

Abdominal wall defects

This information sheet has been given to you to help answer some of the questions you may have about abdominal wall defects. If you have any further questions or concerns, please speak to a doctor or nurse caring for your child.

What is an abdominal wall defect?

An abdominal wall defect is a term used for two conditions: gastroschisis and exomphalos. These occur when a baby's abdomen does not develop fully in the womb, and are generally identified at your 20 week anomaly scan.

Gastroschisis is a defect of the actual abdominal wall, which causes the bowel to protrude. In gastroschisis, the bowel is not protected by any membrane or sac.

Exomphalos, however, is a defect which occurs at the base of the umbilical cord. In exomphalos, the bowel is protected by the membrane surrounding the umbilical cord.

Why do they occur?

Unfortunately, we do not know what causes either defect to occur. There is no evidence to suggest that it is anything you have or have not done during the pregnancy. It has, however, been noticed that the incidence of gastroschisis is rising, occurring in around one in 3,000 births. Exomphalos occurs in around one in every 5,000 births.

Exomphalos is often associated with abnormalities affecting other body systems, whereas gastroschisis is generally an isolated problem. Your baby will be thoroughly examined and monitored for any other problems by the medical team when he or she is born.

What about the delivery?

We will plan for you to deliver your baby at St Thomas' Hospital. However, if you were to deliver locally, we would liaise with your local hospital regarding the plan for your baby and the neonatal transport service will be called to transport your baby to us.

Because there is a risk of reduced growth and fetal wellbeing, particularly in the third trimester (months six to nine), close monitoring will be arranged. Induction of labour is usually planned for around 38 weeks gestation. It should be possible for you to deliver naturally, unless the defect is very large or there are other reasons for needing a caesarean section.

Initial management

In the delivery room

When you are ready to deliver your baby, the midwives will call for the neonatal team so that we are with you when your baby is born. A surgeon may also be present in the delivery suite. When your baby is born, they will be given to the neonatal team. We will fully assess your baby and then wrap the exposed bowel in film to help protect it, and to reduce heat and fluid loss. Once we are happy that your baby is stable, it may be possible for you to have a quick cuddle before they are moved to the neonatal unit.

On the neonatal unit

Once your baby is on the neonatal unit, they will be weighed and placed into an incubator which will help keep them warm and minimise fluid loss from the exposed bowel. Your baby will have a cannula (small tube) placed into a vein so that we will be able to give them intravenous fluids, as they will not be able to feed at first. This tube will also be used to give your baby any medicines that they may need. He or she will also have a small tube passed through their nose into the stomach. This is called a naso-gastric tube (NGT), and will drain away the green fluid (bile) that collects in the stomach because the gut is not working properly. This will reduce discomfort and lessen the risk of your baby vomiting (being sick).

Your baby will also be examined by the neonatal doctors in order to identify any other problems they may have. With both gastroschisis and exomphalus, complications such as infections and obstruction of the bowel can occur. Throughout your child's stay with us you will be kept fully informed of your baby's progress as things arise.

The next steps

With both gastroschisis and exomphalos, surgery may be required to repair the defect. Soon after your baby is born a surgeon will come to assess what needs to be done for your baby. The surgeon will discuss this with you, giving you an opportunity to ask questions, before seeking your consent for the operation.

If the defect is found to be small enough it may be possible for the surgeons to put the bowel back into the abdomen and close the muscle and skin soon after birth. However, it is more likely that a staged approach will be taken to repair the defect.

Gastroschisis

With gastroschisis, something called a 'silo' may be used. A silo is a specially designed bag which covers and protects the bowel. The silo is usually put in place by the surgeon on the neonatal unit soon after the birth of your baby. The bowel will then be gradually 'tucked' back into the abdomen by the surgeons until the defect is completely back in place. This process can take several days. Once this is done, the bag can be removed and the hole which the bowel came through can be closed. This can be done on the ward by applying a dressing over the hole, or the surgeons may take your baby to the operating theatre for this final stage.

What about feeding?

We will need to insert what we call a long line or a central line. This is a special type of drip which is inserted into a small vein in the baby's arm or leg and fed through into a larger vein. This line is needed so that we can give your baby a special drip called total parental nutrition (TPN). TPN will be important for your baby as it provides key nutrients that they will not be getting while they are nil by mouth (not allowed to eat). Because of the condition, feeding is unlikely to be started until the gastroschisis is closed.

Once milk feeds are started, it usually takes a few weeks for your baby to be able to tolerate the milk feeds. This is because the gut may not work properly to start with, as it has been exposed to the amniotic fluid during the pregnancy. Your baby will start with small amounts of milk through the NGT every hour, gradually increasing in amount and frequency, over days and weeks. As the milk feeds increase, the TPN will decrease until the baby is fully milk fed. This period of time can be difficult for you as you may experience several episodes when your baby's milk is increased and then decreased, as the baby's gut slowly begins to work properly.

Exomphalos

The treatment for exomphalos differs from that for gastroschisis because the bowel is already covered and protected. With exomphalos, we are likely to apply a special cream and wait for the skin to grow in order to cover the defect. The time that this will take will depend on the size of the defect. Once there has been enough growth, the surgeons will repair the defect completely.

What about feeding?

As with gastroschisis, a long line will need to be inserted in order to give TPN to your baby. However, with exomphalos it is possible for milk feeds to be started before the defect is completely closed. This will depend on how your baby's bowel is working. Because of the length of time it may take for the skin to grow around the exomphalus, your baby may be discharged home prior to the defect being fully repaired.

Long-term and follow-up

In some situations, St Thomas' 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 surgeons and the neonatal team are happy with your baby's progress.

Following discharge home, your baby will have regular check-ups in the outpatient department in order to monitor their progress. This may be at your local hospital. Your baby should be able to feed and wean normally but this may be slower than with other children. Some babies can also be slower in gaining weight and may have problems with constipation, but these are normally short-term problems.

Useful sources of information

Antenatal Results and Choices (ARC) – [w: www.arc-uk.org](http://www.arc-uk.org) [t: 0845 0772290](tel:08450772290) or [020 77137486](tel:02077137486)

Contact a Family (CAF) – [w: www.contact.org.uk](http://www.contact.org.uk)

NHS Fetal Anomaly Screening Programme – [w: www.fetalanomaly.screening.nhs.uk](http://www.fetalanomaly.screening.nhs.uk)

Contact us

If you have any questions or concerns about anything in this leaflet, or abdominal wall defects in general, please contact the Neonatal Unit, [t: 020 71884045](tel:02071884045).

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

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

[t: 020 7188 3003](tel:02071883003) 10am to 5pm, Monday to Friday [e: letstalkmedicines@gstt.nhs.uk](mailto:letstalkmedicines@gstt.nhs.uk)

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

[t: 020 7188 8801](tel:02071888801) (PALS) [e: pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

[t: 020 7188 3514](tel:02071883514) (complaints) [e: complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch. [t: 020 7188 8815](tel:02071888815) [e: languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

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