

10 Things to Know When Your Baby is Diagnosed with NEC



Created by families affected by NEC for families affected by NEC.
What we wish someone had told us when our baby was diagnosed with NEC.

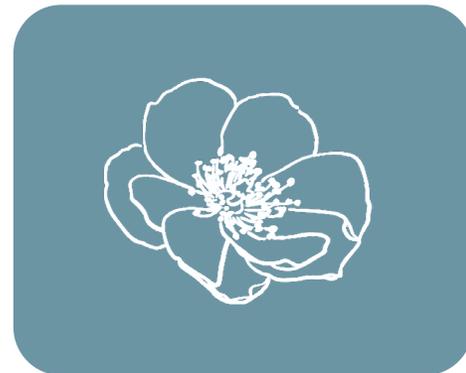


1

This is not your fault. Babies develop NEC (necrotizing enterocolitis) for many reasons, even when they have the most dedicated parents and healthcare providers. Nothing you did caused your baby to develop NEC.

2

Learn and ask questions. NEC is a complicated disease. The details of why or how NEC develops are not yet fully understood. Still, you can learn more and consider questions about the risk factors, protective factors, and potential outcomes by speaking with your baby's care team or visiting NECsociety.org



3

NEC can be a life-altering disease.

Many survivors experience long-term complications, such as short bowel syndrome for those who required extensive surgery. It can even impact other organs like the brain, kidneys, and lungs. Some babies tragically die from NEC. The NEC community is working to build more resources for families affected by this devastating disease.

4



You are the most important member of your baby's care team.

Participate during medical rounds for your baby if you can, even remotely. Your questions, thoughts, and concerns are valid. Speak up. You are your baby's expert, and you know your baby best.

5

Continue to advocate for human milk.

Human milk does not eliminate the risks of NEC, but it is one of the most effective ways to help reduce the risks of NEC and nourish your baby. Pasteurized donor milk should be available to infants at risk of NEC when their mother's own milk is not readily available. Learn more at HMBANA.org

6

Build a team of nurses. Ask if the same small group of nurses can care for your baby. This is called “primary nursing”. When an established team provides care, it helps to foster trust, rapport, and open communication. This continuity of care can also help to lead to better health outcomes for your baby.

7

Become an advocate. It can be hard to speak up, especially when things feel overwhelming and scary. One way to overcome these feelings is by advocating for your baby, your family, and yourself. Ask your baby’s care team to provide access to more information so you can become more informed and empowered.

8

Prioritize yourself. Your baby needs you to be as well as possible. It helps to surround yourself with people who are uplifting and who can help to take care of you. By focusing on your needs you’ll feel more ready to participate as an active member of your baby’s care team.

9



Connect with your baby. Even if your baby is unwell, you can still bond and nurture your little one by reading storybooks, singing lullabies, and massaging their skin. Books, music, and touch can benefit both you and your baby.

10

Capture this moment. For better or worse, you’ll never have this time back. Take photos and videos, even if your baby is critically ill. Use a stamp pad to capture your baby’s handprints and footprints. Keep a journal where you can write down details about this experience so you have them to reflect back on years from now.