

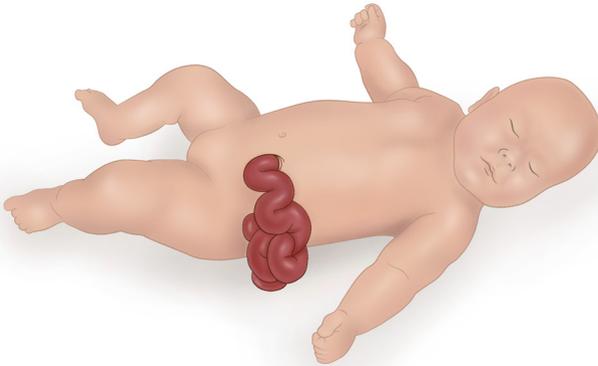
Information leaflet for parents/Carers

Gastroschisis



What is Gastroschisis?

Gastroschisis is an abdominal wall defect. It occurs when a baby's abdomen (tummy) does not develop fully while in the womb. Usually the baby has a defect (hole) on the right of the umbilical cord through which the baby's intestines escape into the amniotic fluid.



Gastroschisis happens in approximately 1 in 3000 births. There is an increased chance that your baby will be born premature and small. The cause of Gastroschisis is unknown but is often associated with pregnancy in younger mothers.

How is Gastroschisis diagnosed?

Gastroschisis is usually diagnosed during pregnancy at the routine 16-20 week scan. If it is not identified before birth, Gastroschisis will be seen immediately as soon as the baby is born.

What happens to the intestines of my baby during pregnancy?

During pregnancy, the escaped intestines float in the amniotic fluid inside the womb. The fluid can irritate the intestines and make them swollen and thick. Sometimes the intestines become twisted as they float and the blood supply may be restricted. Because of that your baby may lose some of their intestines (intestinal atresia). Your Obstetrician will arrange regular ultrasound scans during the pregnancy to monitor your baby's growth and the amount and condition of the intestines lying outside in the amniotic fluid. This monitoring will help determine the best time and place for your baby's delivery.

When, how and where will my baby be born?

Gastroschisis is often associated with the baby being small, so it is normal to plan induction of labour between 37 and 40 weeks of gestation. In a small number of babies, there is a need to deliver the baby before 37 weeks.

Routinely, babies with Gastroschisis are born by normal vaginal delivery. However if the mother or the baby present other risks or complications your Obstetrician will discuss with you the option of a caesarean section.

If induction is needed, it will be necessary to ensure that there are neonatal and surgical beds available for your baby once he/she is born. This can only be agreed on the day of your admission and may mean that the induction is delayed or on rare occasions that you would transfer to another unit for delivery and/or surgery.

What happens to my baby after birth?

Following delivery, the Neonatologists (doctors looking after newborn babies) will ensure that your baby is breathing normally. Some premature babies will need variable amounts of support with their breathing.

Your baby will receive fluids and antibiotics into their veins via a drip.

A nasogastric tube (NG tube) will be passed through your baby's nose and down into their stomach to prevent your baby vomiting.

Your baby's abdomen and exposed intestines will be wrapped in a medical cling film or a special plastic bag to prevent further damage and infection. This also helps to keep your baby warm by reducing heat loss from the exposed intestines.

If your baby is well enough you will be allowed to give them a cuddle.

What happens next?

Once the Neonatologists are happy that your baby is stable, they will arrange for a transfer to the Paediatric Surgical Department at the Birmingham Children's Hospital.

The next important steps will be:

1. Returning the intestines back into the tummy;
2. Repairing the hole in the tummy;
3. Starting your baby on milk feeds.

The surgeon and surgical team will assess your baby's condition and will decide on the type and timing of surgical management to return the intestines back into the tummy and close the defect.

If there is only a small amount of intestines outside the abdomen, these may be put back inside the tummy and the hole closed with dissolving sutures (stitches) shortly after birth. This is called a Primary Repair.

This is an operation performed under general anaesthesia: your baby will be put asleep by an Anaesthetist, who will place him/her on a ventilator (breathing machine) to allow the surgeon to operate.

Sometimes, if the amount of intestines outside the tummy is large and/or the abdominal cavity is small, the surgeons will place a see-through sac (Silo) over your baby's intestines. This can be done in theatre under general anaesthesia or at the cot side under simple sedation and analgesia.



The silo is then suspended from the ceiling of the incubator and gravity, along with a phased reduction in the size of the sack, will help the bowels to slip gradually back inside the tummy.

This may take a few days in total and only then will the final closure of the tummy hole occur. This is called Staged Repair.

Sometimes, at the time of the final repair, the surgeon may need to use a 'patch' of synthetic or biological material if the hole in the tummy is quite large.

Regardless of the type of treatment, your baby should not feel pain. The doctors and nurses will give pain relieving drugs for as long as it is needed. This will probably start as a morphine infusion and then be reduced to less strong painkillers over time.

When my baby will be able to feed?

Normally, after repair of simple Gastroschisis (where no damage occurred to the intestines), it will take a few weeks or longer for your baby to be able to tolerate milk feeds. This is because the intestines may not work properly due to prolonged exposure to the amniotic fluid.

Breast milk is very important for every baby but especially sick babies and even more so for those with bowel/ stomach problems. Breast milk is far more than just food, it contains essential nutrients your baby needs to grow, develop, and recover from surgery or illness.

Although your baby cannot take milk at this time, in order to establish and/or maintain your breast milk supply for when

they are well enough to feed, we encourage you to express your breast milk. It is important that you start expressing milk within 6 hours of birth and continue to do this at least 8-10 times a day, including at least once every night.

