***PCU Progressive Care Unit* 8/16/2022**

I was moved to *PCU Progressive Care Unit* on March 8, 2014. Since I was improving, things changed with my family visits. My youngest son was living in Atlanta and had his own business. He was not able to leave his business and come to Virginia. I knew that, so I didn’t expect him to be there. He would spend a week with me after I came home. David returned to work half days. My older son lived in town, but he had started a new job. He would come to the hospital after work. I did know that hospitals gave him anxiety, so he did other jobs that needed to be done. He would mow our grass at the house, take the cars to be inspected, go to the grocery store, etc. His then wife visited often. They also had two young children to care for. My daughter had a newborn and a two year child, so she had her hands full. During my hospitalization, she also returned back to work after maternity leave. She came to the hospital as much as she could, as did her husband. David worked half-days. He was about a year away from retirement, so he was trying to stay on good terms with his workplace. He thought about how much this long hospitalization was going to cost, as did I. We needed our health insurance. We had always been fortunate to have good health insurance. I tried not to worry about what this hospitalization was costing as I lay in the hospital bed, but it was hard not to think about the medical bills. As it turned out, our insurance paid for the majority of my care. I was fortunate.

PCU turned out to be a nightmare. The first thing said to me by a nurse when I arrived on the unit was “**We don’t know how to take care of you with a trache**.”

I was terrified. I had a tracheostomy breathing for me, I was being fed by a tube in my nose, my legs were paralyzed, my right arm was paralyzed, and I had a port for kidney dialysis. I wasn’t currently getting dialysis, but the doctor would tell me they didn’t want to remove it until they were certain it wasn’t going to be needed. It wouldn’t be removed until 2-3 days before my discharged. However, the trache was breathing for me. I would have it for about 6-7 weeks. I wasn’t even able to roll over on my own. I would have to wait for someone to reposition me when my body would get tired as it lay in one position. I was too weak to ring for a nurse. I could move my left arm, but it was so weak. I would have to hold a marker like a two year old with my fist. It was painful to write. The nurse would take my writing board away often, especially when my family was not there. My family tried an IPAD board, but I was too weak to push the keys to write.

My trache would be downsized that first day on PCU. It was a painful process. There would be several residents watching. One doctor held my hand while it was downsized. She was so kind. I was scared since not only was the process painful, but he was messing with my airway, He instructed a nurse to tape the trache, but the doctor had left the room. She taped my neck in its entirety from chin to chest to behind my head. I wanted David to take a photo, but he refused to take any photos of me until I was discharged. He told me later, I looked like I was 100 years old – I looked like death. It upset him too much to take a photo. I wish to this day that he had. He forbade our children to take any photos either. But the way my trache was taped needed to be documented, even in my weakened state, I knew it needed to be photographed. David regrets that now.

The next day, my doctor yelled at the nurse at the way my trache had been taped and told the nurse to fix that now! What doctors don’t seem to realize when they do that, the nurse will take it out on the patient. After the doctor left, she yanked the tape off my neck with a vengeance. There is a glue removal that should be used and most of the nurses would use that except this time. I couldn’t protest or even scream, because of the trache. I know I cried. I told my family later, and they told my doctor.

My trache would need to be suctioned on a regular basis. My lungs would fill with fluids, and I was constantly coughing. When my coughing would get really bad, the nurse would come and suction my trache with a long tube into what felt like the bottom of my lungs, first one side then the other. I had a suction device like a dentist has that I could use to suck the mucus out of mouth. My hand was too weak to turn it off and on, so it ran constantly. After a few days, it became clogged due to the amount of mucus. When it clogged with mucus, I was given a new one.

My trache would need to be downsized several times, but the issue with the tape didn’t happen again. However, the nurse I had for some reason had great distain for me. I can still see what she looked like – attractive, blonde, blue-eyed, but she had a cold, dark heart.

I had a swallowing test, and I was allowed pureed foods instead of being fed through the nasal tube. However, I was still paralyzed. I could barely move my legs. The nurses would put large boots on my feet to prevent foot drop. There were two types. One was similar to ski boots, but they were padded. They made my feet very hot and sweaty. I knew what they were for, but eventually I would have enough of them, and by this stage of my hospitalization, I could move my feet back towards my body, not against my gravity. When I was tired of the boots, I could wiggle out of the boots. My shoe size is small, Even the nurses mentioned how small my feet are. I guess I kept them on long enough though, I do not have foot drop. I had another type of boot that was stiff and had a dial on it. They could change the dial to tighten it. I couldn’t wiggle out those.

