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This booklet has been developed by NEC UK in conjunction with parents and health professionals. We aim to produce a series of additional sheets on 'complex NEC' and teenage/adult service transition. If you have suggestions for improvement or development please contact NEC UK.

Please remember that many babies who experience NEC live long happy and fulfilled lives



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What is NEC

NEC is an infection/inflammation of the bowel – it can affect anywhere from the stomach to the bottom

It mostly affects preterm infants – at least 9 out of every 10 affected babies is born early

NEC can also affect babies with heart problems and rarely otherwise well term babies

Most babies are around 2-3 weeks old when they get NEC, but they can be younger or older
It is very rare after discharge home

Around half of the babies with NEC will get better with antibiotics and a period of not being fed – we call this ‘medical NEC’

The other babies will need one or more operations to help them to get better – we call this ‘surgical NEC’

In about 1 in 5 cases where surgery is required repeat operations are needed – we call this ‘complex NEC’

Very rarely a baby does not have enough bowel left after surgery to grow with just milk – we call this ‘short bowel syndrome’

Even more rarely all the bowel we be affected – we call this ‘pan NEC’

Think about helping us learn more about NEC and taking part in studies if you can



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How to reduce the risk of NEC

Sadly some babies get NEC even when everything possible has been done to prevent this. Some things can make NEC less likely though.

Most important is giving your baby your own breast milk. This is the best protection we know about for NEC. Even small amounts of Mums own milk are really helpful.

Babies who get the most of their own Mums milk are least likely to get NEC, but in the UK around half the babies with NEC have only ever had their Mums own milk.

Sometimes babies cannot have their own Mums milk – if so, then human donor milk may be better than cows milk based formula milks, but there may be reasons why this is not available or right for your baby. Some babies getting their Mums milk also need something extra to help them grow well (fortifier). These can be made from human or cows milk, but human based fortifiers are not always available. Please ask your health professionals about this if relevant to you.

Being given lots of antibiotics can also be linked to NEC. If a baby has an infection then they need antibiotics, but stopping them as soon as possible is sensible.

Lots of babies ‘spit’, ‘posset’ or ‘reflux’ – some of the medicines used for this in older babies can contribute to NEC in preterm babies, so usually not giving very early babies medicines for ‘reflux’ whilst they are still young helps reduce NEC.

Probiotics are bacteria designed to help build a healthy gut ‘microbiome’ – some neonatal units offer these for some babies – if you wish you can ask your team about this for your baby.

We are learning more about NEC all the time – please take part in studies of feeding/NEC prevention/NEC treatment if you can

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Guide to 'spotting' NEC

NEC presents in different ways – some babies are only a little unwell, and a bit less able to tolerate their milk whilst others get quite sick quite quickly.

In the beginning NEC can look just like any other infection.

This can make it difficult to be sure in the beginning.

Lots of babies will spend a day or two with doctors and nurses worried they may be developing NEC, but then settle down and never really have it.

Things that **MIGHT** mean NEC are:

Being quiet, temperature instability, more breathing pauses (apnoea's)

Starting to vomit – especially if they have previously managed milk well

Lots of milk not being digested (big 'aspirates')

Green or brown vomit, or vomit that looks like poo

Swollen, red, sore, tender tummy

Discoloured tummy – black or greenish coloured

Discoloured testicles in boys

Blood in the nappy or mixed in with poo

Less urine being passed

Generally swollen baby

Please don't be worried to ask if it could be NEC – people won't mind and it is better to ask than worry

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Treatments for NEC

Medical treatments:

This means stopping feeds, but leaving the 'feeding' tube in the stomach to let out gastric juices, giving antibiotics, and sometimes using other 'supportive' treatments like breathing support or blood pressure medicines. In addition some babies need blood or platelet transfusions. Some babies just need a rest from feeds and antibiotics, and get better without anything else, other babies need more support.

Surgery:

Some babies with NEC need an operation. This can be because the baby has got sick quickly, or because they are not getting better over a number of days, or sometimes because they struggle to feed again after an episode of NEC. Some babies are already in units where there are specialised baby surgeons, but some babies need to be moved to a unit with these surgeons in, either for definite surgery or in case surgery is needed quickly.

Urgent surgery:

This is done because the baby is very unwell, and needs an operation to help them get better. Usually there is either a 'hole' in the bowel or some 'dead' bowel which is making the baby sick, and doctors and surgeons feel the baby will not get better without an operation.

Drains: occasionally a baby is so sick that a drain, a small piece of plastic tubing/material is placed in the tummy, to allow the baby get a little better before an operation is done. This drain can usually be placed at the bedside, but not always.

