



**Narratives from the NICU:
Neonatal intensive care units through
the eyes of parents**

A special report from Inspire in recognition of Prematurity Awareness Month 2011

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Introduction

The Premie Roller Coaster

Deb Discenza

Roller coasters are exciting and yet terrifying, because you never know where you are headed next. To many, it is the ultimate test of fear, something to brag and commiserate about afterward with family and friends.

Yet for the parent of a premature baby (aka “preemie”), the term “roller coaster” is used to envisage an experience unlike anything they have had to date. It is as if their worst nightmare has occurred and they have little to no control over the circumstances. And yet they feel immensely responsible for it all as they watch their baby struggle to breathe, to eat, to survive.

For my family, and the birth of our 30-weeker daughter Becky, it was a roller coaster of emotions from the first second as my water broke in the car on the way home from a family outing an hour outside of town. Fast forward 30 hours later full of medications, bed-rest and sheer stress as each contraction made it abundantly clear that my daughter was determined to make an early appearance. She came out and she let out the tiniest kitten cry. She was held up to me for a millisecond and rushed to the neonatal intensive care unit (NICU).

Exhausted, I struggled to stay awake enough to greet my daughter in the NICU. There she was, all hooked up to equipment and alarms sounding. My heart was in my throat. Our roller coaster had already begun. Becky spent 38 days in the NICU, came home on medical equipment that was shed months later and had ongoing specialist appointments, therapy visits and more. While at some points I felt like a mother, there were other times where I felt more like my daughter’s personal assistant and her nurse. Every joy was celebrated tenfold



because my husband and I knew all too well that our spunky little girl was a fighter. We knew there were concerns ahead, but we still felt like the lucky ones. We were lucky because we got to bring our baby home.

Whether the baby is 4, 8, 12 or 16 weeks early, parents of preemies desperately want to crow to the world that their baby is here and it is hard not to feel in the same breath that you have been punched and kicked. Questions regularly surround you internally and externally as to why this happened. Guilt shrouds you every time you walk into the isolating environment of the NICU and view your child being taken care of by total strangers and being kept alive by medical equipment. Fear envelops you when the home phone rings and it is the hospital calling—despite it being about something totally unimportant. Tears become your friend and ally. Friends and family and their odd behaviors and inappropriate comments about this situation anger you.

And yet, parents of preemies are much like their children. They are fighters and they are survivors. The NICU teaches you a lot of lessons about life, about people, and most of all, about the love of a parent. Love that sometimes requires time to ferment. Love that takes hold and creates a parent so fierce to reckon with, so determined to advocate for her/his child that it is a true beauty to behold.

As we mark [Prematurity Awareness Month](#) in November, let's give homage to these very special families and recognize their daily efforts to bring up thriving children despite the challenges ahead. They deserve our love, our support, and our respect.

Deb Discenza is moderator of the [Inspire Premie Support Community](#) and author of [The Premie Parent's Survival Guide to the NICU](#). She resides in Virginia with her husband and daughter.

“Parents of preemies are much like their children. They are fighters and they are survivors.”

Foreword

Fear vs. Hope in the NICU

Sue L. Hall, MD

Parents of preemies usually come into the NICU in a daze, or as one mom described it, “in the middle of a storm.” The storm of emotions may include shock, sadness, anger and guilt about their unexpected premature delivery.

Parents feel their lives are rapidly spiraling out of control, and sense that their baby is slipping into a remote realm where they will be stripped of a meaningful role as parent. And, to make matters worse, parents recognize immediately that they are in a foreign environment where a different language—one they don’t know yet—is spoken. Fear is an ever-present emotion, as every NICU parent will tell you, including the ones who share their narratives here.

Parents of preemies face a challenging task: how to balance their fears with their hopes. As one NICU dad told me, “We are scared out of our minds.” Parents are scared that Baby might not live, scared that Baby might suffer disabling complications, and scared that Baby might have lifelong problems. The unknown future stretching out in front of them can be terrifying; they don’t know what will come next, or even how they will handle it when it does come. On the other side of fear is hope. But, if hope doesn’t balance fear—or better yet, win out over it—fear will overwhelm parents, leaving them feeling so depressed or stressed out that they can barely function.



We should encourage dialogue with parents as our partners, and really listen to what they say about both their fears and hopes.

There is a lot to hope for in a NICU. Most parents have heard stories of premie miracles made possible by both the advanced technologies now available and the meticulous care of the medical staff. They fervently hope their baby will be the next miracle, and that their long-held dreams of growing their family will come true.

NICU staff, both doctors and nurses, can help tip the balance from fear to hope. Whenever I admit a tiny or critically ill baby to the NICU, the primary message I try to communicate to parents from the get-go is, “We don’t know where your journey will take you, but we will be with you every step of the way.” The road through the NICU is long and winding, with lots of hairpin curves to get around, many seemingly impossible hills to surmount, and plenty of deep valleys to tumble into. At times, parents may feel like they are trapped in a cruel game of Chutes and Ladders, as their baby progresses nicely one day, only to have a setback the next.

