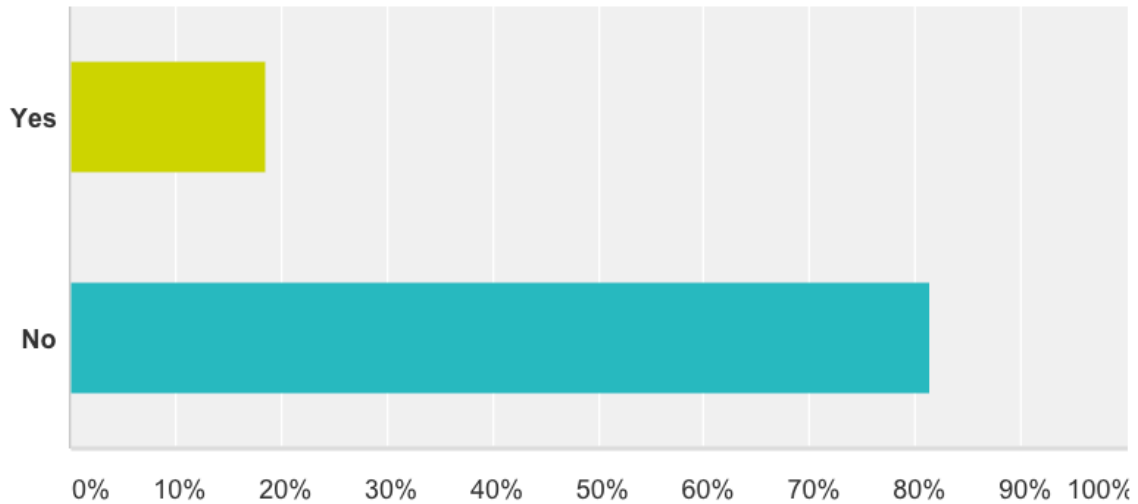


Transitioning Home Babies from the Neonatal ICU

Q1

Did you ever receive counseling from a NICU alumni parent before or during your transition home?

- Answered: 81
- Skipped: 1



Answer Choices	Responses
Yes	18.52% 15
No	81.48% 66
Total	81

Q2

If you did receive pre-transition counseling, please rate your experience. If not, please share how helpful you feel an alumni parent mentor program would have been.

- Answered: 62
- Skipped: 20

Not at all Helpful	Slightly Helpful	Somewhat Helpful	Very Helpful	Extremely Helpful	Total	Average Rating
3.23% 2	9.68% 6	20.97% 13	30.65% 19	35.48% 22	62	3.0

Q3

Thinking back to the first few weeks when your baby was home, what do you wish you would you have done differently to ease the transition from the NICU to home (i.e., ask friends or family to care for other children or hire a babysitter occasionally).

- **Answered: 67**
- **Skipped: 15**

Showing **67** responses

Meals prepared, someone to help with laundry

12/2/2014 3:49 PM

Had more help Avoided mastitis. NICU had me pumping q3h then baby at home drank much less

12/2/2014 10:53 AM

I wish I would've had more people to either come help or to keep me company. I felt so lonely and isolated and overwhelmed. I also felt like I couldn't or wasn't allowed people to come over because of the risk of spreading germs to the babies. Looking back, I wish I wasn't so anxious about that.

12/2/2014 6:59 AM

Would have been helpful to have had more information in general about what to expect.

12/2/2014 6:58 AM

Have a visit from another preemie parent for support.

12/2/2014 6:57 AM

Accept help when offered.

12/2/2014 6:39 AM

Know what type of help to ask family or friends for prior to returning home.

12/2/2014 5:42 AM

Have spoken to a parent that had done it and understood my isolation and trauma and fears, and helped me with tools to deal with that..and also understood reflux more, and understood how to deal with reflux.

12/2/2014 5:10 AM

Nothing

12/2/2014 5:09 AM

Ask friends/family for help (mainly w/ meals, laundry, cleaning bottles/pump parts)

12/2/2014 4:47 AM

Not be afraid to ask for help and not be so fearful they will get sick if you take them places.

12/1/2014 6:53 PM

Be around more family

12/1/2014 6:48 PM

Continued to receive pre-made meals from family and friends.

12/1/2014 5:45 PM

Had my husband feed the baby more in the middle of the night. Gone on Zoloft right away for my PTSD instead of waiting until after I went back to work.

12/1/2014 5:38 PM

I wish that someone had told me to leave a TV on at night. The quiet house was just too much for my daughter. She needed some noise and lights.

12/1/2014 8:56 AM

I would have had my mother continue to come over and help me clean and look after the dogs

12/1/2014 8:30 AM

I would have talked to fellow NICU parents more, they understand the transitions and the care of your preemie first stages at home more than anyone.

12/1/2014 7:44 AM

Having someone to consult that's been where I was would've been great. It would've been nice to be able to text another mom and get some reassurance or wise words

12/1/2014 7:10 AM

Just knowing what to expect as far as appointments and equipment go. Our insurance gave us a case manager that was very helpful.

12/1/2014 7:01 AM

Asked for assistance with our oldest son, prepared the home more so having to run to the store etc wouldn't have been so stressful, prepared frozen meals

12/1/2014 6:46 AM

I wouldn't have done anything differently! I didn't take my son out for the first month he was home! He did perfect!

12/1/2014 6:30 AM

Asked for help

11/30/2014 11:02 AM

I would have done nothing it was an easy transition for everyone I think and my boy was there for 9 weeks

11/29/2014 7:01 AM

With the first preemie (we have 4) I wish we had known to have lights and noise to help ease the nighttime sleeping.

11/28/2014 11:42 PM

Wish I had a bassinet or sleeper right next to my bed right away. Also wish I had a foam wedge since baby was used to sleeping on an incline.

