

Information leaflet for Parents/Carers

Oesophageal Atresia and Tracheo Oesophageal Fistula

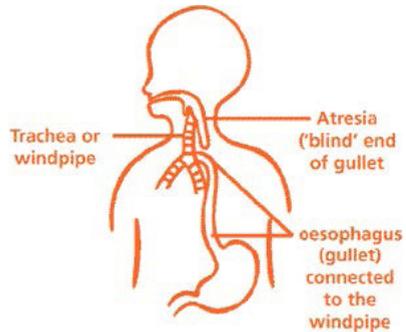


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Your baby has been diagnosed with oesophageal atresia. This means that food is unable to pass from your baby's throat to the stomach.

This leaflet will give you more information on the condition and what you can expect in the care and treatment that your baby will receive.



Oesophageal Atresia / Tracheo-Oesophageal Fistula

Oesophageal atresia (OA) is a rare condition where a short section at the top of the oesophagus (gullet) is closed off. This means food cannot pass from the throat to the stomach.

Tracheo-oesophageal fistula (TOF) is another rare condition, which tends to happen alongside oesophageal atresia. This is where the bottom end of the oesophagus is joined to the trachea (windpipe).

Occasionally OA and TOF might be discovered in an ultrasound scan during pregnancy, particularly if the baby's stomach is not very clear or if you have polyhydramnios (excess amniotic fluid)

Antenatally diagnosed Cases of OA/TOF may require you to have detailed discussion with a fetal medicine specialist before the birth of your baby so further investigations can be discussed.

We do not know what causes OA and TOF. It is not due to anything that happened during pregnancy. It is very rare, occurring in between one in 3500 and one in 5000 births. OA

and TOF can be associated with other problems, so doctors will examine your child closely to check if this is the case.

Treatment and Care After Delivery

After birth the midwife may try to pass a tube through your baby's nose into their stomach (nasogastric tube or NG tube), and find that it is not possible suggesting that there is a blockage. If so the baby will be transferred to the neonatal unit for an x-ray to confirm the diagnosis of OA/TOF.

Once OA/TOF is diagnosed it is very important that your baby stops feeding and fluids are given using a drip-small tube into a vein. Additionally, a small tube is passed through the baby's nose or mouth down into the pouch of the oesophagus to suck out any saliva as your baby swallows. This is called a Replogle tube and it remains in place and on continuous suction until the operation.

OA and TOF always require treatment, to enable your baby to feed. They are both repaired in an operation.

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

To repair the TOF, the surgeon will separate the oesophagus from the trachea and repair the part of the trachea where the oesophagus was originally joined. The method used to repair the OA depends on the distance between the ends of the oesophagus. In most cases, the surgeons will cut the blind end of the oesophagus and then join the two ends together to form a continuous passage from the throat to the stomach.

In rare cases called 'long gap OA' where the distance between the ends of the oesophagus is too large for the surgeon to be able to join them straightaway, different treatment is needed. If this is likely to be the case, the doctors will explain this to you.

If your baby has long gap OA they may be in hospital for several months and will require more than one operation.

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

All surgery carries a small risk of bleeding during or after the operation. 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 complication.

After Surgery

Your baby will come back to the ward to recover. 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. 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 'drip'.

While your baby recovers, he or she may be fed through a tube into the veins (total parenteral nutrition or TPN) or through a tube passed through the repaired oesophagus. This will gradually be replaced by breast or formula milk given by mouth when your baby is able to tolerate this. 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 transferred to another ward at the hospital or to your local hospital once your baby is feeding properly and gaining weight. Your baby will need to be seen again

after they leave hospital to check on their progress, and you will receive a letter to let you know when and where the outpatient appointment will be.

What is the outlook for children with OA and TOF?

If the OA and TOF occur on their own, with no other associated problems, the outlook for children who have them is good, with the majority growing up to live normal lives. The outlook for children with OA and TOF who have other difficulties varies depending on how severe these other problems are.

However, there are a couple of problems which may occur and which you should know about. They tend to happen most often in the first few years after the operation and improve as the child grows older.

Chest problems can occur, which are sometimes serious enough to need a stay in hospital. These tend to improve with age, and have little effect on the child's breathing when older. Some children however, continue to have a distinctive 'TOF cough' but this is not at all serious.

The area of the trachea which was repaired may become floppy (tracheomalacia) which can cause breathing problems. If you are worried about your child's breathing, please talk to your doctor.

Feeding problems may also occur due to the oesophagus narrowing where it was originally repaired. Sometimes it needs widening and this will be done in an operation under general anaesthetic.

Some children also complain of problems with swallowing and need to have a drink with all food. This can be

investigated by a speech and language therapist, who can suggest treatment and exercises. Some children who have had OA and TOF develop a problem with gastro-oesophageal reflux when they are older. This is where the contents of the stomach flow back up the oesophagus (gullet) causing pain and irritation. Your local hospital will continue to monitor your child as they grow up and will be able to support you if this problem develops.

Is there a support group?

TOFS

St George's Centre
91 Victoria Road
Netherfield
Nottingham NG4 2NN

Telephone: 0115 961 3092

Email: info@tofs.org.uk

Website: www.tofs.org.uk

BLISS

Another group which offers general support to families is 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

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.

209-211 City Road

London EC1 1JN

Freephone Helpline: 0808 808 3555

Email: helpline@cafamily.org.uk Website: www.cafamily.org

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.

Birmingham Women's and Children's NHS Foundation Trust
Steelhouse Lane Birmingham B4 6NH
Telephone 0121 333 9999
Fax: 0121 333 9998
Website: www.bwc.nhs.uk

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