

Emotions After Discharge

When you bring your baby home

When your baby is finally ready to leave the NICU and go home with you, it is a very exciting time. But, many parents find that their baby's homecoming is bittersweet. They feel relief and joy, but they also feel many difficult emotions, some of which are a surprise.

It is normal to feel a wide range of emotions when you finally have your baby home with you. This handout describes the feelings that many NICU parents report having after they brought their baby home. You may feel all, some, or none of these feelings.

Unexpected Feelings

The depth and range of your feelings during your baby's first weeks at home may surprise you. You might find yourself reliving the events of your child's birth and hospital stay, and wonder if there was anything you did or didn't do that made a difference.

Most parents are also surprised to find that they actually miss the NICU! While your baby is in the hospital, NICU staff become a part of your life. The nurses, doctors, and other staff share a life experience with you that others may not fully understand. And, you probably planned your days around the NICU routines. Your time in the NICU may have been stressful, but it also provided structure and support.

Many parents feel this "post-NICU letdown" during their first few weeks at home with their baby. Without the daily support provided by the NICU staff and unit, you may feel lonely and isolated. But over time, you will set up new support systems and routines at home.

If you are feeling a letdown after you take your baby home, try to ease your feelings of isolation. Ask trusted friends to visit or schedule some time for yourself away from your baby, if you can.



It is normal to feel lonely and isolated after you leave the NICU.



“Not being able to see her monitors was scary at first. Trying to make sure she took enough milk was scary, too. All of her care was up to us – it was no longer back-stopped by round-the-clock medical care. But, we finally found our routine and settled into it. And because of our NICU stay, we knew a ton about how to take care of Lucy.”

-- Lucy's Dad

Anxiety

While in the NICU, your baby is always monitored and cared for by nurses and other medical staff. You and your baby suddenly lose these comforts when you leave the hospital, and it can be scary. Some NICU parents say that once they take their baby home, they lose their confidence and start to second-guess whether they can keep their baby safe.

One way to ease this normal anxiety is to stay overnight in the NICU for long stretches before your discharge date, if you can. This way, you can become very familiar with your baby's unique behavior and patterns.

Also, remember that our first priority in the NICU is the safety of your baby. We would not send your baby home if we were not 100% confident that your baby is ready and that you are able to care for them on your own.

Friends and Family

In the NICU, we teach how important it is to wash your hands often, since your baby is at high risk for infections. Once your baby is home, your friends and family may not understand why it is so important to always wash their hands before they touch your baby.

Some parents feel distant from family and friends who do not understand or respect their unique needs. They also become closer to those people who do understand.

Parents may also be worried exposing their baby to germs when they leave the house or have a visitor. These are normal feelings. But, friends and family may question why you don't want to go to public places or be around many other people during the winter months.

Try to remind yourself that you are doing the best you can, and that it is OK to have visitors and to leave the house. You just need to take the precautions that you learned while in the NICU. Try to educate your family and friends as best you can, and know that you are doing everything you can to keep your baby safe.

Bonding and Attachment

When a baby is born early, bonding and attachment do not occur as easily as with a full-term birth. Your baby may have arrived before you were prepared. And, while your baby is in the NICU, you may not be able to have much close contact at first. This lack of contact may be due to your baby's medical needs, a lack of privacy, or not being able visit the NICU as much as you would like.



“An anxiety developed within me after he came home – a hypervigilance and an over-protection. I wish someone had told me you could develop post-traumatic stress disorder after your child comes home from the NICU.”

-- Layne's Mom

Even if they spent a lot of time with their child in the NICU, many parents feel like their baby never was truly *theirs*. They were always sharing their baby with the nurses and other care providers. When you get home with your baby, you may still feel some detachment, as if your baby is still not fully yours. This is normal.

The time you were able to spend with your baby in the NICU may have helped you to start to bond with your baby. But true attachment grows slowly. After you bring your baby home, give yourself plenty of time to get to know your child, gain confidence in your parenting skills, and recover from the emotional rollercoaster you have been riding. With time and patience, the bond between you and your baby will grow and strengthen.

Chronic Sorrow

“Chronic sorrow” is sadness that lingers even after the source of pain has eased. After your time in the NICU, events that once didn't bother you can now bring feelings of deep loss.

NICU parents often feel very helpless while their tiny baby is in the hospital. They can still feel this insecurity even after their baby is safely at home. The effect of painful times can stay with families for many years, and may forever change their lives.

These are some symptoms of chronic sorrow:

- Recurring dreams
- Strong reactions to certain sounds
- Seeing images and smelling odors that remind you of the NICU
- The return of pain and fear when your children are sick, even with common illnesses like colds

Chronic sorrow may last months to years, since many preemies are still fragile and may have health and developmental problems after they leave the NICU. During this time, old anxiety and sorrow can return if there is another need to go to the hospital, if your baby needs to be assessed for any reason, or even if you attend a happy event such as a baby shower or a child's birthday party.

Post-Traumatic Stress Disorder (PTSD)

Some experts compare the reactions of NICU parents after discharge to *post-traumatic stress disorder* (PTSD). PTSD is an anxiety disorder that is triggered by witnessing a terrifying event. Symptoms include flashbacks, nightmares, severe anxiety, and not being able to stop thinking about the event.

Many NICU parents have symptoms of PTSD. They may have nightmares, or have flashbacks when the phone rings unexpectedly.



“Coming home felt liberating, but I’ll admit it was a much harder transition than I had anticipated. I suddenly lost all confidence in my ability to be a mother because I no longer had nurses there to validate me. Over time, I regained trust in myself. As I look back, I just wish I hadn’t been so hard on myself.”

-- Kylie’s Mom

Parents with this type of anxiety may clean every surface of their house or wake up to check on their baby many times a night.

The symptoms of PTSD are the same as those for chronic sorrow. It can be a serious problem, so please talk with your primary care provider or mental health professional if you:

- Have a hard time falling asleep or staying asleep
- Are very jumpy or irritable
- Have problems concentrating on anything

Taking Care of Yourself

- Remember that you are a good parent.
- Stay connected to loved ones and talk often with trusted friends.
- Think about talking with a counselor if you are struggling with your feelings after you go home with your baby.

References:

The Preemie Parents’ Companion: The Essential Guide to Caring for Your Premature Baby in the Hospital, at Home, and Through the First Years by Susan L. Madden, M.S.

Preemies - 2nd Edition: The Essential Guide for Parents of Premature Babies by Dana Wechsler Linden, Emma Trenti Paroli, and Mia Wechsler Doron

Questions?

Your questions are important. Talk with a member of your baby’s healthcare team if you have questions or concerns.

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