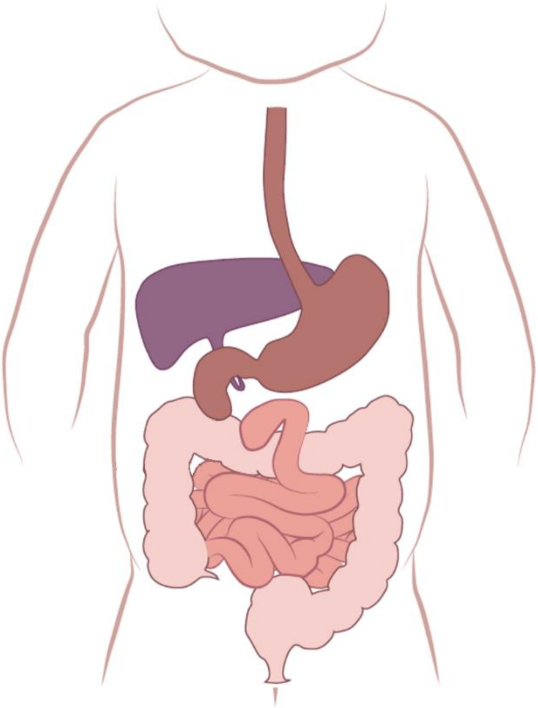
Duodenal atresia

Information for parents and carers



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Finding out that your baby has duodenal atresia can be difficult. This leaflet aims to tell you and your family a bit more about the condition.

Key messages

- Duodenal atresia is a condition where your baby's bowel is blocked at birth
- Your baby will need an operation
- Most babies survive to become healthy adults

What is duodenal atresia?

In duodenal atresia there is a blockage in the duodenum (the first part of the small intestine, just past the stomach). This stops food and fluid passing from the stomach into the intestines. This means your baby cannot feed and digest milk properly. Duodenal atresia happens early in pregnancy but the exact cause is not fully understood. It is not associated with anything you did or didn't do. Figure 1 shows where the blockage is.

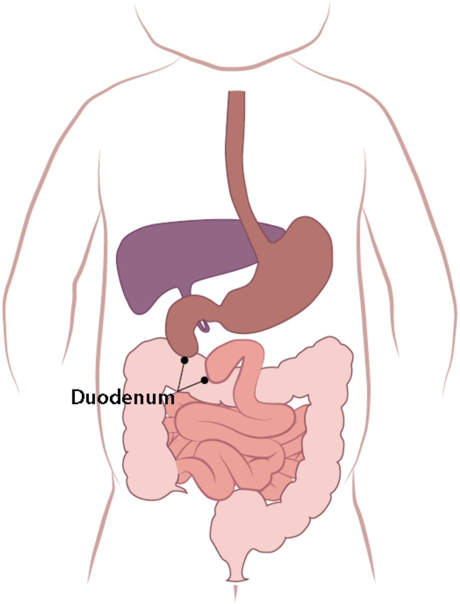

Figure 1

How common is duodenal atresia?

In Scotland, duodenal atresia occurs in about 1 in every 3500 births. Around 15 babies are born with duodenal atresia in Scotland each year.

Could my baby have any other problems?

A third of babies with duodenal atresia may have Down’s syndrome. Duodenal atresia can also be associated with other problems, including heart defects, so your baby will be thoroughly examined after they are born.

What will happen during my pregnancy?

Over half of babies with duodenal atresia will be diagnosed from a routine scan during pregnancy. If the condition is not picked up in an antenatal scan, it is usually noticed when a baby struggles to feed shortly after birth.

The amniotic fluid that surrounds your baby in the womb is usually swallowed then passed as urine. This doesn’t happen in duodenal atresia because of the blockage, and can result in too much fluid around your baby (polyhydramnios). This can cause some mothers to go into labour early. You and your baby will be monitored closely throughout your pregnancy.

What happens when my baby is due?

Babies with duodenal atresia are cared for at neonatal surgical centres at Royal Aberdeen Children’s Hospital; Royal Hospital for Children and Young People, Edinburgh; or Royal Hospital for Children, Glasgow.

Your delivery will be planned for the closest maternity unit linked to these centres. Duodenal atresia needs assessing and managing quickly after birth, and you have a choice of a caesarean or vaginal delivery.

What will happen now?