It is an arduous, frightening journey for parents, and sometimes even for staff. As medical caregivers who guide parents on their journeys, we need to let them know that they are indeed their baby’s parents, and we doctors and nurses are merely privileged to be the baby’s stewards through this part of their lives. We will not replace the parents in their baby’s heart, nor is their baby ours to keep. We need to do everything we can to encourage bonding between parent and child (think Kangaroo Care), and to strengthen parents’ confidence in their roles, giving them hope while continually acknowledging and validating their fears. To minimize their feelings of helplessness, we need to show them how they can help care for their fragile baby—empower them—even if their own hearts race with anxiety while doing so.

We need to respect where parents are on their emotional journeys. We must give them time to sort out their feelings and to find their “new normal.” It may take months. As one father confided in me, “Don’t assume we are okay when we seem to have a handle on everything. I just acted strong for my wife. I was a mess inside. It wasn’t until the end of the third month of our four month NICU stay that I really got a handle on things.” Patience is more than a virtue for medical staff; it’s a necessity. Compassionate patience, that is.

“At times, parents may feel like they are trapped in a cruel game of Chutes and Ladders, as their baby progresses nicely one day, only to have a setback the next.”

We should encourage dialogue with parents as our partners, and really listen to what they say about both their fears and hopes. We must let them decide what to hope for. If their hopes seem unrealistic to us, we need to tread lightly. Because without hope, how can parents keep going forward? And the NICU staff’s best hope for parents should be that they ultimately feel good about themselves as parents, when they finally get to take home the healthiest baby we can give them.

Dr. Sue Hall has been a neonatologist for more than 20 years. Prior to that, she was a master’s level social worker. Hall is currently in private practice in a large neonatal intensive care unit in the Midwest. She is the author of the book, For the Love of Babies: One Doctor’s Stories About Life in the Neonatal ICU. Read more about her online at www.suehallmd.com.

“I felt like an assistant mom, at best”

“Mygirlsmom”

I had a terrible pregnancy, so having my daughters at 30-weeks gestation was not a surprise. We had been shocked when graced with a twin pregnancy (twins do not run in our family and I was not on any fertility treatments) but we came to get used to the idea. At 26 weeks, I went into preterm labor and spent the next four weeks trying to stay pregnant on bed rest.

At week 29, I began to develop pre-eclampsia, which caused me to gain water weight very rapidly, my blood pressure elevated, and generally, I could not remain pregnant much longer. Once contractions started after a manual exam at 30 weeks, the doctors felt that the babies would be healthier in the NICU than in the womb.

So, in some ways, I was prepared with the knowledge that my girls would spend the first few months of their life in the hospital. As a first-time mother, I really had no idea what this meant. I had no idea what being a mother meant, let alone a mother with two sick infants.

Health-wise, our NICU experience was mild compared to many. They were born weighing 2 lbs. 14 oz. and 2 lbs. 15 oz. Their Apgar scores were great and they were breathing room air within two days with absolutely no assistance needed. No infections, no brain bleeds, no surgeries required. For children born very premature, they did wonderfully. They lost some weight but put it back with no problems. Looking back, we were one of the luckiest families I have ever met for getting out of the unit in five weeks with two daughters whose lives have been only mildly affected by the frightening circumstances of their births. Fortunately, I know this is not the norm. I thank my lucky stars and the Big Guy above everyday.

However, emotionally, the NICU experience threw my world upside down. One key emotion I felt the entire time in the unit was that of being insignificant in my girls' lives. I felt like an assistant mom, at best. While the nursing staff did their best to include us in their cares, and we spent many hours a day in the unit, I felt like I was not their mom. I have to assume most new moms need time to get acquainted with the idea of being someone's mom, someone's everything. For me, this supposed bonding moment was being done under the microscope of a medical staff. After two days, I was healthy enough and they were stable enough for me to hold them. While it was a great experience in some ways, the overarching feeling was fear. I kept asking the nurse if she should put them back to avoid them getting cold, as their bodies required the Isolette chamber to help them regulate their body temperatures. I felt like I was doing everything wrong. They were more like fragile pieces of crystal I had to protect with every single movement than my kids.

That feeling changed over the five weeks in the unit. I'm a very take-charge person and I made the NICU routine like a job. Get to unit at 9 a.m., pump, hold one daughter during feed, pump, hold my other daughter during feed, pump, rest in lounge and have a snack, hold one during feed, pump, hold the other during feed, etc. Making it feel like a job helped me detach myself emotionally from the sadness of the experience. And I actually started getting a little joyful. As they reached their birth weigh during week three, I started getting jazzed about the thought of them actually coming home someday. And starting to actually feed them instead of holding them while being tube fed was another momentous occasion. However, this came with mine and my husband's new found obsession: measuring every feed. We put a chart together and wrote down exactly how many ounces they took by mouth, how many by tube, and how many breastfeeding tries we had each day. It was sort of a game, a way to track their progress, and a way to focus on their achievements. And fortunately, they slowly ate more and more and did better and better.

