

We're Coming Home from the NICU

10 Things We Want You to Know

The time has finally arrived for us to bring our baby home! We couldn't be more excited! We appreciate all the love and support you have been giving us. And, we're going to need your continued help and support. Our lives as parents to this little miracle are just beginning. There is still a lot for us to learn – but we want to share with you some of what our baby's doctors and nurses have taught us and what it means for our family right now. Please know that we have thought about all this very carefully and these are the decisions we've made. We're sure you can appreciate that we're doing this all for our baby. Here are some things you should know:

1. We may need some time alone at first. Our NICU stay was not the beginning we expected. Now that our baby is home with us we need time to adjust to our new roles as parents of a medically fragile child and to bond as a family. Please understand that while we want to spend time with you, we also need a few days to settle into our routine and get some much needed rest.

2. We're on a schedule. While our baby is now home with us, we are still following the routine that our baby got used to at the hospital. We are on a round-the-clock schedule of breastfeeding, pumping, fortifying feeds and administering medicine. We're trying to give our baby a safe, quiet environment to rest, grow and develop while still trying to manage multiple specialist and therapist visits. **We encourage you to call, text or email us before coming over.** And don't be surprised if we ask you to pick something up from the store or pharmacy when you come!

3. My other children miss me and need me, too. While it's critically important that we focus on our newborn, our other children need us, too. It's likely the older siblings may feel left out or even a bit jealous. **We're doing what we can to spend extra time with them, but we may need your help.** Please help us set up play dates, read to them, take them on an outing, or help us teach them how to participate in caring for their new baby brother or sister. Visit Hand to Hold's Sibling Support webpage for other ideas.

4. Please respect our need to be "germaphobes"! While some newborns may seem to acclimate to the world of germs and colds quite easily, that is not the case for our baby. Ours is especially vulnerable and is susceptible to severe complications and even re-hospitalizations from what might be a minor cold or slight sniffle to you or me. Our baby's immune system needs time to develop. The most important thing you can do to protect our baby is to **WASH YOUR HANDS!** We need you to do this every time you come to visit and especially before holding or touching the baby.



5. Understand that cold, flu and RSV seasons are serious threats. We need to do everything we can to prevent our baby from contracting any of these illnesses. **If you aren't feeling well or are even slightly worried you might be coming down with something, please wait and visit another time.** One thing you can do to show you care is to get your vaccinations, especially for influenza and whooping cough. And please don't smoke. If you do, please don't be offended if we ask you to bathe and change your clothes before visiting.

6. Do some research. As parents of a NICU baby, we've done a lot of research. We're happy to share what we've learned, but it helps if you can educate yourself as well. We suggest you visit handtohold.org as a start. Learn about safe sleep practices, early childhood development, and conditions that are common to preemies. Please understand that it can be hard on us and emotionally difficult for us to answer the same questions again and again. This is because there are many questions we don't have answers to yet like, "When will you be able to be less protective of her health?" and "When will he catch up with other babies his age?" We will all have to wait to find out. Like all children, our baby will develop at his or her own unique pace.

7. Know that while we may be quarantined, we're still craving interaction. After an isolating NICU stay and an extended quarantine upon arriving home, we feel alone. Even though we might not be able to see you as much as we'd like, we want to stay connected to you. Please call, email and write. Send us photos or videos of your family, and we will, too. **We can share our love without sharing our germs!**

8. We still need help taking care of our most basic needs. It's true, but it may still be hard for us to say. **We need your help now more than ever, but we're still uncomfortable asking.** Please continue to bring us meals, run errands, and keep an eye on the kids when we take a much needed nap. Consider setting up a care calendar where family and friends can sign up to help out.

9. When you offer to help, please be specific. We all appreciate hearing "Let me know if you need anything," but the reality is we are often unprepared to really know and ask for what we need. **You may have to be very direct.** Go ahead and bring by that casserole. Do a load of laundry when you visit. Pick up a bag of diapers on your trip to the store. Offer to drive the car pool. Mow our lawn or wash our car. We will appreciate it, and we'll return the favor when we can.

10. When you ask how we're doing, be willing to listen. Our child's NICU stay is probably the most difficult, challenging thing we will ever go through. We need someone to talk to. Some days we will want to celebrate, and some days we will be discouraged. It's important that we have permission to share what's going on with our child – the good things and the bad things – without judgment. We don't expect you to have the answers or to be able to fix things. We just need you to listen. **And, most of all, please remember to tell us how beautiful and strong our baby is and what wonderful parents we are – and will continue to be!**



Fragile Babies. **Family Support.**

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