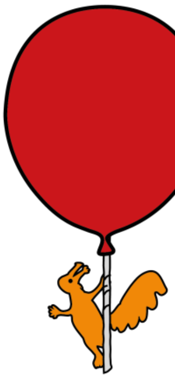


NHS
Alder Hey Children's
NHS Foundation Trust

Ward 1C Neonatal Surgical Unit

Gastroschisis

Information for Parents & Carers

What is Gastroschisis?

Gastroschisis is a birth defect where there is an opening in the abdominal wall, which allows the bowel and sometimes other organs to sit outside the baby's body (as seen in the picture below). Normally, as baby grows in the womb, the bowel will develop inside the umbilical cord, once the bowel has grown, it will move inside the abdomen. With Gastroschisis the abdominal wall does not develop properly and so the bowel will continue to develop outside the stomach. This occurs early into the pregnancy and can be seen on your 12-week scan.

Causes of Gastroschisis

We do not know the exact causes of gastroschisis, and it can happen to anyone who is pregnant. This is not caused by anything you may or may not have done during pregnancy. It is not an inherited condition and so further pregnancies are not at risk of developing this condition. The centre for Disease and prevention report that it is more prevalent in younger mums who are under 20 years of age. The overall incidence is quite low with 1 in 3000 babies being born each year.

How is Gastroschisis Diagnosed?

Diagnosis of Gastroschisis is usually picked up at your 12- or 20-week antenatal scan. Once your baby has been identified with this condition, you will be seen by the surgeons, neonatologists and obstetrics team at the foetal centre over in the Liverpool Women's Hospital. You will have extra ultrasound scans to monitor your baby.

Mothers of babies with gastroschisis usually have a normal birth, but on some occasions if the gastroschisis is very large a caesarean section will be offered to you.

Prior to your appointment with the specialist team, it may be useful to write down any questions you want to ask.

You will also be offered the opportunity to have a look around the surgical neonatal unit over in Alder Hey hospital prior to your baby's delivery.

How is Gastroschisis Treated?

Once your baby is born, the bowel will be wrapped in cling film. This helps to protect the bowel from further damage, it reduces the amount of fluid that can leak from the bowel, and it allows the staff to monitor the colour and condition of the bowel more closely.

Baby will then be brought over to you to say hello and if possible, a cuddle. The neonatal team will then take your baby to the neonatal unit and prepare them for transfer over to Alder Hey, where they will go straight to surgery.

What Happens before Surgery?

Prior to surgery the Anaesthetist will review your baby on the unit and will discuss the anaesthetic with you. Every anaesthetic carries a risk of complications, but this is very small. The anaesthetist is a very experienced doctor and is trained to deal with any complications that arise.

The surgeon who will be performing the operation will explain the operation in more detail and will answer any questions you may have. They will ask for your permission to carry out the surgery either via e-consent or over the phone, as you may still be an inpatient yourself.

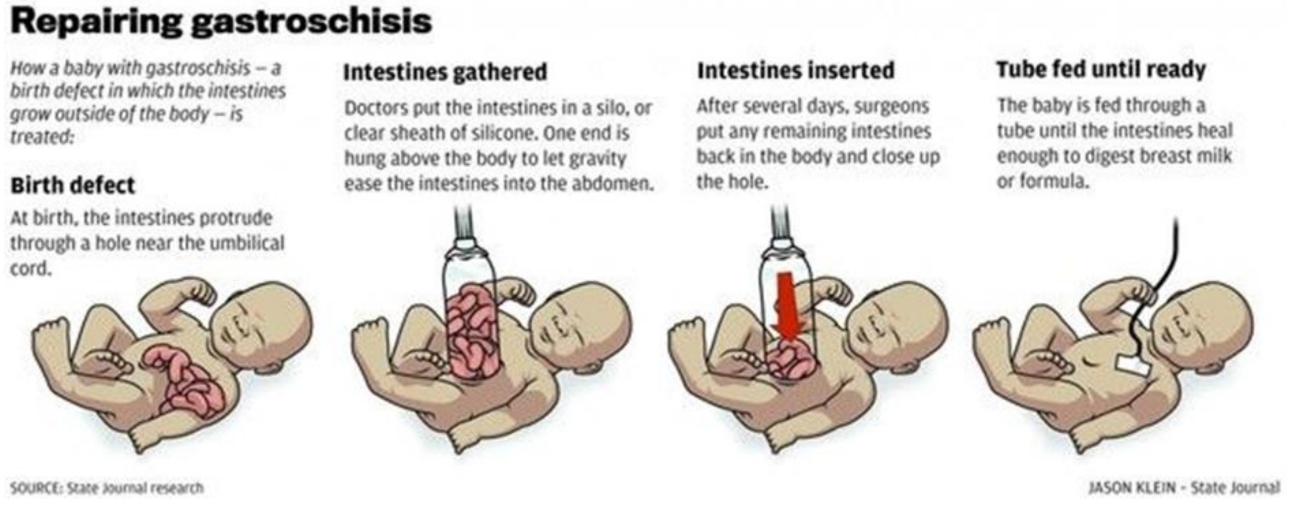
What does the Operation Involve?