 I couldn’t roll over on my own. My right arm and hand was completely paralyzed. The right hand was drawn into a fist. As I lay in the bed, I worked on my hand myself. I slowly started straightening my pinky, then my ring finger. Those were the two fingers I could move first. To lift my arm, I had to reach over with my left hand and grab my right arm or hand and move it. It was just dead. The middle, index and thumb of my right hand were so stiff and didn’t want to cooperate. No one came to help me with my hand. I asked, but didn’t get an answer.

The food tray would be left outside my reach. I only could eat when my family was around to help me. The nurse would yell at me for not eating. “If you don’t eat, I’ll have to feed you through your nasal tube, and that gags you.” I thought, can’t she see the tray is not within my reach? I couldn’t speak because of the trache. I’ll never understand her distain for me.

My eyesight was so blurry and I realized I didn’t have my glasses. I had a picture board. I could point to common items that I wanted – food, water, cold, etc. I was trying to find the photo of eyeglasses on the picture. But the board was blurry. I had one person in my room, I believe he was a resident, of course he never told me his name or who he was. I took my left hand, and pointed to my eyes. Then I took my thumb and index finger and made a ring around my eyes. I went from one eye to the other. I pointed to my eyes. The ‘resident’ or whoever, grabbed the picture board hatefully said, “I don’t know what you want!” and he tossed my picture board across the room like it was a frisbee. Now I have no communication. No glasses. I never saw him again. I finally got my glasses when my family came to visit me later in the day. I even slept in them for fear someone would not give them back.

One day when my husband stopped by a fast food place before coming to see me, he saw a small group of people that I would described as a religious cult. There were about 7-8 of them. David had worked with one of the men. I knew one of the women from Girl Scouts (although she wasn’t allowed to speak to any men outside the small group of the cult). One of the men announced that the “pastor” had been to my ICU room to see me. David was stunned. No one at the hospital had called David for permission for this man to be in my ICU room. There was a list of visitors allowed to be in my room and that was my immediate family. David let it slip to me when this so-called pastor visited me on ICU. So many emotions flooded over me – anger, fear, terror. Why was this strange man coming to my ICU room while I was in a coma!! The hospital admitted he was allowed in. They said anyone who says they are a pastor, is allowed in a patient room, no questions asked. My daughter wrote a HUGE sign for my door that NO ONE was allowed in my room without the family’s permission. She also instructed the nurses that no one was allowed without permission. I still felt completely vulnerable though. I had been in a coma, unable to speak, and paralyzed! My first memory after waking from the coma was being naked from the waist down. My mind raced, was I alone with this stranger, what did he possibly do to me, did he touch me?! These were questions that were never answered by the hospital. Once I could communicate, I wrote to my doctors a complaint about it, and they took up for him! I really felt scared then. I told the nurses and every doctor who came in my room and they all defended him against me!! I will never feel safe in a hospital again. I couldn’t sleep in the hospital for fear he would return. The doctor wrote in his notes on chart, that I was fearful and afraid. But he didn’t ask why. His answer was to give me antidepressants. Before I was discharged, I would be prescribed 4 different types of antidepressants! To be clear, 4 different antidepressants all at the same time. They wouldn’t listen when I would tell them why I was afraid. They all thought it was great that a male stranger off the street, not a hospital employee, unknown to me and my family, was allowed in my room. I was mocked to be afraid of this person, a stranger! I continued to tell them he is not a real pastor! Neither my family nor I had given permission for him to be there. I did not, would not, want him in my room! They did not protect me!! I will never trust a hospital again. I tell everyone, a woman is not safe in hospital. I’m embarrassed as well, since I used to work for the same hospital system, and I get a pension from the same hospital system.

Several hospital employees have tried to tell me that pastors can go anywhere they want within the hospital. This is not true at the hospital I was in. I have since spoken with one of the hospital chaplains after my discharge. He said the patient or patient’s family is the one who asks for a chaplain to visit. Chaplains are not to visit patients on their own. After I was discharged, I filed a complaint with Joint Commission of Hospital Accreditation. The patient never knows how that turns out, but the hospital must investigate the complaint. I do know the hospital admitted that the man was in my room. I have my nurse manager admitting it to me in writing. I had worked with her when I worked at the same hospital. She admitted it via email. I did hear through nurse friends that changes were made about pastor visits. However, eight years later, I still have nightmares.

After my discharge, my PCP helped wean me off all of four of the antidepressants. I have not taken them since. I was diagnosed with PTSD while still hospitalized, but their answer was to drug me. My PCP also diagnosed me with PTSD, but her answer was to send me to therapy. More on that later.

