

Kristen Pelshaw, MSN, RN, CPNP-PC
Sterling Heights, MI

A Brighter “Tomorrow” – A Journey that began in a NICU



“The sun’ll come out tomorrow, bet your bottom dollar that tomorrow, there’ll be sun.”⁽¹⁾
Each birth is a sun rising. Each life is a song sung.

Over 12 years ago, I found myself, in the midst of a family expectant for life of their first child. A preterm delivery was not part of their birth plan; they thought they still had time before their child would be born. However, at 28 weeks gestation Abigail, “Abby” as she was known by family and friends, was welcomed to the world. It was Thanksgiving 1997. Indeed, this family had much to be thankful for. Abby appeared to be doing “well” in her first few hours of life, but then she tired out. Abby required ventilatory support and an umbilical arterial catheter for several days. She spent many weeks on Nasal CPAP. Her parents began to think she would go home with it as if it were her “security blanket”. Eventually, Abby was discharged on February 4, 1998, with a nasal cannula and supplemental oxygen.

As nurses and ministers of health, we often wonder what happens to those we have been entrusted to care for. So often, people come into our lives for a brief period, and then they move on.

“When I’m stuck a day that’s gray and lonely...”⁽¹⁾ Little did I know that our paths would cross again. That gray day would evolve over time and this little gift of life would grow and become a treasured gift. Just a few years ago, I met this precious gift again as Abby now celebrated her 8th year of life; my daughters attend the same school as Abby.

This spring, at the age of 12, Abby played the lead in our school musical of “Annie”. In her red dress, she proclaimed that this “hard knock life” has been transformed into a life where the “sun will come out tomorrow”. I watched this production with a smile in my heart knowing I have a special connection with Abby that no other attendee that night has had. I cared for Abby as one of her NICU nurses; I nurtured her when her parent’s were not able to be at her bedside.

Our lives as nurses, is a life lived for others. It is a life of recognizing that in the midst of a difficult situation, we give of ourselves. As “Annie” reminds us, “maybe far away or maybe

real near by”⁽¹⁾, we can continue to see the value of life. We should celebrate the symbol of the “little red dress” which reminds us that what we do is about the value of life lived for others.

It is with great honor and privilege that I have been blessed to have cared for Abigail, heard her song sung, and may our special connection continue for years to come.

Reference:

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Therese Dansby, BSN RN
Mission, KS

Life in Death

Babies keep me awake at night. I think about my dad's brother Joseph who died before ever leaving the hospital. "He was a blue baby from the moment he was born," they sigh. I've only seen his tiny grave in my mind, marked with a miniature tombstone, prairie grass waving goodbye at his side.

My mom had two miscarriages before I was born. When I was just young enough to create memories, I can recall looking with pride at my two younger brothers lined up next to me on the couch, on close to my age dressed in his Ninja Turtle pajamas and the other, a toddler, gumming on popcorn. I still find myself awake, mourning for what my could-have-been older siblings are missing.

Now I have friends with babies of their own and I watch in awe as the infants' nearly translucent fingers reach for rays of sunlight. Babies grow so rapidly, like seeds, ready to burst at any moment and grow forth into a life of infinite mystery.

In the post-partum ward at the hospital, two-year-old Zoë jumps off of a freshly-made bed into my arms, happy to be getting attention from a nurse. Does she know that the zipper of staples on her mommy's tummy is a part of a scar that will never heal? The doctor speaks in hushed tones to the mother, "By signing here, you give the hospital permission to perform an autopsy on your baby."

In the next room, an Indian woman smiles at her new son as her husband holds the infant for the first time, awkwardly at first, as if the baby will break. Two blonde girls in pigtails and plaid race through the hall toward the nursery with "It's a Boy!" balloons clenched in their fists. Above their shouts and laughter rises the cry of newborn infants, unfamiliar with the air against their skin. *The hospital breathes beneath my feet.* The ebb and flow of life and death gives the building a life of its own.

Over my lunch break I hurry to the NICU to inquire about Baby Girl Doe's death. The nurse, a large, bored-looking woman, looks at me over her gold-rimmed glasses and asks, "What 'cha wanna' know?"

"Her mom's my patient," I say. "I want to be present at the autopsy."

