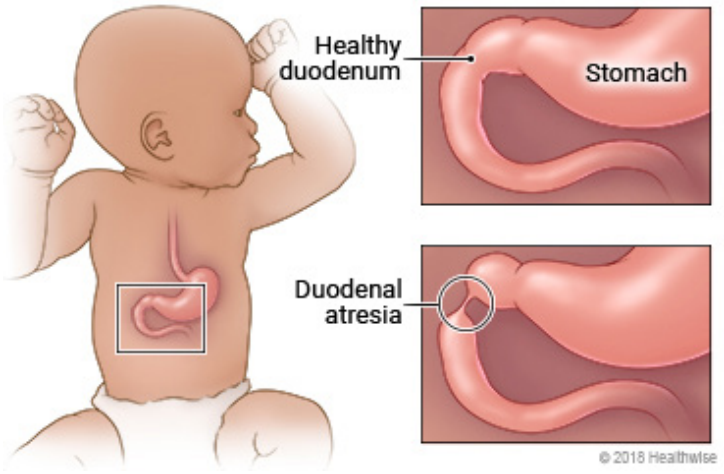
Duodenal atresia

A scan has shown that your baby may have a condition called duodenal atresia. 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 duodenal atresia?

Duodenal atresia means the duodenum (the first part of the small intestine just beyond the stomach) has a blockage or may be narrowed rather than wide open. This stops milk and fluid passing from the stomach into the intestines.



What causes duodenal atresia?

The blockage occurs early in pregnancy when a baby is developing, but the exact cause is not fully understood. Duodenal atresia is a rare condition which affects around one in 6,000 babies.

What does this mean for your baby during pregnancy?

Duodenal atresia can be an isolated condition (which means no other condition occurs with it), but it is also more common in babies with heart (cardiac) conditions or babies with Down's syndrome (Trisomy 21). Approximately a third of babies (one in three) born with duodenal atresia will have Down's syndrome. Down's syndrome is a chromosomal condition.

You will be offered a detailed scan of your baby to examine their development and growth. Please be aware that antenatal scans have limitations and are not always 100% accurate.

You will also be offered a diagnostic test known as an amniocentesis to determine whether or not your baby has a chromosomal condition such as Down's syndrome. It is important that you take time to consider your options and ask any questions you may have before you decide whether or not having a diagnostic test is the right choice for you.

Minimising the likelihood of your baby being born prematurely (before 37 weeks)
The amount of amniotic fluid that surrounds your baby is regulated by your baby swallowing the fluid and passing urine. When your baby has a duodenal atresia, the amniotic fluid builds up in your baby's duodenum because it is unable to pass through the blockage when swallowed. This causes the duodenum to fill up and become larger than normal. The fluid also accumulates around your baby and may lead to a complication known as polyhydramnios.

Polyhydramnios can be associated with women going into labour early and babies being born prematurely (before 37 weeks). We will monitor your pregnancy by offering frequent scans.

If polyhydramnios does occur, we will discuss treatment options with you. These options include:
- medication to reduce the amount of fluid you produce
- amnio-reduction (a procedure, similar to an amniocentesis, which removes some of the excess fluid and alleviates your symptoms)

If either option is appropriate for you and your baby, we will discuss them with you and answer any questions you may have.

Reducing the likelihood of stillbirth
There may be a small increased chance of stillbirth if your baby has a duodenal atresia. In addition to regular scanning, we recommend frequent traces of your baby's heart rate (CTG). We will discuss with you the most appropriate time to start these. 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 including a tour of the neonatal unit.

Giving birth to your baby
For most babies with duodenal atresia, a vaginal birth at around 38 weeks of pregnancy is recommended unless there are other reasons why a caesarean section is needed. Your baby's wellbeing will be closely observed throughout your pregnancy.

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. Once transferred to the neonatal unit, your baby will be weighed and nursed in an incubator or heated cot. If your baby's lungs have been affected by premature birth, they may also need help with their breathing.

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.

An x-ray of your baby's abdomen (tummy) will also be arranged to confirm the duodenal atresia diagnosis.

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

Your baby will require an operation under general anaesthetic (medicines used to send your baby to sleep). The operation involves correcting the blockage (atresia) and repairing the duodenum. It will be carried out through a small incision (cut) in your baby's abdomen. The two ends of the duodenum will be joined together to make a clear passage for food and fluid to travel from your baby's stomach to their intestine. The surgeon will then place a feeding tube called a trans-anastomotic tube (TAT) down through your baby's nose, into their stomach and through the join in the duodenum. This tube will be used to feed your baby after the operation.

We will give your baby pain relief to keep them comfortable throughout and after the operation.

Feeding your baby

We will give your baby milk (either expressed breast milk or formula) through the TAT while their duodenum is recovering. A small number of babies do not tolerate milk given this way. If this is the case, 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. You will be given a separate factsheet about TPN.

Introducing milk feeds by mouth will depend on how well your baby's bowel is working. Most babies are able to start tolerating feeds orally (by mouth) approximately two weeks after their operation. For some babies it may take longer. You will be given help and support with feeding your baby. Once your baby's bowel has recovered, your baby should be able to feed normally by breast or by bottle.

Long-term care and follow up

The length of your baby's stay in hospital will depend on:

- their recovery from the operation
- whether they have any other medical conditions
- whether they were born early

Most babies will usually be cared for on the neonatal unit for about three weeks.

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.

If the duodenal atresia occurs on its own with no other associated problems, the outlook for your baby is very good, with the majority of babies growing up to live normal lives. However, there is always a small risk of future blockages occurring. The surgical team will discuss this with you. The outlook for babies with duodenal atresia and other conditions varies depending on how severe the other problems are.

Contact us

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

Fetal medicine team
Telephone: **023 8120 6025** (Monday to Friday, 9am to 5pm)

Surgical specialist nurses
Telephone: **023 8120 8564** (Monday to Friday, 9am to 5pm)

For urgent queries outside of these hours, please call the maternity triage line on: **0300 123 9001** (if your maternity care is provided by University Hospital Southampton NHS Foundation Trust) or call your local maternity day assessment unit.

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

Useful links

There isn't a support group specifically for duodenal atresia, but the following organisations may be able to help:

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

Bliss
Telephone: **0500 618 140**
Website: www.bliss.org.uk

Contact a Family
Telephone: **0808 808 3555**
Website: www.cafamily.org.uk

Down's Syndrome Association
Telephone: **0845 230 0372**
Website: www.downs-syndrome.org.uk

Wessex Healthier Together
Website: www.what0-18.nhs.uk/pregnant-women/concerns-during-pregnancy/over-20-weeks/reduced-baby-movements-after-24th-week-pregnancy

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

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