After I was discharged, I contacted the woman from the cult group and told her I didn’t appreciate her sending her “pastor” into my room without asking David, and how it terrified me.

Her response was, “Pastors can go anywhere they want in hospitals.” That isn’t true, first of all. The hospital policy is that patient or family has to ask for a pastor to visit. Pastors do not have the run of the hospital. (See above)

Second, it proved she did not take into consideration my feelings at all. If they had, he would have returned when I was conscious when I needed comforting, not when I was in a coma. He only wanted to give himself a pat on the back or worse his visit was nefarious.

Third, I said, “so, they can go into the Delivery Room, Operating Room, they can watch autopsies, etc.” Of course not.

Once I was discharged, this woman and her cohorts in Girl Scouts went on a campaign against me. They took me off mailing lists. I wasn’t invited to the adult Girl Scout events that I previously had been invited to for the past 30 years. Lastly, I was called into the main Girl Scout office and told I had never been an asset to Girl Scouting, etc. Rather strange since I received an honor from the CEO, the Unsung Hero Award for my Public Relations work I had done before I became ill. I received the award the same month I was discharged from the hospital. The Scout employee told me the award wasn’t leadership. She learned she was in the wrong and had to apologize to me, but the damage had been done. I resigned from that scouting area. I tried to go back to one meeting, but I could tell things had changed with the ladies and myself. One woman even asked me, **“Do you have any white light stories, because you almost died!”** then she laughed and laughed. I just walked out and never went back. I realized my illness was a joke to them.

A few years later, I was asked to return, but I refused. By that time, I was volunteering with my granddaughter’s troop 45 minutes drive away.

**Back to PCU.**

I thought I was on PCU about 1 ½ weeks, but I looked at my records, and it was 8 days. **Eight. Long. Days**. I truly think I would have died from neglect and/or incompetence had I stayed there longer.

They had a physical therapist that came in to help me into a standing position and also into a chair. She never introduced herself. But she always called me ‘Gigi’. Gigi is the name my grandchildren call me. I guess she thought it was cute, but to me, she was calling me Grandma. I didn’t like it one bit. It made me not want to cooperate with her. She was the only person during my entire 55 day stay who called me Gigi. I couldn’t speak to tell her NO! I would shake my head no, but she was clueless. As usual, I didn’t have my writing board either, another time the nurse had taken it away from me.

Early into my stay on PCU, I noticed my left shoulder was wet. I pointed this out to my nurse. She responded, “You wet the bed.” I thought ‘On my shoulder?!’ Really? I knew that wasn’t true, not on my shoulder unless I was a contortionist. I slept in a wet bed for days. The nurses insisted I was wetting the bed. Now if I was wetting the bed, why weren’t they changing the sheets? My sheets were not changed during my entire 8 day stay on that unit. Finally, my computer programmer husband discovered that my IV was leaking. The IV with Heparin in it, a medication to prevent blood clots. I had had blood clots in my legs on ICU and even had a pulmonary embolism requiring a Greenfield filter placement. Now, I wasn’t getting my proper dosage of medication. I wanted to scream, but I couldn’t since I still had a trache. My husband made his voice known.

One night I was in a lot pain, my family had told the nurse if I asked for my family to call them. Unfortunately, my 3 month old granddaughter had also been admitted to the same hospital with pneumonia. My daughter told me if she couldn’t come to my room, she would call her dad (my husband, David) for me. Around 10 pm, I wrote on my writing board for the nurse to call my daughter. She refused. I asked a second time. Then the nurse got in my face, nose to nose with me and said, **“Your family can’t be bothered with you.”** She then took my writing board away. Now, I have no means of communication. I wasn’t strong enough to ring for the nurse. I tried tapping out SOS in Morse Code. No one came. I knew that night I was going to die, and my family would never know what that nurse had done. I cried most of the night. I prayed that wouldn’t die. I wanted to tell my family what had happened to me. I was afraid I would not live through the night. I truly thought that night would be my last. It was the only time during my stay that I thought I would die. I wanted my family, bc I didn’t want to die alone. That nurse was blonde, blue-eyed, so attractive, but she hid a dark, cold heart. It was chilling.

Then, I did the unthinkable in the eyes of the nurse. I messed the bed. I had been incontinent since my admission. I wasn’t able to even tell when I was needing to go. The nurse yelled at me for messing the bed. After she yelled at me, she let me lay in my own waste for over an hour. I watched the clock. It was on the wall at the foot of my bed. Then she gave me an injection. I tried to fight it. I feared she would give an overdose. I thought, “This is it. I won’t wake up.”

