



NECROTIZING ENTEROCOLITIS (NEC)

What is NEC?

NEC is an inflammation of the bowel that makes blisters in the bowel wall. Sometimes the blisters heal with antibiotics and rest, and sometimes NEC dissolves the bowel wall so that stool leaks into the abdomen. No one knows exactly why babies get NEC, but we think the immune system of the young bowel can't protect it from bacteria and it overreacts. The damage can be mild or very severe.

Who gets NEC?

NEC is usually a disease of premature babies who have been fed. Some premature babies' intestines don't respond normally to feeding. The intestines become inflamed and irritated and the premature immune system overreacts causing the infection and blistering to get worse.

How is NEC diagnosed?

NEC is diagnosed through a combination of signs and symptoms. These include: undigested food in the stomach, blood in the stool and swelling of the belly. There may also be breathing difficulties, blood clotting problems, problems maintaining body temperature and problems with abnormal blood chemicals.

How is the decision made that surgery is needed?

Most babies get over NEC if feeding is stopped, they get antibiotics and blood products and have their breathing and blood chemistry problems corrected. If this does not stop NEC, or if part of the intestinal wall dies, surgery is needed.

What can I expect from surgery?

The surgeon will remove any dead bowel and will save any bowel that looks sick. Many times sick bowel will recover. If there is a lot of sick bowel, the surgeon may make one or more stomas (ostomies) to watch the health and function of the bowel. Stomas are open pieces of bowel that are stitched to the surface of the abdomen. Some will make stool which is caught in a small pouch. Sometimes when babies are very premature, or too sick to have surgery, the surgeon will put a soft rubber drainage tube into the abdomen until the baby's condition gets better.

When will my child be able to go home?

A baby with NEC will be able to go home when s/he is able to eat and gain weight. Sometimes the feeding will be through a tube which goes through the nose and into the

stomach (an NG tube). If your baby has an NG tube, you will be taught to take care of it and to feed your baby through it until s/he is able to eat on his/her own. Your baby will also have to be making normal stools without any signs of NEC. If your baby is very premature, there may be other health problems that will keep him/her in the hospital.

How much time should I plan off work?

Having a baby with NEC is a difficult time. Sometimes feedings are started, and then signs of NEC begin again and feedings have to be stopped. This is part of the usual way NEC behaves, and it is frustrating. It makes it hard for you to plan your time off. Do the best you can, be honest with your employer about what is happening, and remember that when you are not with your baby, expert nurses will be caring for him/her.

What care is needed at home after surgery?

If your baby goes home with a stoma, expert nurses will teach you to take care of it before you go home. If your baby has an incision, you will be taught to keep it clean and dry, and to protect it from rough play and accidents. Your baby will be fed your breast milk or a special formula if you are unable to pump. By the time you go home, only Tylenol will be needed for pain management. Premature babies can have breathing problems with other pain medicines, so they are usually not given outside of the hospital.

When should I call the surgery team??

Call the surgery team if your baby's stomach becomes swollen and firm, if you see blood in his/her diaper, if s/he is vomiting or if there is a fever greater than 101 F.

When should I call my pediatrician, and when should we see him/her?

Your pediatrician should see your baby in the hospital before discharge so s/he is familiar with the problems that might happen. Otherwise see him/her for immunizations and usual baby care.

What are the long term consequences?

The long term effects of NEC have to do with how much intestine was lost. If your baby doesn't have enough intestine to digest and absorb his/her food (a condition called short gut), s/he will have to get part or all of his/her nourishment by vein. Babies continue to grow more intestine as they get older, so this may be a temporary problem.

Will this affect growth and development?

Most babies with NEC are also premature. It is hard to figure out which development problems are from NEC and which are from prematurity. Recent research shows that very premature children may be small for their age until the age of ten.

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