

Gastroschisis

Information for
parents and carers



What is gastroschisis?

Gastroschisis means “stomach cleft”. Usually, during early pregnancy, the baby’s intestine develops inside the umbilical cord and then moves inside their abdomen (tummy) after a few weeks. In gastroschisis, the abdominal wall does not fully form. This means some of the baby’s intestine escapes through this hole and develops outside the abdomen.

In babies with gastroschisis the part of the intestine which is outside their abdomen is exposed to amniotic fluid in the womb and then air when the baby is born. This can cause damage to the intestine.

The exposed intestine may also become twisted as it floats in the amniotic fluid. This twisting can cut off the blood supply to the intestine, again causing damage.

The damage that may be caused can include a dead portion of the intestine (where blood supply has been completely cut off), a hole in the intestine and a blockage in the intestine.

Gastroschisis is a rare condition with only 4 to 5 babies out of every 10,000 being born with it. It is not known exactly what causes gastroschisis but it is more likely to happen if you have been ill or had an infection either before or during your pregnancy, or if you had or have a drug, cigarette or alcohol dependency.

How is gastroschisis diagnosed?

Gastroschisis is usually diagnosed during routine prenatal ultrasound scans. Part of the baby’s intestine will be able to be seen outside of their abdomen. If it is not identified before birth, gastroschisis will be seen immediately when your baby is born.

What happens when your baby is born

When your baby is born, they will be transferred to the neonatal unit and be examined by a doctor who will then arrange any tests which are needed. Your baby will have a tube passed through their nose or mouth into their stomach (called a naso-gastric or oro-gastric tube). This is used to drain off bile from their stomach and stop your baby feeling and being sick. Your baby will be given fluids directly into their veins via a drip. This will make sure they are getting enough fluid so that they are fully hydrated.

Your baby will be looked after in an incubator or heated cot. Their abdomen will be wrapped in a material like cling film to reduce the amount of fluid and heat lost from the exposed intestine. This see-through covering will also allow staff to closely see and check on the exposed intestine.

The gastroschisis will be attempted to be managed without an operation in the first instance, by the surgeon applying a large plastic pouch called a 'silo' over the bowel on the neonatal unit. The silo is then gently 'tucked' daily to allow the bowel to go back into the abdomen. This does not require a general anaesthetic.

What happens if an operation is required

If there is any damage to the intestine noted which needs repairing, an operation to repair the hole in their abdomen, as well as any damage to their intestine will be required.

This operation will be carried out shortly after they have been born – sometimes on the day they are born or slightly later, depending on how large the hole is in their abdomen and how much intestine is exposed. The surgeon will explain the operation that is required and discuss any worries you may have.

An anaesthetist will visit you to discuss the anaesthetic your baby will have for the operation. They will also talk with you about the pain relief which your baby will need after the operation.

We will ask you for your written consent for the operation to go ahead. If there is anything you are unsure about, or if you have any questions, please ask the doctor before signing the consent form.

Are there any risks?

Surgical risks:

Problems which may occur during surgery include bleeding and damage to the intestine or liver.

Potential problems after the operation include infection, feeding problems and breathing problems.

Your baby may develop adhesions (where parts of the intestine stick together and/or to other organs in the abdomen). These may or may not cause problems when your baby is older.

If some of your baby's intestine has had the blood supply cut off for too long it may need to be removed. This may cause problems with digestion of food and how well your baby absorbs nutrients. This is called short gut syndrome.

Your baby may also need to have a stoma. This is a small opening into their bowel through their tummy, which can be used to collect their faeces (poo). If your baby might need to have a stoma you will have this explained to you. Please also ask for our leaflet 'Formation of a stoma'.

Anaesthetic risks:

In modern anaesthesia, serious problems are uncommon. Risk cannot be removed completely, but modern equipment, training and drugs have made general anaesthesia a much safer procedure in recent years.

Most babies recover quickly after their operation and anaesthetic. Some babies may suffer side effects like sickness. These usually last only a short time and there are medicines available to treat them if necessary.

The exact likelihood of complications depends on your baby's medical condition and on the nature of the surgery and anaesthesia they need. The anaesthetist can talk to you about this in detail prior to the operation.

What does the operation involve?

The operation is done under a general anaesthetic. This means your baby will be asleep throughout the operation. You can go with your baby to the anaesthetic room and stay with them until they are asleep. The nurse will then take you back to the ward.

The surgical team may repair the gastroschisis (the hole in your baby's abdomen) in one of two ways, depending on its size:

- 1)** Your baby may have a single operation to place their intestine into their abdomen, close up the muscles and skin and make a belly-button.
- 2)** If the gastroschisis is too large to be repaired in this way, a see-through sack will be placed over your baby's intestine, allowing it to be contained and protected. This sack will be tightened regularly, which will help to push the intestine back into their abdomen. This will continue until all their intestine is inside their abdomen. Your baby will then have an operation to close up the skin and the muscles and make a belly-button.

In addition to the above operations, your baby may need to have a portion of their intestine removed if it has been damaged. If this has happened, a temporary stoma may be formed. This is where the two cut ends of the intestine are brought out through a hole in their abdomen. A stoma bag is then used to collect their faeces. If your baby has a stoma made, they will need another operation in the future to close the stoma and reattach the two ends of the intestine together. This means your baby will then have a continuous intestine from their stomach to their anus (bottom).

What happens after the operation?

Your baby will come back to the neonatal unit to recover. You will be able to visit your baby as soon as they are settled into an incubator on the ward. In some instances, particularly if your baby is premature, they may need help with breathing and will need to use a ventilator. Your baby will be given pain relief so that they can rest and sleep. To begin with this will be given to them by a drip into a vein.

Your baby will be connected to monitors to measure their heart rate, temperature and blood pressure. Although the many wires and tubes can be scary, your nurse will help you get your baby out for a cuddle.

As your baby improves, the ventilation and monitoring will be reduced and they will be moved into a cot and then transferred to the Tom's ward (the children's surgical ward).

As it may be some time before your baby can digest milk (often many weeks), they will receive nutrition through a tube into a vein. This is called Parenteral Nutrition (PN). Your baby will continue to be fed in this way until their intestine recovers from the operation. You will then be able to feed them normally by either breastfeeding or bottle feeding.

Initially small volumes of milk will be given through the naso-gastric tube. This can be increased as your baby's intestine starts to work normally. As the volume of milk increases, the PN will be decreased until it can be stopped. Until your baby is able to start feeding by mouth, either from the breast or bottle, you may wish to express your milk so that it can be stored ready for use. If you need any help with this please ask one of the nurses.

What happens next?

When feeding is fully established and your baby is gaining weight, you will be able to go home. Establishing full feeds can take a considerable amount of time. Your baby will probably need to be in hospital for a minimum of one month but it is often much longer than this.

When your baby has been discharged home, regular visits from your health visitor will give you help and support depending on your babies individual needs.

Your nurse will also give you information and advice when your baby is ready to be discharged.

Further information

If you have any questions, or there is anything you don't understand, please ask one of the doctors or nurses.

How to contact us

If you have any questions or concerns about your baby after you have left hospital please call:

Tom's ward

Telephone: **01865 234 109** or **01865 234 111**

(24 hours)

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Authors: Tom's Ward and Paediatric Surgical Team
October 2024
Review: October 2027
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