What families should know about NEC and surgery

NEC causes severe inflammation of the intestines, leading to tissue damage. Surgery can help stop the progression of this inflammatory process by surgically removing the affected intestinal tissue. **Surgery can help improve your child's ability to thrive after their NEC diagnosis**.

Your baby needs to be treated by specialized doctors who have been trained to operate on small babies with NEC. Your clinicians will ensure your baby receives the care they need, even if it requires transfer to another hospital.

When will my baby have surgery?

Some babies get very sick, very fast when they develop NEC, and may need to be rushed into surgery. Some babies are more stable and the surgery can be done non-urgently. For urgent surgery, or if your baby is not medically stable, surgery may be done at the bedside.

Preparation for surgery

Surgeons, anesthesiologists, and nurses trained to care for babies undergoing surgery will care for your baby during his/her operation. The surgery team will speak with you beforehand to get consent and explain the benefits and risks of surgery. Write down and share your questions, concerns, or important notes you want to remember. **You are your baby's advocate and the most important part of your baby's care team**.

Types of surgery

There are two types of surgery for NEC:

Laparotomy: The surgeon makes an incision in the belly to remove the inflamed intestines.

Peritoneal Drain: The surgeon places a small drain to release fluid and gas from the belly.

If a laparotomy is performed, the surgeon will remove any damaged bowel and may create an ostomy that brings the end of the bowel out to the belly. In some cases, the surgeon may be able to put the bowel back together without an ostomy. This is called primary anastomosis.

Some babies require more than one operation to ensure their intestines are healthy.

During the operation

Sometimes surgeons find a small hole and/or multiple inflamed areas in the intestine. The damaged tissue will be surgically removed so that it does not continue to spread. In some babies, NEC progresses so quickly that it damages the infant's entire bowel.

What should I expect after my baby's surgery?

It may take several days following surgery for your baby to become more stable. Because they require a lot of fluid before and during surgery, your baby may look swollen and discolored following their operation. As a parent, it can be extremely distressing and painful to see your child endure NEC and the necessary surgeries.

Your baby may remain on antibiotics and not receive enteral feedings from 7 to 14 days after surgery.

If your baby has an ostomy, you can learn to help care for their ostomy. The ostomy is temporary and usually will be reversed with another surgery.

- Continue to care for yourself and your family
- Continue to ask questions, express concerns, and share thoughts
- Continue to write down how you're feeling and what you are experiencing
- Capture this experience with photographs so you can reflect back in the weeks, months, and years ahead

Feeding after surgery for NEC

Mother's **breastmilk is still the best and safest nutrition for your baby**. Pasteurized Donor Human Milk is the next best option for feeding after surgery. Feedings will progress slowly to monitor tolerance and healing after surgery. Some babies may require additional nutrition through an IV, called Total Parenteral Nutrition (TPN).

It may feel difficult to bond with your baby as they go through and recover from surgery. You can **play soft music, sing lullabies, hold their hand, and read to your baby**.

Sometimes babies who need surgery for NEC require more specialists in addition to neonatologists and pediatric surgeons. For example, **your baby may need to be seen by nephrology (kidneys), gastroenterology (GI, digestive), and endocrinology (hormones)** after surgery for NEC. It can be overwhelming to have so many new doctors. Each specialty is there to help your child and family thrive.

Babies who need surgery after a NEC diagnosis are at higher risk for long-term complications and **may need close follow-up after discharge**.

Where can I connect with other families and find more resources?

As a parent, watching your baby endure surgery is extremely distressing and painful. You are not alone. There is a community within the NEC Society to lean on as you navigate this disease.

Ask your care team to connect you with social work and more NICU resources that can help you care for your baby before and after NEC surgery.

Join the NEC Society Connects Facebook Group