

Having a Grandchild on the NICU

Neonatal Department

Having a grandchild on the NICU can be a scary and unfamiliar experience for the whole family. We have written a short booklet with some suggestions of how to manage this tricky time.

Even though it's scary, it's okay to share your excitement about your new grandchild. Sometimes, everyone in the whole family is so scared that they forget to share their joyful feelings.

Understand the emotional strain this is causing your child, and try really hard to put your own needs on the back burner. Many grandparents want to be involved with their new grandchild, but the NICU is a whole different experience. Respect your child's wishes, as hard as it is to do.

Third, learn about the NICU and about prematurity. If you do this on your own time, you'll save your child the strain of having to explain things over and over, which is a burden for many NICU parents. The Bliss website can be a good place to start.

Please be cautious about what you seek out online—many frightening stories exist on the internet, and you'll do no one any favours by getting bogged down in other people's stories. Stick to positive stories and educational articles.

What to Do

There are many awesome things you can do to be a thoughtful and supportive grandparent. NICU parents are generally so overwhelmed that they often can't say what it is that they need, or they are too tired to actually ask for help. So when you offer your help, be specific. Give them an exact day you're available, give them a few specific things you would like to do to help, such as:

- Offer to watch other grandkids so the parents can visit the new baby in the NICU
- Offer to drive new parents to the NICU (if transportation is a challenge)
- Offer to cook meals and fill the freezer
- Offer to clean the house/do the laundry
- Keep an eye out for post-partum depression or post-traumatic stress disorder, which can affect either parent. Help them know when it's time to get help from their GP or unit psychologist.

And most importantly, keep doing these things all throughout the NICU stay. Many parents feel abandoned after the initial excitement of baby's birth wears off. NICU stays can span weeks and even months, and the new parents will still appreciate help for the entire time.

What *Not* to Do

The most important thing to keep in mind is that you need to put the needs of your son or daughter above your own.

Please don't:

- Get upset if you can't visit the baby. Some parents feel overwhelmed and just want to keep their babies safe. It's normal. So even if it's maddening to you, please respect it.
- Get upset if you can't hold the baby (Many NICU mums are upset that anyone *at all* is holding their baby, and they have to watch nurses and doctors doing everything that they wish they were doing. So one thing they can control is who else gets to hold their baby, and sometimes they don't want anyone else to. It's normal, so please respect it.)
- Ask a ton of questions about the baby's condition or prognosis. (Of course you want to show your concern, but keep in mind that NICU parents are so worried. Your worries about the baby need to come second to help keep the parents comforted and calm.)

What to Say

More important than saying anything at all is listening. Just asking "How are you holding up? Really?" and then listening will be incredible support.

Also, these things are great:

- "Congratulations!"
- "Look how sweet she is!"
- "He looks so strong!"
- "She looks like mum / dad"
- "How are you holding up? Really?"
- "I'll keep you in my thoughts "

What *Not* to Say

So many people inadvertently say things that are upsetting to new parents. If you're trying to be sensitive and thoughtful, don't worry too much about exactly what to say. But here are some classic comments that parents dislike:

"He's so tiny." The parents are very aware of how tiny their baby is, and it's a source of great worry. So try to focus on strengths and positives.

"Will she be ok?" The parents wonder the same thing, and they don't have an answer. So making them remember the worry and the uncertainty is a huge strain. Time will tell. Focus on the now and on the positives.

"What did you do wrong?/ What caused this prematurity?" They wonder the same thing and are probably feeling terrible (misguided) guilt about it. There is nothing that modern medicine can truly do to prevent prematurity, and most often it happens in spite of a mother doing everything "right." So don't add to her guilt by implying that there was anything she could have done to prevent it. Even if you thought the mother could have done a "better" job when pregnant, now is not the time to add that burden to a worried family.

"At least the baby is with great "babysitters." Sure, NICU nurses and doctors are highly trained, but nobody wants their own baby to be cared for by someone else — parents want to care for their baby themselves. And they can't.

"I don't know how you're doing it! / I wouldn't be strong enough to handle this." They don't either! They wish they weren't, and it makes them feel more alone because everyone else thinks they're holding up well when in fact they may be feeling like they're falling apart.

"At least you didn't have to gain all that weight." It seems like an innocent thing to say, but nearly all mothers would rather gain all the weight and more — heck many mums would give their left arm! — rather than watch their sweet baby struggle to live.

And the worst of all ... **"When will she come home?"** Again, it seems innocent enough, but the doctors and nurses simply can't tell them when their baby will be ready to go home. Parents almost always hate this question, so just avoid it if you can.

And unless you regularly discuss God with your child, now is not the time to bring that up. Premmie parents are often struggling with their faith and their anger, and they usually resent anyone talking about "God's plan" or "Why God did this." (Think about it — it feels pretty awful to be told that God planned something this hard and painful for them or their child. So it's probably best to just avoid this topic unless your child *really* likes talking about God with you.)

Bring a Gift?

Grandparents are notorious for showering gifts upon their little grandbabies, and parents deserve them too! But in the NICU, many grandparents worry they'll get the "wrong" thing. Here are some gifts that almost always bring much-needed joy:

- Gift Cards for Groceries, Restaurants.
- Books to read aloud to babies
- Care packages, filled with snacks, a journal, hand lotion, and other goodies
- A massage or day at the spa, or any treat you know your child loves
- A hands-free nursing bra for any pumping mum

What *Not* to Buy

These things can be upsetting to some parents, so it might be better to steer clear of these gift items:

- Flowers (They can remind many new parents of funerals)
- Clothes for a full-term or older baby (parents worry their child might not live that long. Plus it doesn't really help right now)

**This document is available in Welsh/
Mae'r ddogfen hon ar gael yn Gymraeg**