

Patient information factsheet

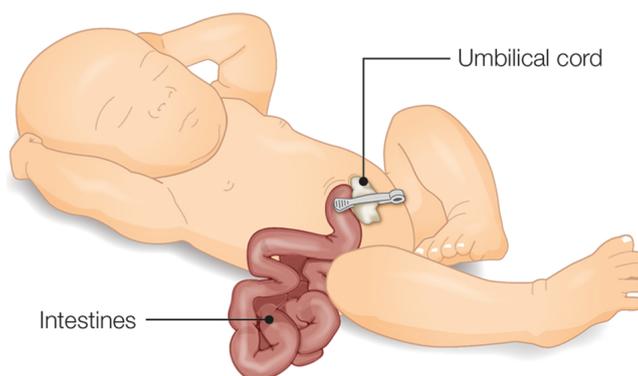
Gastroschisis

A scan has shown that your baby has a condition called gastroschisis. This factsheet has been designed to accompany the individualised discussions you will have about your care and the care of your baby both during pregnancy and after your baby's birth.

We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please speak to a member of the fetal medicine or neonatal surgical team.

What is gastroschisis?

Gastroschisis occurs during early pregnancy when a baby's abdominal (tummy) wall does not fully close. This leaves a hole in their abdominal wall (usually to the right side of their tummy button), which allows their bowel (intestines) and other organs to grow outside of their abdomen instead of inside.



What causes gastroschisis?

The cause of gastroschisis is unknown. It occurs in approximately one in every 2,000 births.

What does this mean for your baby during pregnancy?

Babies with gastroschisis do not usually have any other physical differences. However, you will be offered a detailed scan of your baby to check their development and growth. It is important to be aware that antenatal scans have limitations and are not always 100% accurate.

Babies with gastroschisis are more likely to be born prematurely (before 37 weeks of pregnancy) and be smaller than other babies. You will be offered regular scans throughout your pregnancy to measure your baby's growth and assess their wellbeing.

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Occasionally the development of your baby's intestines outside their abdomen can cause irritation, causing them to become swollen. Unfortunately, a scan cannot always predict this. A thorough assessment of your baby's bowel will be carried out after birth.

The likelihood of stillbirth is increased if your baby has gastroschisis. In addition to regular scanning, we recommend frequent traces of your baby's heart rate (CTG). These are usually arranged from 34 weeks of pregnancy, but may be earlier (if appropriate). However, it is important that you become familiar with your baby's usual daily pattern of movements and contact your local maternity day assessment unit immediately if you feel that the movements have changed.

The birth of your baby

Place of birth

We recommend that you give birth to your baby on the main labour ward at Princess Anne Hospital in Southampton. Your baby will require extra care and support from our neonatal (baby) surgical team immediately after birth.

We will arrange for you to meet with the neonatal surgical team during your pregnancy. This will provide you with the opportunity to discuss the care your baby will receive once they are born, answer any questions you may have and have a tour of the neonatal unit.

Giving birth to your baby

For most babies with gastroschisis, a vaginal birth at around 38 weeks of pregnancy is recommended. If concerns are identified with your baby's heart rate trace (CTG) or overall wellbeing, we may recommend having a caesarean section.

Your baby's care immediately after birth

When your baby is born, they will be looked after by the neonatal team who will assess their wellbeing and wrap the gastroschisis in a plastic film. This will protect your baby's bowel and also allow the neonatal team to monitor it.

Once the neonatal team are happy that your baby is in a stable condition, they will be transferred to the neonatal unit and nursed in an incubator or heated cot.

Your baby will have a cannula (small tube) placed into a vein, to allow us to give them intravenous fluids via a drip, as they will not be able to feed at first. This tube will also be used to give your baby any medicines that they need.

If you are planning to breastfeed your baby, you will be given support to express and store your milk until your baby is ready for milk feeds.

A small tube (nasogastric tube) will also be passed through your baby's nose or mouth, down into their stomach to drain away the fluid that collects there due to their bowel not working properly. This will help to stop your baby being sick.

