Oxford University Hospitals NHS
NHS Trust

The Children's Hospital

Oesophageal atresia with tracheo-oesophageal fistula

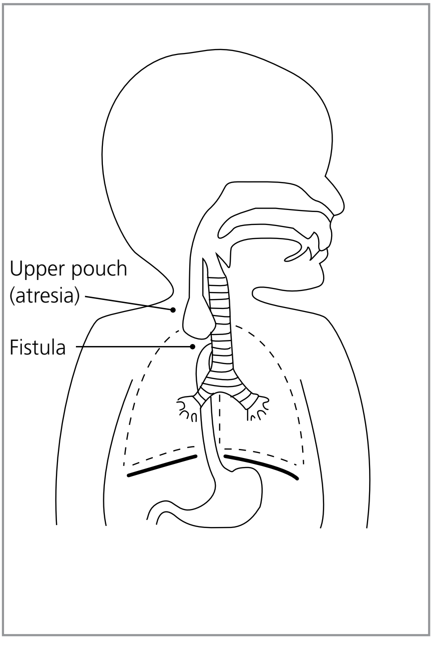
Information for parents and carers

What is oesophageal atresia and tracheo-oesophageal fistula?

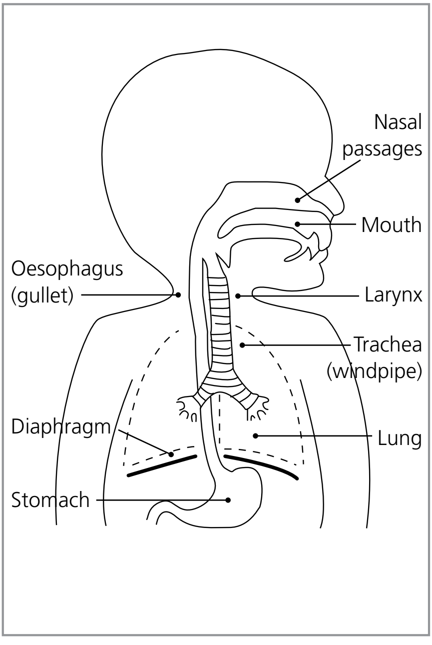
Oesophageal atresia (OA) is a rare birth defect where there is a gap in the food pipe or oesophagus (gullet). The oesophagus will have sealed itself off at either side of the gap. This means there is no continuous passage to the stomach and that your baby's feed cannot pass from their throat to their stomach.

In majority of these cases, this occurs along with tracheo-oesophageal fistula (TOF) where one end of the oesophagus has joined itself to the windpipe (trachea). This can cause your baby's feed to go into their lungs.

An operation will be needed to put the condition right, so that your baby can feed, grow and develop.



Child with TOF/OA



Child without TOF/OA

What causes OA and TOF?

We do not know what causes OA and TOF. It is not due to anything you may have done whilst you were pregnant. It is very rare and occurs in one in 3500 births. OA and TOF can be associated with other problems such as:

- heart abnormality
- kidney abnormality
- spine and other bone abnormalities.

Doctors will examine your baby closely to check if they may also have any of these problems.

How are OA and TOF diagnosed?

This condition is rarely diagnosed before birth. It may be suspected when there is more amniotic fluid detected in the womb (polyhydramnios) than normal, or if other birth defects have been seen on an ultrasound scan.

Often, OA and TOF are only found after birth when a baby has breathing problems. They may also have lots of saliva in their mouth as they cannot swallow it. The midwife or the team looking after newborn babies 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. Your baby will need to have an X-ray to confirm the diagnosis.

What happens to my baby after this condition is diagnosed?

Once the diagnosis is made, the doctors looking after your baby will speak to the surgeons and your baby will be transferred for further treatment.

Sometimes, babies can have breathing difficulties and will need a breathing tube and help with their breathing from a ventilator machine. Your baby will also have a special tube (repogle tube) passed through their nose or mouth into their oesophagus. This tube helps drain the saliva in the oesophagus.

Your baby will be given fluids into one of their veins (through a drip) until the operation can be performed.

What happens before the operation?

The doctor will explain the operation in more detail and talk with you about any concerns you may have.

An anaesthetist will visit you to discuss the anaesthetic your baby will have for the operation. They will also talk with you about the pain relief which your baby will need after the operation.

We will ask you for your written consent for the operation to go ahead. If there is anything you are unsure about, or if you have any questions, please ask the doctor before signing the consent form.

What does the operation involve?

The operation is carried out under a general anaesthetic. This means your baby will be asleep throughout the operation. You can go with your baby to the anaesthetic room and stay with them until they are asleep. The nurse will then take you back to the ward.

The operation is carried out through the chest. The method used to repair the oesophageal atresia depends on the distance between the two ends of the oesophagus. In most cases, the surgeons will firstly open the sealed end of the oesophagus at the top end that comes down from your baby’s mouth and then join it to the end that connects to the stomach. This then forms a continuous passage from the throat to the stomach.

