**Inpatient Rehab** - *Physical Therapy, Occupation Therapy, Speech Language Pathology, Respiratory Therapy*

I was moved via ambulance to inpatient Rehab on March 17, 2014. I was asked to tell in my own words what I knew about my illness. I told them what I knew. I didn’t know everything until I would read my medical records months later. They told me I would be having Physical Therapy, Occupation Therapy, Respiratory Therapy, and Speech Language Pathology. Most of my family was there in the room with me. It was a private room, all the rooms are private at this hospital which is nice. My son recognized one of the nurses, Kara. She was a friend was his from his teenage years. She had even been to my home during those years. She was a wonderful nurse. She would become one of my champions. Another one was Megan, one of my former Girl Scouts. She was a CNA. She asked if I was comfortable having her care for me. She would be helping with some intimate tasks, such as going to the bathroom and helping me get dressed. I said I was if she was. I felt safe when Kara or Megan were on duty. I had other nurses and CNAs who kind as well. Unlike PCU. I told anyone who listened about my bad experiences so far in the hospital. I had one male CNA that worked the night shift who was so understanding about my anxiety. Every time he made his rounds, I would be startled, because of my anxiety. He would respond, “It just me, Mike.” He was kind, and I felt safe with him, too.

The PT, OT, RT and SPT were all understanding. I went to the gym 6 days a week. The first day I made a promise to myself that I would work as hard as I could to regain my strength, and become as much of my “former self” as I could. My right arm and hand were still paralyzed, so I would be taught to dress myself using one hand. It wasn’t easy, because I had to use my left hand, my non-dominant hand. Try brushing your teeth with your non-dominate hand. I taught myself to open a juice box with one hand and even put the straw in it! I never mastered the milk carton nor tying my shoes.

I called my arm my “Bob Dole arm”, but few in the hospital knew who Bob Dole was. As I lifted my right arm with left arm, I would say, “This is my Bob Dole arm, except I wasn’t left for dead on the battlefield.” Gallows humor kept me going. The staff would look at me with a blank stare, and I realized it was a generational thing. My humor was lost on the young crowd.

Putting on a bra by myself was impossible though. (TMI) My feet were swollen, and the shoes David had brought to the hospital were a bit small to prior to my illness. I tried to describe a better pair that I had that I knew were a little big. The next day, he walked in with about 5-6 pairs of sneakers. He said, “*Do you realize how many pairs of shoes you have*?!”

“Yes, yes I do.” But he did bring the correct ones though.

Slowly, the use of my right hand did come back. The OT staff gave me exercises I could do them in room, and I would do them while watching TV after a day in the gym. One day, I tied the drawstring in my jogging pants with my good left hand and the pinkie and ring fingers on my right hand. I was so happy and I showed the staff, but no one seemed to think it was a big deal. At that time, I still couldn’t use my right thumb, index finger, or middle finger. I was reminded of the time when I was in ICU, and I told myself, “*You will need to be your own cheerleader*.” I was so happy when I could actually sign my name with my right hand again. There were times throughout my stay I had had to sign release forms, i.e when I was transported from one facility for a test, and I would have to sign with my left hand. My signature was a mess. My family cheered me on. They came to see me every day at the end of the workday, but the days were long.

PT worked me even harder. I would be taken to the gym 6 days a week. The first day, I was helped up to the parallel bars to try to walk. I could only hold on with one hand since one hand was paralyzed. I did walk 4 steps then my legs turned to jelly. I cried. No one said ‘good job’. I said “good job” to myself. More exercises of various kinds followed. Over the 2 ½ weeks I would be there, I did exercises, then learned to walk with a walker, and walked up and down stairs (more like dragged myself up and down stairs). I was still in a lot of pain. My nurse, Kara, suggested taking a pain pill before I went to the gym, and that helped. Some days I could keep my spirits up and some days I went back to my room and just cried. The staff would measure how far I had walked each day, using the walker, and I asked them to write it on the dry erase board in my room. I would show my progress to my family when they visited each day. Most days, I walked further, not always. I wondered why they didn’t suggest it. “*You will need to be your own cheerleader*.”