My parents were a wonderful source of support. My mother was amazing in hiding her fears from me. She was available, a great listener, and hid the fact that she was terrified for me. Other family members had a way of making it about them, which was so disappointing. I'm most disappointed that I actually fed into their

drama and let it bother me as much as I did. If I could go back in time, I would try to ignore those who were incapable of supporting us with just love. But maybe it was my own way of distracting myself with other people's negativity to not focus on my fears? Regardless, my own parents and sister were very supportive. Our friends definitely made themselves available to us, but backed off a lot. And I think this was because they really didn't know what to do, nor do I blame them. None of them had ever had a baby in the NICU. I tried to relieve everyone's fears

by sending out emails frequently on their progress. I think everyone handles the experience differently, but withdrawing is not my way—I loved being in contact with everyone and talking, talking, talking out my emotions.

I was very blessed to work for a company that basically let me leave work from 24 weeks until the girls were 6 months actual age. It was a wonderful place to work, and they let me have as much time as needed, while still paying my entire family's healthcare premiums—at no cost to me. A rare situation, indeed, but of course, I felt so loyal I went back their immediately and was very understanding when the economy warranted pay cuts. I did whatever I could to help them stay in business because of all they had done for me.

I have to assume most new moms need time to get acquainted with the idea of being someone's mom, someone's everything. For me, this supposed bonding moment was being done under the microscope of a medical staff.

Needing to share “otherness” with others

Upon leaving the NICU with baby number one, I felt scared and elated. I was totally ignorant to what preemies face after the NICU, which I learned a lot about since. After baby number one was home for five days, number two followed. With both kids home, the NICU became a distant memory quickly, but the experience transformed me forever. Within one year of their homecoming, I began volunteering at the hospital’s NICU as a support group mentor and heading up the Family Advisory Committee. I began to reach out to other preemie parents, as I desperately needed to share my “otherness” with moms who got it. That’s when I found the online support community on Inspire.

Health-wise, my girls have done well considering the circumstances of their birth. But it hasn’t been all roses. We spent two years avoiding RSV and illness, and unfortunately, they got RSV twice, which has caused ongoing lung issues. While other moms were planning playgroups, we were inside, and I was lonely. The moms on Inspire were in the same boat. As my girls grew, they began to have vision issues, and now both wear glasses to help with immature eyes, strabismus and farsightedness. They have experienced fine motor delays, and behavioral issues that are too complicated to describe here. In summary, while they “look” good, their prematurity has left its mark and has put us in the gray zone with many of their doctors – they definitely don’t have autism, but they have some “stuff” going on that’s difficult to deal with. Lots of things doctors just can’t put their fingers on.

And so we keep moving forward hoping that we can put it all behind us. But I will personally never put the NICU behind me. It has been the most life-altering event of my life. Last week, we had a new member join the NICU Family Advisory Committee. Our group is small, only 6 active members, and we’re like lifelong friends—giggling, goofing around, all with the bond of having lived and survived the NICU journey. Some of our members have lost babies, as the new mom joining our group had just experienced this, 18 months prior.

At the end of the meeting, she began opening up to us about her story, which she admitted she had never shared with anyone, because no one ever “got it.” She left our meeting thanking us profusely, saying she couldn’t wait to support other parents and that she didn’t feel so alone. She’s one of us. And we welcomed her the way the moms on [Inspire](#) welcome others. The worst club in the world to have to join, but we’re so thankful we have it.

Memories of NICU never completely out of mind

Ashley Hall
Leesburg, VA

In 2003, my daughter, Katelyn, was born at 25 weeks gestation weighing only 15.5 oz. (440 grams), barely longer than a ball point pen and given a 5% chance to live. She was born early because I developed HELLP syndrome and they had to deliver her to save my life. I also had problems with clotting in the placenta, which is why she was born with IUGR (Intrauterine Growth Restriction) and was the size of a 21 weeker. After 159 days (over 5 months) in the NICU, Katelyn came home.

During her stay at the NICU, she endured many of the obstacles that are presented to these micro preemies. She was on the ventilator for two months, and as a result, suffered from chronic lung disease (CLD/BPD). Finally, after two months she graduated to CPAP and much to her dismay spent about a week with that awful thing strapped to her nose. From there she went to vapotherm (high flow humidified nasal cannula) and then finally to a regular low flow nasal cannula. She had heart surgery at one week old to close her PDA (Patent Ductus Arteriosus). She had multiple blood and platelet transfusions during her first two months of life. She suffered a number of brain injuries including: a Grade I IVH, a lesion in the thalamus, suspected PVL that was later ruled out, 80% atrophy of her left cerebellum, 20% atrophy of her right cerebellum, and overall atrophy of the brain.

