their comments reflect that narrow focus. How long would it have taken me to figure that out, if not for this man?

A lot of the frustration I felt as I chased after valuable tidbits of information about my husband's condition could have been alleviated with just a few words. Some days it would have been enough just to have had my anguish acknowledged with something as simple as "I know you're frustrated and tired of hearing that we have no clear answers. Believe me, we want a better understanding of what's happening to your husband, too."

Aside from having to assemble the comments my husband's many doctors gave me into a comprehensive picture, I grew very weary of trying to catch these men and women as they came through on their rounds. Some routinely came through the ICU before the start of visiting hours each day. A

few had no discernable routine at all—I was as likely to encounter them at 8:30 p.m. as at 3 p.m. or 10 a.m. Yet if I was not at my husband's bedside or in the ICU waiting room, I'd get no report from them that day. This system forces the family to forgo any semblance of a normal life. In my case, there were no other family members with which to trade off this vigil, so I missed doctors whenever I went home or out of the room for a bite to eat.

I do not believe that our local hospital is unusual in any of these respects. In talking to people in other parts of the country who've been through a hospital experience, I have heard similar complaints voiced over and over.

And I do not question the quality of the medical care my husband received. As far as I know, everyone involved did their best to save him. Sadly, they did not succeed. Doug died on March 16, 2005, after five and a half weeks in the ICU. Many very good-hearted, caring people worked on him during that time.

But some, though pleasant, didn't go out of their way to help me one iota. The day my husband started waking up after 25 days in a comalike state, I was in a funk and had found excuses to stay home until midafternoon, figuring there'd be no change in his condition. When I finally dragged myself into his room and spoke to him, I was astonished to see him react with a very slight head movement. Overjoyed, I immediately informed his nurse that he had responded to me, and she replied with a smile, "Yes, I know. He's been responsive all day!"

Now, these people knew that I'd been hovering at his bedside for 25 days, anxiously waiting for him to wake up, pestering them about why he wasn't and asking what was wrong. Did no one think this development worth a phone call to me?

Since my husband's death, I have heard that some hospitals have patient advocates and hospitalists, but my impression is that a fairly small percentage of hospitals have invested in these types of positions. And I question how well one or two such people in a hospital full of sick patients can help everyone who needs their services. It was hard enough for me to connect with the one woman in our hospital who, during the short time my husband seemed to be on the way to recovering, could help to arrange his transfer to a long-term care facility.

My point is, the system that is routinely followed in most hospitals—the system that determines doctors' routines, the system that causes

health care workers to tend to treat patients and their families more like objects than human beings—does not do service to those it was set up to serve.

My point is, when it's everyone's responsibility to communicate with a patient's family, it winds up being no one's responsibility. Hospitals need to assign this responsibility to a specific person when

a critically ill patient is in the care of a team of specialists.

My point is, please think of us wandering lost and scared in that foreign land you call home the next time you encounter one of us there.

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