

# Necrotising enterocolitis

## Newborn Services

**This leaflet offers more information about the treatment of necrotising enterocolitis (NEC). If you have any further questions or concerns, please speak to the staff member in charge of your baby's care.**

### What is necrotising enterocolitis?

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

NEC is the most common surgical emergency in newborn babies and tends to affect more babies born prematurely than those born full-term. It also happens more frequently in babies who have not grown well in the womb and those that have other bowel abnormalities or heart problems.

It is not clear what causes NEC, but it is considered to be a complex condition that is caused by many different factors.

### Can I reduce the risk of my baby getting NEC?

Research shows that breastfeeding your baby can help reduce the risk of NEC. Using breast milk may also be helpful when a baby is recovering from NEC and is able to start milk feeds again.

If breastfeeding is not possible, breast milk can be expressed and fed to baby through a feeding tube. This way, they can still get the benefits of having mother's milk. If there is insufficient breast milk, we can provide a safe alternative in the form of donated breast milk. One of our clinical team will discuss this option with you if it is appropriate.

### What are the signs and symptoms of NEC?

NEC can be difficult to diagnose and some of the early symptoms are non-specific and commonly seen in premature babies. Non-specific symptoms include:

- Being lethargic or more sleepy than usual
- Having unstable temperatures
- Increased episodes of drops in heart rate (bradys) or saturations (desats).

More specific symptoms include:

- A painful, swollen or discoloured stomach
- Being sick (vomiting), especially if the vomit is dark green (bile)
- If being fed by a tube, fluid may be found to accumulate in the stomach (increased aspirates)
- Blood in the stools (poo).

These symptoms may come on slowly and be difficult to distinguish from other neonatal illnesses, or they can occur extremely rapidly, in a matter of a few hours.

## What tests are done to diagnose NEC?

If NEC is suspected, your baby will be thoroughly examined by one of the neonatal medical team. If the clinical examination raises the suspicion that your baby is suffering from NEC, X-rays of the abdomen are frequently requested and blood tests taken to look for signs of infection and inflammation. Additional tests of the blood and ultrasound scans of the abdomen may also be required. A paediatric surgeon will usually also be asked to review your baby to advise on any further tests.

## How is NEC treated?

In most cases, NEC can be treated without surgery. The first steps in the treatment are to:

- Support baby's other organs. This may include having breathing support with a ventilator, medication to help improve blood pressure (inotropes) and transfusions with red blood cells and/or other blood products.
- Stop milk feeds to allow the gut to rest
- Provide feeding through a drip (usually a long-line is inserted into one of your baby's veins) to keep your baby nourished
- Start a course of antibiotics to treat any infections
- Pass a naso-gastric (NG) tube through baby's nose to reduce the amount of accumulated fluid in the stomach

This is called 'conservative' treatment. Surgery is considered if your baby fails to respond to the conservative treatment or if there are signs that the gut has perforated. Sometimes an operation is needed some time after recovery from the initial NEC, if the intestine becomes narrowed with scar tissue (strictures) and this causes a blockage.

The operation is carried out under a general anaesthetic and the surgeon will aim to remove the part of the bowel that has died. Usually a stoma (bowel opening onto the surface of the baby's tummy) is created to rest the bowel and in this case will be reconnected in a later operation. Sometimes, if only a small part of the bowel is affected it can be removed and the bowel reconnected at the same time.

## What happens after the operation?

Your baby will:

- continue to need help with breathing and support for other organs as described above
- need drugs for pain relief
- be fed by their long line with intravenous feeding (PN) because they cannot have milk until the intestines have recovered - usually about 10 days after surgery
- continue antibiotics.

During this time you may notice that your baby looks puffy as their body tries to deal with the inflammation in the body. They will also need regular blood tests to ensure that they are getting the right amounts of salts, fluid and blood products.

## Restarting milk feeds

Because your baby is small and has suffered a problem with their bowel, we would recommend using breast milk. Milk feeds are introduced slowly. The nursing staff can help with expressing and storing breast milk. If there is no breast milk available, we have donor-expressed breast milk

(see leaflet). The nurse looking after your baby will talk to you about this option. Sometimes it may be necessary to use specially formulated formula feeds.

## Caring for your baby's stoma

The stoma nurse will visit once the stoma begins to work and choose the right size stoma bag. The stoma nurse and the neonatal nurses will teach you how to look after the stoma. Occasionally babies go home with stomas while they are waiting to grow and before their intestine is reconnected.

## Are there any long-term problems?

Many babies treated medically do recover well and make full recoveries. Babies who have undergone surgery may have longer recoveries, but they too can recover exceptionally well. Other babies can have more complex recoveries and have problems such as:

- the wound can become infected or break down
- the long-line site can become infected
- NEC can recur
- there can be difficulties in re-establishing milk feeds
- scar tissue (adhesions) may develop inside your baby's tummy where the surgery took place and a further operation be required
- if a lot of bowel had to be removed, this may cause problems with feeding and require longer term intravenous feeding (PN).

Developmental difficulties later in life have been linked to having had NEC. Unfortunately NEC is sometimes life threatening, and very sadly some babies may not be well enough to have surgery and others might not survive after the procedure.

## If St George's Hospital is not your local hospital

After your baby has had surgery and made a good recovery i.e. when their specialist medical and nursing requirements are less, the baby will be transferred back to the care of your local hospital.

This transfer is a sign of progress and will not occur until the baby is ready. It will allow you to be closer to home and become familiar with your local healthcare professionals.

## Useful sources of information

Use your smartphone to scan the QR code (you may need to download a QR code scanning app) to go directly to the page.

Bliss: <http://www.nhs.uk/conditions/pregnancy-and-baby/>

BLISS is a support group which is able to offer support and advice to families with babies with a range of conditions.

68 South Lambeth Road

London SW8 1RL

Helpline: 0870 7700 337

Email: [Information@bliss.org.uk](mailto:Information@bliss.org.uk)

Website: [www.bliss.org.uk](http://www.bliss.org.uk)



NEC UK is the first charity in the UK exclusively for the condition Necrotising Enterocolitis (NEC).

It primarily offers support to families affected by the condition at any stage of their journey.

Email: [info@necuk.org.uk](mailto:info@necuk.org.uk)

Enquiries: 0113 4407154



## Contact us

If you have any questions or concerns about NEC, please contact a member of the neonatal team on the neonatal unit.

**For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.stgeorges.nhs.uk](http://www.stgeorges.nhs.uk)**

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## Additional services

### Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).

**Tel:** 020 8725 2453 **Email:** [pals@stgeorges.nhs.uk](mailto:pals@stgeorges.nhs.uk)

### NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

**Web:** [www.nhs.uk](http://www.nhs.uk)

### NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

**Tel:** 111



Reference: NEC\_NEC\_01 Published: July 2018 Review date: July 2020