

Friends and Family: How to support someone who has a baby in the NICU

NICU stays are incredibly variable in terms of length of stay and medical requirements, but most families in the NICU experience increased stress and a wide range of emotions. Families can certainly use extra support from friends and family during this time. The Connections Program has compiled several ways to help, including both practical and emotional support. This list is meant to give a variety of possibilities, but some pieces might not be applicable or appropriate for every family. It is important to consider the family you are supporting and what their unique needs might be, even if it may be different from what you would find helpful.

Practical Help:

- A family in the NICU might find it difficult to ask for help, do not want to bother anyone, or feel that they can do it on their own. While it is important to respect each family's comfort level in accepting support, below are a list of helpful tips.
 - **Avoid asking if you can help and instead say "I would like to help, can I...."** Offer a few concrete ways to help (see pdf of 'List of practical ways to offer to help') and then ask what would be the most helpful. Offering choices can reduce the number of decisions that families need to make, which is often appreciated.
 - **Ask the caregivers if they would like help telling other family members and friends about the baby's condition and progress.** This is something you can do even if you live far away. Find out exactly whom the parents want to contact. Share only information that the parents have asked you to. Create a blog for the family to update everyone at once like www.caringbridge.org/
- **We have also created a 'List of practical ways to offer to help'**
 - How to use this list if you are the caregiver:
 - We know it can be difficult to ask for help, especially if you are someone who usually does not ask for help. Having a baby is already hard but having a baby in the NICU is often unexpected and difficult to fully prepare for (meaning that it is okay to ask for help and can relieve a lot of additional worries and stressors outside of the most important- your baby's health). Many times, your supports do want to help, but don't know exactly how to best support you.
 - You can send this full list to your supports who ask if they can help and have them choose what they feel comfortable doing. You can also go through the list and circle one that you would like to prioritize.
 - How to use this list if you are a friend or family member:
 - You can use this list for concrete ideas of how you can offer support to someone who has a baby in the NICU.
 - You can send this list to others who would like to help, but do not know exactly how to or talk with the family directly on what they would find helpful on this list.

Tips on communicating support:

Suggestions	Examples	Rationale
Text the person to check-in, but don't expect a reply.	Do: "I'm here if/when you need to talk. Please don't feel you need to reply" "We are here for you if you need us for anything"	<ul style="list-style-type: none">• This will help communicate that you care and are there if they need support.• If you do not get a response, don't take it personally. The NICU can be emotionally exhausting and often a family's only focus is on their newborn and their immediate medical needs.
Listen.	Brene Brown on empathy: 3-minute clip	<ul style="list-style-type: none">• Sometimes the best thing you can do is be a listening ear, without trying to fix the problem or make the other person feel better.

	https://www.thersa.org/video/shorts/2013/12/brene-brown-on-empathy	
Avoid trying to find the silver lining.	Avoid: “Just be grateful they are alive”, “It could have been worse.” Avoid using “still”, “yet”, or “at least”	<ul style="list-style-type: none"> • Can make parents feel you are not listening or dismissing their concerns about their baby.

Tips on communicating support continued:

