

The NICU
by
Karen J. Olson
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All I wanted to do was hold my baby. I sat on the outside of his egg-like incubator, looking in. Ryan was connected to a snake's nest of wires and tubes in the Neonatal Intensive Care Unit (NICU). A ventilator sprouted from his tiny rosebud mouth to help him breathe and tape covered half his face to keep the tubes in place. A pharmacopoeia of drugs surged through his small body doing only God knew what.

I stood and gazed at my two-week old baby, a child I had never held. My arms ached with longing as I hung over his isolette, touching the small head with its bruises and soft fuzzy hair through holes on the side of the enclosed plastic bubble. A bandage flapped loosely on his purple, swollen heel where blood draws had been performed until the skin was angry, bloody and distorted. Grief pushed me down. I sank slowly into hell ... the trip there as bad as the arrival.

I became familiar with "A" and "B" spells; a ghastly combination of apnea, when breathing stops and bradycardia, a slowing of the heart rate. Sometimes this brought on seizures.

I listened carefully as nurses talked to me about Phenobarbital, Dilantin, renal function, catheters, oxygen saturation and ventilators. I struggled to understand all of the new terms and what they meant to my baby who already looked like a pod-person from *The Matrix* with tubes and cords twisting out of his plasticene holding crate. I signed permission forms I didn't understand and recorded numbers that had only vague meaning.

All I wanted to do was hold him. If I could just hold him it might help him, it might be all right ... it might be.

I glanced at the family across the aisle, where another row of isolettes sat like a macabre hatching area. A woman cried quiet, heart-wrenching sobs into her husband's shoulder as they listened to the doctor discussing their infant daughter who was blind. I thought about my baby. Would he ever see my face? Would he die before I ever held him? Do they let parents hold their dead babies?

The fear of my son dying without me holding him ... ever ... became an obsession and I started to touch him more and more. I stroked his silky hair with the back of my index finger, afraid I might hurt him. I touched his cheek gently when he cried or patted his finger-sized arm to comfort him. One of the nurses told me that at this point in his baby life he equated every touch with pain because of all the medical procedures that had been performed. My heart cracked wide open and I swallowed hard to stem my nausea but continued to touch him with gentle, loving caresses. I was determined that not every touch would be equated with pain and I trusted that my baby knew the difference between a mother's loving caress and the pain of a medical procedure.

I asked the nurses to let me change Ryan's diapers, arrange his bedding and take care of whatever needs I could. Little by little they taught me how to care for my medically fragile baby.

I recorded statistics on a clipboard; I watched oxygen levels and learned to deal with lead wires that became disconnected by Ryan's movement and sounded false alarms. I weighed diapers to measure the amount of urine coming out of his kidneys and I wrote

down heart rates. The doctors, concerned for my health, finally ordered me back to my room to rest. My mother pushed my wheelchair, my body still weak from the stroke I'd suffered when I gave birth.

Exhausted, I wanted it to go away ... all of it. I tried to sleep but tossed and turned. Nightmares of someone moving my baby, hurting him, and losing him saturated my sleep and I would awake in a cold sweat. I set my jaw as I climbed back into the wheelchair for the ride back to my son. I returned to the NICU, unable to stay away any longer than a couple of hours. I just wanted to hold my baby.

I learned the unspoken NICU protocol. The isolettes are fairly close together and as such I was an unwilling witness to other families' most intimate moments of pain. My eyes stayed on my baby but I peeked at other infants when their parents weren't around. I made fleeting eye contact with other parents and we smiled tense half-smiles to acknowledge our common state of affairs and occasionally low conversations started between us. Sometimes I lacked the desire, or energy, to talk.

When the neonatal pediatricians attempted to take Ryan off the ventilator a wild and terrifying roller coaster ride ensued. It was truly horrifying ... waiting for that first breath. We all held ours and waited.

The roller coaster careened up and swirled down with Ryan on board, around bends and seemingly out-of-control, but it never left the tracks. Sometimes my fear felt like an out of body experience. I rode my own roller-coaster, dipping and swaying with each turn, terrified of the possible free-fall.

First they pulled the ventilator, but kept blowing small amounts of oxygen near his face to ease the strain on his newly functioning lungs. The medical staff put Ryan back on the ventilator as his A and B spells increased and he quit breathing. My own breathing felt shallow, my skin prickled and my hair stood on end. Feverish and chilled at the same time, my vision tunneled.

A few days later, we re-boarded the same ride and I griped the sides of my wheelchair, wishing for a safety harness of some type, something that would reassure me that we were safe. Doctors and nurses clustered around the isolette in teddy-bear and clown covered smocks, gruesome in their gaiety. I would have preferred the pastels of gently colored Easter eggs.

They removed the ventilator again without any blow-by oxygen, hoping that if his lungs were forced to work on their own, they would. After a number of failed attempts and tortuous rides Ryan was off the ventilator for good.

After Ryan was taken off the ventilator we took the hood off his isolette, secured the remaining wires and tubes with Velcro™ computer ties and I finally got to hold my baby boy.

I leaned back in the rocker, feeling full for the first time since he'd been born. I sat back in the padding and let out a sigh of thanks. I closed my eyes, took a deep breath, kissed the small downy head and relaxed. Our fight had only begun, but we were in God's hands.

Because it was the only thing we could do, we went on.

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