At about a month and half old, she started having seizures and they suspected a fungal meningitis, but a spinal tap grew nothing. She had many infections and was on many different antibiotics. She developed Stage 3+ ROP (Retinopathy of Prematurity), which was corrected with laser surgery. She also had hypothyroidism.

Parents often use the term “roller coaster” when they refer to the experiences of the NICU. Our journey was much like riding a roller coaster since there were many ups and downs along the way. There were times we didn’t feel like we were making much headway—for every step forward we were taking two steps backward. That was true of our first 3 1/2 months in the NICU. The last two months were much better with steady progress when she finally entered the “feeders and growers” stage of her prematurity.

The NICU is a scary place filled with acronyms a mile long describing the state of your baby.

Tubes, wires, machines and daunting acronyms

The NICU is a scary place filled with acronyms a mile long describing the state of your baby. It is very difficult and emotional to see your baby lying in the Isolette hooked up to machines that are keeping your baby alive. Tubes and wires are protruding from all over their tiny bodies and you are lucky if you get to see their face for the first few weeks because their eyes are covered due to the Bilirubin lights. We couldn’t hold our daughter for the first month. Her skin was translucent and her eyes were fused shut for the first week. We lived 45 minutes from the hospital and traveled there every day to spend time with her. It was difficult to leave her there every day for 159 days.

Katelyn came home on oxygen, an NG tube, an apnea monitor, a pulse ox monitor, neb treatments four times a day, and on 10 different medications. For the first several months at home she was fed continuously through her NG tube via a pump due to risk of aspiration (something she did once in the hospital after an eye exam and had to go back on the ventilator for a brief period of time). She finally got rid of her NG tube at nine months of age (actual age). She also suffers from a fairly bad case of GERD (Reflux). She suffers

“Tubes and wires are protruding from all over their tiny bodies and you are lucky if you get to see their face for the first few weeks because their eyes are covered due to the Bilirubin lights.

from slight cerebral palsy (CP) on the left side of her body. She receives speech, physical, and occupational therapy through the county along with private speech, occupational, and physical therapy to address her issues. But despite these things she is progressing beautifully and has surpassed many of the possible outcomes that may have resulted from her extreme prematurity. She

didn't start walking until she was three and talking until she was four, but she hasn't stopped since and has definitely made up for lost time. As time goes on the experiences of the NICU tend to fade, but they never really go away.

We were the National Ambassador Family for the March of Dimes in 2009, and spent the year traveling the country telling our story to thousands of people and helping educate others about prematurity. So, we are out there in the public eye. We also formed our own foundation (www.khallfoundation.com) and do lots of local events to raise money to help prematurity related causes. I also started www.katelynsjourney.com (unrelated to our foundation) while Katelyn was in the NICU, and it shows her progress up until she was around five years old.

Three things I did in the NICU

Lisa Cline
Albuquerque, NM

We spent 100 days in the NICU with our daughter, Rainy, who was born at 26 weeks. She had lots of complications and was very ill. There were three things I did that I'd like to share with those currently in the NICU.

1) I touched her as often as I could. An occupational therapist (OT) showed me to cup my hand on top of her head, the other hand cupped at her feet. The OT showed me other ways to touch her, including massage. Skin to skin where the baby is in a diaper against mom's chest, or, Kangaroo Care—can't say enough good things about it. It helps baby's brain and body cope more effectively.

2) I talked, sang and read to her. I said "Mommy's here, and I'm so glad to be with you", "I'm soooo proud of you, you are so strong and beautiful", "You have everything you need inside of you, and all these people are here to help you", "I love you, I love you, I love you." You get the idea. . . I also introduced the staff to her: "Chris is here to take some blood. It'll hurt for a sec and I'm here."

I touched her as often as I could. Skin to skin where the baby is in a diaper against mom's chest, or, Kangaroo Care—can't say enough good things about it.

3) I scoped her WHOLE body out everyday, and asked lots of questions.

“Alex”

Jeff Stimpson
New York, NY

Alex was born early on a June afternoon in 1998, in a hospital in New York City. He was three months early. They shouted “Boy!” and rushed past me. His head was a gray tennis ball, his arms and legs thick as magic markers. The father’s first kick of awe and love sank into a feeling that Alex looked like a doll. The doctors dove on him.

Most families stay in NICUs for a few days or a week. Some stay longer. NICUs have been compared to casinos: bright lights, beeps, people with tired faces clustered in small, intense groups. The babies live in plastic boxes. Tubes run in and out of the boxes. Wires and tubes run into and out of the babies. There’s always a bell going off. A lot of people in NICUs talk about “odds.”