Suggestions	Examples	Rationale
Expect parents are doing everything they can.	Avoid: “Have you thought of...” “Have you considered...” “What about....”	<ul style="list-style-type: none"> • Can make parents feel they aren’t doing enough. • Can also increase frustration as they are the ones that are hearing daily updates and know the most about the situation.
Avoid asking them to explain what is going on with baby.	Avoid: “What does CPAP mean? Is that bad?” “How much longer will she be there?” “What tests is he having done?”	<ul style="list-style-type: none"> • It can be emotionally difficult for caregivers to talk about how baby is doing. • Parents may not want to share the story and will share when they feel comfortable.
Avoid comparing a similar experience to what the family is going through or compare your own pregnancy or newborn journey.	Avoid: “I know this one family that had a NICU stay...” “I know when I was pregnant...” “My baby was little when he was born and...”	<ul style="list-style-type: none"> • Most NICU stories are unique and comparison can make the person feel that you are not hearing their concerns or that you are not understanding their perspective.
Specific rather than general questions can be easier to answer.	“How are you doing <i>right now</i> ?” “How is baby doing <i>today</i> ?”	<ul style="list-style-type: none"> • The NICU can feel like a rollercoaster with many ups and downs, sometimes in a single day. Caregivers may not know how to reply if the question is too general.
Continue to check in with the family.	Do: “Just know we continue to think about you and your family. We are here if you need us.”	<ul style="list-style-type: none"> • NICU stays can last from a few days to a few months.
Follow-up with families once they are home.	Do: “We are so excited you are home. We would love to talk/see you whenever you feel ready for company.”	<ul style="list-style-type: none"> • Even after a baby leaves the NICU, the baby may still need medical care and require frequent appointments to the hospital. • Also, bringing home a newborn in general is always a big transition for a family.
When at home, don’t take it personally if the family is not ready for visitors.	Do: “We would love to see you whenever you feel comfortable to have visitors.”	<ul style="list-style-type: none"> • NICU babies, even after discharge, are often at an increased risk for respiratory issues and continued health concerns. It can be very normal for families to be extra protective of their baby’s exposure to germs.
Due dates (potentially other dates as well) can be hard for NICU parents.	Do: Mark these dates on a calendar and send a card/texts/etc “Just thinking about you on this day, I’m here for you if you need to talk.”	<ul style="list-style-type: none"> • Even if baby is healthy and discharged from the NICU, due dates can bring up feelings of sadness or grief for what a caregiver expected their pregnancy or newborn experience to be like.

		<ul style="list-style-type: none"> • Sending a message can let the family know they are supported.
Caregivers can sometimes have a hard time being around pregnant people or babies of similar age to their own child.	<p style="text-align: center;">Do:</p> <p>If you notice they are more distant than normal, you can tell them that you are here for them. If they tell you the reason they are distant, you can also add you understand.</p>	<ul style="list-style-type: none"> • Don't take this personally and it does not mean they do not care about you or your child. • For some people, seeing others can bring about their own memories of having a shortened pregnancy or their time in the NICU, and sometimes comparison with their own child and what they are or are not doing yet.

List of practical ways to offer to help:

*Note: It is important to consider your relationship with the family that is in the NICU. Some suggestions below may be more appropriate if you have a very close bond with the family.

<p>Household tasks:</p> <ul style="list-style-type: none"> ○ Take out trash ○ Pick up mail ○ Load/empty Dishwasher ○ Washing and folding laundry ○ Vacuuming/sweeping ○ Hire cleaning crew ○ Offer to run an errand ○ Picking up groceries ○ Help setting up things for when baby comes home ○ Other _____ ○ Other _____ 	<p>Logistics:</p> <ul style="list-style-type: none"> ○ Gift cards to hospital cafeteria or nearby restaurants, coffee shops, pharmacies, visa gift cards, uber eats or another meal delivery service ○ Rides to the hospital ○ Gas cards ○ Other _____ ○ Other _____
<p>Childcare:</p> <ul style="list-style-type: none"> ○ Watching other children in the home ○ Pick up or take to school, activities, or to NICU if allowed ○ Organize play dates ○ Other _____ ○ Other _____ 	<p>Food:</p> <ul style="list-style-type: none"> ○ Give quarters for vending machine ○ Organize a meal train ○ If you bring food make sure they are in disposable containers that do not need to be washed and returned ○ Other _____ ○ Other _____
<p>Petcare:</p> <ul style="list-style-type: none"> ○ Feed/water ○ Take on walks or play ○ Care for pets in home ○ Other _____ ○ Other _____ 	<p>Parent's needs:</p> <ul style="list-style-type: none"> ○ Adult activity books ○ Books ○ Audible gift card ○ Pampering (scented products in NICU are not allowed) ○ Other _____ ○ Other _____
<p>Things needed while in the NICU:</p> <ul style="list-style-type: none"> ○ Books to read baby ○ Premie sized hats or socks 	<p>Visitation if allowed:</p> <ul style="list-style-type: none"> ○ Offering to stay with baby in the NICU so parents can take a break or do a chore

<ul style="list-style-type: none">○ If baby has a g-tube, clothing with snaps rather than zippers for tube and wire access○ Small decorations for baby's room○ Other _____○ Other _____	<ul style="list-style-type: none">○ Sit with and provide comfort to caregiver (follow caregiver's lead on how much you should interact with baby)○ Other _____○ Other _____
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