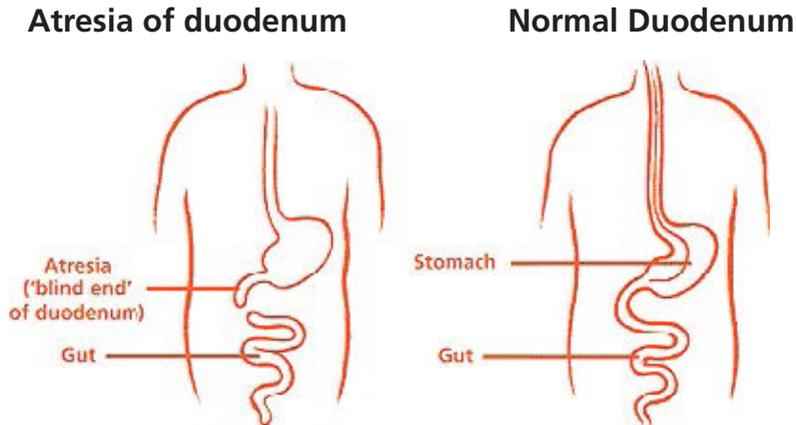


Information leaflet for Parents/Carers

Duodenal Atresia



Your baby has been diagnosed with duodenal atresia. This means that first part of the small intestine just after the stomach is closed off rather than being a tube. This stops food and fluid passing from the stomach into the intestines.



This leaflet will give you more information on the condition and what you can expect during pregnancy, delivery and after your baby is born.

Duodenal atresia is a rare condition and happens in about one in 10,000 births. It can be associated with other problems, so the doctors will examine your child closely to check if this is the case. 1 out of 5 children with duodenal atresia will also have Down's syndrome. A test to check the baby's chromosomes before (or if you wish after birth) is likely to be discussed with you.

During pregnancy

Duodenal atresia when discovered during pregnancy shows up on antenatal ultrasound scanning. Some babies with this condition are born prematurely.

Many babies appear well at birth but when they start to

feed, they are sick and their vomit is green. An Xray can confirm this diagnosis.

If the condition is identified during pregnancy then you will be referred to a surgical team so that they can meet with you and discuss the options for treatment after birth.

Delivery

Ideally you will be able to go ahead with a normal vaginal delivery between 38 and 42 weeks. A Caesarian section is only needed if there are specific problems that require this. This will be discussed with you if necessary.

Treatment and Care After Delivery

To begin with, your baby will be nursed in an incubator and will have a naso-gastric (NG) tube passed through his or her nose into the stomach. This will drain off the contents of the stomach and stop your child feeling and being sick. It also releases any excess air from the stomach, which could make your child uncomfortable. He or she will also have an intravenous infusion (drip) of fluids. Your baby should then be safe and stable and can be transferred to a surgical unit at a mutually convenient time.

Feeding

Breast milk is very important for every baby but especially sick babies and even more so for those with bowel/ stomach problems. Breast milk is far more than just food, it contains essential nutrients your baby needs to grow, develop, and recover from surgery or illness.

Although your baby cannot take milk at this time, in order

to establish and/or maintain your breast milk supply for when they are well enough to feed, we encourage you to express your breast milk. It is important that you start expressing milk within 6 hours of birth and continue to do this at least 8-10 times a day, including at least once every night.

There is a quiet, private area on the ward that you can use to breast feed your baby or express breast milk. Expressing milk can be done by hand, which is useful in the first few days after birth when you can expect to express small amounts of sticky clear or yellow fluid called 'colostrum'.

Electric breast pumps are available for use on the ward. Your expressed breast milk will be stored safely until your baby is well enough to feed. The nursing staff will be able to show you how to express and store your milk and arrange for you to have access to a breast pump.

Surgery

Duodenal atresia is repaired in an operation under general anaesthetic (so your baby is asleep), which lasts around 90 minutes. The surgeon will cut the blind end of the duodenum and connect it to the rest of the intestine. This provides a clear tube for food and fluid to travel from your child's stomach to his or her intestine. This is the only way to treat this condition. Duodenal atresia always requires an operation to allow your baby to feed.

The surgeon will explain about the operation in more detail, discuss any worries you may have and ask you to sign a form giving consent for your child to have the operation. An anaesthetist will also visit you to explain about the anaesthetic.

All the doctors who perform this operation have had lots of experience and will minimise the chance of problems occurring.

All operations carry a small risk of bleeding, during or afterwards. Every anaesthetic carries a risk of complications, but this is very small. Your child's anaesthetist is a very experienced doctor who is trained to deal with any complications.

After Surgery

Your baby will come back to the ward to recover, and you will be able to visit as soon as he or she is settled back in the incubator. All babies are closely monitored after the operation, and so your baby will be connected to monitors to check his or her breathing, heart rate and oxygen levels. He or she will also be given pain relief through the intravenous infusion (drip).

While your child's intestines recover and start to work, he or she may be fed through a tube into his or her veins (this is known as total parenteral nutrition or TPN). This will gradually be replaced by breast or formula milk, given through the naso-gastric tube when your child is able to tolerate this. As your baby recovers, you will be able to feed him or her from the breast or bottle. Over time, the drips and monitors will be removed one by one.

The nurses on the ward will encourage you to look after your baby as much as you feel able while he or she is recovering. You may feel anxious, especially while your baby is connected to drips and monitors, but it will become easier with time. If you are worried about caring for your baby, please talk to the nurses.

You will be able to go home or be transferred back to your local hospital once your baby is feeding properly and gaining weight. Your local health visitor or community paediatric nurse will visit you regularly. Your baby will need to be seen again by the surgeon after discharge to check that everything is okay, and we will send you a letter in the post to tell you when the clinic appointment will be.

What is the outlook for children with duodenal atresia?

The outlook is very good after surgical repair with children developing healthily. Your local hospital will continue to monitor your child as they grow and offer any support and advice needed.

Is there a support group?

BLISS is a group which is able to offer support to families with babies with a range of conditions

BLISS

68 South Lambeth Road
London SW8 1RL

Helpline: 0870 7700 337

Email: information@bliss.org.uk

Website: www.bliss.org.uk

Contact a Family

209-211 City Road
London EC1 1JN

Freephone Helpline: 0808 808
3555

Email: helpline@cafamily.org.uk

Website: www.cafamily.org.uk

Contact a Family

A UK wide charity offering support, advice and information regardless of a child's condition or disability. Through their Making Contact service they may also be able to put you in touch with other families who are affected by the same disability / medical condition as your child.

Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets:

Information is collected about patients relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some patient information with other people and organisations who are either responsible or directly involved in the patient's care. This may involve taking the patient's information off site. We may also have to share some information for other purposes; such as research etc. Any information that is shared in this way will not identify the patient unless we have the patient's and parent's/carer's consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403.

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