Gastroschisis

This leaflet provides information about gastroschisis. If you have any further questions or concerns, please speak to the staff member in charge of your baby's care.

What is gastroschisis?

Gastroschisis is a condition in which a baby has a small hole in the front wall of their abdomen, just to the right side of the umbilical cord, through which some of the bowel (intestine) is protruding.
The condition occurs in about 5 in 10,000 births.

Your antenatal scans should enable us to diagnose this condition, as this bowel is easily seen on the ultrasound scan. Having some of the intestines on the outside means that they are exposed to the amniotic fluid (fluid around the baby inside of your womb) and can become covered by a thick membrane.

Your baby may need more frequent scans to monitor the baby's growth, as gastroschisis babies are sometimes small and to monitor the aspect of the bowel that is inside and outside of their body.

Gastroschisis can be simple whereby only bowel passes through the hole and this bowel does not have any blockages. It can also be complicated, if the bowel outside the body has become tangled or twisted and can be extremely damaged, or there is an intestinal atresia (a portion of bowel that hasn't developed correctly, leading to a blockage) or if other organs, such as the stomach or liver, protrude out of the opening as well.

Simple cases are more common than complicated ones.

What happens at the delivery?

It is possible for you to deliver your baby vaginally unless there are other reasons why you need a caesarean section. However, it is recommended that your baby is delivered at St George's Hospital or at a unit where neonatal surgery is available as your baby will need to be transferred to the neonatal unit after birth and to be seen by a paediatric surgeon.

Is gastroschisis associated with any other congenital problems?

Gastroschisis is not normally associated with other problems at birth and we expect most babies born with this condition to develop normally.

In some babies with gastroschisis there is narrowing / blockage of the bowel called an atresia. Usually, an atresia is noticed at birth but can be diagnosed in the next few weeks when the baby is not able to tolerate milk. X-ray tests can be helpful in confirming whether an atresia is present. If an atresia is confirmed, the baby would need a further operation to put this right.

In a small number of babies, gastroschisis is complicated by further problems with the bowel that are not normally detected until after the baby is born. The blood supply to the bowel is sometimes interrupted, resulting in parts of the bowel being irreversibly damaged or missing. If there is a significant loss of bowel length, there will not be enough bowel to absorb all the milk feed required for growth and the baby will need long term parenteral nutrition through a central line (we have a separate leaflet we can give to parents about this procedure). This is known as short bowel syndrome and it could mean long term hospitalisation for drip feeding and other interventions. Sadly, some of these babies with

short bowel syndrome do not survive but this is an uncommon situation.

Initial management

Following the birth, your baby's bowel will be wrapped in a protective film (Cling Film - designed for kitchen use) to help reduce heat and fluid loss and to protect the intestines. A drip will be placed into a small vein so that intravenous fluids and medications can be given. At first, your baby will not be able to feed as babies with gastroschisis won't be able to easily digest milk for a few weeks, sometimes longer. A naso-gastric tube (NG tube) will be passed through your baby's nose into their stomach to drain away the bile (green fluid) that collects here. This lessens the risk of your baby vomiting and reduces discomfort.

Treatment

Soon after delivery we will start to put the bowel back inside the baby's abdomen. If there is little bowel outside and there is a space in the baby's tummy, this may be done in one operation. However, if not, it may need to be done in stages, especially if there is a large amount of bowel outside the abdomen. Replacing it in the abdomen in one session may put too much pressure on the baby's lungs, not allowing them to breathe properly or impede blood from circulating back to the heart.

In this situation, the bowel needs to be placed in a pre-formed plastic bag called a "silo". With simple gastroschisis, the bowel is often placed in the silo in the neonatal unit without an anaesthetic but with pain relief. The sac sits on top of your baby's abdomen like a tower and is suspended so that gravity helps the bowel return to the abdominal cavity. The sac is also tightened regularly to reduce the bowel gradually over a period of five to seven days on the neonatal unit.

