

Thoughts About Being in the Hospital and Extended Care

These entries represent things I thought about and wrote about as I was trying to recover from leukemia (APL). Writing helped me get better because doing so required that I think about myself, who I love, what I believe, and what I accomplished. When I was really ill and struggling to get well in the back of my mind I thought that if I didn't recover, at least I had left my loved ones with memories.

Isolation, Particularly Leukemia

Thoughts I have about being isolated during leukemia. When you think about it you might appreciate going out to see friends, going out for a dinner, going to a movie, going shopping, watching your own children doing something fun or challenging, and when your activities are over you can return to where you live and relax. I think most of us don't know how it is to be an isolate, in a single room, in a hospital, and feeling worse than any flu, or cold, or even when you have a broken arm. With those things, you don't have to stay in the hospital and be isolated.

Treatment of Chemotherapy

It's somewhat like getting flu vaccination each winter to protect any of us who choose. It doesn't hurt right away but can make an individual's arm ache and be sore. That can last for one to two days but then it goes away. The length of time for the chemotherapy is far different from that. They give four large dosages that they divide into four "shots" and require you go into the hospital four days in a row to have it put into your body. It actually doesn't hurt when they are giving me the four "shots". In fact, the description of the Chemotherapy they are using with me has its description I can read that tells me when I should expect what. They call it Nadir and tell me my body will be there from 10-15 days. They suggest recovery comes at 21 days. What that means is that I can feel normal during the time they are putting it into me and then there it is. I am stuck just waiting each day for how my body is going to respond particularly my blood. They are telling me that my body is declining. In my head and heart, I feel like there is something wrong with our approach to health. Instead of doing things to improve us their techniques require them to attack and destroy us and of course, destroy the cancer along with our healthy cells. I would go back to the hospital on Wednesdays and they take my blood to determine what my body was doing. When I was at Providence Everett, they did the same thing and the outcomes that followed were horrendous.

I think it is essential that patients ask and record any questions they have about what medical situation is in front of them. My mom taught me that. We went to each meeting and I could ask questions that I had and record them so I could remember them. Sometimes when we are thinking about things we don't remember what was said. I think with medical needs not remembering something that might seem minor can over time be something you have to know, have to remember, and have to understand.

How I Think About Leukemia To Understand

Working with people who are great nurses in the MAC at Whidbey remind me of football fans. For football, we sit up in the stands and cheer for our favorite. We do that and we can watch it and imagine what it feels like. A player can take a hard tackle or have his body totally rattled when thrown down. We fans sigh and grip the moment watching the player and hoping he is able to get up and move effectively again. We think we understand disappointment, being hurt, and we applaud a player supporting them when they are down and out. I have been a typical football fan my whole life. I believe that my brain aneurism and my leukemia, as well as trying to recover along the new various steps on surviving them, made me understand the football players in an entirely different way.

Healthy young men play football for the most part who are in fantastic physical shape when they start. It is a game. It is not about life or death. It is however, an analogy for what happens to healthy bodies based upon the game and the treatment if their bodies are injured. Some are injured to the extent that they cannot play the game any more. Others get by their injury and damage so they can continue to play the game. The things done to their bodies at their primes have a different outcome when they get older. It makes me wonder if the leukemia treatments, four different sessions and then maintenance are like football. At first, there is a lot of pain and an attempt to get through it so you can continue to live. Once you have managed that, as you grow older the impact of those treatments may create long-term negative impacts.

Memories Of My Mom Who Died of Cancer Helped Me

I was tired and was fundamentally frightened. I don't act or talk like that, because there isn't anything friends or family can do to change the reality of having leukemia. It reminds me of my mother when she had esophageal cancer. One day I was with her at the hospital and the oncologist she had. They had said they could use radiation to try to get her throat to work. The doctor said they couldn't guarantee that but they needed to try to do that. We were in the hospital room with her and she showed my mom and me an x-ray picture of her throat. When I saw it, I could hardly believe it. I stared at it. The bottom half of her throat was totally covered and appeared to be under a massive glob of cancer cells. I kept looking at it and my brain was racing, thinking about my mom. I turned around and looked at my mom. She smiled her great smile at me. I asked her what she thought about the x-ray and what did she see. She told me she couldn't see anything that would prevent her being alive. I remember saying that was good. She smiled again.

