



For many, having a baby admitted to the Neonatal Intensive Care Unit (NICU) is overwhelming. Most parents don't anticipate that their newborn will need a stay in the NICU. When a NICU stay *is* needed, parents may find it difficult to understand exactly what is happening.

Medical professionals can be difficult to approach, especially in a busy unit like the NICU. In large teaching hospitals, there is often a complex team of experienced providers and trainees. Parents may find themselves confused by the amount of medical information thrown at them.

If you don't understand your baby's diagnoses, if you feel like your concerns are being brushed off, or if you simply feel overwhelmed, there are a few additional things you can do to do get your voice heard and feel more empowered in the NICU:

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## 1. Advocating for Your Child in the NICU

Doctors care for many different babies and often rely on medical charts and verbal reports for medical decision-making. Physicians are people. People make mistakes. Important information can be lost in written and verbal communications. Things can be charted incorrectly or not documented at all. Below are a few suggestions for how parents may be able to advocate for their babies:

- Speak with providers. During a NICU hospitalization, there may be many medical professionals involved in the care of your baby. It is helpful to become familiar or comfortable with one or two doctor(s)/nurse(s) that you may be able to speak with. If you have concerns or questions it is often easier to share them with a doctor and/or nurse that you know and are comfortable with.
- Keep a journal and take notes about your child's care. Most parents are overwhelmed and exhausted during the first few days of a baby's NICU admission, especially if the mom had a difficult labor and/or an emergency cesarean delivery. Journaling during your child's



hospitalization may help you keep track of important information, recommendations, and medical questions. You may want to take the notebook with you when you visit the NICU and write down all diagnoses, procedures, or prognoses. If several specialists are consulted during the hospitalization, it might be helpful to write down their names and roles. When you think of a question for your provider, write it down and leave a space so that you can fill in the doctor's answer/response. Here are a few suggestions on places to start:

- The formal names of your child's diagnoses and what these diagnoses could mean long-term. Nurses and other NICU staffers can help walk you through these details.
- The results of any tests, imaging, or assessments the doctors tell you about.
- Observations about your baby that you see when you visit them in the NICU, *especially* things you find peculiar, concerning, or that you don't understand.
- Questions about your baby's care: Any time you have a question about your child's care, you may want to write it down and ask it when you can speak with a medical professional. With the amount of information you're getting thrown at you, this may help you remember what your questions are. For example: Why is my baby on a ventilator? Why does my baby need this particular surgery? Why did you have to use a PICC line? What do the results of head imaging show?

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## 2. Making Observations

Parents don't usually have access to their baby's charts or medical documents. This may make journaling about observations, questions, and concerns a helpful and important practice. Parents might find it helpful to write down any observations that concern them, such as seizure-like activity or changing color after feeding.

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## 3. Expressing Your Concerns

If you think that your concerns are being ignored or dismissed, you can go up the professional chain:



- You have a right to talk to your child's *specialists* if you feel the neonatology team is dismissing you. For example, if you have a concern about your baby's brain function, you have the right to ask to speak to the *neurology specialist*. If you have a concern about your baby's feeding (ability to suck and swallow), you could request a consultation with a *doctor of rehabilitation medicine* or an *occupational or speech & language therapist*.
- If you have multiple concerns involving your baby's overall medical management, you may want to request a conference with the medical team. A conference is an opportunity to gather all of the specialists, as well as the primary care team members, and discuss your concerns. Not many parents know they can schedule a conference about their child's care, and it's a great way to voice your concerns to the medical professionals who provide care to your baby.

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#### 4. How You Might Advocate After Discharge from the NICU

##### Setting Appointments

When your baby finally gets to go home, things can be very different depending on their prognosis. For example, a late-term preemie with no other health issues or neurological abnormalities may be discharged with some simple instructions to follow up with a pediatrician. A child with more severe diagnoses can have much more paperwork and follow-up that needs to be done.

Before discharge, you may have to work with your medical caregivers and social workers to conduct all the follow-up your child needs. Some follow-up may be scheduled even before your child leaves the hospital. Your child may be sent for follow-up with a developmental clinic or neonatal clinic; there may also be services provided relating to home care transition (this could involve a traveling nurse visiting you and your baby at home to see how the baby is developing). These home care visits may be a single session, or they may last for several months, depending on your child's needs.



### Journaling for Follow-up

Just like in the NICU, many parents find it helpful to keep journal records of everything related to their child's care, some of these may include:

- Who their follow-up doctors and specialists are
- The medical provider's contact information
- What happened at appointments
- When those appointments were
- What recommendations the medical provider had (ie, continued therapy, specific exercises, etc.)

Sometimes if you have records of appointments, it's easier to speak to medical practitioners about your concerns, especially if ongoing problems worsen or stay the same.

Just like during the NICU stay, continued journaling after discharge may be helpful. This can help during follow-up appointments with your child's pediatrician or developmental specialist. When your baby's at home, you may want to try keeping track of the following items so you can recognize changes or bring up specific concerns:

- How many wet diapers does your baby have per day? Per night?
- How many bowel movements does your baby have per day? Per night?
- How much is your baby drinking during the day? During the night?
- How often does your baby wake up for feedings throughout the night?
- How often does your baby cry? For how long?

Some parents find it helpful to continue journaling after the baby goes home and throughout the first few years of a child's life. By keeping track of your baby's habits and any changes in them, you may be able to provide a pediatrician with a better picture of how your baby is doing.



