

NEONATAL ICU SURVIVAL GUIDE

Resources and tips from a dad who's been there.

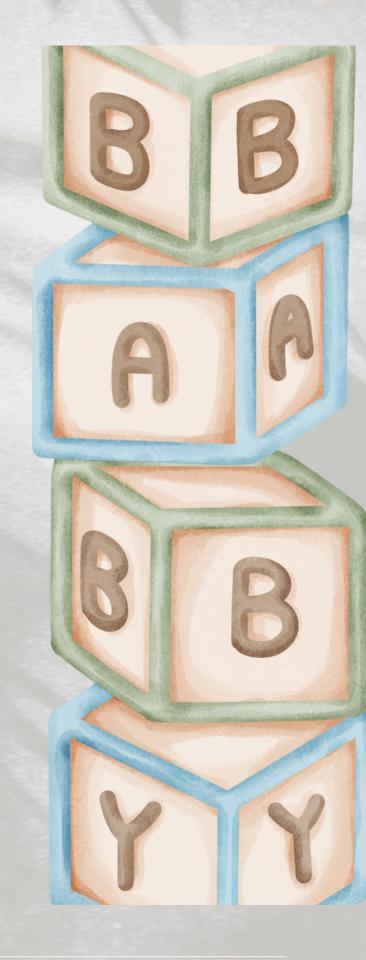
TABLE OF CONTENTS



<u> </u>	Our Story
2	Bonding with Your Baby in the NICU
4	Practical Tips for Navigating the NiCU
<u>6</u>	Coping with Emotional and Mental Health
<u>8</u>	Making Life Easier During the NICU Stay
10	Understanding and Managing Your Baby's Care
12	Additional Tips and Resoucres

OUR STORY

When my wife was admitted to the hospital at just over 32 weeks gestational and told that we would not be leaving the hospital without a baby we were completely blindsided. Never did I anticipate that a nearly month long NICU stay would be a part of our birth story. With 1 in 10 births in the United States being preterm, many parents find themselves in a similar situation to us. The NICU experience is incredibly overwhelming to say the least and it is normal to feel completely lost. There is a lot to do and a lot to know, but you really don't even know where to begin. Hopefully, this NICU Survival Guide can be a good place for you to start.



BONDING WITH YOUR BABY IN THE NICU

Bond with a private room

Many hospitals have private NICU rooms, but they may be in limited supply. Make sure your care team knows you'd like a private room. A private room can be hugely helpful as you seek to bond with your baby. If you're breastfeeding or pumping, a private room will make the process a lot less stressful. Plus, you'll help your baby, and yourself, get some peace and quiet from their crying neighbors.

Share your desire to care for your baby

The nursing staff wants to help facilitate your bond with your baby, but they may not proactively suggest ways you can bond. Make sure to let your nursing staff know when you want to hold your baby, enjoy skin-to-skin cuddles, bathe your baby or change your baby's diapers. If you feel nervous about caring for your little one, the nurses are ready to jump in with helpful tips and tricks.

Support your baby's brain with reading

Depending on the type of care your baby is receiving, you might not be able to snuggle the little one as often as you'd like. But one thing you can do, even as you gaze at your baby through the isolette, is read to your baby. Reading to your baby is incredibly healthy for their brain development, and was recommended by the doctors to help our baby combat his brain bleed. NICU days are long, so make sure you pick up one of your favorite long-form children's books to read while passing the time. We chose to read The Chronicles of Narnia to our little one while in the NICU, and made it through the first three books in the series!

BONDING WITH YOUR BABY IN THE NICU

Drown out the noise with calming music

There's beeping and ringing coming from every direction. Create a soothing environment for you and your baby by bringing a bluetooth speaker to the hospital. You can introduce your baby to your favorite artists, play calming nature sounds, or even crank up white noise all day to combat the stressful hospital noises.

View your baby from a distance

When you have to be away from the NICU, getting eyes on your baby can provide peace of mind. Check to see if your hospital provides access to a digital camera-feed of your baby. Our hospital made sure that the camera was on 24/7, except when the baby was naked during diaper changes or had to have a complex procedure. We were even able to give the link to our family to peek in on the baby as well.