11/28/2014 11:12 PM

It was pretty OK, honestly. We were super nervous, but our baby is our first child and I had a lot of help from family.

11/28/2014 10:59 PM

Asked for help. Sleep when baby slept

11/28/2014 10:18 PM

Help family understand the need and importance of isolation.

11/28/2014 9:07 PM

Have family more understanding of need to limit visitors

11/28/2014 6:01 AM

I wish 6 years ago that I took a paternity leave of absence instead of taking the Friday and Monday off and going back to work. I don't regret letting my wife extend her leave of absence past the 3 months so that she could bond with our daughter.

11/27/2014 7:28 PM

That I didn't have to follow all of the time schedules that were used in the NICU.

11/26/2014 11:13 PM

Try to make home sound more like the NICU. It was too quiet for him. We got a sound machine and that helped at night.

11/26/2014 10:15 PM

Asked for someone to help with household stuff and older children.

11/26/2014 9:54 PM

We really could have used in home nursing. We asked for home hospice but could not get help due to the limitations with our insurance.

11/26/2014 8:09 PM

Connect with more of the parents at my NICU. They became my extended family, and I missed seeing them every day.

11/26/2014 7:32 PM

Asked people to let us home with less visitors. Asked for meals.

11/26/2014 5:40 PM

Asked a friend or family if they could cook some freezer friendly food.

11/26/2014 2:19 PM

Hire a babysitter just for sleep or to take care of household duties.

11/26/2014 1:24 PM

Nothing can prepare you. But having access to a NICU nurse that you can call with any question.

11/26/2014 12:58 PM

I would not have worried about the schedule as much as I did. But after 95 days on a schedule in the NICU it is hard to relax.

11/26/2014 11:56 AM

Ask for friends/family to come over to help with my 3 year old son. I would not have wanted him to have to leave me and his little sister, but someone helping with his needs would have been very helpful.

11/26/2014 11:13 AM

Somebody to do the cooking cleaning laundry so I could rest and spend time with my babies.

11/26/2014 10:34 AM

Would've made sure nursing care was in place.

11/26/2014 10:07 AM

As feeding was our biggest struggle, I wish we would have transitioned him to the formula he would be on at home before discharge. Because it turns out he HATED it, so between that and reflux it felt like he wasn't keeping anything down. It would've been nice to problem solve that in the NICU rather than at home where it felt so overwhelming.

11/26/2014 10:03 AM

hire some assistance

11/26/2014 9:35 AM

Taken more time off of work.

11/26/2014 9:04 AM

Ask for more help from anyone. For laundry, shopping, etc.

11/26/2014 8:47 AM

Trusted family more to help out

11/26/2014 8:30 AM

As a single parent I wish I had been more willing to ask for and accept offers of help.

11/26/2014 8:14 AM

I can't remember. Just kidding. I know those first few months home were a blur! I was blessed to have family near who came over to help every few days. I don't know what I would have done without extra hands and an occasional nap. It is helpful to have someone knowledgeable about your premie to take a shift. I have not let untrained people watch my boys. It is too stressful to have just anyone without any NICU knowledge come help.

11/26/2014 8:10 AM

Accepted help from family members from the beginning.

11/26/2014 7:57 AM

Fortunately, I had a great support system from family that was readily available to help. The best for me would have had someone that had been there to let me know that what I was feeling, externally, was okay and normal and that we would get through this.

11/26/2014 7:54 AM

That my child would be more transitioned from day/night schedules. She would sleep all day and be up all night.

11/26/2014 7:45 AM

I wish I knew more about reflux and colic. That is what we have dealt with.

11/26/2014 7:44 AM

This is my first child and everything was smooth.

11/26/2014 7:33 AM

Ask for them to deliver take-out. It was not realistic to have a babysitter as our baby was a micropremie and on O2/cardiac monitor and could not be exposed to germs.

11/26/2014 7:27 AM

Got counseling for myself. The residual grief, PTSD, anxiety and latent fear was overwhelming.

11/26/2014 7:12 AM

Yes, childcare for older kids which would have allowed me more time to get comfortable with baby and perhaps get more sleep. I made myself sick because of lack of sleep the first few weeks.

11/26/2014 7:11 AM

Asked for the nicu staff to help us bathe him for the first time

11/26/2014 7:02 AM

I wish that the multitude of doctors appointments were all on one day or that there was a team working together so I didn't have to drive out of town everyday for a different appointment.

11/26/2014 6:56 AM

Get more info for on things like when to increase feeds and by how much for my g-tube baby, what specialists I would need to have follow him regularly. We were told the pediatrician would take care of it, but he just kept referring us out without really explaining anything.

11/26/2014 6:37 AM

Prepared more meals & freeze them

11/26/2014 6:34 AM

I tried to breastfeed my child and when we got home I gave him all the milk I had pumped instead of breastfeeding him when he was with me. Well I used all my stored breastmilk in the first few weeks he was home, so when I went back to work I had a shortage of breastmilk because i couldn't pump when he was with me. I wish someone would have helped me with the transition to breastfeeding and someone would have told me not to use all my stored breastmilk!

11/26/2014 6:28 AM

I wish we would have learned how to make a bottle properly before heading home. Our Parent-to-Parent program was good, but our connection could have been stronger. I feel that we should have met with them a bit more than we did before coming home.

11/25/2014 1:28 PM

had a nurse "buddy" - having that person "on call" to answer questions and ease concerns.

11/24/2014 6:52 AM

Had completed a true training program in the hospital and had gained access to nurses/doctors after release (whether with LPCH or not)

11/23/2014 10:53 PM

connection with a nurse I trusted when there were questions Go bag! All the stuff you would need if there was an emergency Transitional nursing support at home/transitional NICU alumni parent

11/23/2014 10:42 PM

When would you have attended a scheduled meetup with other NICU parents upon bringing your baby home?

