

10 Things to Know When Your Baby is Diagnosed with NEC

Created by families affected by NEC, for families affected by NEC

2

Learn and ask questions. NEC is a complicated disease. More research is needed to fully understand why and how NEC develops. You can learn more about the risk factors, protective factors, and potential outcomes by speaking with your baby's care team or visiting NECsociety.org

4

Ask for human milk. Human milk does not eliminate the risks of NEC, but it provides the most protection against NEC, helping your baby thrive. When mother's own milk is not available, pasteurized donor human milk offers the next best protection. Formula does not offer any protection against 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.

3

You are the most important member of your baby's care team. When you can, participate in medical rounds, even remotely. Your questions, thoughts, and concerns are valid. Speak up. You are your baby's expert, and you know your baby best.

5

NEC can be a life-altering disease. Many babies recover fully from NEC, and many other babies recover but face lifelong neurological and nutritional complications. Tragically, too many babies die from NEC. Your care team is working hard to help your baby thrive after NEC.

6

Build a team of nurses. Ask if the same group of nurses can care for your baby. This is called primary nursing. An established team helps provide more consistent care, fostering trust, rapport, and open communication. This continuity can also help your baby have better health outcomes.

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.

10

Capture this moment. 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 to write down details about this experience, so you can reflect back on your family's journey together.

7

Become an advocate. It can be hard to speak up and ask questions, especially when things feel overwhelming and scary. Sharing your thoughts and concerns can help you, your baby, and your family. Ask your baby's care team for more information so you can become more informed and empowered.

9

Connect with your baby. Even if your baby is unwell, you can bond and nurture your child by reading storybooks, singing lullabies, and resting your hands on their skin. Books, music, and touch can benefit both you and your baby.



NECsociety.org