Alex weighed 600 grams at birth—about as much as a couple of sticks of butter—and he didn’t grow in the NICU for, well, a lifetime. Lungs are the last thing to develop in a baby in the womb; premies often have trouble breathing. He wiggled. He didn’t make a sound, because the tube was between his vocal cords. The oxygen scarred the tissue of his lungs, making the absorption of oxygen into his blood difficult. They called it BPD, or broncho-pulmonary disease.

“It’s ‘damage,’” my wife Jill used to say. “Call it what it is: ‘damage.’”

Alex spent six months in the NICU, came home a week, suffered some kind of respiratory crash in a pulmonologist’s office—we think a nurse put him on an empty tank of oxygen—and he went right back on the tube and right back in the hospital. In the pediatric ICU, they had to keep this alert, willful, 6-month-old baby chemically paralyzed to prevent him pulling out his breathing tube. I asked one of his former neonatologists, who worked two doors down the hall, to advise a little on Alex’s care.

"I have to tell you something," the doctor replied. "It's my opinion that the aggressive questioning by you and your wife during Alex's stay in the NICU altered the course of his treatment to his detriment."

As I watched a nurse wet Alex's eyes with artificial tears (paralyzed, he couldn't blink on his own), somebody came by with a charity Christmas present. I unwrapped it, looked at the little plastic panda face, pressed the nose to produce the tinny circus music, and wondered, if it wasn't too aggressive a question, what I had ever done to deserve this? Seeking an answer, I went to a psychiatrist. She was pregnant. It was Christmas Eve, 1998. "What you've been through," she murmured, looking out her office window at twinkling lights, "it's inhuman." Good word, doctor. What kind of human spends a year in the hospital and then comes out to begin his life? But he did.

Today, Alex lives on chicken nuggets, hot dogs, chocolate milk, yogurt, and anything from The Vitamin Shoppe that will dissolve in water. He likes Elmo and his iPad. He has few words, but is learning more. Next summer, he'll be 14; his mother and father have aged many, many more years than that, and the hard lessons of the NICU, the lessons learned in that game of pinball played badly, are starting to serve us well in the new world of monetized healthcare and jumbled avenues of insurance. We live with these lessons, and will for the rest of his life.

NOTE: Jeff Stimpson is the author of Alex: The Fathering of a Premie and Alex the Boy: Episodes From a Family's Life With Autism. Stimpson blogs about his family at <http://jeffslife.tripod.com/alextheboy>.

“What kind of human spends a year in the hospital and then comes out to begin his life? But he did.”

“The emotional roller coaster ride took a toll on me”

Patrice Kendall
Indianapolis, IN

Our son Carson was born at 25 weeks, weighing 1 lb. 12 oz. He spent 4 1/2 months in the NICU. The day he came into this world was one of the most frightening experiences I have ever had. The nurses tried to prepare us the best they could by letting us know the stay was going to be a roller coaster ride. Boy, were they right. So many ups and downs; two steps forward, five steps back. The emotional roller coaster ride took a toll on me. I suffered with PTSD and depression for quite awhile. I had days I couldn't get out of bed. I had days of just breaking down and I felt down right horrible about it because I didn't feel strong enough for my family. I did seek help and treatment thanks to my husband, my rock.

I wish I could have spent more time in the NICU, but I had a three-year-old daughter to care for at home and a job to keep; same with my husband. Not being with my son as much as I wanted to was probably one of the hardest things to deal with. A lot of our strength and comfort came from the nurses and RTs that cared for our little guy. I will always have a special place in my heart for NICU nurses.

I had days I couldn't get out of bed. I had days of just breaking down and I felt down right horrible about it because I didn't feel strong enough for my family.

Preparing for discharge was very frustrating. Having the oxygen tank home on time was a big hassle. The company's truck that had our tank kept breaking down all over town. I had to get all of my son's meds from three different pharmacies because none of them carried everything he needed. The end experience was filled with a lot of frustration, worry, nervousness—and most of all, elation—to have our son home with his family where he belongs.

Carson is now four and doing great.

“There were days when it was easy for her to breathe, and days when it wasn’t”

“Becca”
Lansing, MI

I am the mother of a 24-weeker named Rihanna. She was 1 lb., 6 oz. at birth in January 2008. She stayed in the NICU almost five months.

It was a very difficult time for me because I didn’t know what was going to happen and I didn’t know whether she would live or die. I was constantly scared and worried about her and I usually never wanted to leave her. It was extremely hard. There were a lot of things I missed out on with her that come naturally for a regular mom or a mom of a full term baby. A few examples of this are: I couldn’t hold her when she was born, I couldn’t breastfeed her, and after she was born and in the NICU for two months, I still couldn’t hold her. All I could do was touch her on her face with two fingers only. She was extremely small. Her skin was so thin at the beginning that it reminded me of a frog’s skin. She had a head about the size of a baseball and her arms and her legs were about the width and length of two pencils side by side.