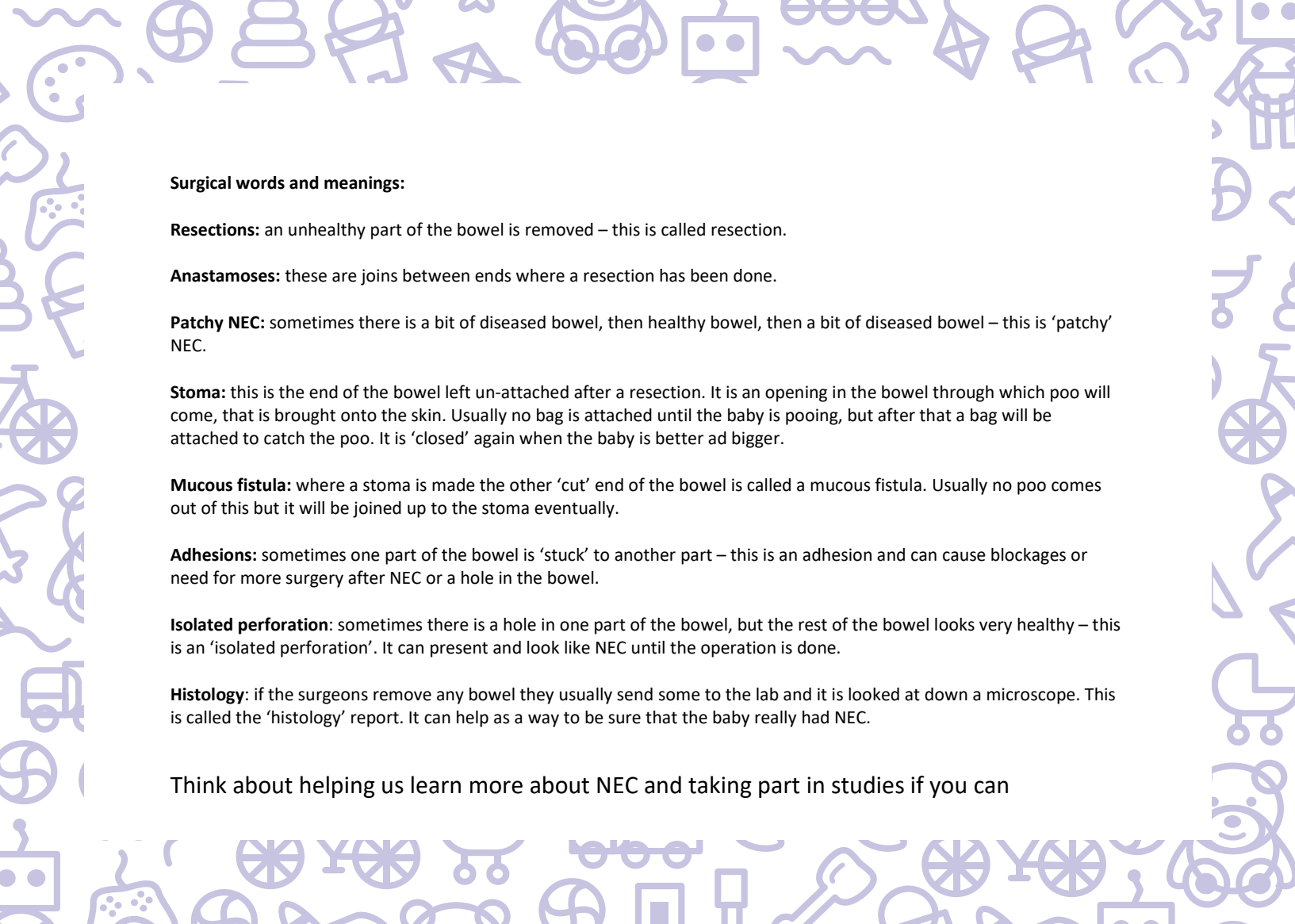
'Planned' surgery: is sometimes needed because the bowel looks 'obstructed' or 'blocked' after NEC, or because the baby has not got better despite not being fed for some time.

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Surgical words and meanings:

Resections: an unhealthy part of the bowel is removed – this is called resection.

Anastamoses: these are joins between ends where a resection has been done.

Patchy NEC: sometimes there is a bit of diseased bowel, then healthy bowel, then a bit of diseased bowel – this is ‘patchy’ NEC.

Stoma: this is the end of the bowel left un-attached after a resection. It is an opening in the bowel through which poo will come, that is brought onto the skin. Usually no bag is attached until the baby is pooing, but after that a bag will be attached to catch the poo. It is ‘closed’ again when the baby is better and bigger.