The nurse sighs, walks to her desk, and pulls a chart from beneath a mess of papers. "Mmmm-hmmm. Ain't gonna' find nuttin' wrong but prematurity with that little girl. Thirty-two weeks gestation, C-section, APGARs of 7 and 7. Condition rapidly deteriorated about 22 hours after birth. Blood was dripping out of her chest tubes. At 23 hours, she died."

I take the chart downstairs to the blindingly bright pathology lab. The pathologist on call greets me. Her gray hair is cut in a smooth bob and her flat shoes echo cheerfully through the front lab filled with microscopes. As she starts talking, I can tell she loves what she does. "I went through four years of med school and six years of residency," she says in reply to my question about what it takes to be a pathologist. I immediately disregard any musings about becoming one myself. *Ten more years of school?* She justifies it by commenting, "I love working down here because you get to see the scientific aspects of medicine but don't have to deal with whiny patients."

She pulls a soft, bulging package the size of a shoebox out of a big steel refrigerator. It's wrapped in blue absorbent bed pads and taped shut. I follow her and the bundle into a small, windowless room to the side of the lab.

"We're not going into the autopsy room because this is going to be so quick," she tells me.

The lab tech next to us waves hello and asks if I want to see what breast cancer looks like. I peer at the pale yellow, globular remains of a woman's breast tissue floating in sterile water. "She must've been at least a double-D cup!"

The tech smiles, "Between the ten pounds in this carton and a cancer-free diagnosis, she probably feels like she lost 100 pounds!" *Clearly these labs don't deal solely with death.*

When I turn around, the pathologist has cut the tape on her package and unrolls the blue pads until they are flat and we're all staring at a three-pound baby girl, stark naked and pale white, with lips closed in a tiny bow and hands clenched at her side. With minimal imagination, I can see her full cheeks molding into a frown and her arms flailing at the injustice of the cool air as she begins to cry. I look again and her cheeks remain pudgy and still. Her limbs are tiny, but her skin still folds with baby fat. From here she doesn't look sick at all. *After all, I only weighed four pounds at birth and I'm still here.*

I'm shocked at my reaction. I expected tears to sting my eyes but instead, a soothing warmth surfaces and I know that this baby was relieved to find its suffering at an end. The body may still hold the hopes and dreams of a mourning mother, but everything that makes babies a joy to behold is gone and only a shell remains. She won't open her eyes at any moment, and there are no barely-perceptible emotions flickering across her face as she sleeps, there are no twitches in her limbs as her body adjusts to its own heaviness outside its former fluid maternal home.

The pathologist takes the scalpel and cuts a thin line down the baby's midline, from the clavicle to the symphysis pubis. I cringe slightly as the flesh parts. The song "The First Cut is the Deepest" rises into my mind and I reassure myself that this is probably the first time that the baby hasn't felt pain since being pulled out of her mother's open abdomen, stained with the contents of fetal bowels let loose from the stress of pre-term contractions.

The pathologist makes another cut perpendicular to the first, from nipple to nipple, and in a fluid motion, begins to separate the skin from the muscles beneath. I glance at the infant's face and find reassurance in the fact that her eyes remain closed and her pudgy cheeks are still. The pathologist notes, "The mom tested positive for barbs and opiates. But I don't really think that's the cause of death. Unless we find something abnormal inside, I'm going to say that this baby died because it just wasn't old enough to have fully developed lungs."

She lifts the flap of ribs up and we pause to admire the baby's organs, so intricately placed in proximity to one another. The first thing we notice is the thymus—an organ that is the size of the infant's heart. The pearly white surface looks blood-shot. Like tired eyes, this organ has been working too hard for too long to build this baby's immunity against a world she greeted too soon. The pathologist removes it carefully and places it in a jar of sterile water. "To examine more closely later," she explains.

With the thymus removed, the cardiovascular system stares back at us from the chest cavity. Everything lies perfectly pieced together between the walls of the rib cage in the same way a loving hand would frame a prized jigsaw puzzle. The pathologist says, "No one thinks their heart is really smaller than their fist, but look." She cuts through the main arteries and veins going in and out of the infant's heart and removes it. Sure enough, it is tiny enough to fit into the

palm of the baby's own hand. It lies void of motion now, but for the last seven months, this heart had been beating, keeping rhythm to the symphony of growth within the womb.