SLP worked on teaching me to relearn to swallow. After having the tracheostomy, I couldn’t tell if food and liquids were going the right way, stomach or lungs. I know it sounds weird, it sounded weird to me, too. I still had a terrific cough from the pneumonia. I had several swallowing tests. They would have me eat or drink different things and watch which way it went down. It was like an x-ray. I failed the tests several times. I was given exercises to do, and I could do them while watching TV in my room. Because of swallowing issues, I was limited on my diet. I had to drink thicken liquids. They were the consistency of honey. The speech therapist told me it didn’t have a taste, but it did. It was hard to swallow and didn’t quench my thirst. I was allowed popsicles. It was wonderful when I finally passed the test, and I could have a big glass of ice water!

I also saw a respiratory therapist. She would check my trache stoma for infection and making sure it was closing, as well as changing the dressing. I would have to hold my hand over the bandaged area where the hole was in my neck whenever I needed to speak. I wasn’t ready to look at the hole in my neck just yet. She gave me some exercises to help strength my lungs. I could do those in my room.

I knew my hair was falling out. I couldn’t ignore it every time I brushed my hair big clumps were in my hands. I asked the nurses and my doctor, and all I got was “huh”. But of course, they knew that a critical illness causes hair loss. I don’t understand why someone didn’t address that with me. I wasn’t aware. I did not have chemo, so I wasn’t expecting it. I would go on to lose most of my hair, not all, but it would become very thin. It did grow back after about a year. But it was grayish-white now. Reflective of what I had been through.

Meals were sometimes an issue because of my previous six jaw surgeries. I didn’t fit the typical patient. Once a day, dietary would come to the room and had a menu of two choices for the next day. The meals weren’t too bad for hospital food. I could choose foods that were easier for me chew with my jaw issues. However, the evening snack was always a turkey sandwich. My jaw would allow not me to chew any poultry (turkey, chicken, etc). Their response was that I wouldn’t get a snack in the evening. That was unacceptable. I sternly said, “I’m paying a lot money for a snack. I should get one. I can’t help that it that I have special circumstances.” So we settled on an orange and a carton of milk. Hmmm, not too difficult to prepare.

And then there was Nurse Gordon. He walked into my room, never introduced himself, but anytime someone entered my room, it startled me. His first words to me were, “You have a lot of anxiety, don’t you?”

I answered, “Duh, do you have any idea what I have been through?”

He wanted to give me Miralax which I refused. I had had trouble controlling my bowels the entire hospital stay. I had even been yelled at for messing the bed while on PCU while I was completely paralyzed and unable to ring for a nurse. I was wearing diapers at this time. It was 10:00 am and I had gone to the bathroom 4 times already. He wanted to give me a laxative. I had been refusing it from the other nurses without incident. Next thing I know he got the doctor, and the doctor is arguing with me. Really? I again said, “It’s 10 am. I have gone 4 times already. I can’t make it to the potty. The nurses have to change my diaper. How many times do you want me to go??!! Please go ask the nurses.” I never was asked to take to Miralax again. But Gordon was not done with me.

Every morning before breakfast, a CNA would prick my finger and test it for blood sugar. In ICU my blood sugar was crazy (typical for a critical patient). But I had not needed insulin since I was admitted to rehab. They were still testing me daily. Gordon insisted I needed to be tested after meals. I didn’t realize at first what he was saying, so I agreed to the injection. Within an hour or two, I became faint and started dry heaving. I became really ill, especially since I am not diabetic. After I felt better, I realized I shouldn’t have taken that insulin. Gordon wanted to give me more insulin later in the day. I refused. He told me I HAD TO TAKE IT. I said, “Oh no, I don’t! I can refuse a medication anytime I want!” and then, I said something I know really angered him, and it was meant to anger him, “You are NOT going to turn me into another Sunny Von Bulow.” I’ll let the reader google who she was. Gordon left my room in a huff.

Later that evening I rang for someone to help me to the bathroom. I still could not walk, could not stand up by myself. I was still getting therapy on my right arm. It was painful to use it. (A little background on that arm. About 6 years prior, I had had two surgeries on my right shoulder to repair an injury when I fell down some stairs. It never healed completely. It still bothers me to this day. I use a TENS unit to control the pain.) David and my daughter-in-law were visiting. Gordon and a CNA came to help me. He asked where my walker was. Why wasn’t I taking myself to the bathroom. I told him I couldn’t walk. He had been my nurse all day now, there was a sign above my bed stating I couldn’t walk, but he insisted I could. I could assist myself somewhat into the wheelchair, but he didn’t like the way I was doing it. He yelled me. I sat back into the bed. I realized something bad was going to happen. Then he insisted I was doing everything wrong. I told him I was doing what PT had told me. I had been in rehab two weeks by this time.