It was a rough road for the first two months because they were trying to get her heart valve to close with medicine and time. But it didn’t, and her doctors decided it was time for her to go to another hospital to have the surgery performed. They told us that if she doesn’t have it she’ll die and if she did have it there was a 50/50 chance that she could still die. These words were so hard to hear especially after losing my first. I was scared and completely on edge. I didn’t know what the outcome would be and everything was so uncertain. She was transferred to University of Michigan Hospital. Once there, everything hit me like a ton of bricks. I could not hold myself together. I was extremely scared, worried, and I feared the worse outcome. I felt like I was in a dream—part of me was there and the other part was lost. But Rihanna made it through surgery, and recovered quickly.

Our NICU stay after that was full of ups and downs. There were days when it was easy for her to breathe, and days when it wasn’t. There were days when I could and couldn’t hold her. Those days were the hardest to deal with. Much of those days was spent crying—lots of days were spent crying.

I have learned to welcome questions from all, and to ignore the comments made from those who do not know my daughter's situation. I have learned to live our lives to the fullest and not allow obstacles to get in the way.

She had laser eye surgery during her stay to prevent her from going blind. Her vision isn't good and she wears glasses to see but we are grateful that she has some vision. She has mild cerebral palsy on the left side, chronic respiratory issues, global delays or delays in many areas and a lack of age appropriate weight gain.

Since her NICU leave she has continued to have her ups and downs with her health. She has been sick countless times due to respiratory issues. She has had other surgeries such as a vocal cord injection and a feeding tube placement. She has reflux, lung issues, aspirating issues, braces on her legs, glasses, and she's extremely small for a 3 1/2 year old.

Although she has had so many complications she is a happy, fun, life-loving little cutie. She has overcome a world of obstacles and continues to tackle more. She is a joy to be around and she reminds me every day of the small things we take for granted.

Through this experience I have learned a great deal of things about preemies and special needs children. I have learned to welcome questions from all, and to ignore the comments made from those who do not know my daughter's situation. I have learned to live our lives to the fullest and not allow obstacles to get in the way.

If I could say anything to someone who may not be a mom of a preemie or a special needs child I would tell them to please take the time to learn something by asking a question to one of us so that we can help you learn about our little miracle.

The NICU staff “will always be considered family”

Christina Ardis Pitman
San Antonio, TX

I am a proud mother of a 25-week premature baby boy named Madden Silas Ruiz. He was born in December 2010, though his due date was March 2011. I was put in the hospital when I was 24 1/2 weeks pregnant because I was diagnosed with a short cervix. My doctor wanted me to stay pregnant three more weeks but I lasted four days. I went into labor and I had an emergency C-section because my son's hand was coming first. All I can remember when he was born is me staring at him with no emotions. I kept saying over and over, “Breathe boy, you have to breathe for me.” He became stable when they put him on the ventilator. I went to see my son four hours after birth. I forced myself out of bed, refusing help from the nurses and my family members.

My first moments with him I just cried because I felt like, “This is my fault, I could have prevented this.” But the truth is, I couldn't.

The first couple of days were good, but then he was diagnosed with brain bleeds grade 2 on the left and 3 on the right. I was devastated, thinking my son would die on me. His neurologist told me it would be inhumane to keep him alive and I told him to do whatever he can for him. If my son wants to fight, then I'm going to let him give this life everything he has. The brain bleeds were the worst part. He was also diagnosed with a PDA and a closed heart valve, but he had his heart valve reopened inside the NICU and he did remarkably well.

My son spent three months in the NICU at St. Luke's Baptist and I thank them every day for the life they gave my son. They will always be considered family to us. They were in my place for so long and went through this experience with me. I thank God for them. My son came home March 20, 2011. And he came home on oxygen. The first couple of days, I was nervous but happy, scared but thankful. I cried because I knew it was going to be a long journey but love conquers all, I think. My son had heart surgery two days ago to close his PDA.

He is now officially off the oxygen and doing better every day. He is ten months old now and has said, "Mama" and "Dada," and hey, I love him. He is my inspiration to do better.

“My first moments with him I just cried because I felt like, 'This is my fault, I could have prevented this.' But the truth is, I couldn't.”

Taking care of self critical to managing the NICU stay

“Kate K.”
Tucson, AZ

Usually, when parents have a preemie, the first couple of weeks are scary, and mingled with shock. Once the shock wears off and you are more cognizant of your new reality, things begin to feel even crappier than before.

Many preemies face a lot of ups and downs in the NICU. Baby doing well today doesn't guarantee a good tomorrow. As baby faces new developmental phases, new risks crop up. This is very hard on preemie parents because once baby seems like s/he is doing well, the parents relax, and boom—a new problem arises. That ends up being emotionally wearing. Not atypical at all, especially for those with children born very light or very early.