Your baby will need to be transferred to one of the specialist neonatal centres by a specialist neonatal transfer team. If you cannot be discharged from hospital, arrangements will be made for you to be transferred as soon as possible.

General care

Where possible, you will be able to have some cuddles with your new baby before they are transferred to the neonatal intensive care unit soon after birth. When babies with duodenal atresia are born they look well, but will start vomiting when they start to feed. The vomit might be green. Your baby will have an x-ray to confirm the diagnosis. A nasogastric tube will be passed through their nose into their stomach to stop them vomiting. They will also have a drip, to allow them to have fluids and medicines.

Surgical care

Your baby will need to have an operation under general anaesthetic to correct the blockage in their bowel.

The paediatric surgeon will see you before the operation and go through what it involves. The surgeon will open the blocked end of the duodenum and connect it to the rest of the bowel. This allows food and fluid to pass freely from your baby’s stomach to the rest of their bowel. You will be asked to sign a consent form to show that you understand and agree to the operation. Unfortunately, there are no alternatives to surgery for this condition. Figure 2 shows the operation to join the bowel together.

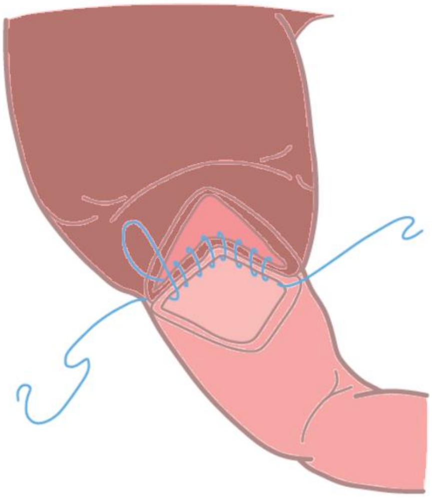

Figure 2

What happens next?

Your baby will be transferred back to the neonatal intensive care unit after their operation and will be closely monitored. They may need help with their breathing and be on a ventilator for a short while. It can take a bit of time for the bowel that has been joined together to start working. Your baby may have a tube inserted during the operation, to allow milk to be given below the new join. They will receive nutrition through a vein until they are properly digesting milk. As they recover they will be able to feed from the breast or bottle. You should be able to go home or be transferred back to your local hospital once your baby is feeding properly and gaining weight.

What can I do to help my baby?

There are lots of things that you can do to help your baby including cuddles, positive touch and reading to them. The staff will also support you to become partners in your baby's care so that when you feel comfortable you can help with things like nappy changes and nasogastric tube feeding. We call this approach family integrated care.

Breast milk is the best milk for all babies, especially babies born with duodenal atresia, and many mothers find this a positive way to help their baby. However we recognise that not everyone chooses this option and other milks (including donated breast milk and specialist formula) are available.

What is the likely outcome for my baby?

If duodenal atresia occurs on its own with no other problems, the outlook is very good. Depending on how severe any other conditions are, the outlook for babies with duodenal atresia will vary. Some children with duodenal atresia develop a problem with acid reflux later in life (where liquid from the stomach comes up into the oesophagus). The chance of having another baby with duodenal atresia is low.

How long will my baby be in hospital?

Most babies are in hospital for an average of three weeks, although some may need to stay for longer.

Where can I get further information and support?

The fetal medicine, paediatric surgical and neonatology teams will be able to answer any questions that you have during your appointments.

In 2018, the Surgery for Conditions Affecting Newborns in Scotland (SCANS) was formed. This is a national network of doctors, midwives, nurses and parents. It was set up to produce standards of care so that you and your baby get the best treatment. You can find more information at www.scans.scot.nhs.uk. We have listed other support groups below.

Other useful sources of information

There is no official support group for duodenal atresia, but the following organisations may be able to help.

www.bliss.org.uk   www.dsscotland.org.uk/

SCANS collects anonymised data (information that you and your baby cannot be identified from) about the different conditions we treat. We use this information to plan and deliver services to children with these conditions, understand how we can improve patient care and provide it in the best way possible for all of our patients. All information is handled securely and confidentially by NHS staff and we do not share it with outside organisations. If you have any questions or concerns about the information we collect or your data protection rights, please email nss.scans@nhs.scot.

You can find more information about how the NHS handles your personal information at NHS Inform.