

Finding a Balance between NICU and Home

We've all been told that being in the NICU is a rollercoaster ride. If you haven't yet, trust us... you will. This is because parents experience the full range of emotions while we're here with our babies – fear, joy, anxiety, and elation - often all in the same day! But there is one emotion we all carry with us, not matter how long we're here... guilt.

When your baby ends up in the NICU it's as if time stops. All your normal daily routines are disrupted and set aside. Nothing outside these unit doors seems to matter as much as the life and death battle that is going on inside. But soon you realize that life is going on out there. And there are still things you need to take care of. Your job is to figure out how to find a balance between your desire to be with your baby in the NICU and the responsibilities you still have at home and work. While you will do your best, you may feel like there are never enough hours in the day.



We know this is hard, but you are not alone. We've talked to other families about how they dealt with this dilemma and we want to share these tips with you:

Let People Help You

Let everyone know what is going on. People want to help you but they don't know what to do. So 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

A NICU stay can have a real impact on your finances. For one thing, you may need to take time away from work. Even just the cost of driving back and forth to the hospital can add up. Then there's the question of how much your baby's care is going to cost you.

Please know that there are resources available to help you and your family. Talk to you NICU social worker. Inquire about Medicaid, SSI benefits for premature and low birth weight infants, and other programs. If you need help navigating insurance – or the lack of it – there are people who can assist you. But that's not your only concern.

In addition to all the new bills, you still have to manage your usual, every day household expenses. There are ways to make this easier. Consider getting direct deposit for your paychecks. 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.

Be sure to remind yourself that this is a temporary situation. Things will get better. You will find the help you need to manage the impact of this hospital stay. Until then, be patient with yourself. "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 and rest, the travel schedule to the NICU, breast milk pumping, and communicating with friends and 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 know you would do anything you 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 sitting next to them feels like the best you can do. But while being here in the NICU 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 where 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 always realistic, but it can help. This is especially true if you have other children. They need reassurance. Tell

them that even though things are hard right now it's going to be ok. Let them know you are still thinking of them and that 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

Do whatever you can to make sure that you spend time with each other. Find a few moments to share a meal together, even if it's just snack between pumping sessions. Be affectionate towards each other. Remember that the little things and small gestures mean a lot. Don't forget to say, "I love you." Be sure to share a hug, to cuddle, or even to look within each other's eyes each day. You're in this together, despite how difficult it is. Above all, be patient with one another. You're each going to have bad days, and they will often be the same day. Be mindful of that and be 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

You may discover that you have different strengths. Take advantage of this. 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."

Finally, 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!





HAND to HOLD

Fragile babies. Strong support.

Useful Information:

Helpful People:

Unit Nurse _____

Social Worker _____

Neonatologist _____

Lactation Consultant _____

Pastoral Care _____

Helpful Resources:

Medicaid	1-877-543-7669	www.medicaid.gov
SSI for Infants	1-800-772-1213	www.ssa.gov
Women, Infants & Children Program (WIC)	1-703-305-2286	www.fns.usda.gov/wic
Free or Low-Cost Perinatal Care	1-800-311-BABY	www.mchb.hrsa.gov

Helpful Organizations:

Hand to Hold	1-855-424-6428	www.handtohold.org
March of Dimes	1-914-997-4488	www.marchofdimes.com
Ronald McDonald House Charities	1-630-623-7048	www.rmhc.org
American Academy of Pediatrics	1-847-434-4000	www.healthychildren.org
CareFlash		www.careflash.com
Local Support Group	_____	

If you are interested in connecting with other families you can always contact Hand to Hold.

Hand to Hold's Mission: To provide comprehensive navigation resources and support programs to parents of preemies, babies born with special health care needs and those who have experienced a loss due to these or other complications. **Call 1-855-H2H-NICU or visit www.handtohold.org**



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