The pathologist tenderly places the solidly muscular heart on an examining surface next to the body and points to the various large blood vessels at the top. "See how the pulmonary artery comes out of the right ventricle and splits into two above the apex of the heart—one artery for each lung?" I nod. "We can also see the aorta above the apex here, coming out of the left atrium," she continues. Taking a small probe, she isolates another blood vessel bridging the pulmonary artery and the aorta. "Looks like the ductus arteriosus is still intact. This usually turns into a ligament once the baby begins to breathe air outside the womb. Since she was a preemie, it's less likely to close on its own. That means some of her blood bypassed her lungs and just went into circulation again without picking up any new oxygen."

"But that's not enough to kill a baby, is it?" I ask. "I mean, it's pretty frequent as far as premature heart problems go."

"Exactly," replies the pathologist. "But we'll need to look closer to make sure."

She cuts through the bottom tip of the heart as easily as if she were an executive chef preparing steak for fajitas. *A master and her masterpiece.* I bend down and look inside at the clearly defined left and right ventricle—tiny spaces between the blood-red walls of the heart. She cuts a few more slices until we can see the valves between the atria and the ventricles. They're all intact and we cut again to see the left and right aorta separated by a solid wall of muscle. Besides the patent ductus arteriosus, the heart is in perfect condition.

We move to the lungs and the pathologist immediately notes the discoloration, "Normally, they should be pink and rosy, almost the color of the baby's skin." Instead, they are dense with blood and resemble a liver. The alveoli—little air sacs in the lungs—stuck together like syrupy fingers instead of opening to allow air in.

At the time of her birth, these symptoms would be minor—increased heart rate, nasal flaring. Then they'd get more serious—if you watched her bare chest, you'd see the muscles in between each rib retract as they attempt to pull more air in. Meanwhile, alveoli collapsed, preventing any air from entering.

Section by section, her lungs closed in on her, resulting in respiratory acidosis. She began to hyperventilate but her lungs were unable to accept the oxygen and her body swung into metabolic alkalosis. More and more blood gathered in the lungs, in a futile attempt to pick up some oxygen to take to the heart, brain, organs, and muscles. Eventually her body tired and she finally found rest in death. *Rest.*

Tonight I lie awake thinking of the baby girl's life. If my older siblings had survived, they may not have had the capacity to see life as I do. If I were this child's mother, I would be able to write the saddest lines tonight. Pablo Neruda lost a lover, but a parent should never lose a child:

To think that I do not have her. To feel that I have lost her.

To hear the immense night, still more immense without her.

And the verse falls to the soul like dew to the pasture.

Instead, I see my journal pages filled with the line, *How could one not have loved her great still eyes?* I spend my days fretting about finding happiness in life, but who can find happiness in death?

This baby did.

Heather Goodall, MSN, RNC-NIC, IBCLC
Colorado Springs, CO

Three Shifts Changed My Life

My life's work as a nurse was supposed to be in the NICU. That reality was almost shattered after working 3 night shifts in a row, 4 years ago.

I had 6 years of NICU experience behind me and was really starting to feel like I was finally getting close to becoming an "expert" in neonatal nursing. Colleagues relied on me to care for the high acuity babies, families requested me to become a primary nurse for their baby, and I was getting more involved in the unit-based committees. How could I continue to work in this area of specialized nursing after suffering through those 3 shifts with babies that died during each shift under my care? Did I miss something? Did I do something wrong? What symptom did I not pay enough attention to? I would replay each shift in minute detail over and over in my head. Each colleague I spoke with after those shifts said, "There was nothing you could have done differently. Your patients were extremely premature or born with defects that weren't compatible with life. Don't beat yourself up about this. You are a great nurse. No one thinks otherwise." I had taken care of babies that had died before during my career, but not for 3 shifts in a row. The nightmares would continue for weeks and I still occasionally have them.

Something that was said during casual conversations and slightly emphasized during nursing education in/out of school was the need for nurses to care for themselves. I always thought, "Sure, of course, I do that, on my days off." That never seemed to happen, though. Besides, how was I going to do that with 3 small children, a husband, and everything else?