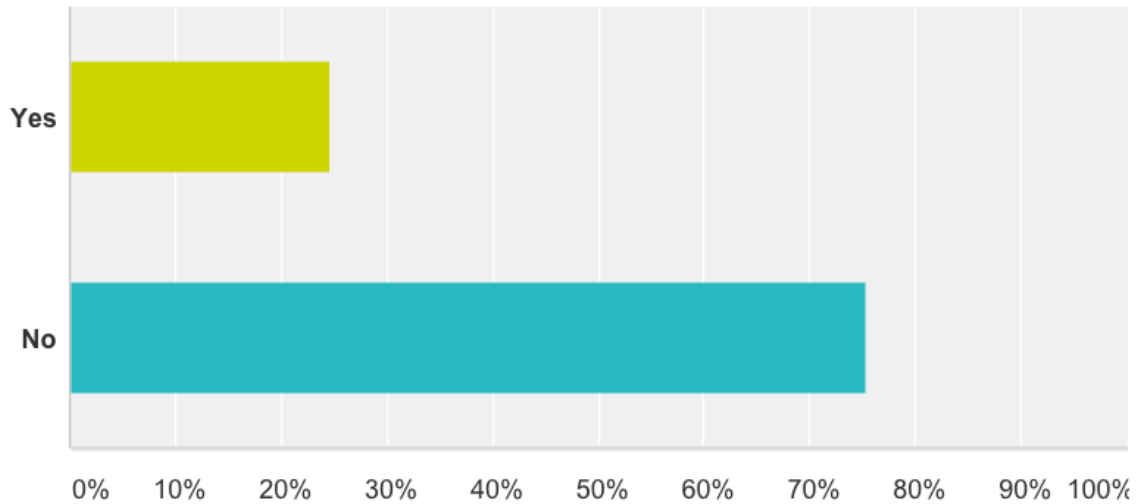
- Answered: 82
- Skipped: 0

	Would not have Attended	Within the First Week	Within the First Month	Within the First Three Months	After the First Six Months	Total	Average Rating
	9.76% 8	17.07% 14	36.59% 30	24.39% 20	12.20% 10	82	3.12

Q5

Was your baby transferred to a nursery room where you were the primary caretaker while he or she was still in the hospital?

- Answered: 81
- Skipped: 1



Answer Choices	Responses
Yes	24.69% 20
No	75.31% 61

Answer Choices	Responses
Total	81

Q6

If your baby was transferred to a nursery-like setting, please rate your experience. If not, please share how helpful the transition to a nursery-like room would have been for you as a parent.

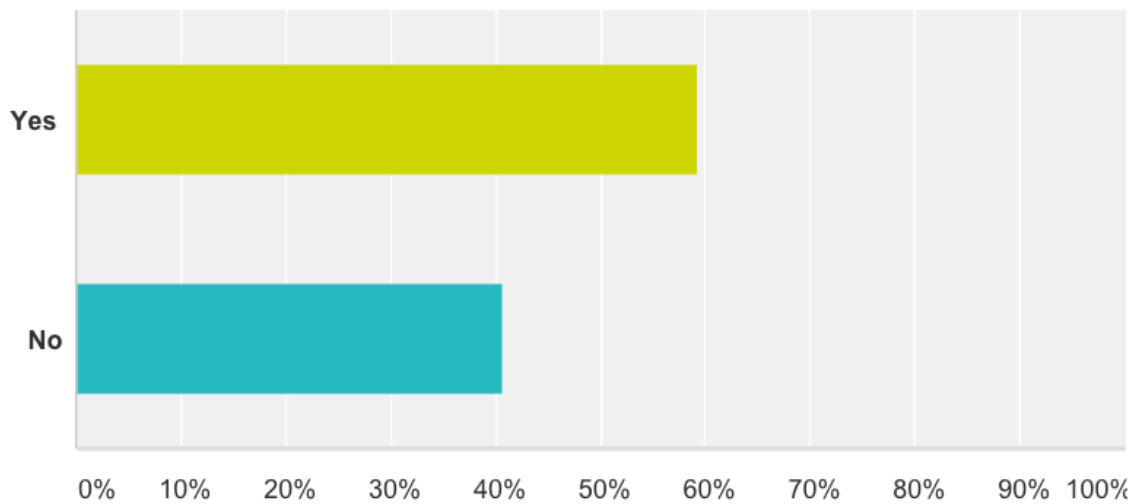
- Answered: 60
- Skipped: 22

	Not at all Helpful	Slightly Helpful	Somewhat Helpful	Very Helpful	Extremely Helpful	Total	Average Rating
	8.33% 5	18.33% 11	28.33% 17	26.67% 16	18.33% 11	60	3.28

Q7

Did your baby have a medical condition upon being discharged from the hospital?

