Transitions

Over the past 4 years, I have been hospitalized approximately 20 times due to a staph infection that I acquired in the hospital in 2007. I soon learned that transitioning from the hospital to the home was NOT automatic and easy, as I had always expected it to be, but rather that it required my careful attention and guidance in order to accomplish it effectively and safely.

After numerous hospitalizations, I eventually became an expert in making sure that everything went smoothly during such transitions. However, I believe that a patient should only have to worry about regaining his/her health, and should NOT have to be in charge of ensuring a smooth transition to home care following discharge from the hospital. On the contrary, I believe that the hospital staff and the patient's care-givers should be in charge of such transitions.

Below are a couple of examples of transitions from inpatient hospital care to home care that I experienced from 2007 to 2011.

Bad Timing

After being in the hospital for approximately two weeks (after learning that I had acquired a staphylococcus infection during surgery), I was getting ready to go home. This was the FIRST of my 20 hospitalizations, in 2007. The doctors had inserted a PICC line so that I would be able to continue to receive antibiotics intravenously at home. I was petrified. I had never had to deal with an IV at home before, had never had to give myself intravenous medication, and had never had to care for a PICC line. I lived with my mom, and knowing that I was not alone at home provided me with some comfort, but my mom was terrified too! This was all so new to us. And the hospital staff did not handle this first transition well at all.

First of all, the doctors and the hospital staff told me at 4pm that day that I was being discharged a half hour later! I had previously told them that given all of the new information that I had to learn (about the PICC line, etc.) that I wanted to be discharged in the MORNING, so that I would have plenty of time to get home, meet the visiting nurse from the home health company, learn what I needed to do regarding my intravenous medications, and get to bed at a decent hour. Keep in mind that I was in a LOT of pain practically every hour of every day, and doing simple things like talking to someone, brushing my teeth, even sitting up in bed, ALL took INCREDIBLE EFFORT. That is why we had told the hospital staff that if we had to deal with the PICC line and intravenous medications at home, that we would like to be discharged in the morning, not at night.

Apparently no-one got the memo, because my nurse came into my hospital room at 4pm that day and told me I was being discharged. I had been in the hospital for almost 3 weeks at that point, so my mom and I had a LOT of packing up to do! Hospital staff does not realize that patients try to make the hospital room like home! We had paintings on the walls, stuffed animals everywhere, candy and potato chips on the table, pajamas and robes in the closet, and toiletries in the

bathroom. The staff did not give us enough time to pack up. We felt rushed the whole time. Then someone from the home health company came in and gave me a ridiculously brief demonstration about how to operate, deal with, and clean, etc. my PICC line. The presentation was way too short, and way too rushed. I wished she had given me a DVD to watch the DAY BEFORE I was discharged, so that I could watch it with my mom and then ask questions when she arrived the next day. I was also extremely STRESSED about the fact that I was due for another dose of antibiotic at 8pm that night, but I had NO IDEA who was going to be coming over to my house to help me administer that dose. The nurse at the hospital told me that a visiting nurse would come over every day until I got the "hang of" dealing with my PICC line at home by myself. But when I asked who would be coming over that night and at what time, all that the nurse said was: "Don't worry about it. Someone will call you and come over tonight." Then I said: "But it's already 4pm now, so how do you know that the visiting nurse from the home health company will be on time? My antibiotics have to be administered at 8pm, and that's only 4 hours from now, and I have not even been discharged yet." The nurse assured me that "everything would be okay" but she did not provide me with ANY information that would actually lead me to BELIEVE that everything would be okay! I didn't even know the NAME of the home health company, let alone the name of the nurse who would be coming over some time before 8pm to administer my antibiotic. In addition, the company that was to deliver the antibiotic was a SEPARATE company than the company that provided the visiting nurses, and nobody was able to tell me the name of the antibiotic/medicine company either! I just had to hope that someone would show up with a two-week supply of the antibiotics some time before 8pm that night!

My mom and I were worried all evening. And when 8pm rolled around, and NOBODY (from either the home health company or the antibiotic/medicine company) had shown up at our house, we were panicked. I was exhausted and was running a fever, and just wanted to go to sleep. My mom and I called the number listed on our discharge paperwork, and nobody answered that number. The nurse had told us that she was giving us the phone number of the nurse's station (on the floor where I had been a patient), so that if we had any problems we could call and talk to my nurse specifically, but that number was not a valid number. We had no idea what to do.

Thankfully, at 10pm, the drug company showed up with the antibiotics (that were supposed to be administered at 8pm) and a few minutes later the visiting nurse (from the home health company) showed up, apologizing that she was running late because of a previous client. She said that she had wanted to call me, but had not been given my phone number and so was unable to call me to tell me that she was running late. Why had the hospital not provided the home health company (and specifically my visiting nurse) with my phone number?