Once the bowel is back inside the abdomen, the baby is taken to theatre and placed under anaesthetic, after which the bag will be removed, the bowel is inspected then pushed inside the abdomen by the surgeons and the hole is closed. This can be done using sutures or with a sutureless closure using Steri-strips (paper strips) with a further dressing applied over the top. This dressing usually stays on for seven days before removal. The hole heals over the next two weeks.

Sometimes the bowel is too swollen or the hole is too small and a silo cannot be placed on the neonatal unit. The baby will need an operation under anaesthetic for the bowel and the hole to be inspected. Sometimes it is possible to put the bowel back inside the abdomen and to stitch the hole closed. However, this is not always possible if there is not enough room in the abdomen. In this case, a temporary surgical silo is placed on the outside of your baby's abdomen and the bowel is then gently reduced back inside the abdomen which can take up to one to two weeks. A second operation is needed to remove the silo and to close the hole.

Sometimes, if the hole is quite large, the surgeons may need to use a "patch" of material to close your baby's abdomen. They will cover the area with a dressing to protect the wound while it heals.

Babies with complex gastroschisis usually need undergo a general anaesthetic to be carefully assessed. If there is damaged bowel, this will need to be removed. If there is bowel atresia (blockage), this may be left and planned for repair at a later stage, especially if the bowel is very thickened as a bowel join-up may not heal properly at this point.

If the hole has been closed, we will monitor your baby to ensure the closure is not too tight. If your baby's abdomen becomes distended,

s/he may need help with their breathing by mechanical ventilation for a few days. Very rarely, the closure puts too much pressure on their chest and does not allow blood to circulate properly; in this situation, they may need another operation to relieve this pressure and to have their abdomen closed with a patch instead. Your neonatal and surgical team will inform you about this.

After the operation

Sometimes complications do occur after the operation, such as wound infections, wound breakdowns, inflammation / infection of the bowel and further obstruction. We will keep you fully informed of your baby's condition and further management steps, should this happen.

Can I feed my baby?

Immediately following birth, feeding your baby with milk is not possible until the abdomen has been closed. Starting milk feeds can take up to several weeks. We would recommend expressing breast milk in preparation and the neonatal nurses are more than happy to discuss this process with you. During this time your baby will need Parenteral Nutrition (PN) through a long line. A long line is a special type of drip that is placed in a small vein in an arm or leg and feeds into larger veins, which allows the drip to last longer.

Once the bowel is back inside the abdomen and the green aspirates (bile) coming through their NG tube (from the stomach) are less, your baby can start milk feeds through the feeding tube. However, this will be small volumes to start with and the amounts will be increased slowly depending on how your baby tolerates them. It can take a month or more sometimes before your baby can tolerate and reached full feeds, as having the bowels on the outside of the body at birth leads to the bowel being dismotile (unable to move in a coordinated fashion to push food through the bowel). Once recovery

has occurred the baby should be able to feed normally, either by breast or bottle.

Long-term and follow-up

Following discharge from the neonatal unit, there will be regular check-ups to monitor your baby's progress. Your baby will be seen in the outpatient's department, which may take place at your local hospital. Your baby should be able to feed and wean normally. Some babies with gastroschisis take a little longer to gain weight and some may have problems with constipation. These are normally short-term problems.

Babies who have had gastroschisis will not have a typical navel (belly button) but a scar is usually present.

Following an operation there is always a small risk of a future bowel obstruction (blockage) occurring. If your baby has a bilious (green) vomit, is not passing bowel motions or has a distended (swollen) abdomen, medical advice should be sought.

If St George's Hospital is not your local hospital

When your baby has had surgery and made a good recovery, i.e. when their specialist medical and nursing requirements are fewer, 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

NHS pregnancy and baby guide
http://www.nhs.uk/conditions/pregnancy-and-baby/

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

Bliss
1st Floor North
10-18 Union Street
London
SE1 1SZ

Enquiries: 020 7378 1122
Email: hello@bliss.org.uk Website: www.bliss.org.uk

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

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

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 wings (near the lift foyer).
Tel: 020 8725 2453 **Email:** 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

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

AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

Reference: NNU_GAS_LP_03 **Published:** May 2023 **Review date:** May 2025