- Answered: 81
- Skipped: 1



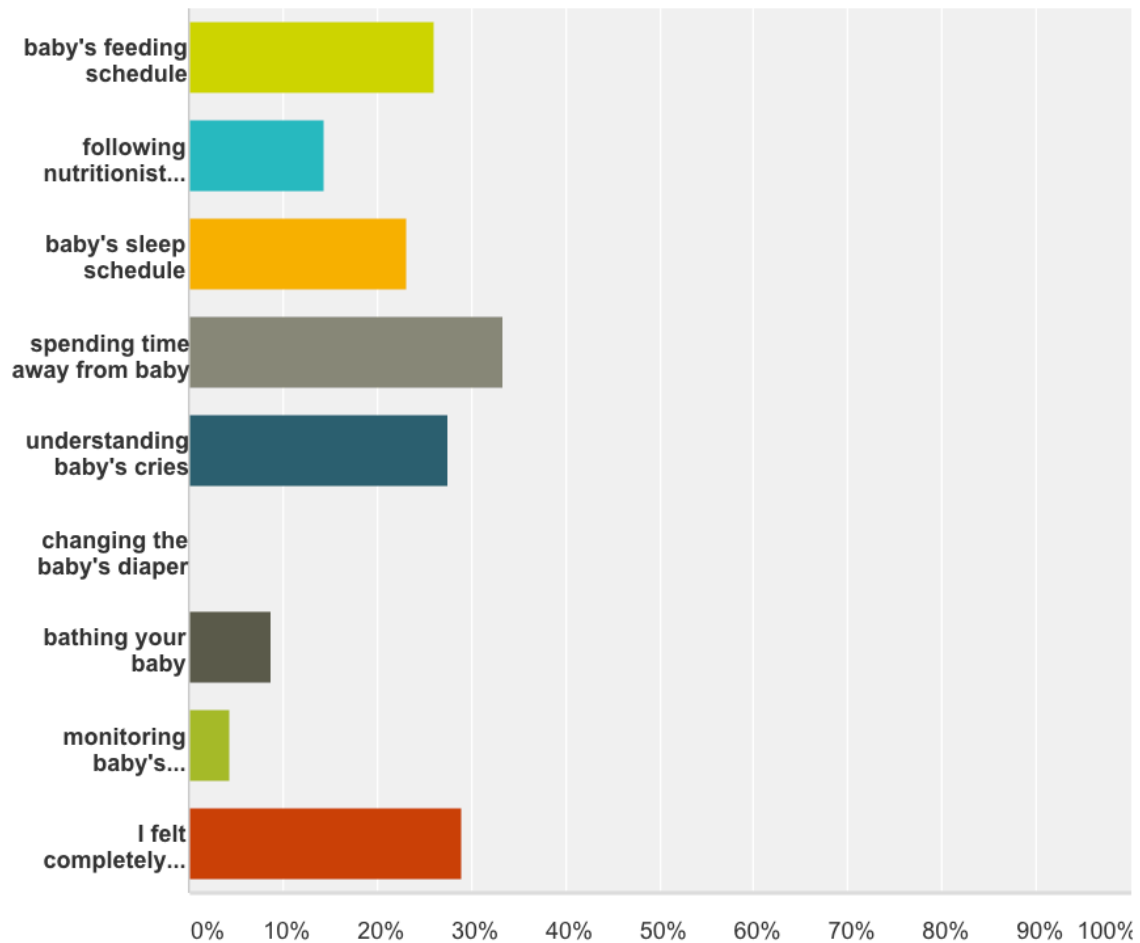
Answer Choices	Responses
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Answer Choices	Responses
– Yes	59.26% 48
– No	40.74% 33
Total	81

Q8

Please select any of the following situations which you felt underprepared to handle upon your baby's arrival home?

- Answered: 69
- Skipped: 13



Answer Choices	Responses
–	26.09%

Answer Choices	Responses
– baby's feeding schedule	18
– following nutritionist's guidelines for feeding	14.49% 10
– baby's sleep schedule	23.19% 16
– spending time away from baby	33.33% 23
– understanding baby's cries	27.54% 19
– changing the baby's diaper	0.00% 0
– bathing your baby	8.70% 6
– monitoring baby's temperature	4.35% 3
– I felt completely prepared	28.99% 20

Total Respondents: 69

[Comments](#)(33)

Nursing

12/2/2014 3:49 PM

Our babies were very colicky and were up consistently from 10:00pm till 5:00am just screaming. I felt so overwhelmed and totally at a loss for how to care for them.

12/2/2014 6:59 AM

This is our third child. We were pretty prepared.

12/2/2014 6:39 AM

The common issue of reflux and milk sensitivity in preemies... No talk of this during our time in the NICU.

12/2/2014 5:42 AM

Monitoring my babies breathing while sleeping and the noises she makes while doing so

12/2/2014 5:09 AM

My NICU let me do all of those things before I took her home

12/1/2014 7:01 PM

CPR/First Aid

12/1/2014 6:53 PM

Answer Choices-	Responses-
Being a single mom and having to work 45+ hrs a week with no help. 12/1/2014 6:48 PM	
The stress and pressure put upon us from family and friends to visit during RSV season, when we were keeping him free of visits for the first 3 months at home 12/1/2014 7:44 AM	
When to worry about/signs of distressed breathing 12/1/2014 7:10 AM	
I was scared to leave my baby after I brought him home. I'd leave pages of notes for my parents when they kept him! My advice would be not to be so skeptical and trust our instincts. 12/1/2014 6:30 AM	
Knowing how to help the oldest sleep better at night when the house was quiet. 11/28/2014 11:42 PM	
I felt unprepared mentally. I was a nervous wreck. 11/26/2014 9:54 PM	
Using managing machines that come home with us. 11/26/2014 8:09 PM	
Not being able to be with baby 24-7 11/26/2014 12:58 PM	
Holding and loving on baby, I was so used to only holding during hands on a feeds I didn't know how to transition to home. 11/26/2014 11:56 AM	
Navigating oxygen tanks and probes/monitor 11/26/2014 10:07 AM	
Dealing with reflux 11/26/2014 10:03 AM	
Meds, respiratory issues 11/26/2014 9:48 AM	
Understanding his oxygen needs. 11/26/2014 9:04 AM	
But I'm also a pediatric nurse 11/26/2014 8:30 AM	
dealing with the medical equipment (O2, pulse ox, apnea monitor) and multiple medications. The sheer number of appointments that she would have in the first year of life. 11/26/2014 8:14 AM	
My twins had unpredictable sleeping habits due to their 2 and a half mont stay in the NICU 11/26/2014 8:10 AM	
Baby being on oxygen, pulse ox and apnea monitor. 11/26/2014 7:57 AM	
I felt completely prepared, however what I wasn't prepared for and not	

Answer Choices-**Responses-**

warned about, was that my son would have a transition period and would need some time to adjust once home. He spent 140 days in the NICU and he came home and every schedule, every "norm" for him, changed the moment we walked through our doors home, and he was like a different baby with new issues. I was terrified bc I immediately felt like I didn't know what to do.

