



# Necrotising enterocolitis

**This leaflet explains about necrotising enterocolitis, how it is treated and what to expect when your child comes to Great Ormond Street Hospital (GOSH).**

## What is necrotising enterocolitis?

Necrotising enterocolitis (NEC) is a serious illness in which the tissues in the bowel (gut) become inflamed and start to die. This can lead to a perforation (hole) developing which allows the contents of the bowel to leak into the abdomen (tummy). This can cause a very dangerous infection.

NEC can be difficult to diagnose but the symptoms tend to include general signs of illness, problems feeding or vomiting, and a swollen and tender abdomen.

NEC is the most common surgical emergency in newborn babies and tends to affect more babies born prematurely than those born full-term. NEC seems to be becoming more common, but it is likely that this is because more premature babies are surviving.

## How is it treated?

In many cases, NEC can be treated without surgery, by resting the bowel by using intravenous feeding and treating any infection with antibiotics. During this period, your child will have a nasogastric (NG) tube passed through their nose to drain off the contents of their stomach. They will also have an intravenous infusion (drip) of fluids and medicines.

However, your child will need an operation if they develop a perforation or do not respond to the treatment above. The operation is carried out under a general anaesthetic and can last between one and four hours depending on the severity of the NEC.

## What happens before the operation?

The surgeon will explain about the operation in more detail, discuss any worries you may have and ask you to sign a consent form giving permission for your child to have the operation. An anaesthetist will visit you to explain about the anaesthetic.

## What does the operation involve?

The surgeon will carry out the operation while your child is under general anaesthetic. Generally the surgeons use open surgery through an incision (cut) in the abdominal wall. Occasionally, they may use keyhole (laparoscopic) surgery to explore the inside of the abdomen, but often they will then use open surgery for the rest of the operation.

The surgeon will remove any parts of the bowel where tissue has died. The amount removed can vary, but the surgeons will leave as much of the intestine as possible. If the surgeons have to remove a large part of the bowel, they may need to bring it to the skin surface so that your child can pass faeces (poo). This is called a 'stoma' and if your child needs one the stoma care nurse specialist will visit you to explain further.

If your child is not well enough to be transferred to the operating theatre, the surgeons may operate in the intensive care unit. The unit will be closed to parents and other visitors while this is happening. The same preparations will be carried out as in the operating theatre so this carries no additional risk to your child.



## **Are there any risks?**

Sometimes if a baby is very ill, the operation may not be successful. This operation carries a risk of bleeding during or after the operation. There is also a risk of further bowel damage and your child may remain seriously ill after the operation. Scar tissue (adhesions) may form in the abdomen after surgery, which may need correcting at a later stage. Strictures, where the bowel becomes narrowed due to scarring, are a complication of NEC whether it is treated with antibiotics or an operation. These often form in the large bowel, which may cause problems with feeding and/or passing faeces. This may need to be corrected in a further operation. Every anaesthetic carries a risk of complications. However your child's anaesthetist is a very experienced doctor who is trained to deal with any complications.

## **What happens afterwards?**

Your child will usually return to the intensive care unit to recover, and you will be able to visit as soon as they are settled back in the incubator. For a while after the operation, your baby will need help with breathing so will be connected to a ventilator. All babies are closely monitored after the operation, and so your child will be connected to monitors to check his or her breathing, heart rate and oxygen levels. They will also be given pain relief through the intravenous infusion (drip).

While your child's bowel recovers and start to work, they will continue to be fed through a tube into their veins (total parenteral nutrition or TPN). This will gradually be replaced by breast or bottled milk given through the nasogastric (NG) tube, when your child is ready for this. Over time, the drips and monitors will be removed one by one.

The nurses on the ward will encourage you to look after your child as much as you feel able while they are recovering. This can be daunting, especially while they are connected to drips and monitors, but it will become easier with time. If you are worried about caring for your child, please talk to the nurses. Your child will be transferred to another ward within the hospital or to your local hospital, once they are feeding properly and gaining weight. We will send you details of your outpatient appointment in the post, soon after you leave hospital.

## **What is the outlook for children with NEC?**

The outlook is dependent on how prematurely your child was born. When NEC is successfully treated by resting the bowel and giving antibiotics, the outlook is good with most children growing up to lead normal lives. For children who have had surgery, the outlook depends on the amount of bowel removed. If your child had a large amount of bowel removed, he or she may need to stay on TPN for a longer period, until the bowel can absorb enough nutrients for normal growth and development.

## **Is there a support group?**

There is no support group specifically for babies with NEC, but BLISS – the support organisation for premature babies – may be able to help. You can telephone them on 0870 7700 337 or visit their website at [www.bliss.org.uk](http://www.bliss.org.uk).