The neonatal team will involve you as much as possible in your baby's care and will explain the reason for any treatment they are receiving. They will also be happy to answer any questions you may have.

Treatment

Soon after your baby is born, we will begin to put their bowel back inside their abdomen. It is usually possible to place your baby's bowel into a silo (plastic bag) where it will remain for a few days. During this time, the intestine will be gently squeezed back inside your baby's abdomen. Once it is all back inside the abdomen, the bag will be removed, and dressings will be placed over the hole in your baby's abdomen. The hole will then heal up over the next two weeks. Using this technique, most babies do not need an operation.

If it is not possible to put all of your baby's intestine into the silo, they will need an operation under general anaesthetic (medicines used to send your baby to sleep). Usually it is possible to put the intestine back into the abdomen and close the hole during this operation. Occasionally a temporary envelope made of plastic sheeting (called a surgical silo) will be made on the outside of your baby's abdomen to hold the bowel. In this case, a second operation will be needed in 10 to 14 days to remove this and close the hole.

Your baby will be given pain relief to keep them comfortable during and after all operations.

Babies who have had a surgical silo will not have an umbilicus (tummy button).

Feeding your baby

Until your baby's bowel is working normally, your baby will be fed intravenously (straight into their veins) through a central line with a special drip called total parental nutrition (TPN). The central line will be placed in a small vein in your baby's arm or leg and fed through into a larger vein. TPN will provide your baby with all the nutrients they need while they are unable to eat, and their bowel is recovering. You will be given a separate factsheet about TPN.

We will slowly introduce milk feeds through your baby's nasogastric tube, increasing the amount and frequency as your baby is able to tolerate them. As the milk feeds increase, the TPN will decrease until your baby is fully milk-fed. On average this takes four to six weeks. Once your baby's bowel has recovered, your baby should be able to feed normally by breast or by bottle.

Other risks to your baby

A small number of babies may have a blockage in their bowel. This is known as bowel atresia. For some babies, this is identified shortly after birth. However, for other babies, this may not become apparent until later on when they are unable to tolerate milk. If bowel atresia is suspected, X-rays will be arranged for your baby. These will determine whether or not an operation is required to repair the atresia.

In a very small number of babies, gastroschisis is complicated by further problems with the bowel that are not normally detected until after your baby is born. The blood supply to the bowel is sometimes interrupted, which can result in parts of the bowel being irreversibly damaged or missing. This is known as 'short bowel syndrome' and could mean a longer hospital stay. Your baby may also require TPN for longer. Sadly, some babies with short bowel syndrome do not survive.

Long-term care and follow up

Your baby should be able to feed and wean normally, but this may take a bit longer. Babies with gastroschisis may also be slower in gaining weight, and may have problems with vomiting, reflux, diarrhoea or constipation. These are normally short-term problems.

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After your baby leaves the neonatal unit, you will be offered regular appointments to monitor their progress. We will try to arrange these appointments to suit your family's needs. In some situations, Southampton may not be your local hospital. If this is the case, we may transfer your baby's care to your local hospital. This will not happen until the neonatal team are happy with your baby's progress.

Some babies may have an umbilical (tummy button) hernia. In rare cases, an operation may be needed to correct this. The neonatal surgical team will discuss this with you and answer any questions you may have.

Most babies born with gastroschisis (without additional conditions) make a full recovery after receiving treatment.

Contact us

If you have any questions or concerns, please contact us.

Specialist midwives in fetal medicine
Telephone: **023 8120 6025**

Surgical specialist nurses
Telephone: **023 8120 8564**

Your GP, midwife and obstetrician may also be able to give you more information.

For urgent enquiries outside of this time, please call the labour ward on **023 8120 6002**.

Useful links

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

A support group for parents of babies with exomphalos and gastroschisis.

Website: **www.geeps.org**

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www.gov.uk/government/publications/gastroschisis-description-in-brief/abdominal-wall-defects-gastroschisis-guide-for-parents

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For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit **www.uhs.nhs.uk/additionalsupport**