PRACTICAL TIPS FOR NAVIGATING THE NICU

Understand visiting hours

Get as much information on visiting hours as you can. At our NICU, visitors could stay all day and all night. The only caveat was you couldn't come in during shift change from 7-7:30 each morning and evening. If you were in the room during shift change, however, they would not kick you out. Make sure you have this information early on so you know when you can and can't see your baby. Also, don't worry about going to see your little one whenever you feel you need to. There were times we went to be with our little guy in the middle of the night when worry kept us from sleeping.

Stay close with the Ronald McDonald House or hotel discounts

If your hospital is far from home, check to see if you're eligible to stay at the <u>Ronald McDonald House</u>, a charity that offers extremely discounted lodging for families whose children are undergoing medical procedures. If you don't qualify, check with your hospital to see if they offer discounts to local hotels.

Nourish yourself with discounted food

When your baby is in the NICU, the last thing you want to think about is feeding yourself. Many hospitals have a cafeteria, and often offer discounts for NICU families. My hospital, in particular, offered 3 free meals a day for breastfeeding mothers. Check with your hospital about food options before shelling out money each day.

PRACTICAL TIPS FOR NAVIGATING THE NICU

Save money with validated parking

Frequent visits to the NICU can quickly rack up parking fees. I talked to a NICU mom who shelled out hundreds in parking before finding out that validation was available. Make sure you check with your care team to see if parking can be validated or discounted.

Find help at a family resource center

The hospital we were at had a very nice area for family members of children staying in the hospital. Many children's hospitals have something similar. There are numerous services that the resource center offered including internet access, free coffee, hotel/gas vouchers, television and video game consoles, free lunches a few times a week, assistance with connecting with chaplain or social services, education and sales of safety products such as car seats and bike helmets, and many other services.

COPING WITH EMOTIONAL AND MENTAL HEALTH

Cope with counseling services, chaplains, and social workers

Having a baby in the NICU takes a major toll on you emotionally, mentally, and spiritually. Hospitals have no shortage of people on staff to assist in these areas. They employ chaplains from many different faith traditions to talk and pray with you. They also have counselors and mental health professionals to help with postpartum issues and dealing with having a NICU stay. For help outside of the hospital, many non-profits offer support services, such as peer-to-peer mentoring, parent support groups, and even FREE counseling. Hand to Hold, for example, offers free limited counseling (8 - 12 sessions) to parents who have experienced a NICU stay.

Take advantage of nurses and family for much-needed self care

Spending a lot of time in the NICU is exhausting. There is absolutely nothing wrong with doing something to feel normal for just a bit. In fact, it can be extremely refreshing. Take an evening to go out for a nice meal. Leverage the nurses. After all, they are there to help take care of the babies. They are more than happy to take over feeding and changing the baby for you to get out for a couple of hours. It's not just the nurses who want to help, either. Grandparents, aunts, and family are eager to help as well. Leverage family visits to take time for self-care.

COPING WITH EMOTIONAL AND MENTAL HEALTH

Connect to community and resouces online

There are a number of resources you can access online and through social media that can help provide insight, support, and community. Dear NICU Mama offers community-based and trauma-informed support offerings that give NICU parents the chance to heal at their own pace. Hand to Hold offers an app for parents to find resources and community when and where they need it. Project NICU also runs over 200 support groups while providing free or discounted counseling services.

Project NICU: www.projectnicu.com & www.instagram.com/projectnicu

Hand to Hold: www.instagram.com/handtohold

Dear NICU Mama: www.instagram.com/dearnicumama







MAKING LIFE EASIER DURING THE NICU STAY

Build a milk stash at the hospital

Hospitals want to facilitate breastfeeding for their NICU families. The staff will help ensure that your pumped milk makes it to your baby. When your baby is super tiny, they may not be able to eat enough to keep pace with your supply. Check with the infant nutrition center to see if they store excess milk, and if you're able to take it home with you when you're discharged. We were able to take home a stash of hospital-pumped frozen milk that lasted us 3 weeks!

Keep your hands moisturized despite frequent washes

No one tells you about the trauma to your hands after scrubbing them raw during countless visits to the NICU. Our hands were so raw from frequent hand washing that it hurt when water touched our skin. Invest in a high quality, restorative hand-cream to prevent moisture loss and keep your skin-barrier healthy.

