

NON-FICTION | SPRING 2014

Wednesdays and Sundays

By Susan Wigoda

My heart has eyes that remember those Wednesday and Sunday evenings after my 13 year-old son Jake was diagnosed with leukemia in Mid-may 1998.

I am in my large bedroom with its dark brown oversized furniture that made deep dents in the rich gold carpet. I am in the house I once owned in Skokie, where Lauren and Jake grew up. The beautiful glass and bronze light fixture is long gone—a casualty of my mechanical ineptitude as a single mom. I broke it when I tried to change the blown out bulbs. Jake's response to this mishap had become a mantra for me: "Mom, if something breaks, please don't try to fix it." I had not replaced the fixture because I had no time for such trivial household tasks, certainly not after Jake's diagnosis.

It is either a Wednesday or a Sunday night and it is time to change the dressing on Jake's central line. As soon as Jake was diagnosed, he was rushed into surgery for the insertion of a central venous line into a large vein in his chest. The central line carried nutrients and medication into his body and was used for blood draws and transfusions. It was flushed twice daily with an anticoagulant fluid called heparin. The central line had two thin tubes that hung outside of Jake's chest – their exit point was covered with a sterile dressing that had to be changed twice a week.

Jake is downstairs engrossed in the Internet or a video game while I get ready. I unplug the phone and place the sterile medical supplies on fresh paper towels at the foot of my queen sized faux patchwork bedspread. I try to remember the correct order every time Jake and I perform this ritual. I place two surgical masks in their packaging next to each other, followed by two sets of plastic gloves; still sealed in their sterile coverings. Then come the small packets of betadine swabs, alcohol pads, a new sterile dressing and new plastic caps. Finally, there are two syringes filled with heparin.

Next come my twice weekly moments of self-doubt. What medical professional in their right mind decided that I was capable of changing the dressing on my son's central line? What if I miss a step, forget a procedure or contaminate the gaping hole in Jake's chest?

These thoughts swirled in my head like a menacing tornado every time I ventured into medical territory that was so vital to Jake's well being, and so alien to my thought processes. The nurses at Lutheran General Hospital taught me how to change the dressing several times. They laid out all of the supplies on a sterile cloth as I watched them clean the site and place a new dressing over the catheter's exit spot. Jake's favorite nurse Margaret saw the panic on my face and said: "Susan, I know you can learn to do this."

I thought to myself, that's easy for you to say—you've probably done this a thousand times and you never forget anything. Margaret changed the dressing while she joked with Jake. I kept thinking that I would never be that confident or calm...

Margaret walked me through the procedure several times before I took Jake home from the hospital. Why did I think I could do this? I could have easily asked for a twice-weekly visit from a home health care nurse. I bet they never left out any part of the sterile procedure.

I looked at my son in his hospital bed and I knew exactly why I wanted to do this. My child was facing a life-threatening illness with courage, and I wanted to step up and take care of him in any way that I could. I also wanted to be brave for Jake; I knew he was tired of strangers poking him and asking endless questions. I wanted to make him more comfortable. If I learn to change his dressing that's one less stranger intruding into his fragile space.

When I had my supplies ready, I called downstairs to Jake. "I'll be right up Mom." While I waited, I made sure that our dog Zoe was sleeping quietly on the floor in the hallway outside of my room. Jake came upstairs and smiled at me – his smile always helped me relax. He took off his shirt and lay down on the bed. "Ok Mom, let's go."

I handed Jake his surgical mask and put mine over my nose and mouth. I opened the package of gloves and slipped them over my hands. I made a mental note to remember to change gloves before I put on the new dressing. I gently pulled the edge of the plastic bandage and removed it from Jake's skin. Jake never winced, even if I pulled too hard. I reached for the betadine swabs and cleaned the skin around the raw site where the plastic catheter came out of Jake's chest. Sometimes I had to steel myself in the middle of this as I looked at the plastic tubing hanging out of my son's chest. "Remember Mom, swab clockwise first, then use the second swab to go in the opposite direction, and don't forget to use two swabs." I almost forgot once but Jake was vigilant. When I hesitated, Jake's warm and twinkling hazel eyes that were mirrors of my own encouraged me to go on.

I removed the gloves and put on the second sterile pair before I placed a new dressing on Jake's chest." "We're almost done, Jake." After I replaced the dressing, I removed the blue caps on the two plastic catheters and flushed the lines with heparin before I put new caps on. I often wondered if I was the only Mom in Skokie who had a Ziploc bag in her refrigerator loaded with heparin-filled syringes?

We were done. I gathered up all of the medical detritus and put it in the red plastic container that was covered with warnings about disposing of medical waste. We took off our masks, and I pulled off the sterile gloves. Jake put his shirt back on and he was ready to go downstairs to re-connect with his 13 year-old reality. He never forgot to turn to me to say, "Thanks Mom."

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