

A Hospital Stay: Lessons Learned

About 7 months ago, my wife went to the hospital for "routine surgery." She was supposed to be there one or two days. The routine surgery turned out to be what the hospital called an "adverse event," and what I called a botched surgery. In any case, my wife spent 6 weeks in the hospital.... in critical care, surgical care, skilled nursing and home healthcare. Fortunately, she recovered and is living a healthy life.

I thought I knew everything a family member of a critical patient could know about how to navigate the hospital setting. After all, I have taught TIP volunteers about how to help family members of injured patients in hospitals, and as a mental health counselor I listened to many clients' stories about their hospital stays.

But there is a difference between knowing and **KNOWING.** I knew, theoretically, and from afar about the experience of family members of critically ill patients. Now I KNOW from firsthand experience. The fact is... neither my wife nor I was prepared for our journey through the healthcare system. We were strangers in a strange land.

Much of the stress of our hospital experience came from the fact that we didn't know what to expect. We didn't know the buttons to push to get things done, and we stressed about things we had no control over. We were like a couple going hiking without knowing the territory, without the proper clothing and without the physical stamina required. Because we weren't prepared, we felt out of control for most of the time during those 6 weeks of my wife's hospitalization.

I guess you can never be totally prepared for a crisis in your life. But my wife and I are now better prepared for future hospitals stays involving ourselves or others. We now know what to expect. Below, we share what we have learned so that you have an idea of what to expect if you or others you know are hospitalized.

We share these lessons humbly, knowing many of you have been through what we have experienced, and maybe worse. And we know that many of you are much more familiar with the healthcare system than we are. But for the uninitiated, here you go...

- **EXPECT** to feel helpless...because you are. You are no longer calling the shots. You are now a bit player in your own life.
- **EXPECT** a hierarchical system in the hospital. You will interact with many people in the hospital, but there is only one person who is calling the shots. That person is called **THE DOCTOR.** Nothing happens without doctor's orders. Be nice to the doctor.

- **EXPECT** to see PAs (physician's assistants) much more than the doctor. You will need to advocate to see the doctor.
- **EXPECT** to wait...wait...wait. Some waits are excruciating. My 6 hour wait during what I was told would be my wife's 2 hour surgery were the worst hours of my life. Other waits are just very irritating. The hospital system moves at its own pace. You or an advocate can try to nudge it along, but mostly you will just have to practice patience.
- **EXPECT** the possibility that hospital personnel will make mistakes. If something doesn't sound or look right, call "time out" and insist on getting an explanation.
- **EXPECT** to have to set limits. I had to firmly say NO to hospital personnel when they insisted that I (exhausted and traumatized) use a computerized feeding machine to tube feed my wife at home on a 24/7 basis.
- **EXPECT** to have many hospital personnel come and go (chaplains, social workers, doctors, nurses...) Get their names and contact information. You never know when you will need to call for their help.
- **EXPECT** to be contacted by the hospital's patient ombudsman. If they do not contact you, contact them. They can be very helpful, as they were in our situation.
- **EXPECT** to encounter many wonderful healthcare professionals. Express your appreciation. They have tough jobs. Every day they deal with stressed people who are scared, angry, depressed and demanding.
- **EXPECT** an avalanche of paperwork, bills and administrative tasks that come along with being in the healthcare system. Expect these demands to keep on coming long after you have left the hospital.
- **EXPECT** a bumpy road. Take one step at a time.
- **EXPECT** other life stressors to continue during the hospital stay. Life doesn't stop because you or a loved one are in the hospital. In our case, I had to put our dog down a couple of weeks into my wife's hospitalization.
- **EXPECT** the unexpected. No surgery is "routine". I should have had someone with me during my wife's "routine" surgery.
- **EXPECT** physical and emotional healing to take longer than you think.
- **EXPECT** family members to have a clearer memory of the hospital experience than the patient. I remember everything. My wife remembers little. ("I just survived minute by minute.")

The individuals who work in the healthcare system are caring professionals. But the healthcare SYSTEM is a "monster" which churns at its own pace with its own goals and mandates. The danger is that individual patients and family members will "fall through the cracks," and not get their needs met. The key to survival in this system is to SPEAK UP: LOUDLY...PERSISTENTLY...AND NICELY.