There is a quiet, private area on the ward that you can use to breast feed your baby or express breast milk. Expressing milk can be done by hand, which is useful in the first few days after birth when you can expect to express small amounts of sticky clear or yellow fluid called 'colostrum'.

Electric breast pumps are available for use on the ward. Your expressed breast milk will be stored safely until your baby is well enough to feed. The nursing staff will be able to show you how to express and store your milk and arrange for you to have access to a breast pump.

Until your baby is able to tolerate full milk feeds, they will receive parenteral nutrition (PN), a special intravenous nutrition fluid delivered via a long drip called a central line. This feeding line can be inserted by the doctors into a large vein of your baby at the time of the primary repair or shortly after silo placement. Please also see our leaflet 'Central Venous Line Insertion'.

Once the intestines are put back into the tummy and the defect is closed, the surgeons will monitor on a regular basis the amount of green fluid (bile) drained from the stomach by the NG tube. The amount of bile will get less as the bowel gets better. Once the surgeons are satisfied that the bile drainage has stopped and that your baby is opening their bowels, they will allow small amounts of milk to stimulate the bowel to work. This amount will be increased slowly as tolerated. This can sometimes take several weeks. Feeding by mouth will be encouraged but some babies will often require feeds through the nasogastric tube too.

Feeding may be more problematic in case of complicated Gastroschisis (where damage occurred to the intestines): please see the following section.

What are the risks and complications of Gastroschisis?

Overall, the outcome of babies with Gastroschisis is very good. Research shows that children with simple Gastroschisis (where no damage occurred to the intestines) start to feed normally within a few weeks from the repair and stay in hospital for about a month. Children with simple Gastroschisis are expected to live a normal lifestyle.

However, if the intestines become twisted whilst floating in the amniotic fluids, a portion may become damaged. This damaged portion is called intestinal atresia and can be diagnosed at the time of primary repair, when the silo is inserted or can be diagnosed several weeks after the repair of Gastroschisis. If the damaged portion is small, this can be repaired with a second operation few weeks after the Gastroschisis repair when the bowels are less swollen. In a very small number of cases, the portion of intestines damaged while in the womb can be very long.

Those babies will be dependent on intravenous feeding for several months and even years, which can affect the liver.

Very rarely, the damage to the intestines while in the womb is so bad that the bowel length at birth may not be sufficient to sustain normal life.

What are the risks and complications of Gastroschisis treatment?

Anaesthetic risks:

- These are very rare. Side effects cannot be removed completely, but modern expertise, equipment and medications have made general anaesthesia a much safer procedure in recent times. The Anaesthetist will discuss this with you in detail before the operation.

Surgical risks:

- Bleeding and damage to the intestines or liver are the risks associated with surgery for a primary repair.
- Wound infection, feeding and breathing problems are potential problems after primary and staged repair.
- Damage to the bowel (enterocolitis). During the staged repair or after the primary repair there is a small risk of the blood supply to the intestines getting cut off. The consequent bowel damage will require an operation to remove damaged segments of bowel and join the two ends of healthy bowel together (anastomosis). There is a chance that the anastomosis could start to leak, allowing faeces to escape into the abdomen. This is usually treated with antibiotics, but a second operation may be needed to repair the leaking portion. Sometimes it may be necessary to make a stoma. This is when the bowel opens onto the tummy. The stoma will empty the faeces into a pouch (bag) on the outside of the body. The stoma is usually a temporary measure until it is possible to join up the bowel as normal. Please also see our leaflet 'Formation of a stoma'.
- Adhesions are bands of scar tissue that form between bowel and organs, causing them to stick together.

Gastroschisis itself or operations for any bowel complications related to this disease are potential causes of adhesions. These may cause blockage and/or twisting of the bowel which causes green vomiting. Bowel blockage due to adhesions is a life-long risk and your child may require an operation to resolve the blockage.

- Short bowel syndrome. Removing damaged portions of intestine will not usually cause any long term problems unless a large amount of intestine needs to be removed. Short bowel syndrome is a condition where there is not enough intestine to absorb all the nutrients needed for good growth and development. Children with short bowel syndrome will need some intravenous feeding (PN) either on a short term basis while their intestine recovers or for a longer period of time.
- Infection, blockage of central lines and liver failure are problems related to prolonged use of PN.

How long are we expected to stay in hospital?

This varies depending on how premature your baby is and on the amount of time your baby needs to tolerate milk. In uncomplicated cases it usually takes 4-8 weeks but may take several months particularly if there were complications or your baby needed more surgery to their bowel.

Follow up

Once your baby has been discharged home, regular visits from your Health Visitor or Community Nurse will make sure that you and your baby receive the help and support required.

Your baby will also be given a follow-up outpatient appointment at the Birmingham Children's Hospital which will be sent to you in the post. You can report any urgent or general concerns related to the operation after you go home to your GP. Out of hours, you can report these to your baby's surgical team, who can be contacted via the hospital switchboard on 0121 333 9999. In an emergency please call 999 or bring your child to the Emergency Department at the Birmingham Children's Hospital.

Support group

GEEPS

GEEPS is a none-profit making network run by the families and friends of affected children to support families by sharing experience and advice.

<http://www.geeps.co.uk>

(Gastroschisis Exomphalos Extrophies Parents Support Network)

BLISS

BLISS is a support for families of premature babies through helpline, parent forum, and support groups and volunteers.

<http://www.bliss.org.uk>

Contact a family

Contact a family supports families with children with disabilities or health conditions.

www.cafamily.org.uk

Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets: Information is collected about your child relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some of your information with other people and organisations who are either responsible or directly involved in your child's care. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8611

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