

How to **Survive** the NICU



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How does one do it? How do you care for other children and obligations at home while nurturing and loving your very sick preemie? How do you hold your marriage together? Eat decent meals? Keep your sanity alive?

I don't know that I have expert answers to any of those questions, but I can share what worked for me. My most important advice? **Learn to forgive yourself.** You will not win an award for "Best Put Together NICU Mom", there is no such honor. Living the NICU experience was the hardest thing I've ever done. I yelled at God, my kids, my husband and myself, the house looked horrible, I was completely anti-social and I put up walls with people I loved because all my energy was expended on making it to the next minute. You will get your life back, it just won't be what it was before. And that's ok. You don't have to have it all figured out. You just have to love your family. The rest will come in time.

YOU ARE NOT ALONE. Just close your eyes for a moment, girl, and feel the love. So many of us have walked in your shoes. We know how heavy the cross is, how uncertain and scared you feel. I know that you feel like life is spinning out of control and you just want to get off the tilt-a-whirl. I never wanted to join the Premie Mom Club, it didn't sound too glamorous. { it isn't } But, it is full of some of the strongest

women I know. I've learned to do things I never thought possible and I've learned to love until it hurts. You can do this. No really, you can. You will. You ARE.

TOP TEN: HOW TO SURVIVE THE NICU

- 1 Say YES to help.** When friends ask how to help, tell them. Whether you need someone to run carpool, pick up groceries, mow your lawn, take you to lunch, buy you granny underwear for that unexpected c-section—whatever you need, humble yourself and ask. You can't go this alone.
- 2 Journal, blog or write it down wherever you must,** but find a place to put your thoughts and feelings on paper. Whether you make it public or not, it helps you sort through the torrent of emotions, but it also serves as a beautiful record for you and your child of how far you've come. This blog was my emotional outlet. I came to covet the half hour of time each evening in front of my computer. On the really horrible days, it helped to put it out there so folks could offer up prayers on our behalf. It made the isolation a little better.
- 3 Eat as healthy as you can.** Some NICUs pay for nursing moms' meals. Ask to see if your hospital does the same. At the very least, stash some snacks in your bag as you head to the hospital, an apple, crackers or some water.
- 4 Get out of the hospital and check your guilt at the door.** If a friend offers to take you to lunch, say yes. While the time with your sweet baby is precious, constantly living in the NICU world will eventually get you down. Enjoy the fresh air and the reconnection with a friend. You'll come back a happier mom.

- 5 If you have other children at home, **work with your family and spouse to figure out a routine that works.** It won't be perfect, but just know that trying to strike a balance is better than not trying at all. Engage your children at home and answer their questions as honestly as you can. They worry just as much as you do.
- 6 **Get a notebook** for all those EOBs (explanation of benefits from your insurance), medical bills, ECI and medical information. You can sort through it all later, but put it one place so you can refer to it when you're ready. You'll need that gold mine of information once you arrive home. Click [HERE](#) for a few of my insurance tips.
- 7 Take a step out of your pity party and **write a note of gratitude** to someone that's really touched you. Taking the time to express your thanks will remind you that you're not in this alone. It might even improve your spirit. At our local children's hospital, many of the rooms were named for a donor. I contacted the development officer and asked for their address and wrote them a note. One family, in particular, really touched my heart. Their generosity allowed me to room just steps away from Luke's NICU room for an entire week. That was the most critical time of his stay and I will be eternally grateful that I spent that time with him. Their donation really did make a difference.
- 8 **Consider counseling after your NICU stay.** No doubt, the stress and anxiety that comes with a NICU stay and/or a special needs child will leave you with invisible, yet very real, scars. There is no shame in asking for help. A licensed counselor can help you put it all in perspective and renew your relationships with family and friends, too. Six months after our son was born, we took that advice and it was so needed.
- 9 **Get connected with other moms—both physically and virtually.** We all need a group of moms who "gets it." Staying in touch with them via Facebook, Twitter and blogs allows you to access their advice and empathy at any hour. Staying in touch with them in real life will help you navigate the scary post-NICU world upon discharge. Consider calling Hand to Hold to be matched with a mentor!
- 10 **Rely on your faith.** Pray and ask for others to do the same. In our darkest moments, our faith is what carried us through.

Kathryn is the mother of five, her youngest born early at 36 weeks at just 3lbs. 9oz. He was an IUGR baby (intrauterine growth restriction) and did not grow well in utero. A few days after birth, Luke contracted necrotizing enterocolitis, underwent emergency surgery and lost several centimeters of small bowel and colon. Since that initial surgery, doctors discovered various defects with his heart, kidneys, brain, spinal cord and feet.



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