Mucous fistula: where a stoma is made the other ‘cut’ end of the bowel is called a mucous fistula. Usually no poo comes out of this but it will be joined up to the stoma eventually.

Adhesions: sometimes one part of the bowel is ‘stuck’ to another part – this is an adhesion and can cause blockages or need for more surgery after NEC or a hole in the bowel.

Isolated perforation: sometimes there is a hole in one part of the bowel, but the rest of the bowel looks very healthy – this is an ‘isolated perforation’. It can present and look like NEC until the operation is done.

Histology: if the surgeons remove any bowel they usually send some to the lab and it is looked at down a microscope. This is called the ‘histology’ report. It can help as a way to be sure that the baby really had NEC.

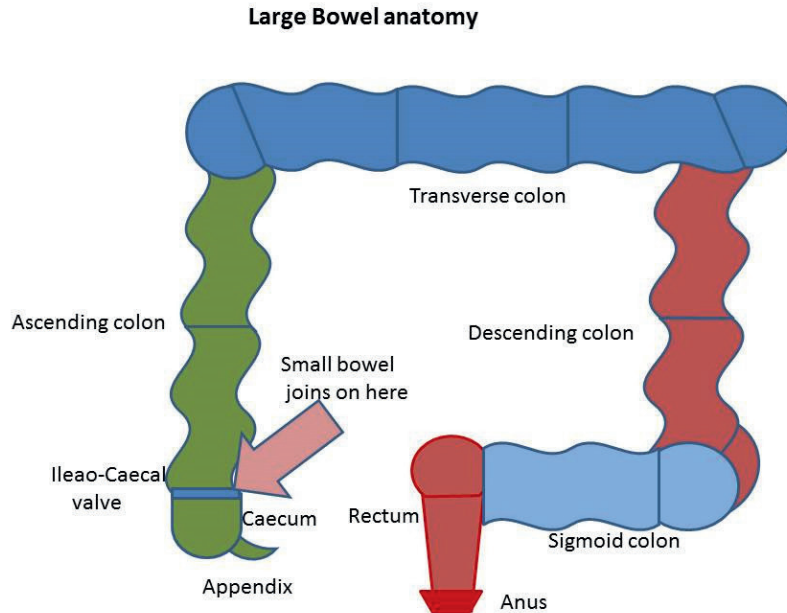
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Normal large bowel anatomy



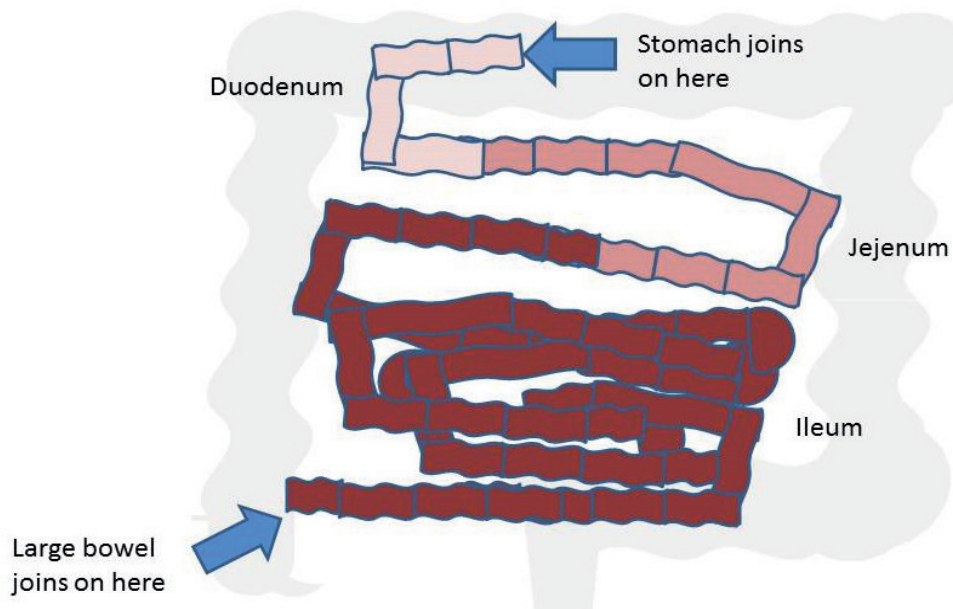
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Normal small bowel anatomy



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Your baby's operation detail:

Date __/__/__ Surgeon _____ Small intestine



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Your baby's further operation detail

Date __/__/__ Surgeon _____



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Anatomy at discharge or transfer:

Lead neonatologist name _____ **contact** _____

Lead paediatric surgeon name _____ **contact** _____



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NEC related problems in the NICU

Some babies recover really well from NEC and have no problems re-feeding or growing. Others will experience some of the following things:

Failure to thrive: when growth is less good than we think it should be, and weight and length are difficult to gain. This is shown on growth charts and usually talked about on ward rounds.