To repair the tracheo-oesophageal fistula, the surgeon will separate the oesophagus from the trachea and then repair the part of the trachea where the oesophagus was originally joined. They would then join the two ends of the oesophagus as in the oesophageal atresia operation.

In rare cases called ‘long gap oesophageal atresia’ the gap between the ends of the oesophagus is too large for the surgeon to be able to join them straight away. A different treatment is needed for this problem. If this is likely to be the case for your baby, the doctors will explain this to you.

What are the risks of the operation?

Surgical risks:

Any surgery carries a small risk of infection or bleeding. Your surgeon will discuss these and other risks with you fully before you consent to the operation. All the doctors who perform this operation are specialist surgeons with lots of experience and will minimise the chance of problems occurring.

Anaesthetic risks:

In modern anaesthesia, serious problems are uncommon.
Risk cannot be removed completely, but modern equipment, training and drugs have made general anaesthesia a much safer procedure in recent years.

Most babies recover quickly after their operation and anaesthetic. Some babies may suffer side effects like sickness. These usually last only a short time and there are medicines available to treat them if necessary.

The exact likelihood of complications depends on your baby's medical condition and on the nature of the surgery and anaesthesia they need. The anaesthetist can talk to you about this in detail prior to the operation.

Are there any alternatives?

No. OA and TOF always require surgical treatment to enable your baby to feed.

What happens after the operation?

Your baby will come back to the ward to recover. You will be able to visit as soon as they are settled back into the incubator. Initially, after the operation, your baby will need help with breathing and will need to use a ventilator. Your baby will also be given pain relief (through a drip into a vein) so that they can rest and sleep.

Your baby will be connected to monitors to measure their heart rate, temperature and oxygen levels after the operation. As your baby improves, the ventilation and monitoring will be reduced and they will be moved into a cot.

Your baby will be assessed regularly for pain using a pain assessment chart. This will help the nurse to effectively manage your baby's pain after the operation.

Your baby may have a tube called a chest drain inserted during the operation to drain any air or fluid which might be trapped. This drain will be removed after a few days when the doctors are happy with your baby's progress.

How will I feed my baby?

It may be a while before your baby is able to take milk by mouth to allow the joins to heal. Initially, your baby will be fed through a tube into one of their veins (parenteral nutrition or PN). This will gradually be replaced by breast or bottled milk given through their nasogastric tube. As your baby recovers, you will be able to feed them from the breast or bottle.

Until your baby is able to start feeding by mouth either from the breast or bottle, you can express your milk so that it can be stored ready for use. If you would like help with this please speak to the nurses or midwife.

Will I be allowed to be with my baby?

The nurses on the ward will encourage you to be involved in your baby’s day to day care as much as you feel able to while they are recovering. This can be daunting, especially when 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 and they will be happy to help you.

When can we go home?

When your baby is feeding well and gaining weight you will be able to return to your local hospital or go home. Regular visits from your health visitor or local community paediatric nurse will give you help and support. Soon after your baby leaves hospital we will send you a letter with details of your baby’s outpatient appointment, when we will check how they are progressing.

Are there any long-term problems with this condition?

The majority of babies who had OA and/or TOF with no other complications will go on to develop well. If your baby has been born with other associated problems, their long-term development will depend on the severity of these conditions.

Breathing problems

Some babies may continue to have a barking cough (TOF cough), which might sound worrying but is not serious. They may develop chest infections and asthma which, if serious, might mean they need to be admitted hospital. But the risk of this will lessen as your child grows older.

The area of the trachea which was repaired after an OA or TOF operation may become floppy. This is called tracheomalacia and can cause breathing problems. If you are worried about your child's breathing, please talk to your doctor.

Swallowing problems

This may also occur due to the oesophagus narrowing where it was repaired. If the narrowing is severe, your doctors will recommend stretching it. This will be done in an operation under general anaesthetic.

Some children can have difficulties swallowing certain foods. Your doctor will recommend that they sip a drink between mouthfuls whenever they are eating to help with this.

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 causing pain and irritation. If your child does develop this please speak to their hospital doctor for further advice.

When do I need to contact our GP or the hospital?

You should call your GP or the hospital if your baby:

- is coughing or choking when feeding
- has difficulty in swallowing saliva or feeds
- is failing to gain weight.

How do I contact you if I have any concerns?

If you have any worries or queries about your baby once you get home, please contact the John Radcliffe hospital switchboard:

Tel: **01865 741 166**

Ask to speak to the secretary of your baby's consultant or ask to be put through to the paediatric surgical doctor on call.

You can also telephone Tom's ward to speak to one of the nurses.

Tel: **01865 234 109** or **01865 234 111 (24 hours)**

Useful support group information

TOFS (Tracheo Oesophageal Fistula Support)

Tel:	**0115 961 3092**
Email:	**info@tofs.org.uk**
Website:	**www.tofs.org.uk**

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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