Please know that PPD (postpartum depression) happens to 20-25% of women who have kids. And for those with children in the NICU, the risks are even higher! PPD can take many forms. It might not manifest in you like the way you've seen it portrayed on TV. For me, I cried a lot when my son was about six weeks old (and recovering from NEC) and acted like I had OCD. It was PPD-light (but PPD nevertheless). Incidentally, it isn't uncommon to feel particularly down when your child is finally stabilizing or doing “well.” I suspect that when things are going wrong, your body goes into a ready mode of taking in information. And when baby is doing well, you finally have time to process the emotional aspects of what the situation entails.

Some tips I learned on trying to ward off PPD symptoms:

(1) Exercise. Even walking around the hospital for 20 minutes a day would be better than not exercising at all. Exercise has been empirically shown to minimize the effects of PPD.

(2) Massage. Some research suggests that massage helps minimize PPD.

(3) Nutrition. Often times, parents in the NICU neglect their own nutritional needs. They will grab a candy bar out of a machine rather than getting the protein and veggies/fruit needed to keep one healthy. Sugar depresses the immune system and stresses out the body. The last thing a NICU parent needs is more stress. So even if it means spending 20 minutes less time by your child's side, get thee to a restaurant or home and eat a decent meal.

(4) Sleep. There is a reason why sleep deprivation is used as a form of torture. People don't make as rational decisions when sleep deprived. I know my sleep threshold. I can function fairly well with only four hours of sleep. I do much better of course when I have slept 6-8 hours.

I suspect that when things are going wrong, your body goes into a ready mode of taking in information. And when baby is doing well, you finally have time to process the emotional aspects of what the situation entails.

Even walking around the hospital for 20 minutes a day would be better than not exercising at all.

When my son came home a couple days after his due date, he had insomnia. That meant that my husband and I only slept 1-3 hours per day each. It is hard to see the glass as half full when one is sleep deprived. Once we figured out the cause of our son's insomnia (Reglan), we were able to get him off it. His sleep eventually got better. And everyone getting sleep immensely improved our outlooks.

And of course if you think that you already have PPD, see a doctor. PPD is physiological, meaning that you can't "will" yourself out of it. The great news is that it is treatable. Treatments vary based on the individual. Sometimes parents don't pay attention to their needs (sleep and food are needs, not mere "wants"). And that isn't good for baby.

Baby needs a healthy parent, so that means it is a parent's responsibility to make sure that his or her needs are secured. In the end, mom (or dad) feeling better will help make baby happier too.

“Our Little Acorn”

Tabitha and Aaron McCartney
Hamilton, Ontario

Our son was born at 25 weeks, weighing 1 lb., 15 oz.

At first he did really well for the first three days, then everything fell apart. He had a pulmonary hemorrhage and he had to be on the oscillator to shake his lungs and keep them from filling with blood and drowning. He was on life support. He had a bad bleed grade 4 on his left side and grade 3 on his right side. He dropped down to 1 lb. 9 oz.

They told us that if any more dramatic things happened to him, he would not live. They did not think he would live through the weekend, and they asked us to bring in a pastor to bless him and our parents to meet and say goodbye. We wanted to die—everything was crashing down around us. I had an emergency C-section, so I was still in the hospital. We would go in every two hours to see him. They had to fill him up with drugs and put the jaundice light over him. They had to fill him with drugs because his body was fighting against the machines and causing his heart rate and breathing to drop so low.

They kept him this way for five days.

Every two hours we would go in and the doctors and nurses would say, “There has been no change,” and we would thank God that there had been no change. He hadn’t gotten worse and he was still alive. On the 6th day things got much better. He was taken off life support and put on the CPAP.

But after about two weeks, he was put back on the life support. He was on it for quite a while over two months. He spent four months in the NICU.

Finally he came home, and began breast-feeding and bottle-feeding—no breathing tubes and no feeding tubes. We were so happy.

He has been doing well. He smiles all the time, laughs. When he sees you, he holds your gaze and laughs. He gurgles endlessly and blows raspberries. He can hold his head up very well, and holds his head right up when on his stomach and pushes up about one inch from the ground with his arms.

He can sit for about five seconds and then topples over. He is very good at weight bearing in his legs and can stand for a very long time and balance well also. He grabs at toys and puts them in his mouth and bangs things. He loves to play. His right hand is a bit delayed and can't do as much as his left hand. They say this is due to the level 4 bleed on his left side, but his right hand can hold things and grasp things. If you block his left hand, he will start then using his right hand right away. It's just not as talented as his left hand. Both his legs are fine and kick equally and have no problems. He is starting to eat solids.

He is starting to mimic faces and sounds. He recognizes some songs. He can grab his feet. When he is on his stomach, he makes the crawling motions but cannot bear the weight in his arms yet.