TPN dependence: when milk alone (or later solids) are not able to grow a baby well enough and they need some or all of their nutrition given into their veins.

Feed intolerance: when milk causes vomiting or diarrhoea, or repeated episodes of blood in the poo ('colitis').

Lines/infections: when intravenous nutrition is needed it is given through long lines (also called Broviac's or Hickman's) and these can become infected needing antibiotics and/or removal. Some lines are put in on the ward, others in theatre.

Milk choices: breast milk has lots of benefits for all babies including those who have had NEC. Sometimes milk that has the proteins already partly broken down (hydrolysed) is tried, or even one that is completely broken down (elemental or amino acid formula) to help a baby grow and tolerate its's milk.

Constipation: sometimes babies find it hard to poo after NEC – this is true of toddlers too.

Diarrhoea/high output: when a stoma is in the small bowel, especially in the jejunum or high up the ileum, the poo is quite watery. This is because the large bowel that absorbs water is disconnected. It can also happen if the small bowel is connected to the large bowel but some of the large bowel has been removed. Medicines and milk changes can help, but sometimes fluid needs to be given back to babies to compensate (replacement fluid).

Blockages/obstruction: some time after NEC (usually several weeks) the bowel can 'block' or 'obstruct' as part of the healing process and this sometimes needs another operation.

Jaundice/liver problems: babies who need a lot of intravenous nutrition can get yellow (jaundice) and their liver can be under stress, shown by abnormal 'liver function tests'. Some medicines and vitamins can help this, as well as managing to feed, even small amounts.

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Food behaviours: oral feeding and food related behaviours can be more difficult after NEC. This sometimes relates to a later introduction of oral feeds than would usually occur, and so children miss the ‘window’ in which they would have learned to enjoy food. Health visitors, speech and language therapists and dietitians can all help, and mentioning NEC might help these professionals understand how best to help.

Toilet training: this can be more difficult after NEC, especially if constipation has been a problem. Health visitors have a wealth of experience, and it will help them to know about the background of NEC.

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Information for health professionals:

This baby has had necrotising enterocolitis (NEC) as a baby. They may experience problems with feeding and growth as babies and might have trouble with bowels/ toilet training/ feeding as a toddler. The family have details of surgical interventions and current feeding strategies.

The current involved professionals are:

Name	Role	Contact number	Date no longer involved

If they are presenting to A and E please consider whether the presentation could be relevant to their NEC and seek advice from those above

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Words used and abbreviations

Gut / bowel/intestines: all mean the same thing. This is the part of the body that digests our food and absorbs water.

Small bowel: this is the top bit of the bowel after the stomach, and includes the duodenum, jejunum and ileum. The longest part is the ileum, and this absorbs most of the nutrients and vitamins.

Large bowel: this is the lower part of the bowel, and includes the caecum, colon, rectum, and anus. This part absorbs most of the water.

Ileo-caecal valve: sits between the small and large bowel.

Short gut/short bowel: this means that the length of small bowel is too short to expect that a baby will easily feed and grow on milk as a baby.

TPN/PN dependency: this means that the baby needs intravenous nutrition in the veins to allow the baby to grow.

Stoma: an opening in the bowel brought to the surface of the tummy for poo to come out of

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Neonatal unit _____
Paediatric unit _____

Paediatric unit _____

Tel 07375813907

Tel 020 7378 1122

Tel 02074860341

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Media

Below are links to film clips and other potentially useful resources

Please bear in mind that not all families are helped by the same things, and some of these may not be for you

We have offered a brief idea of content beside each

Breast feeding a preterm baby advice:

<https://www.bestbeginnings.org.uk/fbtb-sick-or-pre-term>

Action medical research – NEC focused film on research

<https://action.org.uk/about-us/videos> or <https://vimeo.com/374373474>

General film for parents about neonatal unit life:

<https://charityfilmawards.com/videos/a-stay-in-neonatal-care-an-animated-guide>

Butterfly films: focused on twin loss and bereavement but also covers some NEC related concerns:

<https://www.neonatalbutterflyproject.org>

NEC UK host a variety of information including some film clips on their website

www.necuk.org.uk

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