Invest in sanitizing

Your baby's immune system is still in the works. It's critical to avoid contaminating the NICU with pathogens (hence the heavy hand washing). One of the most dirty objects in our possession is our phone. Scientists at the University of Arizona have found that cell phones carry 10 times more bacteria than toilets. When you're unable to avoid phone use, consider picking up a sanitizing wipes or a UV phone sanitizer to keep your phone as clean as possible. Be sure to also keep extra hand sanitizer around too!

MAKING LIFE EASIER DURING THE NICU STAY

Freshen up with laundry and showers

If you want to quickly refresh your or your baby's clothes while at the hospital, check to see if they offer laundry service. Our hospital had a Family Resource Center that allowed NICU families to utilize an on-site laundry room, and would even bring your clean clothes to your NICU room if requested! Likewise, many hospitals have showers where you can quickly wash up whenever you need to.



UNDERSTANDING AND MANAGING YOUR BABY'S CARE

Understand newborn screens

Newborns get a lot of tests. NICU newborns get even more. Make sure you ask your doctor about the results of your child's newborn screens. Sometimes, certain tests or procedures, like hearing tests or head scans, need to be delayed until a child is older, so be sure to ask your doctor about when you child can expect additional routine screens.

Get access to your baby's digital medical chart

Many of us are used to accessing our health information through an online portal. Make sure you ask about how to set up your newborn's digital medical chart. Having access to the chart can help you keep track of results of numerous newborn screens, and help you understand upcoming or past procedures.

Monitor your baby's progress with early intervention

Did you know you can get free occupational, speech, and physical therapy for your child? <u>Early Intervention</u> services are available in each state to track the progress of children at risk for developmental delays, including NICU graduates. Most hospitals will automatically refer your NICU graduate to early intervention, but anyone can make a referral, including parents! If you're eligible, you'll be paired with a case worker who can connect you to the appropriate therapists for your child. Even if you don't have any particular concerns after leaving the hospital, early intervention services can provide much needed peace of mind as you track your child's developmental milestones.

UNDERSTANDING AND MANAGING YOUR BABY'S CARE

Research NICU follow-up programs

Doctors want to take extra care to follow up on their NICU patients. Our area offers a NICU follow up program that provides extra support for premature and medically complex infants after leaving the hospital. Check with your hospital, or local medical providers, to see if there are similar programs in your area.



ADDITIONAL TIPS AND RESOURCES

Lighten the load with hospital storage

Visiting the NICU can be a huge undertaking. You may be toting around baby books, pumping gear, and snacks each visit. Lighten your everyday load by checking with your care team about storing items at the hospital. We kept our own bottle of dawn, sponges, baby clothes, and milk storage at the hospital in drawers reserved for our family. Check with your care team about where you can store your necessities.

Drive safely with car seat certification

If you think bringing your newborn home in a carseat for the first time will be scary, try bringing home a four pound preemie. Our baby looked teeny tiny in his car seat, but the hospital offered car seat fittings and car seat installation certification for extra peace of mind for NICU parents.



ADDITIONAL TIPS AND RESOURCES

Reflection Section: What's working for me?

Tips for using this section

- Keep it Simple: Write whatever comes to mind; this is your space, and there's no "right" or "wrong" way to use it.
- Celebrate Often: Even small wins, like holding your baby's hand for the first time, are worth documenting.
- Be Honest: It's okay to acknowledge the tough moments. Reflecting on challenges can lead to personal growth.
- Set Intentions: Use your reflections to identify actionable next steps for yourself or ways to seek additional support.

Prompt questions to guide your refletions Bonding with baby

- What has been the most meaningful way for me to bond with my baby?
- Are there additional ways I'd like to bond that I haven't tried vet?

Self-Care

- How have I been taking care of my well-being?
- What's one small thing I can do today to recharge or feel more centered?

ADDITIONAL TIPS AND RESOURCES

Support System

- Who has been my biggest source of support?
- How can I communicate my needs to my support network?

Gratitude

- What am I most grateful for today?
- Has someone's kidness or support stood out to me this week?

Challenges and Resilience

- What has been the most challenging part of this experience so far?
- What personal strengths have helped me overcome tough moments?

Small Wins

- What small victories have I celebrated recently?
- How did celebrating those wins make me feel?

Goals and Progess

- What is one goal I have for the next week (e.g., learning more about my baby's care, making time for myself, etc.)?
- What progress have I noticed in ,mself or my baby

Notes Section

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