He is doing very well. Despite all the odds against him, we are very thankful for his life and his progress. Something we would have loved for the doctors and nurses to do would be more consistent. It was very confusing and stressful most of the time, hearing so many differing opinions and updates from every doctor and nurse. Sometimes we didn't even know what was really going on, as stories would change so often.

We know it's hard to keep everything on the same page, but it would definitely relive stress and confusion from parents if the doctors and nurses tried harder to be consistent.

“It was very confusing and stressful most of the time, hearing so many differing opinions and updates from every doctor and nurse.”

Each NICU day “seemed to last a lifetime”

Anna Jones
Dearborn, MI

There is no easy way to describe the NICU experience because its simply one of a kind. The emotional spectrum the parents go through and the unpredictable ups and downs of your premature baby’s health leave you feeling completely helpless and drained. Even if you have parented a full-term child you find yourself feeling unprepared and incompetent when you have a preemie. Every time you walk through those doors dividing the “incubator world” from the rest of us, you never know what you are going to find.

Not knowing for sure and not being in control of the situation were the most difficult things for me to deal with. God forbid your baby was moved to a different pod while you were gone—your heart starts to race and you get that sick feeling in your stomach. The people who help you get through the NICU journey are all the great nurses and doctors who understand the situation and keep you informed and involved as much as they can.

In the end, you do come out stronger and wiser than you have ever been.

Being able to call and visit 24/7 helped me a great deal. I think it’s extremely important to do a lot of research and ask a lot of questions about your child’s care and medical problems.

You need information to educate people around you—family and friends who have no idea what its like to have a baby in the NICU. It would help to minimize hurtful comments you might get from time to time mainly because of lack of knowledge or simple ignorance.

Discharge day is full of mixed emotions... All the stress that was building up for weeks starts to come out.

In the end, you do come out stronger and wiser than you have ever been.

Discharge day is full of mixed emotions—the joy of finally going home, the fear of what lies ahead (especially if it involves using different machines at home and practically becoming a nurse yourself) and just the tears that you can't stop. All the stress that was building up for weeks starts to come out. My daughter, who was born in 2007 at 27 weeks gestation, spent 66 days in the NICU. Every one of those days seemed to last a lifetime.

I am very grateful to all the people that helped my daughter and me in that journey. I think the NICU experience is one of those things that stay with you for the rest of your life.

Tipsheet

What I'd Like You to Know About My Life As A Premie Parent

Note: The following is intended for parents of babies in the NICU to use as a guide in communicating with relatives, friends and co-workers.

Maybe you have been inside the Neonatal Intensive Care Unit (NICU) for a visit or perhaps you have visited me at home during the times I was there. As fascinating as a "tiny baby" may seem, there are things I want you to know that could help me greatly as I focus on the journey through the NICU and, hopefully, to come home with my baby.

- It scares me to visit the NICU but I want to in order to be with my child and to care for his/her needs as best I can. I will need to figure out the appropriate amount of time to stay at the NICU and all I need from you is a shoulder, a hug, or a kind comment. Telling me how to handle this situation from the outside is not going to help.
- I often feel like an outsider in the NICU and even at home. The early birth of my baby turned me inside out physically and mentally. Nothing seems normal anymore. I am doing my best to create a "new normal." This event has changed my life permanently in many ways.
- Just because the baby is gaining weight or coming off medical equipment does not mean that everything is now "better." My baby could take a turn for the worse at any moment and I am really worried about him/her.

- It is hard to be around pregnant women right now, since I feel as though I failed in my pregnancy. Even if it wasn't my fault and we have no idea what happened, I still cannot help but feel guilty. My baby should be in my womb right now, all safe and snug, not hooked up to medical equipment. If you are pregnant, please understand I am not angry with you but I may not want to be around you or celebrate in your joy right now. I need time to adjust to this new reality.
- Sometimes I just want to be left alone. Sometimes I want people around me helping me. This can change in a day, in an hour, in a minute. Please know that this stress is normal for a preemie parent and your understanding goes a long way.
- Bringing my baby home is exciting yet terrifying. All of a sudden the baby's care is all on me. It is not like bringing home a normal full-term baby. My baby had a rough start and the NICU has trained me in the ways to care for my preemie. It may not look like the way you took care of your babies or it may seem extreme to you. But know that I am listening to doctors and nurses who are giving me excellent advice. I know you want to help the baby to thrive. If we ask you to wash hands or not visit, please listen to me.
- The best baby shower gift you can give me is your ongoing understanding and your respect regarding my care of my preemie. We do not know what the future holds with our baby and we will be watching over him/her closely for years to come. Whatever comes our way, we still love our child.

Source: Deb Discenza, www.PremieWorld.com, moderator, [Inspire Premie Support Community](#)

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