He yelled at me to look in the mirror. I wasn’t ready to look at myself in the mirror. I had yet to look at myself. He continued to yell at me, until I complied. I was completely shocked. I was so gaunt. My eyes were sunken and I had dark circles around them. I had a hole in my neck from the tracheostomy. There was no bandage on my neck by this time. I had very hair by this time. I looked like I was out of a horror film. (David would not allow anyone to take photos of me while I was hospitalized.) I fought back the tears. How would I ever be **me** again?

Suddenly and without warning, he grabbed my right arm - the arm that was been paralyzed, the arm that I was having therapy on, the arm that I had had two previous shoulder surgeries, and still suffered pain prior to my critical illness, the arm that I had trouble lifting over my head, and suddenly in one swooping painful motion lifted me by that arm only into the wheelchair. I screamed in pain. My legs dangled underneath me, bc they weren’t used to supporting my weight just yet. My daughter-in-law gasped. My husband jumped up to assist to me. He took over helping me to the bathroom. Gordon left the room. My husband left the room and went to the nurse’s station. I was crying. In one horrible motion, my trust was broken. Gordon and his CNA (who followed him around like a puppy-dog) were smart-alecky to my husband. There is always a fine line – if you say too much they will retaliate against the patient. Later, I talked to the charge nurse. At first, I was told there is no one in charge on the weekends. I knew that was a lie. I threatened to call 911 and report a assault. So the charge nurse decided to listen to me instead. I had him switched from my care. But I slept with the telephone that night.

 The next day I called the Director of Nursing to report the incident. The first thing he said was there would be no retaliation. I knew that wasn’t true. Just the same, I told him what happened. He also talked to my husband. I’m sure he talked to Gordon.

Dietary would come every day and give me choices for the next day’s meals. With the chaos of in the incident, I didn’t notice, they hadn’t come in the next day. That morning, not only did I not have my morning tea (how hard is a hot cup of water and a tea bag, no sugar?), but I had two things with Nutrisweet which I am allergic to. I burst into tears. I never could prove it, but I knew the retaliation had started. I was so angry. I called the Director of Nursing and left a message. “YOU LIED! You said no retaliation. I have a breakfast with items I am allergic to! There is nothing I can eat except a tiny juice box!”

Suddenly, the DON was there. He tried to tell me I had to eat the breakfast tray, bc of my diabetes. Again, with the diabetes? I tried to tell him I didn’t have diabetes, and added that Gordon that was trying to make me into another Sunny Von Bulow. He said he was insulted (he knew who Sunny von Bulow had been). I said good, I meant it as meant as an insult. But I also meant it as the truth. Then, my nurse, Kara, came in and told the DON, I was NOT a diabetic. The DON realized he had told the wrong info. The DON then called for a new tray and told me I could have anything I wanted. He also apologized to me. An apology! A rarity in the hospital. He knew who was telling the truth.

I quickly realized news of the incident spread through the unit. Another nurse who looked similar to Gordon came into my room. I jumped. My anxiety was rampant. He immediately said, “I’m not Gordon! I’m not Gordon!” He treated me like gold. I had had him before. Mike, the kind CNA, would massage my shoulder (not in a creepy way). OT put heat on shoulder trying to ease the pain. But I kept my guard up double time at that point.

During the entire rehab stay, I would ask my rehab doctor about the ovarian cyst, Who was I going to call after discharge? As usual, he never answered me. The ovarian cyst had not been mentioned since that one day in ICU. Now my discharge date was nearly here. My smart-alecky-ness kicks in here and I said, “What am I to do about my ovarian cyst once I’m discharged?”

He started to walk out of the room. I called him back, and asked again. I got a bit forceful this time, “What am I to do about my ovarian cyst once I’m discharged, bc I would hate to DIE from an ovarian cyst!”

He answered me, “The first time you see your PCP, remind her, and she will set you up with someone.”

I responded with, “Was that so hard to answer my question? I don’t get it” I was so done with doctors at that point, especially ones that won’t answer my questions.

Interestingly, the ovarian cyst wasn’t even mentioned on my discharged papers. Had I not overheard the two doctors discussing it in ICU, I would have never known about it. I never had symptoms.

Before my discharge, I had the port for kidney dialysis removed. The surgeon removed it in my room. It took about an hour and was rather overwhelming Nurse Kara was with me. She kept me calm throughout the process.

