

Abdominal wall defects: gastroschisis

Information for parents



Information to help you understand more about gastroschisis.

1. What is gastroschisis?

Gastroschisis is what doctors call an abdominal wall defect.

An abdominal wall defect is where a baby's abdomen (tummy) does not develop fully while in the womb (uterus).

With gastroschisis, a baby has a hole in the abdominal wall, usually to the side of the umbilical cord. Some of the intestine comes through this hole and continues to develop outside the baby's abdomen.

The intestine outside the abdomen floats in the amniotic fluid and may become thickened. This often means that the baby cannot feed properly after birth.

2. How common is it?

The condition occurs in about 5 of every 10,000 births.

3. How is it diagnosed and confirmed?

Gastroschisis is usually noticed at the Fetal Anomaly ultrasound scan carried out between 18 weeks and 21 weeks of pregnancy.

Sometimes it is noticed during a scan earlier in pregnancy, but usually after 12 weeks. This is because a baby's abdominal wall does not normally close before this time.

You will need a second scan to confirm the diagnosis.

4. Is there any treatment?

All babies with gastroschisis need an operation after they are born.

Your specialist doctor will talk to you about the type of treatment your baby will need, although this may not be clear until after your baby is born.

5. What is the outlook for the baby?

About 90% (9 in 10) of babies born with gastroschisis make a full recovery. However, there is an increased chance that your baby will be born premature and be smaller than other babies.

Most babies born with gastroschisis cannot digest milk for the first two to four weeks and so are fed artificially

for this time. Most babies can go home when they are feeding normally. A small percentage of babies have difficulty feeding or absorbing food for longer than four weeks. This is not usually a severe problem, and it usually solves itself with time.

6. What happens next?

You will be given the chance to talk to specialists about what having a baby with gastroschisis might mean to you and your family.

Your doctor may talk to you about the option of having a termination to end your pregnancy. You will have the opportunity to discuss the possible implications of continuing or ending your pregnancy.

If you choose to continue your pregnancy, your healthcare team will help you plan how your care, including delivery, is managed. You will be offered regular ultrasound scans to monitor your baby. More detailed monitoring of the baby's well-being may be performed towards the end of the pregnancy. Arrangements will be made for you meet some of the paediatric team, including one of the paediatric surgeons, who will care for your baby after the birth. There are a range of options for the delivery of your baby. Your health professional will discuss these options with you.

If you choose to have a termination, your health professional will talk to you about the procedure and support you through the process.

Whatever you decide, your decision will be respected and you will be supported by your midwife and doctor.

7. How likely is it to happen in a future pregnancy?

You are much more likely to have a normal, healthy baby in your next pregnancy than to have another baby with gastroschisis.

There is no way to prevent this condition. It is not due to anything you have or have not done.

8. Where can I get more information and support?

You may feel you only want to talk to your family and friends, or a particular doctor or midwife from the hospital. However, there are other people and organisations that can provide information, help you make your decisions and support you in your pregnancy and afterwards. You may also want to talk things through with the hospital chaplain or your own minister or faith leader.

9. Further information, charities and support organisations

The following organisations can offer you support. There are details of other support organisations on our website at www.fetalanomaly.screening.nhs.uk. If you have any questions about the information in this leaflet or where the information came from, email us at enquiries@ansnc.co.uk.

Antenatal Results and Choices (ARC)

Email: info@arc-uk.org

Helpline: 0845 077 2290

Website: www.arc-uk.org

Antenatal Results and Choices (ARC) provides information and support to parents before, during and after antenatal screening and diagnostic tests, especially those parents making difficult decisions about testing, or about continuing or ending a pregnancy after a diagnosis. ARC offers ongoing support whatever decisions are made.

Gastroschisis.co.uk

Website: www.gastroschisis.co.uk

Gastroschisis.co.uk is dedicated to raising awareness about gastroschisis. It is also a resource for parents who have experienced this condition.

GEEPS

Email: geeps@btinternet.com

Website: www.geeps.co.uk

GEEPS is an international network of families and friends of children born with abdominal wall defects. GEEPS is run by the families and friends of affected children and is a non-profit-making network. The aim of GEEPS is to support families through the shock of diagnosis and beyond in the hope that some of the stress can be relieved by sharing thoughts and fears with other parents who have been in a similar situation.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. In other countries, check with a health professional to find out whether there are any differences in approaches to screening.

This leaflet has been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups.

All of our publications can be found online at www.fetalanomaly.screening.nhs.uk.

NHS staff can reproduce any information in this booklet. Please make sure you have permission to reuse images. You must discuss any amendments with the original author.

© NHS Fetal Anomaly Screening Programme 2012

If you have any comments or feedback, email them to us at enquiries@ansnsc.co.uk.