11/26/2014 7:54 AM

I wish I had more assistance of babys reflux.

11/26/2014 7:44 AM

Handling O2, cardiac monitor, medical tech, multiple doctors whose advice conflicts or is incomplete, the isolation of not being able to leave the house with child or have people over due to exposure risk, the lack of understanding of friends, family, coworkers. Fear, anxiety, PTSD.

11/26/2014 7:27 AM

I felt confident with the basics. I was more worried about how to handle the situation of my infant had a Brady or stopped breathing. I watched the infant cpr video but was worried about that because my preemies were very small.

11/26/2014 7:11 AM

I felt unprepared with my 25 weeker because of her oxygen and apnea monitor. With my 29 weeker I felt unprepared because of her gtube.

11/26/2014 6:56 AM

I didn't realize how little sleep I'd get (twins)

11/26/2014 6:34 AM

understanding breathing patterns, and not each breath was an issue

11/24/2014 6:52 AM

Developmental plan - cognitive & motor skills

11/23/2014 10:53 PM

Respiratory related needs; equipment related needs

11/23/2014 10:42 PM

Q9

For each of the situations you felt underprepared for in question 8, please share why you felt underprepared.

- Answered: 49
- Skipped: 33

Showing **49** responses

No training, no one to turn to

12/2/2014 3:49 PM

Scared about hypoxia and hypothermia

12/2/2014 10:53 AM

Was concerned about feeding, in general (choking, coordinated breath, suck swallow, etc).

12/2/2014 10:20 AM

There were times when the babies were just screaming and I don't know if they were hungry or not but I was told to feed them every 3 hours. Maybe I should've fed them more? I was told that the babies couldn't handle being up for more than two hours at a time- they were up for hours on end and with no end in sight. I felt at times that I was the last one that knew what the baby wanted. I didn't know why they would get so upset.

12/2/2014 6:59 AM

Anxiety when leaving the babies (twins). The common issue of reflux and milk sensitivity in preemies... No talk of this during our time in the NICU.

12/2/2014 5:42 AM

did not understand how much more each baby could take, was worried about weight but may have over fed, or try to over feed which became more reflux...allergies, and knowing the difference in the cry for pain of tummy ache versus tired etc...

12/2/2014 5:10 AM

Didn't realize how many different noises she makes while sleeping

12/2/2014 5:09 AM

I was instructed to feed every 2-3 hours. I was too naive to realize how difficult this would be. A) Baby didn't want to wake sometimes B) By the time you are done feeding you have 1-2 hours before feeding again ... Not to mention you have to clean bottle/pump parts in between. I didn't want to accept spending time away from the baby. She needed me and I didn't want to leave her (even if it was with my husband) but Mom's need their alone time to clear their mind and refresh. There are so many bathing products out there and prior to having the baby you don't know which feature is most important. My child hated baths at first. She slowly came around.

12/2/2014 4:47 AM

I didn't want to leave my baby because I was so fearful something would happen to her. I also would have liked more CPR training since my daughter had apnea and I was always terrified she might stop breathing. I felt like our mini course was too short.

12/1/2014 6:53 PM

I could not stand the thought of someone else taking care of my MP right away let alone leaving him at daycare with all the sickness. But when you have no other choice you have to deal as best as you can. With his cries I had no clue cause he hardly ever cried in the NICU so when he did I got scared. I was a first time mom with no family or other women around to help.

12/1/2014 6:48 PM

Time away: I didn't ever want to leave her again because of the pain of leaving her in the Nicu over and over again. We didn't have room-in Nicu at my hospital. Bathing: I barely did it in the hospital. It was scary because I had to take off her apnea monitor probes and I was so dependent on her monitor to tell me she was still breathing.

12/1/2014 5:38 PM

We spent everyday in the nicu with him and when we weren't in the nicu we were driving to and from the nicu or sleeping, after 11 weeks it became hard to convince myself it was good to take back some 'me' time.

12/1/2014 8:30 AM

We thought after seeing what the NICU experience was like for us (the struggles, etc), we would have a little more understanding

12/1/2014 7:44 AM

I was so nervous he was in distress and I was missing signs and in turn I was too nervous to let anyone watch him.

12/1/2014 7:10 AM

Needed to add a scoop of formula to my breast milk. It became too time consuming to pump then feed. Wasn't sure what was more important--my breast milk or switching to formula for the extra calories

12/1/2014 7:01 AM

The nutritional guidelines were complex and confusing and with the other things I hadn't done or been there 24/7 like the nicu staff had so I had to still learn a lot when baby came home

12/1/2014 6:46 AM

I wanted to make sure my child was safe, and I was unprepared because I didn't feel like I was doing the right thing when I was. After being separated from him while I stayed at the RMH I didn't want to leave him at all. But I learned that it's ok to have a break and let someone keep him, and if the child has medical problems after he is sent home just to educate our family on understanding how to handle it and what to do! Everyone needs a break!

12/1/2014 6:30 AM

She si didn't cry in NICU

11/30/2014 11:02 AM

I felt I didn't know how to train someone else to take care of him. It took some time to learn the meaning of his cries. They were different in the quiet house than in the loud NICU, where more often we just watched the monitors or the schedule to tell what was needed.

11/28/2014 11:12 PM

We transitioned to exclusive breast feeding in the first few weeks at home and that was a complicated process. (Partially because our baby had reflux.) But lactation consultants and nutritionists all seemed to have different ideas about what we should do, and in the end, it was figuring out what worked for us on our own. It was scary, though.