That was an EXTREMELY stressful night for me and my mom, as you can imagine. What are some ways we could prevent this fiasco from ever happening again?

(1) Allow plenty of time to make sure EVERYTHING is taken care of: if a caregiver is unsure if things can be organized in time for discharge in late afternoon or early evening, then postpone discharge until the following morning;
(2) Make sure the patient knows WHO the drug company is who is delivering medications or antibiotics to the home, including the company's phone number and address (and make sure the drug company knows the patient's phone number and home address);
(3) Make sure the patient knows WHO the visiting nurse is who will be there that night, and what company she is from, and the phone number and address of that company (and make sure that the visiting nurse knows not only the address of the patient but also the home phone number in case she gets stuck in traffic or is otherwise running late);
(4) Make sure that the nurses on the hospital floor provide the patient with an ACCURATE phone number or method to reach the nurses/doctors at the hospital in the event that neither the visiting nurse nor the drug company shows up at the patient's home when they are supposed to.

The above are just a few suggestions to make sure that a patient's transition from hospital to home goes smoothly and is as painless and stress-free as possible. The patient has enough to worry about without being even more terrified about things that should be taken care of ahead of time.

Lack of Preparation

Approximately one year after my health problems started, in 2008, I was given a total femur and knee replacement, and was in the hospital for a couple of weeks following this major surgery. I was very anxious to get home, but after all that I had been through, we ALL (me and my mom, and ALL my doctors and surgeons) wanted to make sure that I was 100% ready to go home before I was discharged.

However, despite this desire on all of our parts, somehow I was scheduled for discharge by a hospitalist, who was not even familiar with my care. The way the health care system works in the United States is that when you are admitted to the hospital, a "hospitalist" takes over your care (as opposed to your regular doctor or surgeon), in particular if you are in the hospital for more than a few days following surgery. This is what happened to me. And my hospitalist decided that it was time for me to go home, even though I had NO physical therapy regimen set up at home, NO visiting nurse ready to come to my home, and NO "hip kit" which I was told I would need in order to pick items up off the floor and to perform other basic tasks until my leg began to heal.

Once again, I saw the rush to send a patient home and get him/her out of the hospital without the proper preparation! This time, I appealed to my surgeons via e-mail, demanding that they arrange for my visiting nurse, my hip kit, and my physical therapy BEFORE my discharge from the hospital. My surgeons/doctors made sure that everything I asked for was taken care of. However, I know that MOST patients would NOT have questioned the hospitalist (the doctor in charge)

and would have suffered needless worry and confusion as a result. Care-givers at hospitals should not put the patient in such a horrible situation to begin with. There needs to be MORE COMMUNICATION among the patients doctors/surgeons and the hospitalists; and the nurses/doctors need to make sure that a proper post-hospitalization (at-home) care system is IN PLACE (including occupational therapy, physical therapy, etc.) PRIOR to discharge and that the patient UNDERSTANDS the plan following discharge and knows who to call in the event of any confusion or questions.

Common Mistakes, Common Sense

From my own experiences and from speaking to other patients and their families, it seems that many of the problems with transitions from hospital care to home care are a result of the following:

(1) Doctors/care-givers/hospitalists are too eager to get the patient out of the hospital, so eager that they neglect to make sure that all the proper "at-home-care" matters are addressed;

(2) The discharge plan does not address what to do in the event of a problem the VERY NIGHT of discharge (for example, what should the patient do if the drug company does not show up or if the visiting nurse does not show up?);

(3) The hospital staff does not give the patient all necessary phone numbers and contact info. (e.g. the numbers of the drug company and the home health company);

(4) The doctors/care-givers tell the patient that he/she needs to have occupational therapy/physical therapy, etc. and yet does not put this information on the discharge papers or set these appointments up on behalf of the patient PRIOR to discharge;

(5) The hospital staff/doctors/care-givers do not give the patient and his/her family adequate time to be discharged from the hospital—if a patient has been staying in the hospital for one week or more, chances are that that patient and his/her family have been practically living at the hospital, and have set up their "home" there (with photos/pictures on the walls, their own bedding and stuffed animals, books on the shelves, clothes in the drawers, and toiletries in the bathroom); and so to tell the patient and his/her family that they have to leave in one hour or less is not only unreasonable, but also HIGHLY STRESSFUL and UNNECESSARY. Nothing good can come out of such a rushed situation. Inevitably things will be forgotten, and questions will be lost. Nobody will feel prepared under such circumstances. A patient and his/her family need to be given at LEAST 5 hours' notice before discharge from the hospital, ESPECIALLY if they have been staying there for more than one week.