

Finding a Balance between NICU and Home

We've all been told that being in the NICU is a rollercoaster ride. Parents experience the full range of emotions – fear, joy, anxiety, and elation - often all in the same day! But there is one emotion we all carry with us, no matter how long we're here...guilt.

When our baby ended up in the NICU it was like time stopped. Nothing outside the unit doors mattered as much as the life and death battle that was going on inside. But we soon realized that life was going on out there. And we had to figure out how to find a balance between our desire to be with our baby in the NICU and responsibilities we still had at home and work. While we did our best, there were never enough hours in the day.



We've talked to other families about how they dealt with this dilemma and we want to share those tips with you.

Let People Help You

Let everyone know what is going on. When people come to you and say, “Please let me know if there’s anything I can do” assume that they really mean it and give them something to do. There are not going to be many times in your life when you will need the help as much as you need it now. Take people up on their offers. Ask them to walk your dog, cook a meal, pick up your groceries or take your spot in the carpool. We know it’s hard, but learning how to ask for and accept help will make things a lot easier.

Simplify Your Finances and Your Life

We all know that dealing with insurance - or the lack of it – is difficult when your child is in the NICU. But that’s not our only concern. In addition to all the new bills, we still have to deal with the usual, every day household expenses. Consider getting direct deposit for your paycheck. Set up automatic payments on your utilities, car payments, and other regular bills. Load up the children’s lunch account at school. And if you can, keep your gas tank full and some cash handy. It will lower your stress level.

“It’s okay to just do the essentials especially when your child is in the NICU,” says Blaine Carr, PhD, licensed psychologist and father of a 35-weeker. “Focus on the things that really matter - regular

meals, keeping a roof over your family's head, finding time to sleep/rest, the travel schedule to the NICU, breast milk pumping, and communicating with friends/family. You have plenty on your plate - so be gentle with yourself. Don't let dishes in the sink or a late charge on a credit card bill add to the worry. Keep your perspective on the things and the people in your life that need your attention at this moment. Other things can wait."

Choose a Spokesperson

While your friends and loved ones want to know what is going on it is nearly impossible to keep everyone up to date on your own. Not to mention that it can be physically and emotionally exhausting to share the same news over and over again – especially when there has been a setback. Let someone you trust become the family spokesperson. Keep them informed and ask that they take charge of making phone calls for you. Many families have also found it useful to start a blog or create a webpage. Hand to Hold likes CareFlash because besides allowing you to share news and photographs it also has a tool for setting up a care calendar where people can volunteer to help out.

Go Home

Nothing is as hard as leaving your child's bedside. We would do anything we could to make things better and spare them this experience. When you feel like you can't hold and care for your baby the way you want to, just being there feels like the best you can do. But while being there matters, remember even nurses work in shifts. Being in the NICU every available hour of your day may not be the best thing for you or your baby. Take time to eat well, exercise, and get some sleep. Find quiet times and places to be alone and regroup. Allow yourself and your loved ones "NICU-Free Time" where you talk about things other than your babies' medical needs. Rest assured that even when you're not in the NICU your presence is felt. And you can always call!

Be with Your Family

No matter where you are – at the NICU or at home – you're going to feel like you are needed wherever you aren't. There's probably no way to avoid this. What is important is that wherever you are you give it your full attention and be honest about how you feel. Trying to keep a normal routine isn't denying things have changed or that your baby is very fragile right now. But it does give your other children the reassurance that while things are hard, it's going to be ok. You are still with them and they can count on you. On the other hand, let them know that you are not the only one who cares for them. Friends and family can provide comfort and diversion while you are away.

Be with Your Partner

Find time to share a meal together, even if it's a snack between meals or pumping schedules. Remember that the little things and small gestures mean a lot. Don't forget the "I love you's" and to

share a hug, cuddle, or even to look within each other's eyes each day. You're both in this together despite how difficult it is. Above all, be patient with one another. There are going to be hard days for each of you, and they will often be the exact same day. Be mindful of that and compassionate with each other. Everyone has their limits. And finally, try to find the humor in small things. It will keep you sane.

Find Your Strengths and Set Your Limits

Amy, who is mom to Ella, who spent time in the NICU says, "I was exhausted by the unending schedule of going back and forth between the hospital and home, not to mention the unending breast pumping schedule and daily emotional overload. I was committed to pumping because it was the one thing I could do - the one thing I could control to care for my baby while she was in the hospital learning to breathe on her own. My husband flew into action settling medical bill snafus, sanitizing pumping equipment, securing breast milk storage equipment, supplies, and special bolsters to hold our baby's head correctly in her car seat so we could safely transport her home. Looking back on this time in our lives - it is clear to me that we each had our roles - and doing those helped keep us sane. "

You can't do everything. And you shouldn't expect to. Be reasonable. Often we are hardest on ourselves. That said, be prepared. People will judge you and say things to you that will hurt. Most of the time this is out of ignorance. They might think you are being overly protective or you're not being careful enough. They will question what you do and how you do it. That's ok. Find the strength to set boundaries and say what you need to say. You are learning what is best for your baby and what will work for your family. Repeat this handy phrase, "Thanks for caring and for the advice. These are hard decisions, and we've given them a lot of thought. I'm sure you can appreciate that and honor our decision."

Love Each Other

And don't forget to celebrate! You have a beautiful new baby. Get to know each other. Love each other. And we look forward to seeing you on the other side of those NICU doors!

