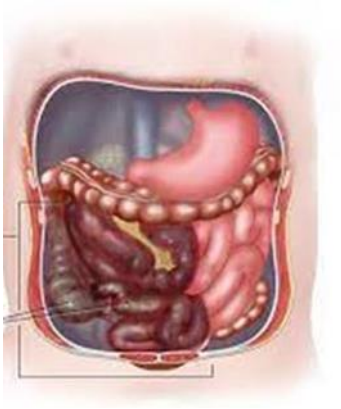
Alder Hey Children's NHS Foundation Trust

Ward 1C Neonatal Surgical Unit

Necrotising Enterocolitis

Information for Parent/Carers

What is Necrotising Enterocolitis (NEC)?



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) which allows the contents of the bowel to leak into the abdomen and can cause a very dangerous infection. NEC is the most common surgical emergency in newborn babies and tends to affect prematurely born babies more than those born full term.

What Causes NEC?

NEC seems to be becoming more common, but it is likely that this is because more premature babies are surviving. Some of the factors that can increase the risk of NEC are infection, breathing problems, heart problems, babies who have not grown well whilst in the womb. There is plenty of evidence to suggest, breast milk offers better protection of the bowel compared to formula feeds.

Early Signs of NEC and Diagnosis

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. There may also be blood in the stools. Your baby may become unwell, needing more breathing support or more intensive care. Sometimes it is hard to know if these symptoms are related to NEC or other conditions. To help with the diagnosis of NEC your baby will require tests such X-ray of the tummy and blood tests.

Treatment and Care after NEC is Suspected/Diagnosed

In most cases NEC can be treated without surgery. This will mean your baby will not be fed milk for at least seven to 14 days to allow time for the gut to rest and heal. Nutrition will be given intravenously via a drip known as Parenteral Nutrition (PN) and treating the infection with antibiotics. During this time, a naso/orogastric tube will be passed through their nose to drain off the contents of their stomach.

Your baby will need close monitoring of their heart rate/breathing/temperature and oxygen saturations. They will usually be nursed in the incubator to enable visible observations. Some babies may also need support with their breathing which may be on an intensive care unit.

However, your baby will need an operation if they do not respond the treatment above and develop a hole in their bowel. They will then need to be transferred to a specialist surgical unit for surgery.

Are there any Risks with Surgery?

The surgeon will explain about the operation, risks involved and discuss any worries you have. You will be asked to sign a form giving consent or an e-form, for your baby to have an operation. An anaesthetist will also visit you to explain about the anaesthetic and discuss pain relief for your baby.

What does the Operation Involve?

During the operation, the surgeon will remove any parts of the bowel where the tissue has died. The remaining healthy ends of the bowel will be re-joined together. If it is not possible to re-join the two ends at the time of surgery, the surgeon may create a temporary stoma. A stoma is where the bowel is brought out onto the skin of your baby's tummy. This then allows the bowel to open into a small bag which is placed on the outside of your baby's body. Stoma plays a very important part in helping the inflammation of the bowel to heal and in helping your baby recover. Afterwards, the surgeon will discuss with you how long your baby is likely to need stoma and what their future treatment is likely to be.

After Surgery

Following the operation your baby will return to the unit and be closely monitored. He/she may need support for their breathing. They will also be given pain relief through the intravenous infusion (drip). Until your baby's bowel recovers and starts to work, they will continue to be fed through a tube into their veins (PN). This will gradually be replaced by milk (ideally expressed breast milk) through the nasogastric/oro-gastric (NG) tube when your baby is ready for this and on the advice of the surgeon. Overtime, the drips will be removed, and monitoring will be reduced.

The nurses on the ward will encourage you to look after your baby 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 baby, please talk to the nurses. Your baby will be transferred to local unit or discharged once he/she is fully fed/gaining weight and surgeons are pleased with their progress. The surgeons will see your baby in an outpatient clinic after discharge or plan for closure of the stomas at an appropriate time.

What does the Future hold for my Baby 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 babies growing up to lead normal lives. For babies who have had surgery, the outlook depends on the amount of bowel removed. If a large amount of bowel is removed, he or she may require longer term management. In very severe cases, despite exhaustive treatment, some babies with NEC might sadly die.

Contact:

If you have any concerns or worries about your baby once you are home you can call the Neonatal Surgical Unit and one of our Nurses will be happy to give you advice and reassurance.

Neonatal Unit 1C Yellow Pod
Tel:0151 252 5378

Other Useful Contacts

BLISS
Support for babies born premature or sick.
Website: https://www.bliss.org.uk
Tel: 020 7378 1122
Email: hello@bliss.org.uk

Space for Parent/Carer Notes

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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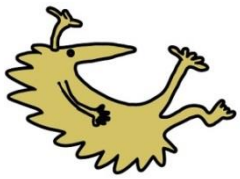

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