

Necrotising enterocolitis (NEC)

This leaflet gives more information about NEC. It explains what it is, the symptoms of it, how we diagnose it and the treatments available. If you have any questions, please speak to a doctor or nurse caring for your child.

What NEC is and why your baby has it

NEC is a serious condition which causes a baby's intestines to become inflamed, and may mean that certain parts of the intestine die. Sometimes the inflamed intestine may perforate (get a hole) and the contents of the intestine will 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 sometimes affects babies who have not been born early. Problems in the womb or during birth may lead to some babies getting NEC, as might some other problems, such as bowel abnormalities or heart conditions.

The signs and symptoms of NEC

There may be only one symptom or a collection of them. They include:

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

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

Does your baby need tests to confirm NEC?

If your doctor thinks your baby might have NEC, they will order an X-ray of your baby's abdomen, and sometimes an ultrasound scan. These will be done on the neonatal unit. Your baby will also need to have blood tests to determine if they 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 surgery. 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 7-14 days. During this time, your baby will receive intravenous (through a vein) nutrition (parenteral nutrition (PN)), and may need extra help with their breathing while they recover. Your baby will have a line (long line) inserted so that we will be able to give the intravenous nutrition. This will also be used to give your baby any antibiotics they need. Please ask your baby's doctor or nurse for more information about the antibiotics being given to your baby.

Sometimes, the doctors will recommend surgery. This might be because your baby's condition is not improving despite the antibiotics, or it may be because the inflamed intestines have developed a perforation.

What if your baby needs surgery?

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. This means they will be asleep and do not feel any pain during the operation. Anaesthetists care for all patients who have an anaesthetic. 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 our leaflet, **Your child's general anaesthetic**.

Consent – asking for your consent

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 future treatment is likely to be. Not all babies will need a stoma.

The surgical clinical nurse specialist (CNS) will also give you a special booklet called an NEC passport. This will give you a lot more information about NEC as well as explain some of the terminology you may hear. It also has some diagrams of the intestines which the surgeon will use to explain in more detail what was found during the operation, and let you know the effects this may have in the future.

When will your baby be able to have milk again?

The doctors and surgeons will decide this. Usually this is 7-14 days after your baby has been diagnosed with NEC, but might be longer if your baby needed surgery. Your baby will be given your breast milk, if available, or a specially made milk, which is gentler on the intestine than ordinary formula milk. Some babies with a stoma cannot cope with the full amount of milk needed for good growth, and they remain on a combination of milk and PN until the stoma is closed/reversed and the intestines are joined back together.

The prognosis for babies with NEC

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 is, and the likely recovery time for your baby.

Useful sources of information

NEC UK, a support group specifically for babies with NEC, **w:** www.necuk.org.uk

BLISS, the support organisation for premature babies, **t:** 0808 801 0322, **e:** hello@bliss.org.uk, **w:** www.bliss.org.uk

Contact us

If you have any questions or concerns about NEC, please contact the neonatal unit, **t:** 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, **w:** 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, Monday to Friday, 10am-5pm
e: letstalkmedicines@gstt.nhs.uk

Language and accessible 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 111

This service offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111 **w:** www.111.nhs.uk

NHS website

This website gives information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk/membership

Leaflet number: 4500/VER2

Date published: December 2020

Review date: December 2023

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A list of sources is available on request