Once your baby is under general anaesthetic the surgeons will examine the bowel to see if there are any damaged areas. If there are they may need to remove that part of the bowel and join the ends together.

The surgeon will attempt to place all the bowel and other organs back in the abdomen depending on how much bowel is outside and how much space is there within the abdomen.

There is the primary repair of a gastroschisis, and this is where the surgeons can replace the entire bowel into the abdominal space and close the hole in the abdominal wall.

The other repair is called a staged repair. This is where there is too much bowel on the outside and not enough room on the inside of the abdomen. Rather than causing damage to the bowel, the surgeons will place the bowel inside a sterile plastic sac (as you can see in the picture below).



Repairing gastroschisis

How a baby with gastroschisis – a birth defect in which the intestines grow outside of the body – is treated:

Birth defect

At birth, the intestines protrude through a hole near the umbilical cord.

Intestines gathered

Doctors put the intestines in a silo, or clear sheath of silicone. One end is hung above the body to let gravity ease the intestines into the abdomen.

Intestines inserted

After several days, surgeons put any remaining intestines back in the body and close up the hole.

Tube fed until ready

The baby is fed through a tube until the intestines heal enough to digest breast milk or formula.

SOURCE: State Journal research

JASON KLEIN - State Journal

Over a period of days gravity will push the bowel back inside the abdomen. The surgeons will assess each day and when there is space at the top of the sac the surgeons will tighten it. Eventually your baby will go back to theatre and have the abdomen closed. Sometimes they may need to use a patch as the hole is too large. As the baby grows, the abdominal cavity will grow and eventually the patch is removed and abdomen closed.

After the operation your baby may return to the surgical neonatal unit or may need to spend time on the Intensive care unit ventilated, this is to allow your baby time to recover from the surgery. They will be monitored closely, connected to monitors which will help check their breathing, heart rate and saturation levels.

They will receive adequate pain relief through intravenous infusion in the form of morphine and paracetamol.

When can my Baby Start to Feed?

Initially your baby will be fed via intravenous fluids called Total parental nutrition or TPN / Numeta. As the bowel begins to work, i.e., bowels opening and aspirates from his tummy change colour and reduce in volume, the surgeons will then consider introducing some feeds. As your baby tolerates these feeds the IV fluids will be reduced and eventually turned off completely.

How long this will take depends on how quickly your baby recovers from their operation and this can take around 4 weeks before being fully fed. Some babies will need to continue TPN for much longer due to the bowel not working properly and cannot absorb the nutrients. Some babies with complex gastroschisis will have more serious health problems. The possible outlook for you and your baby will depend on your individual circumstances. The specialist team looking after your baby will discuss the treatments available.

Once your baby is feeding and putting on weight, we will start to plan for your discharge home or transfer back to your referring hospital. We will ensure that your health visitor and GP are aware of your discharge, so that they can arrange to see your baby out in the community. On the day of discharge a follow up appointment will be made for you to bring your baby back to clinic to see the surgical consultant, who will assess how your baby is doing and answer any questions you have.

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

Antenatal Results and Choices (ARC)
ARC is a national charity that supports people making decisions about screening and diagnosis and whether or not to continue a pregnancy.
Website: www.arc-uk.org

GEEPS (Gastroschisis, Exomphalos and Exstrophies Parents Support)
GEEPS can offer help and support.
Website: www.geeps.org

Space for Parent/Carers Notes

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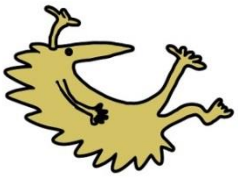
www.alderhey.nhs.uk



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