I went home in a wheelchair and on oxygen. I still couldn’t get from a sitting to standing position by myself. My husband had bought car ramps like the ones used to get a lawn mower into a pick-up truck, and that is what he used at our kitchen door until I could walk up and down the steps. I only needed to maneuver three steps. I still had significant pain. But like Dorothy in Wizard of Oz, I was home!!

**Home Health and More**

I had six weeks of home health. I signed up with the company my daughter worked for. She worked for the hospice department, but it also had a home health department. She said that way she would know who was caring for me. There was never an issue. David took a month off from work to stay with me. The fifth week, my youngest son came from Atlanta and stayed with me. The last week, I was able to stay by myself during the day.

One day, David took me into the backyard. I was still in the wheelchair, so it wasn’t easy for him. He wanted to show me something. The backyard was full of wild violets! He had asked our lawn guy to not mow the area where the violets were. It sure did make this old Girl Scout’s heart sing again.

Over time, I did get off the supplemental oxygen. I went from a wheelchair to a walked to a cane to walking independently. Some fine motor skills are still difficult such as a ziplock bag. But I do most everything I did before my illness.

One year after my discharge, I had to have the Greenfield filter removed. That was high anxiety. I was not sedated, oh they say you are, but…. The doctor was not understanding about PTSD, and he was rather abrupt. Thankfully, the nurse was kind. The doctor told me I couldn’t have the Greenfield filter to keep, but the nurse slipped it to me under the sheet. I have it to this day.

Two years after discharge, I had the ovarian cyst removed. I had to wait until I was strong enough for surgery and general anesthesia. During that time, I had scans to watch the growth of the cyst. Interestingly, the first time I saw the GYN oncologist, I recognized her from ICU and that conversation at my bedside discussing my ovarian cyst. That told me I had indeed come out that the coma sooner than the doctors realized. I couldn’t speak, bc of the trache. She was a very kind doctor as was her staff. I was so anxious when I went into surgery. It turned out the cyst was a tumor, but it was benign. It does anger me that it never made onto discharge papers. What if I had never been awake enough to overhear the two doctors talking about it in ICU?

I discussed many of the things that had happened to me while hospitalized with my PCP. She diagnosed me with PTSD. Later when I would read my medical records, I would read another doctor also diagnosed me PTSD. However, the hospital doctor’s answer was to give me anti-depressants. When that didn’t help, they gave me another, then another, until I was on four – all at the same time! Not one doctor asked me why I was afraid. I could have told them. Why would they not send a therapist in to talk to me, instead of taking my communication board away?!

My PCP realized, as did I, that anti-depressants were not what I needed. Together, we worked to wean me off of all them. I am no longer taking any of them. She recommended a therapist instead. The first therapist was a bust. (If I just converted to her religion, I would be fine.) So I stopped seeing her, and found someone else. I saw him for several years, until insurance issues require I change. Now I see another equally good therapist. I’m not against anti-depressants, but they are not for me.

My PCP, Dr Polk, told me in regards to PTSD – “***You fought your own war***.” I have repeated those words to myself over and over. Too many times, people think PTSD is only for soldiers. It can happen to anyone who has faced life threatening circumstances.

I am thankful for this blog and letting me tell my story. I had asked one of my ICU doctors about talking to residents, nurses, etc. He told me my story “had no teaching value” (even though he spent most of my visit teaching his resident about my case). He also said I was a miracle, and then said he “didn’t believe in PTSD” (is it like Santa Claus?) and I needed to forget about my ordeal. When he said that, my husband spoke up and told him he had PTSD as well from being a Vietnam combat veteran. He said, “I had a man shove a gun in my mouth yelling at me in language I couldn’t understand. To this day, I can still taste the gun metal. It has taken me 50 years to have peaceful nights’ sleep. Don’t tell me there is no such as PTSD.” The doctor said nothing else after that. We left his office and never went back.

Some other health professionals have called me a liar (I couldn’t have survived what I did), told me the devil caused my illness, called me a freak, bc I survived, and I hallucinated my illness (that was a resident. I told him I guess I donated a half a million dollars to the hospital). I did not continue seeing these ‘health professions’.

I was interviewed by Vanderbilt University Medical Center about my illness. They treated me kindly and were glad to get my story. I am scheduled to participate in a study for the University of Pennsylvania.

Over the years, I have stopped telling doctors about my medical history unless I deem it necessary. It’s there in the computer if they decide to read about it. I have had some ask me about it, and then I will tell them. I’m surprised when they have actual read my chart.