

Necrotising enterocolitis

This leaflet explains about necrotising enterocolitis. It explains what it is, the symptoms of it, the diagnostic process, the treatments available and the prognosis.

What is necrotising enterocolitis and why does my baby have it?

Necrotising enterocolitis (NEC) is a serious condition which causes a baby's intestine to become inflamed, and may mean that certain parts of the intestine die. Sometimes the inflamed intestine may perforate (get a hole) and this will cause the contents of the intestine to leak into the abdomen (tummy). This can cause a very serious infection.

The causes of NEC are not known, but certain things do increase a baby's risk of getting NEC. NEC mostly affects premature babies, and babies who are small for their age when they are born. However, NEC may occasionally affect babies who have not been born early. Problems in the womb or during birth may lead to certain babies getting NEC, as do some other problems such as bowel abnormalities or heart conditions.

What are the signs and symptoms?

There may be only one symptom of NEC or a collection of symptoms, which include

- a swollen and sore abdomen
- blood in the stool (poo)
- not tolerating feeds (eg vomiting or not absorbing the milk in their tummy)
- lethargy, or being more sleepy than normal
- having high or low temperatures.

Your baby may not display all of the symptoms listed above, and not all babies with these symptoms have NEC.

Does my baby need any tests to confirm the diagnosis?

If your doctor thinks your baby may have NEC then they will order an x-ray of your baby's abdomen, and maybe an ultrasound scan. These will be done on the neonatal unit. Your baby will also need to have blood tests to determine if they might have an infection. As NEC can sometimes be difficult to diagnose, your doctors may say that they **suspect** NEC and will treat your baby for it.

What treatments are available?

Many cases of NEC can be treated without an operation. In this case, your baby will be given antibiotics, and will not be allowed to have any milk while the intestine heals. Your doctors will decide how long this will last for, but it is usually between seven and 14 days. During this time, your baby will receive intravenous nutrition (parenteral nutrition (PN)), and may need extra help with their breathing while they recover. Your baby will have a cannula (drip) placed into a small vein so that we will be able to give the intravenous nutrition. This will also be used to give your baby the antibiotics which he or she may need.

Please ask your baby's doctor or nurse for more information about any antibiotics being given to your baby.

Sometimes, the doctor will recommend an operation. This may be because your baby's condition is not improving despite the antibiotics, or it may be because the inflamed intestine has developed a perforation.

What if my baby needs an operation?

If your baby needs an operation then a surgeon will come and talk to you about the procedure and the risks and benefits of it.

Your baby will need a general anaesthetic for the operation. General anaesthetic is medicine that is used to make sure a person is asleep and does not feel any pain during an operation. Specially trained doctors, called anaesthetists, care for all patients who have an anaesthetic, and specialised paediatric (children's) anaesthetists who have been specifically trained to care for children. The anaesthetist will come and assess your baby on the neonatal unit and explain to you what will happen. For more information about this, please ask for a copy of **Your child's general anaesthetic** leaflet.

Giving my consent (permission)

We want to involve you in decisions about your child's care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree for your baby to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for your baby.

What does the operation involve?

During the operation, your baby's surgeon may remove parts of the intestine if the tissue is badly damaged or has died. The amount of intestine that is removed will depend on how badly it is affected, but the surgeon will leave behind as much of the intestine as possible.

As the intestine is inflamed and damaged, it is very common for the surgeon to create a temporary stoma during the operation. The stoma will allow your baby's stool to drain out into a bag on the front of the abdomen. This plays a very important part in helping the inflammation of the bowel to heal and in helping your baby to recover. Afterwards, the surgeon will discuss with you how long your baby is likely to need the stoma, and what their further treatment is likely to be. Not all babies will have a stoma.

When will my baby be able to have milk again?

The doctors and surgeons will decide when your baby can have milk again. Usually this is seven to 14 days after your baby has been diagnosed with NEC, and may be longer than this if your baby has needed an operation. Your baby will be given your breast milk, if available, or a specially made milk, which is more gentle on the intestine than ordinary formula milk. Some babies with a stoma are unable to cope with the full amount of milk required for good growth and remain on a combination of milk and intravenous nutrition until the stoma is closed (removed).

What is the prognosis if my baby is diagnosed with necrotising enterocolitis?

The prognosis of a baby with NEC varies greatly depending on a number of factors. It is best to ask your doctors and surgeon what they think the prognosis and likely recovery time is for your baby.

Useful sources of information

There is no support group specifically for babies with NEC, but **BLISS**, the support organisation for premature babies, may be able to help.

t: 0808 801 0322 **e:** hello@bliss.org.uk **w:** www.bliss.org.uk

Contact us

If you have any questions or concerns about necrotising enterocolitis, please contact the Neonatal Unit on 020 7188 4045 and select the option to speak to the nurse in charge.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003 10am to 5pm, Monday to Friday **e:** letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk
t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

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