I decided that I needed to take care of myself immediately or else I was not going to be able to continue to be a NICU nurse, mother, wife, or friend. Through many tears, I talked with my primary care physician who suggested I take time off from work. I was able to negotiate with the nursing manager, again through many tears, to take LOA for a month. I was given the name of a local psychologist that specialized in helping healthcare workers. I was hesitant to call but decided that I needed more help than what my husband and friends could give. Talking through this traumatic experience during a few appointments with the psychologist, having the time off, and being able to focus on myself helped me recover.

Preparing to return to work was painful to think about at first. How was I going to take care of any other babies? Would the same thing happen? However, after that month off, I was able to return to my first nursing love, the NICU. To this day, I am able to care for those babies and families that need me and I am able to care for myself too.

Heidi Staub, RN
Lyons, Australia

You're Not in Kansas Any More

NICU nursing always interested me, and it was a hail-Mary attempt at rediscovering happiness in my career. After 17+ years perfecting my skills in the trenches of the ER, I needed a change of scene and new professional challenges, because I was headed down the path of burn-out.

I rocked up for my first shift in a Level IIIC NICU. In that first morning hand-over, I was thrown into the deep end. I guess my ER credentials impressed. I did have a valuable life preserver, though, my preceptor, the unit's Clinical Nursing Educator. I had completed the unit's self-learning packets and had observed a NICU nursing veteran for two shifts, and was on the list to take Neonatal Advanced Life Support. Was I ready for this?

Deep down, fear gnawed my innards, but I was confident in my skills as a nurse, and did I mention my safety net? I learned that en route from an outlying, smaller hospital was a 36-week gestation male with signs of respiratory distress.

First task, ready the bed and ensure the equipment was available and worked. Check. The bubbie arrived and proceeded with the flurry of getting the patient admitted, worked-up and settled. My eyeball assessment made this ER nurse very uneasy. Not only could I count ribs, but I swear I could count vertebrae every time this boy rapidly struggled in a breath!

My mind was flying through what I envisioned this little guy needing: 100% oxygen and a tube! The SaO₂ level was 86%! I couldn't move fast enough to reach for the ambu bag and oxygen flow meter when a Zen voice gave me a verbal hand-smack with a calm and succinct explanation of normal SaO₂ values in the neonate as well as the effect of free radicals.

Under the watchful eye of my Obi One, I proceeded with setting up for a rapid sequence intubation. At least my internal alarms were being answered; preparing to intubate! I was guided to get the surfactant. Now we're talking! That wonder-drug I read so much about. I finally took a relieved breath as the doctor deftly passed the tube and instilled the miraculous liquid lung. Then, to my horror, the ETT was removed, and once again, I stopped breathing! Panicked, I looked to my sen-sei. Warmly she smiled upon me and praised my performance. Seeing confusion in my eyes and reading my mind she answered, "Now we wait and see."

For the next couple of hours the little man chugged away, but by the end of my shift he wasn't working nearly as hard, and within a week, had graduated to rooming in with Mom.

That first day took me from ER nursing jedi to NICU nursing padawan. Ahh, the learning and challenges ahead. Now, two years on, I'm loving being a nurse again. A NICU nurse!

Sandy Taylor, RN
Raleigh, NC

Baby Mannie

I have always felt that faith plays an important role for parents in the NICU. This became evident to me during my nursing care for Baby Mannie.

Baby Mannie was born at 24 week gestation. His father was of the Muslim faith, his mother was Catholic. Mannie's first few months were complicated by premature lungs, persistent ventilator support, bilateral grade 4 bleeds and subsequent development of hydrocephalus. His parents were not able to visit often. Soon after Mannie's birth, his father brought in a copy of the Koran and asked to leave it at his baby's bedside; he was given permission. Mannie's father would read a passage from the Koran whenever he visited. He would carefully tuck the Koran into the corner of Mannie's bed before leaving.

When Mannie was 6 months old, he developed a VP shunt infection. His father looked angry as the doctors explained how they would have to treat the infection. Mannie's father said little as he sat with his son. Upon his leaving, I discovered that his father had removed the Koran from Mannie's bed. I feared that this action meant Mannie's father had lost his faith.

I decided to begin a scrap book of Mannie for his parents. During Mannie's six months of hospitalization, his bed had been surrounded by many pictures taken from the time he was born until present. I purchased a scrap book and began arranging pictures on several pages. I had also bought several stickers to accent the pages. The stickers had written messages such as "beautiful baby boy" and "cute and cuddly". One particular message struck home for me: it was a message called "miracle" – it went on to state: "miracle - noun: an effect or extraordinary event in the physical world that surpasses all known human or natural powers – such an event to be considered as a work of God".

