



# Gastroschisis

**This information sheet from Great Ormond Street Hospital (GOSH) explains the causes, symptoms and treatment of gastroschisis and where to get help.**

Gastroschisis is a type of abdominal wall defect. It occurs when a child's abdomen does not develop fully while in the womb.

Early in all pregnancies, the intestine develops inside the umbilical cord and then usually moves inside the abdomen a few weeks later.

In gastroschisis, the abdominal wall does not form completely so the intestines develop outside and are open to the air when the child is born.

## What causes gastroschisis?

We do not know exactly what causes gastroschisis although we do know that they are becoming more common, particularly in younger mothers under the age of 20 years. However, overall the incidence is quite low with 1 in 3000 babies being born with gastroschisis each year. Gastroschisis can be associated with other problems but the doctors will examine your child closely to check if this is the case.

## What are the signs and symptoms of gastroschisis?

Gastroschisis is immediately recognisable because the child's intestines are outside of the abdomen. Some areas of the intestines may look darker as they have been in contact with the amniotic fluid inside the womb, which can damage them. The umbilical cord is visible but pushed to the side by the exposed intestines.

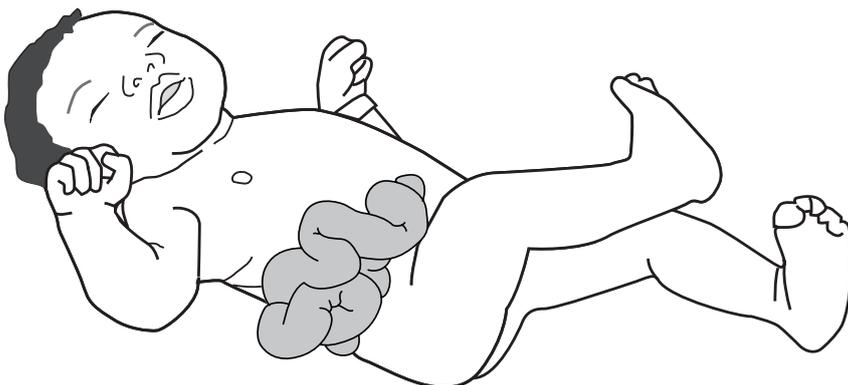
## How is gastroschisis diagnosed?

In many cases, it can be visible on prenatal ultrasound scanning, which is useful because it gives time for discussion and planning for when and where to give birth. Many children with gastroschisis are born prematurely, often at around 35 weeks. Most are induced at around 37 weeks as there are increased risks after this time. Generally children are born naturally (vaginal childbirth) but some may need a caesarean section for other reasons.

## How is gastroschisis treated?

Gastroschisis is a serious condition so needs prompt treatment soon after birth. Children born with gastroschisis will usually be transferred to Great Ormond Street Hospital (GOSH) within a few hours of birth.

Immediately after birth, doctors at your local hospital will wrap the exposed intestines in a type of 'cling film' which reduces the amount of fluids and body heat lost, protects the intestines from further damage and also





allows staff to monitor them closely. Your child will then be transferred to GOSH, either to our intensive care unit or another of our specialist wards.

Once your child is stable, they will have an operation under general anaesthetic to put the intestines back inside your child's abdomen and close up the abdominal wall. Sometimes this needs to be done in stages, replacing the intestines a bit at a time until they can all be contained within the abdomen.

Occasionally, children have treatment for gastroschisis in the intensive care unit. This involves placing a ready-made mesh sac over the intestines so that are contained and moved back into the abdomen. The sac is put in place on the intensive care unit without anaesthetic but with pain relief. This sac is then suspended above your child so that gravity gradually moves the intestines back inside the abdomen. It is tightened regularly until all the intestine is inside the abdomen, which usually takes a few days.

## **What happens before the operation?**

The doctors will explain the operation in more detail, discuss any worries you may have and ask you to give permission for the surgery by signing a consent form. Another doctor will also visit you to explain about the anaesthetic.

## **What does the operation involve?**

Once your child is under general anaesthetic, the surgeon will examine the exposed areas of intestine closely to see if any parts have been damaged. If there are any damaged areas, the surgeon will remove them and join up the healthy ends of intestine to form a complete tube as normal or plan a second operation to do this at a later stage when the abdomen is closed and your baby is stable. The surgeons will try to leave as much healthy intestine as possible while removing any damaged areas that could cause problems in the future.

Depending on the amount of intestine outside the abdomen and the space available inside, the surgeon will repair the gastroschisis in one operation or in stages over a period of a few days.

In the one-stage repair, the surgeon will replace your child's entire intestine into the abdominal space and close up the hole in the abdominal wall.

