What to know after a NEC diagnosis

Necrotizing enterocolitis (NEC) is a neonatal inflammatory disease that affects an infant's intestines. It causes swelling, tissue damage, and can make babies very sick, very fast. NEC can be life-threatening and progress quickly.

What causes NEC?

NEC is a complicated disease and not yet fully understood. More science is needed to understand the cause and why some babies develop NEC. There are likely many factors that lead to NEC. Nothing you did caused your baby's NEC diagnosis.



Learn more about NEC



What can I do to care for my baby after a NEC diagnosis?

A NEC diagnosis can be scary and overwhelming. You can help your baby by taking care of yourself so you can stay actively engaged with the clinicians caring for your baby. It can help to **spend time at your child's bedside, ask questions, and share your concerns.**

If possible, continue pumping and storing breastmilk even if your baby cannot take in enteral nutrition. Breastmilk helps your baby fight infection, absorb nutrients, and heal. Pumping will also help you keep your milk supply for when your baby is ready to receive your milk again.

By working together, we can help you better understand what is happening and navigate this difficult time. **You are not alone.** The NEC Society is a nonprofit organization working in collaboration with families, clinicians, and scientists.

NECsociety.org

theCHNC.org





Family resource boxes are available through the NEC Society for families diagnosed with NEC.

Families affected by NEC help to lead the NEC Society and have created Family Resource Boxes to share information they wish someone had told them when their child was diagnosed with NEC. The boxes include information about NEC and resources to empower families.





How is NEC treated?

Treatment for NEC depends on how your baby is doing. Because NEC is a lifethreatening condition that can progress quickly, your baby's doctor may stop feedings and give your baby nutrition through an IV, called Total Parenteral Nutrition (TPN). Your baby may also get antibiotics and have regular lab tests, x-rays, or ultrasounds to check for changes.

Your baby may need help breathing, medicine for low blood pressure, blood transfusions, and surgery. Surgery is needed if your baby's intestines become infected, rupture, swell, or if there is air in their belly. Surgery can help stop the progression of NEC by surgically removing the affected intestinal tissue. Surgery can help improve your child's ability to thrive after their NEC diagnosis.

NECsociety.org