Early the next morning, my daughter came in my room, and asked, “Where is your writing board?” she found paper and marker. I replied, “Nurse took it” My daughter then marched out to the nurse’s station and demanded an answer. Shift change had happened, so they didn’t know anything about the night before. My daughter then called the Director of Nursing. Next thing I know, David, the Director of Nursing, and my daughter are there. The Director of Nursing has already talked to the nurse. The nurse told the Director of Nursing that I had been **“difficult and demanding”.** My daughter was livid. She said, “Look at her! She can’t speak, she has a trache! She can’t walk, she’s paralyzed! She has to be fed by a tube in her nose! She still has a port for kidney dialysis! She can’t even tell when she has to go to the bathroom! She isn’t stupid, she has a Master Degree! She’s sick!!! She wanted her family, because she thought she was dying, and she didn’t want to die alone.” Then, the Director of Nursing responded with, “I like to think of this as a learning experience.” I was angry now. I wrote what I thought of the experience. I could tell she didn’t care about the patient. I never received an apology from anyone.

Next, my daughter called the Vice President of the hospital. Soon I have “three suits”, vice presidents of the hospital and assistants. I could tell they were important by the way were dressed. My daughter, David, nor I are intimidated though. My daughter and I both have worked in healthcare, My daughter currently works in hospice. David had been around the world in the Air Force and in Vietnam in combat. He’s not intimidated either. They stood against the wall as they listened to my story, I wrote it. But I could tell they were shocked when they saw me. No one had told them how ill I was. They weren’t used to seeing someone with a tracheostomy, nasal tube, port for kidney dialysis, paralysis, and by that time I was losing my hair, I had bald spots. The nurse had told them the same thing, that I was **“difficult and demanding**”. The “suits” realized they had been lied to. My daughter gave them my medical history from this hospital stay – coma, pulmonary embolism, sepsis, paralysis, failing kidneys, even calling organ donation. The fact that all I wanted that night was my family, and the fact the nurse had told me my family couldn’t be bothered with me, and the fact the nurse had taken my only means of communication.” The suits” never apologized, but the nurse was fired. Fired! I then got two very nice nurses who treated me especially kind, and two very nice CNAs as well.

This is why we call our daughter, The Little General.

My doctor had told me several times that I would go to a rehab center to relearn to walk. It was hard to believe him. I was still so very ill. He tried to reassure me, but I had so little trust in the healthcare system.

Several times while on PCU, I had my trache downsized until one day I had a trache placed with a button that allowed me to speak. I had to cover the button with my hand and then I could speak. At first, my voice was a mere whisper, but I could speak! I was so happy! I wasn’t mute anymore. When I had my last trache removed, the doctor asked me I wanted to keep the trache. He jokingly said, “you can hang it on your Christmas tree.” I shook my head yes. He wrapped it up in a paper towel and gave it to me. My family took it home. Later, I would run it through the dishwasher bc it was covered with blood and mucus. But I did hang it on my Christmas tree that year. I have included a photo.

The day before I was discharged from PCU to Rehab, a young man who may have been a resident, who never introduced himself to me or my family, came into my room and loudly announced to my family, ***“You need to pick out a nursing home, because this is the best she’s going to be!”*** He acted like I couldn’t hear. But I could speak by then and I responded to my family, “Don’t send me to a nursing home, I’ll die.” I’ll never forget how dejected I felt at that moment. His callousness was overwhelming. I went from feeling hopeful; because my trache had been removed, and I had been told I was going to a rehab center to relearn to walk; to once again I felt hopeless, and I was going to die.

Soon after he said that, my doctor walked in my room and ushered him out. He told me I was going to rehab and I would be brand new again. But my trust was broken again. I was cautious about who to trust.

At that point, I had been hospitalized 37 days. I was transferred on March 17th. I had just missed our city’s big St Patrick’s Day Parade. I was disappointed, bc it’s a favorite event, and I would have had a bird’s eye view from the 7th floor of the rehab center. But I did have a beautiful view of the city park. One of my favorite things to watch were the hook and ladder fire trucks as raced down the city street and rounded another city street before entering the interstate. They made calls several times a day. I got really good maneuvering my wheelchair to the window. It’s weird the simple things that will entertain one after being cooped up for nearly two months.

*Next Installment – Rehab: Physical Therapy, Occupation Therapy, Speech Language Pathology* Jane Garnett