In a staged repair, there is too much intestine outside of the abdomen to put back without causing further damage or the space inside the abdomen is too tight. While your child is under general anaesthetic, the surgeon will make a mesh sac and put it over the intestine which keeps it contained and protected. This sac is then suspended above your child so that gravity gradually moves the intestines back inside the abdomen. It is tightened regularly until all the intestine is inside the abdomen, which usually takes a few days. Your child will then have an operation under general anaesthetic to close up the skin and muscles. Sometimes, they may need to use a 'patch' of material if the hole is quite large. They will cover the area with a dressing to protect the wound while it heals. Sometimes a second operation is needed to treat any other intestinal problems.

## **Are there any risks with the operation?**

All surgery carries a small risk of bleeding during or after the operation. During the operation, the surgeon will minimise any bleeding by sealing off the blood vessels affected. There is a very small chance that nearby structures in the abdomen could be damaged during surgery but this is a very rare occurrence.

Every anaesthetic carries a risk of complications, but this is very small. Your child's anaesthetist is a very experienced doctor who is trained to deal with any complications.

It can take a while after the operation for the intestine to start working properly so your



child may need to be fed intravenously using total parenteral nutrition (TPN) for a while. This affects many children and is explained further in the next section.

Sometimes the intestines can be damaged by being outside the abdomen so the surgeon has to remove a portion. This is also a risk associated with staged repair, although your child's intestines will be monitored closely while they mesh sac is being used to reduce this risk. Removing damaged portions of intestine will not usually cause any long term problems unless a large amount of intestine needs to be removed, leading to 'short bowel syndrome'.

Short bowel syndrome is the name given to the condition where there is not enough intestine to absorb all the nutrients needed for good growth and development. Children with short bowel syndrome may need their feeds topped up or replaced with TPN either on a short term basis while their intestine recovers or for a longer period of time.

There is a chance that the area where the two ends of bowel were joined could start to leak, allowing intestinal contents to escape into the abdomen. This is usually treated with antibiotics, but a second operation may be needed to check the leaking portion.

### **Are there any alternatives to the operation?**

No – abdominal wall defects need to be repaired to prevent fluid and body heat loss from the exposed intestines and reduce the risk of damage. Ultimately, the condition needs to be treated to allow your child to grow and develop.

### **What happens afterwards?**

Your baby will come back to recover either on the intensive care unit or our surgical ward. You will be able to visit as soon as they are settled. All babies are closely monitored after the operation, and so your baby will be connected to monitors to check their breathing, heart rate and oxygen levels. If your child needs help with breathing, they will be nursed on the intensive care unit and connected to a ventilator. They will also be given pain relief through the intravenous infusion (drip).

While your child's intestines recover and start to work, they will be fed through a tube into their veins (total parenteral nutrition or TPN). This will gradually be replaced by breast or bottled milk, given through the naso-gastric tube when your child is able to tolerate this. As your baby recovers, you will be able to feed them from the breast or bottle. Over time, the drips and monitors will be removed one by one.

The nurses on the ward will encourage you to look after your baby as much as you feel able while they are recovering. This can be daunting, especially while your baby is connected to drips and monitors, but it will become easier with time. If you are worried about caring for your baby, please talk to the nurses. You will be able to go home or be transferred back to your local hospital once your baby is feeding properly and gaining weight.

Your local health visitor or community paediatric nurse will visit you regularly. We will send you details of your outpatient appointment in the post, soon after you leave hospital.

### **When you get home**

If your child is unwell, please take your child to your local hospital. The doctors there will discuss any concerns with the team at GOSH.



## **What happens next?**

The outlook for children with gastroschisis is good, with the majority growing up to live normal lives, working and raising a family.

Research shows that children with simple gastroschisis, where no damage occurred to the intestines stay in hospital for about a month and start to feed normally within a few weeks of treatment.

Some children need to continue with TPN for a longer period so that they can gain weight to reach the right size and weight for their age. They may seem smaller than other children of the same age for the first few years but the majority catch up in time.

There is a very small chance that despite treatment the intestines may not work properly to absorb nutrients. This is called intestinal failure and requires long term TPN which can occasionally cause liver problems.

Children who have had a gastroschisis repair may develop hernias in the years after the operation. This is because the abdomen has fewer muscles than usual. If you notice a bulge in your child's abdomen, please talk to your doctor.

## **Is there a support group?**

The GEEPS (Gastroschisis, Exomphalos and Exstrophy Parents Support) group can offer help and support. You can visit their website at [www.geeps.co.uk](http://www.geeps.co.uk)

**If you have any questions, please telephone  
020 7405 9200 and ask for the ward from  
which your child was discharged.**

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Compiled by the Department of Specialist Neonatal and Paediatric Surgery  
in collaboration with the Child and Family Information Group

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