11/28/2014 10:59 PM

I felt like I didn't spend enough time with my daughter. Initially, I took off 2 days when we brought her home. Upon returning back to work, I fell into a horrible work situation where I was working 10 hour days and had a long commute.

11/27/2014 7:28 PM

That I should follow her cues rather than the set schedule from the NICU for feeding. She was cluster feeding.

11/26/2014 11:13 PM

I just wanted to get it correct. Thankfully the NICU staff were able to answer questions even after we came home.

11/26/2014 10:15 PM

We had 24x7 nursing care when the baby was in the hospital. When we got home we had to do the feeding 24x7. It really took a toll on us. We didn't sleep and didn't eat. Everything went on hold.

11/26/2014 8:09 PM

I felt guilty spending time away from my baby.

11/26/2014 7:32 PM

I never wanted to leave him again.

11/26/2014 5:40 PM

Attempting to breast feed, following up with a bottle and then pumping afterwards every two hours....was extremely difficult for me 24hrs a day, 7 days a week at first. And sleeping and getting up every two hours? Sleep deprivation sucked.

11/26/2014 2:19 PM

Because the schedule in the NICU was so strict and looking for cues from baby were hard to find so I always felt stressed about what my baby needed. I felt I had to keep the same strict schedule which stresses me out.

11/26/2014 11:56 AM

Wish I was just told that the day and night were reversed.

11/26/2014 10:34 AM

Feeding teaching was rushed. Had no real teaching with oxygen.

Different to do in home vs hospital. Would've helped to have someone at home first day to watch over us.

11/26/2014 10:07 AM

Spending time away: In the NICU, we spent every minute we could with him, so it felt wrong at home to walk away and work on other things, especially without monitors to let me know if he was having trouble breathing, etc. But this was a minor adjustment to get used to.

Understanding his cries: This also just took some learning. In the NICU, he hated his breathing equipment so it was easy to think that was why he was crying. Also, not being there all the time meant we didn't deal with as much crying as at home. Reflux: We weren't aware it was a big issue in the NICU. We knew he spit up some, but this seemed like he threw up his entire meal, which is very concerning when you're concerned about weight gain and growth.

11/26/2014 10:03 AM

they were not there in the hospital they came out later. We also felt rushed out of the nicu

11/26/2014 9:48 AM

my baby was a gtube fed. I had only 1 day training. Wasn't comfortable.

11/26/2014 9:35 AM

nobody explained how to cope with the constant alarms or if baby was desat what to do.

11/26/2014 9:04 AM

Leaving your preemie for work once they are home is really difficult.

Special childcare assistance would be helpful.

11/26/2014 8:47 AM

There was little to no instruction on the use of the equipment, the medications were not easily administered due to my daughter's condition. While we were referred to specialists and a pediatrician upon discharge there was real "warning" that my daughter would have 2 or 3 appointment per week with an additional 10 to 15 hours of Early Intervention added on in the ensuing months.

11/26/2014 8:14 AM

I had trouble trusting others to care for my boys. What if they stopped breathing, aspirated....endless worry!

11/26/2014 8:10 AM

I don't think anything could prepare me it was something we just had to go thru. It was just all overwhelming especially, being that we had twins so all the beeps and alarms where times 2!

11/26/2014 7:57 AM

See above comment

11/26/2014 7:54 AM

The schedule for sleep was off due to lights and the noises from the machines and constantly being checked on by nurses. I felt guilt being away from her, because in the NICU a nurse stated we could be there 24/7 because she needed us (the father and i). They didn't teach us to understand the cries, they felt we should know that, we were first time parents.

11/26/2014 7:45 AM

I didnt know if baby was getting enough milk because she throw it and then be hungry. This was during all feeding in the first twi months she was home. She was later prescribed RX. Prevacid 1/2 tab. Now she is getting much better.

11/26/2014 7:44 AM

A 5 minute training with a med tech is nothing like keeping a squirmy infant hooked up to equip meant for adults.

11/26/2014 7:27 AM

Lack of experience, which is normal with preemie parents. Would have liked to have a little more medical training in case there was an episode.

11/26/2014 7:11 AM

We were only allowed to stay with him one night and never given an opportunity to bathe him before he came home

11/26/2014 7:02 AM

Not enough training. Especially with g-tube.

11/26/2014 6:56 AM

G-tube was new to us and since he didn't feel or respond to hunger cues, everything was calculated out and scheduled. We didn't have the calculations when we went home and were not told that we would have to have a GI doctor and dietician follow us monthly

11/26/2014 6:37 AM

Feeding schedule - Trying to time the preparation of meals for twins was problematic. As in, we always waited until meltdown had commenced.

Sleep Schedule - Tips on keeping one asleep while the other was awake in the middle of the night would have been helpful. Also tips on when it was okay NOT to feed them in the middle of the night would have been appreciated.

Time Away - Learning a balance between being a parent and being a spouse and being an individual has been trying at times.

Understanding baby's cries - Because our twins were on ventilators for so long we didn't hear their cries until much later in our stay in the NICU. Tough to recognize when we were discharged.

11/25/2014 1:28 PM

no one really explained to us the different types of breathing.

11/24/2014 6:52 AM

Inadequate in hospital training

11/23/2014 10:53 PM

Q10

Please share any other thoughts you have on transitioning a baby home from the NICU.

- **Answered: 46**
- **Skipped: 36**

Showing **46** responses

should have a test run in hospital, or spend day in nicu to understand cries, schedules

12/2/2014 3:49 PM

Having a premature baby is not the same as having a full term baby.

Especially not for the mother recovering from an early delivery. I could've used a lot more support for my own mental health in the very early weeks.

12/2/2014 6:59 AM

I was trained and assisted with her care at the hospital, but it is still a frightening and wonderful experience once you are home. They are some

delicate and need so much care and it's terrifying to think you may mess up. My little lady has been home a little over a month and I am still nervous. I did connect with another preemie mom from the nicu and having her and my better half to talk to does help tremendously.