I pondered; do I dare place this sticker in Mannie's scrapbook? I had two "miracle" stickers. I decided to place one "miracle" sticker on the first page under the picture taken of Mannie at birth and the second miracle sticker was placed on page 4 under a more current picture. The scrapbook pages I prepared had outlined the life of Mannie as a joyful event. Extra pictures, ribbon, stickers and paper were left for his parents to complete the book – to make it "theirs". The scrap book was left at Mannie's bedside.

Mannie's father had not visited for two weeks since he removed the Koran. Many messages were left for the parents but the calls were not returned. Mannie's infection was now resolving and surgery was scheduled in order to replace his shunt. A phone call was placed to his parents; this time they returned the call to state that they would visit Mannie before his surgery.

One morning I went to Mannie's bed to discover that the scrap book was gone. The night shift nurse stated that Mannie's parents had visited during her shift. I was told that the parents had looked at the book but had not said anything. Upon leaving, the father took the scrap book with him.

I cared for Mannie the day he went to surgery. Mannie's parents arrived before he was taken to the OR. The father stopped and asked if he could have a moment with his son. In his arms was the Koran. He sat down beside his son, held his hand and read to him from the book. Afterward he placed the Koran back into Mannie's bed. The Koran remained at Mannie's bedside during the remainder of his hospital stay.

Deborah Wall, RNC-NIC, C-NPT
Grovetown, GA

Looking Through the Glass

Transporting sick infants to the Medical College of Georgia is my primary job responsibility. One day in August, I received a transport page from our Neonatology Fellow. A baby was critically ill and needed to get to a Pediatric Surgeon as quickly as possible. "Bri" was only 9 days old but obviously a fighter. Born prematurely, she developed respiratory distress and was on a breathing machine. Her bowel had perforated sending air and stool into her belly. The odds of her survival were decreasing with every moment.

As a transport nurse, I would be the family's first contact with our hospital. It is not uncommon that a special bond develops between our families and the transport nurse. When I arrived, they knew she was being taken from them and might die. It was important that they also knew our care would be compassionate and dedicated to her welfare. After I transferred her to our NICU, I checked on them daily.

Bri remained critical all of her brief life. Because she was so sick, decisions had to be made about how aggressive her treatment should be. She was showing signs of multiple organ failure. She looked terrible. As weeks passed, nurses and respiratory therapists were starting to vent concerns for her "suffering". We discussed our feelings during rounds. On the day before her death, Bri's mom made the agonizing decision to withhold chest compressions. The next day, she became worse. We called her mom. When the family arrived, they were prepared for her death. Mom held her until she passed.

After her death, Bri's nurse provided time for her family to stay with her. She was bathed, dressed, and mementos obtained like hair and footprints. We tried to provide privacy and alone time while mom held her again. Before the family left, funeral arrangements had to be discussed. Mom mentioned that when she lost her other premature baby, the other hospital provided a funeral service in the hospital. We had never been asked this before. The charge nurse was reluctant and I suggested she talk with our nurse manager. I knew we needed to make this happen for Bri and her family. I talked with our chaplain. He showed the family our large chapel. Plans were made for the family to come back the next day and we would have Bri's funeral.

The next day, our chaplain found me and we walked to the morgue together. His wife had printed beautiful programs for the service. I encouraged staff to come to her funeral. I dressed Bri in the cutest smocked dress, put a white bonnet on her head, placed her in a wicker cradle lined with the softest pink blanket and I carried her to the chapel. When her family arrived, all they could see was beautiful Bri. After her funeral, staff members went back to work. I stayed with Bri's family. I helped mom hold her for the last time. We undressed her together and wrapped her clothes and blanket together for mom to keep. We hugged each other and I thanked her for letting me be a part of Bri's life.

This experience taught me that I couldn't have made a difference with out having done things differently. Change is sometimes radical. There can be more than one way to look at things. "Sometimes you break glass; sometimes you bend it; sometimes you leave it the way it is and look through it." The truth --, acting autonomously required the help of others. Experiences that challenge us as nurses in what we think will be negative are truly life altering moments.

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