

10 THINGS ALL PARENTS OF PREEMIES NEED TO KNOW

1 You are an integral part of your preemie's care team. Your feelings and observations are critically important. Speak up, respectfully. Ask questions. Voice your concerns. Share what is important to you. If you feel strongly that something is in the best interest of your baby, insist on it being that way.



3 You know your preemie best. Learn your baby's cues. Preemies can become critically ill fast. If you sense something isn't quite right, voice your concerns and make sure they are addressed. Watch for these subtle signs that something may be wrong:

- Abnormally distended belly
- Temperature instability
- Blood in stool
- Frequent dry diapers
- Frequent or large amounts of vomit
- Constipation
- Lethargic or not as responsive
- Difficulty or change in breathing

4 Insist on having primary caregivers. A primary team who knows your baby and family will help to ensure better communication and continuity of care, which increases patient safety. Take time to build a respectful, trusting relationship with your baby's primary caregivers.

Created by parents of NICU babies impacted by NEC: what we wish we had known from day one in the NICU

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Preemies need breast milk.

Human milk can be life-saving for fragile infants. Mothers should begin pumping as soon as possible. When mothers' own milk is unavailable, pasteurized donor breast milk is the next best option. Formula increases a preemie's risk of developing NEC.

5 Learn how to care for your preemie. Ask your baby's nurse to teach you how to provide basic care for your preemie. Provide kangaroo care as often as you can. When you cannot kangaroo your baby, hold hands, sing and read to him/her.

6 Pay attention to details. Keep a journal documenting your baby's routines, behavior, as well as his/her setbacks and accomplishments. Take notes during rounds. You may notice details that no one else will.

Become your preemie's expert. Learn everything you can about your preemie's health or condition. If you're not sure where to find credible information, ask your baby's care team. Reach out to other NICU families. Reach out to other institutions, neonatologists or researchers if you have specific questions that your baby's care team cannot address.

8 You are your baby's voice. Attend rounds. Do not let anyone intimidate or shame you for being your baby's advocate. You are not annoying. You are not stupid. Your baby needs you to speak up for him/her, respectfully.



9 Create a haven of peace and healing. Leave behind your frustrations and fears so that you can be present and tune into your baby. Make your preemie's space your home away from home. Smile at your baby. Sing to your baby. Bring in special blankets. Hang up family photos. Play soothing music. Celebrate the smallest of milestones.

Live your life fully. Having a baby in the NICU is exhausting and overwhelming. The NICU journey may feel like it's never going to end, but it will be over soon. For better or worse, you'll never have this time back. Live it fully, without regrets. Make hand and footprints. Read special books to your baby. Take pictures and videos with your baby, even if s/he is critically ill. Savor this time with your baby.