12/2/2014 5:15 AM

Parent mentors a must, and home visits from a qualified pedi or neonatal nurse...

12/2/2014 5:10 AM

Pumping at home while baby in the NICU made it easy to transition her feedings went home

12/2/2014 5:09 AM

Accept any offered help. Sleep! If possible, but an abundance of bottles so you can go longer between cleaning them. Make it a nightly chore rather than after every feeding.

12/2/2014 4:47 AM

It's scary to be home with the equipment and no nurses.. Getting to know the new machine ins and outs takes time..

12/1/2014 7:01 PM

Make it known to the mother that she is not alone. Don't let the mother feel that she is the cause of why her baby came early. We need more support from people at Children's hospitals for after they are released.

12/1/2014 6:48 PM

It was incredibly helpful to have a connection to a former preemie parent to help us evaluate how we were doing at home and to contact when we needed some advice. Our daughter was released on O2, so weekly contact with the NICU follow-up staff was also very valuable and helped us give an overall picture on how she was doing with O2 needs.

12/1/2014 5:45 PM

I wish I would have known about Facebook pages like Graham's Foundation when I first had her. They should also tell you in birthing classes that it's possible your baby might have to be hospitalized.

12/1/2014 5:38 PM

My daughter was born at 31 weeks 2 lbs 14 oz due to Pre E. She spent 67 days in the NICU at kaiser San Diego. I spent many hours each day with her. I took care of her diapering, temperature taking etc. I asked many questions and became friendly to staff to ensure I knew what was happening. I am a special education teacher and know how important early intervention is. My aunt, in education administration immediately went and bought me a preemie parenting book that helped tremendously to better understand what was occurring. It also clarified issues I didn't quite understand. With all this front loaded knowledge and hands on preparation. The transition home was extremely smooth. I also had home nurse visits weekly for four weeks to assist with concerns, check weight gain etc at home.

12/1/2014 4:35 PM

We kept our daughter on her feeding schedule from the hospital. She came home weighing under 4lbs and we wanted to make sure that she continued to gain weight.

12/1/2014 8:56 AM

Since my son was so premature our insurance advised us to have home visits from a nurse every week for about 5 months, a friend of mine who was in the nicu for less time didn't have a home visiting nurse available and she became quickly overwhelmed by being "unsupervised" with this baby who had been looked after by so many in the hospital.

12/1/2014 8:30 AM

A fellow NICU mom and I always felt it would have been helpful to be able to talk to NICU moms who had already made the transition for advice and tips

12/1/2014 7:44 AM

I sort of felt just pushed out. I wasn't offered much reassurance or a safety net of any sorts.

12/1/2014 7:10 AM

We had a fantastic nicu experience; transitioning him was easy because of it

12/1/2014 7:01 AM

I think a mentor program would be great. I could have used the support while baby was there as well as when transitioning home.

12/1/2014 6:46 AM

After having the first preemie home, I made sure to share my experiences with the first time preemie parents in the NICU with the remaining three preemies. All of the parents seemed grateful and would ask lots of questions. I would love to participate in a nicu parent mentoring group.

11/28/2014 11:42 PM

It's so different for everyone. Our baby came home on oxygen (which she had for about two months? Maybe two and a half?) and we had weekly nurse visits for 3-ish months which was super reassuring and helpful. If we'd come home with additional medical equipment or medication (our baby took vitamins and reflux meds at first, not a huge deal) I would've wanted and expected to receive, detailed instruction before discharge. Early intervention services were more stressful than helpful at first, because there was so much paperwork to fill out and something like three initial evaluation type visits. It's very scary to be suddenly cast adrift after constant professional monitoring for the entirety of your once very fragile baby's life. In some sense, you just have to do it, to learn how to take care of your kid, and I think we did get one follow up phone call from the hospital, I can't remember exactly. If we did, it wasn't a nurse we knew well. (And I think it was a nurse.) A call from a doctor (I know they're busy) or one of our primary nurses (busier still!) would've been comforting. I don't know, like the NICU itself we just got through the first few months at home. Our daughter is just fine now. It still blows my mind.

11/28/2014 10:59 PM

I believe the hospital had the resources while our daughter was in the NICU; however, I feel like a follow-up call would have given a gentle reminder for the other services or things to do, etc.

11/27/2014 7:28 PM

Online support groups were helpful because I wasn't able to have her around other children due to her CLD and risk of infection.

11/26/2014 11:13 PM

It was exciting and scary with my first preemie. We just wanted him to do well but we were nervous first time parents. It was much easier with our 2nd preemie. While in the NICU the second time I really enjoyed talking to other families. It was great to offer encouragement and support being an "experienced post NICU mom".

11/26/2014 10:15 PM

It would have been nice to talk to former nicu parents. Mostly for reassurance. It was scary bringing this tiny little thing home who had previously been hooked up to breathing monitors and heart rate monitors 24/7.

11/26/2014 9:54 PM

No one really prepares you for the dr. appts that you have to go to after baby is discharged. We had pediatrician, pulmonologist, heart center, radiology, gastroenterology, Occupational Therapy, Physical Therapy, ENT, Behavioral and Dev, just to name a few. The hospital really really didn't prepare us on how to deal with so many appts. We had to be the case worker for our child it was a HUGE learning curve.

11/26/2014 8:09 PM

Family education that the baby still has a fragile immune system and hand washing when family arrived is so important. Also keeping baby home for a long time before venturing out to keep them safe.

11/26/2014 11:56 AM

The NICU we left in Denver, CO was amazing - the developmental therapist was great in getting me and my husband ready for our transition home. The greatest thing she told me was to reach out to our county to set a meeting for early intervention. I've been told that many NICU's do not inform parents of this resource when leaving.