Later she was in another room and I talked to the doctor. I told the doctor I thought the x-ray looked horrific; what does it mean? She told me it was very serious and she hoped that the radiation would provide some room on her throat so in her last few months she would be able to swallow. The doctor said she wasn't sure that could happen but she was going to try. She said if they could make some progress, my mother could live a few more months up to six. If nothing was done, she had a few weeks to live. I told this story to Paula when I found out I had leukemia. The radiation gave my mother not just a few months but five more years so she lived to be 68 instead of dying at 63. She never did see the cancer cells on her throat, she worked very hard to get through radiation, and work to do what was needed by her.

I think what happened with my mom made me continue to keep working at doing my best. I love my family and friends and I want to be around them, feeling okay, and being able to talk with them and enjoy time with them.

My Starting at Whidbey with Oncology Nurse

I went into Whidbey hospital and went to the oncology ward. I met with Ann Bell, the nurse, assigned to me that day. She was very patient and kind. I was just starting working with Whidbey. The induction therapy took place in Everett. I didn't want the same sort of thing, where I came in touched with dying, that happened at Providence in Everett to happen at Whidbey. I talked with Ann for about three hours where she reviewed meds and the first chemotherapy into the port. I had gone to a Doctor who works for Whidbey.

Ann went over the medicines with which I would have to deal. Though she was very nice, hearing the names of "medicines" set the anticipation for me on what this was going to be like. The pre-meds are Ethylchloride (numbing drug on port), Aloxi (anti-nausea), and Decadron (steroid that increases appetite and prevents nausea). The chemotherapy is 9.3 mg of Idamycin. Ann also set up and shared information about LPA 99 protocol (www.bloodjournal.org) and chemotherapy information (Chemocare.com). She gave me advice and said to drink 8 to 10 glasses of fluids per day, rinse my mouth 3 times a day using ½ tsp. of salt and ½ tsp. of baking soda added to water, wash my hands with antibacterial soap, using chewing gum decreases nausea and hydrates, and call triage nurse if I get a 100.5 fever. That is some of the questions and information on the first day of Session 2. I was arriving for them around 12:30pm and they took from an hour and a half to two hours on July 21, 22, and 23. I also talked with Ann about diarrhea. The third day I had someone else assigned as well as the fourth day. By the third day, I didn't have any other questions and I felt like Ann had moved herself away from me because I asked too many questions and took too much time. I wasn't angry with her I was just disappointed. If I, as a patient, had many questions, it might interfere with how much time they needed so that is why they trade off with each other. That way they are never stuck with one patient. They can move them around to lighten their loads. There were people I saw getting chemotherapy put into their body who said nothing at all and just sat there. Ann showed me a letter written by one of the patients she had. Dennis Wischmeier has written his view of his Stage 3 Testicular Cancer, which had metastasis into an 11cm tumor in his abdomen. Two of the paragraphs really stand out to me.

“Ann was there as my doctor told me the tumor had not dissipated as desired, and that my blood tumor markers did not drop to the rock-bottom level they wanted (but they had taken a nose-dive). I was to undergo a major surgery, Retroperitoneal Lymph Node Dissection (RPLND), to rid me of the tumor and surrounding lymph nodes. After my oncologist left, Ann swooped in, held my hands, looked me right in the eye, and said, “This is a good thing. Remember this. You will survive; you’ve won. Recuperate; enjoy your family and the holidays (my surgery was planned for January 4, 2006). Call me any time at home or work. I wish all my patients were like you.”

By God’s grace, I am now a 4-year cancer survivor, I am still in the Navy, and keep in touch with Nurse Ann as often as I can! ...To all survivors out there – Thank your oncology nurses today!”

I had to go in once a week for a blood check after the chemotherapy was ended. That is the way I was monitored relative to what was happening under the chemotherapy. I could also share with them what side effects had in fact kicked in. On the induction and Session 2 and Session 4, they used Idarubicin. They were used at different levels so the impact was somewhat different. The list of possible side effects of Idarubicin depends on the individuality of needs to the progress of patients. For them some of the items on lists are as follows: nausea, vomiting, mouth sores, hair loss, diarrhea, abdominal cramps, fever, and headache. The list is longer and people who are having chemotherapy need to know everything on the lists that apply to them.