Personal Example: When I brought my twins home from the NICU, I was worried about losing track of how much I fed each baby. I kept a journal for the first year and wrote down the feeding start/stop times and the amount taken for each baby. I also wrote down if a baby spit-up any formula as well as if I saw any trouble with feedings (like choking or gagging). When the pediatrician asked me how the twins were feeding, I could give them details to evaluate.

### Developmental Care and Follow-up

In some cases, your child may be referred to developmental programs like Head Start, Help Me Grow, or Zero to Three. These are called different things in different states. If your child isn't referred to one of these programs by the medical professionals themselves, parents should know that *they can request their child be evaluated by the program*. These programs are billed as being for children who either *have* developmental delays or are *at risk for* developmental delays.

One of the things that's really important for children with suspected neurological issues like hypoxic-ischemic encephalopathy (HIE) is following up with a neurologist. One of the key things to remember is that often babies can have brain imaging done in the NICU, and doctors may recommend that follow up imaging be done later. Serial imaging can be important to see how the baby's brain is developing. In the case of HIE, damage that might not have shown up during a NICU stay after cooling therapy may be revealed as the child grows.

Head imaging findings might be important for getting a child early intervention services. Early intervention will help assist with possible delays so that child doesn't become severely delayed like they may be if problems aren't recognized until the child is in preschool or kindergarten. You may want to ask about continued surveillance for your child if they're at



risk for developmental delays or ask if their birth or NICU stay might have qualified them for therapies and other medical care.

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## 5. Getting a Second Opinion If Necessary

You know your baby best. If something your doctor or nurse is saying doesn't sit well with you, you are allowed to seek a second opinion. Hospital systems will have different specialties, facilities, sizes, and areas of focus, so you may find that your baby receives a different degree of attention or care at another hospital. If your child is receiving all care through a single hospital network, you may not receive a diversity of opinions as to your child's care. In addition, in the case of a medical mistake, medical staff may tend to minimize errors, for example where the baby ends up in the NICU because of a traumatic birth or birth injury. When medical staff working within the same hospital network hand off medical reports and notes, there can be a tendency to minimize injuries caused by errors. It may be the case that avoiding medical malpractice or birth injury lawsuits takes precedence over accurate reporting.

Care standards require all medical professionals to provide safe medical care to their patients. Unfortunately, medical professionals make errors. Some parents may choose to seek a second opinion. Here's how you may go about getting a second opinion on your pregnancy or your child's traumatic birth:

- You might want to request your medical records: Obtain records of the opinions from the doctors and specialists that analyzed your child's neurology records, brain imaging, EEGs, and all other paperwork and imaging from the original hospital.
- Have medical records reviewed by new caregivers as a fresh set of eyes: You may want to find a completely different set of specialists *outside the original hospital* where your baby was born so that you can get a second, unbiased opinion. To learn more about potential medical providers, you can check *U.S. News and World Report*, *Doximity*, and *Healthgrades* to see what hospital they're affiliated with, what their specialty is, and how



long they've been working in the field.

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## 6. Being Objective

Nobody wants to think their child might have developmental delays or that their growth isn't progressing normally, especially if they're told their child is doing better than expected after their NICU stay. You may want to monitor your child to make sure they're hitting their developmental milestones. New parents sometimes don't fully realize the importance of developmental milestones, because they're often told there is a lot of leeway when it comes to when the child should be hitting those milestones. While there is some leeway, though, there are certain red flags that can [signal a developmental issue](#). For example, if a child retains their primitive reflexes at six months, this may indicate developmental delays. [This article](#) has charts that use uppermost age limits for the latest normal age at which a particular milestone is developed, which means that if a child is missing a milestone by that specific age, they are clearly delayed, requiring further intervention and follow-up.

Personal Example: Catching developmental delays can be especially difficult for new parents. My twins were my first children. When they were discharged, they were hitting all the newborn milestones and did not require further follow-up with specialists. While they were physically healthy and met all the gross motor milestones, they were mildly delayed in other ways. Unfortunately, I did not realize this until they were in kindergarten. Some delays are very subtle and can be missed by both new parents and their pediatricians. It may be helpful to get high-risk babies evaluated by developmental specialists throughout the first five years of life.



## 7. Being Persistent

As a parent, you have a right to know what's going on. If you're not getting the answers you need, you can ask questions. If you have to, you may want to work your way up the professional chain of providers at the hospital until your concerns get addressed. Once you're out of the NICU, you might want to keep monitoring your child closely with the help of medical providers to make sure that you catch any developmental concerns as quickly as possible and get Early Intervention or therapies in place.

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### Related Reading:

- [Record-Keeping for Your Child](#)
- [Parent Support Groups & Mental Health Resources](#)
- [More Community Blog Posts](#)



### Andrea Shea

Andrea Shea is the mother of four children (two babies admitted to the NICU), a former labor and delivery nurse, and an investigative legal nurse. She was a very young mom, giving birth to twins at age 21 via emergency C-section. During her twins' three-week stay in the NICU, she found that her best resources in the NICU were the nurses. Inspired by their work, she began her nursing degree and became a labor and delivery nurse and clinical instructor. After many years working in labor and delivery, she became an investigative nurse and analyzed client medical records for adherence to standards of care. She is a former nurse consultant for the HIE Help Center, an informational resource for parents of kids diagnosed with hypoxic-ischemic encephalopathy (HIE).