11/26/2014 11:13 AM

Loved that before discharge our case worker set up all needed appointments.

11/26/2014 10:34 AM

Staff needs to listen more when a parent expresses concern vs just reassuring you that you have good instincts.

11/26/2014 10:07 AM

We did get to spend 1 night in a family room with just the 3 of us and no monitors or equipment and it was wonderful. The nurse checked on us every 3 hours so we still felt like there was help, but it was a small taste of how life would be at home. Having a child in the NICU can be a

traumatizing experience - watching your newborn fight for their life and undergo procedures many adults have never gone through. I didn't really process that while he was in because I was just trying to survive it. I was so excited to get him home, that I don't think I was really prepared for things to be difficult at home. Although that may be no one's fault but my own.

11/26/2014 10:03 AM

there needs to be more follow up for later on. My daughter had reflux and I had no clue what she needed. She now also has reactive airway disease and needed speech therapy all things I had to figure out and deal with on my own. I had no idea they were common premie problems!

11/26/2014 9:48 AM

within 20 minutes of coming home. My baby's extension tube was attached. It popped off while putting her in the crib along the with gtube plug. We had no teaching on how to replace so we ended back in the emergency room which was luckily down the street from our home.

11/26/2014 9:35 AM

its a lot harder than I thought especially having one in the NICU still.

11/26/2014 9:04 AM

More time should be spent educating parents on cpr, choking, rescue breathing

11/26/2014 8:30 AM

If your baby is coming home with multiple medical issues have the nurses show you how to administer the medications since it is not always easy to master that. If your child is being referred to multiple specialists, and you have access to other parents who have babies in similar situations and how have been discharged ask for their recommendations, not just the recommendations made by the hospital. If your child will need multiple specialists and you have access to a large children's hospital it is often easier to have all of the specialists at one hospital since they generally can access all of your child's records so you need not repeat your child's history and progress to multiple providers.

11/26/2014 8:14 AM

We stayed one night with the boys in a room before alone the night before discharge. It was a crazy uncomfortable night. It would have been nice to have a more typical situation to ease out of the high stress of the NICU to a more typical delivery to home. Also maybe information from experienced parents during our stay at the NICU to help us prep for the homecoming. It was emotionally overwhelming too.

11/26/2014 8:10 AM

Accept help from family and friends! You cannot do it all! Allow people to help!!!! Try to rest when you can and communicate regularly with your spouse to make sure both Mommy/Daddy are good!

11/26/2014 7:57 AM

I feel discharge preparation should not be uniform. If a baby is a 34 weeker that spent two weeks in the NICU, vs a 26 wkr that spent 20

weeks in the NICU-- the discharge prep should be different. The types of behavior changes and periods of adjustment once home were never talked about before discharge and I was more of a "mess" the first few months he came home, than the four months he was in the NICU.

11/26/2014 7:54 AM

On discharge day the hospital should be more prepared and not have people wait 6 hours to be discharged, if you know the child is ready, be ready yourself. Having a preemie that he desats made for very sleepless nights and days, if we could hear breathing or movement, we went in a panic mode and shook the child gently to see if she was ok.

11/26/2014 7:45 AM

The last weeks at the NICU were nerve wrecking because I was given a primary nurse and then she ended up not taking care of my baby. My daughter was still learning to feed and breath at the same time. Some nurses would act to lazy to feed my baby and they would try to gavage her. Then they would give me the excuse that she was too tired to feed or that she was desating. Which most of time was not true. The last 2 weeks I basically lived at the NICU because I wanted my baby home.

11/26/2014 7:44 AM

My baby seemed to be ready to go home faster than any of the Drs or nurses could have predicted and therefore didn't have time to go to a nursery. She was under 5lbs at discharge. We had an excellent staff that spent hours preparing me for pretty much any scenario.

11/26/2014 7:33 AM

This survey was not designed for those with medically fragile preemies or micropreemies. ie: We could not spend time away from our baby as no one else was qualified to medically care for her. We also could not have attended a support group in person. Fortunately, there is an awesome international group online available 24/7. Those are the folks who provided alumni counseling to me. There was no one arranged through the hospital. But I did meet someone in person from the listserv who happened to live in the town we adopted our daughter from and seeing them was important beyond measure. They gave us advice and brought their 5yo micropreemie and she gave us hope. Rock on and best wishes in your research.

11/26/2014 7:27 AM

The tangibles were easy. I knew how to care for my baby --- it was myself that needed help. Once the NICU roller coaster ride ends and the noise, speed and terror abate, you are left alone. Alone --- with just your baby and your thoughts. It would have been a great time for formal counseling or even peer counseling to help all with all of the emotions, thoughts, fears, etc. that come rushing in once the ride is over.

11/26/2014 7:12 AM

I had nurses visiting my home, so that was nice. But a parent support group would have been extremely helpful, especially emotionally helpful.

I needed help less with my second nicu baby, but it would have been wonderful with the first.

11/26/2014 7:11 AM

Having the public health nurse was great and we were transitioned well to therapy services. We could have used a guideline of things to ask a pediatrician in a meet and greet visit to help us find the right one to start with. We figured it all out, and eventually ended up switching doctors.

11/26/2014 6:37 AM

Our discharge date and arrival home was pretty comical. We look back and laugh at how we thought we were super parents and could get home, unpack 5 months of a NICU stay, get the boys inside, make two bottles and feed them all within the 30 minute time frame we had was completely insane! We should have fed them in the hospital like our nurses told us. We were too excited to get home:)

11/25/2014 1:28 PM

The biggest help would have been having a nurse in the house for the first day, shadowing us. Alternatively, it could have been a former NICU parent. Or check-in 2 to 3 times per day with doctors/nurses for the first week. Simple check-in calls.

11/23/2014 10:53 PM