Oesophageal Atresia with Tracheo-oesophageal Fistula

This leaflet provides information about oesophageal atresia with tracheo-oesophageal fistula. If you have any further questions, please speak to a doctor or nurse caring for your baby.

What is oesophageal atresia?

Oesophageal atresia (OA) is a rare condition where the oesophagus (food pipe) has a gap; its top part is blind-ended and does not connect to the lower part and stomach. This means food and secretions cannot pass from the mouth to the stomach.

What is tracheo-oesophageal fistula?

Tracheo-oesophageal fistula (TOF) is a related pattern of abnormal development. It is a connection between the oesophagus and trachea (breathing pipe). This connection is called a fistula or tracheo-oesophageal fistula.

How are they diagnosed?

Occasionally an OA / TOF can be suspected on an antenatal scan by an absent or small stomach in the setting of polyhydramnios (increased fluid surrounding your baby) but more often OA / TOF are diagnosed soon after birth. Following birth, your baby may have excess oral secretions and breathing problems when feeding. Part of confirming the diagnosis involves the nurse trying to pass a naso-gastric (NG) tube through your baby’s nose into their stomach. A chest and abdominal X-ray are then performed - if the tube fails to pass into the stomach and the tube can be seen coiled in the oesophagus, this will confirm OA.

What causes this?

We do not know what causes OA and TOF. It is rare and occurs in 1 in 3,500 births. Some babies with OA and TOF can have other problems with their kidneys, bottom (anorectal abnormalities) and spine, rarely heart and limbs. The doctors will examine your baby closely to check if this is the case. Your baby will have a scan of their heart (Echo), usually prior to the surgery to repair their food pipe.

Feeding

Your baby will not be able to receive any milk until after the surgery to repair their oesophagus. The nursing staff will teach you how to express and store your milk to feed to your baby when they are ready.

How are OA / TOF treated?

Once OA / TOF is diagnosed, it is important to stop milk feeds. Fluids will be given through a drip. A special tube (replogle tube) will be passed through the baby's nose into the blind-ending oesophagus to drain the secretions (saliva) that are swallowed but cannot pass into the stomach. Your baby will be nursed in the neonatal unit while preparing for surgery.

What does the operation involve?

The aim of the operation is to close the fistula and repair the oesophagus. The method to repair the OA depends on the distance between the two ends of the oesophagus. In most cases, the two ends are joined together to form a continuous passage from the throat to the stomach. Usually, we will ask an Ear, Nose and Throat surgeon to assess your baby's airway to ensure this is normal and to visualize the connection/s of the food pipe to the airway.

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

What happens after the operation?

Your baby will come back to the neonatal unit to recover. After the operation, your baby will need help with breathing so will be connected to a ventilator. All babies are closely monitored after the operation. He or she will also be given pain relief through the 'drip'. Most babies will be given medication to keep them still (muscle relaxants), to allow the new join in their food pipe to heal.

During the operation, a feeding tube (naso-gastric tube) will have been passed through your baby's nose through the now-joined food pipe into their stomach. This tube is called a trans-anastomotic tube (TAT) and will be used a few days later when your baby is able to start milk feeds. It is important that this tube is not accidentally pulled out, as it protects the area where the surgeon has made the join. We suggest your baby should wear mittens on their hands immediately following surgery until the TAT is removed. The mittens can be removed for washing their hands and while you are there to supervise them.

Your baby will also start anti-reflux (antacid) medicine to help protect their oesophagus from acid reflux, especially the area where the two ends were joined (anastomosis).

While your baby's operation site heals, he or she will be fed through a drip into the veins with parenteral nutrition (PN). When s/he is ready, milk feeds will be started slowly through the TAT. Once your baby is tolerating their full amount of milk and the surgeon is happy with their progress, you will be able to feed him or her from the breast or bottle. In some cases, the surgeon may organise a contrast study (having the baby swallow a dye) before allowing oral feeds.

Discharge and follow-up

This depends on your baby’s recovery and how long it has taken them to achieve and complete oral feeds. This is usually about seven to ten days but may be longer. Your baby will need to continue taking their anti-reflux medication for up to one year and will have follow up appointments with the surgical and medical teams.

Babies who have OA with TOF repaired can encounter some complications and you should seek medical advice if your baby:

- is coughing or choking when feeding
- has very noisy breathing or has a ‘blue spell’
- has difficulty in swallowing saliva or feeds
- is failing to gain weight.

If your baby is unwell you should go to A&E, otherwise you can contact the paediatric surgical registrar through **St George’s Hospital switchboard on 020 8672 1255**.

Long term issues

Children with OA / TOF can have specific problems of which their families need to be aware. They can have respiratory problems, especially if a floppy airway or a problem with their swallow had been identified during their neonatal stay. Sometimes these may require further interventions. Children can have chest / respiratory problems that usually improve as the child grows. Parents usually learn their child’s distinctive ‘TOF cough’ which can persist long term and is not serious. Some children will have gastroesophageal reflux for which they may need to continue antireflux medication.

Feeding problems can occur if the area of the joint narrows and no longer allows passage of saliva, milk or food. This will require a stretch(dilatation) that is done under general anaesthesia.

Sometimes feeding problems may be due to uncoordination of the movement of the food pipe rather than a narrowing – this is called dysmotility of the oesophagus. This will lead to a slower advancement of feeds and children with OA / TOF need to stay on pureed food and purees with soft lumps for longer to reduce the risk of choking on foods with chunks and certain foods that are stickier (chicken, white bread etc).

If St George’s Hospital is not your local hospital

When your baby has had surgery and made a good recovery, i.e. when their specialist medical and nursing requirements are fewer, s/he will be transferred back to the care of your local hospital. This transfer is a sign of progress and will not occur until your baby is ready. It will allow you to be closer to home and become familiar with your local healthcare professionals.

Useful sources of information

NHS pregnancy and baby advice

Pregnancy - NHS (www.nhs.uk)

BLISS

Bliss is a support group which can offer support and advice to families with babies with a range of conditions.

1st Floor North
10-18 Union Street
London
SE1 1SZ

Tel. 020 7378 1122
Email: hello@bliss.org.uk Website: www.bliss.org.uk

Use your smartphone to scan the QR code (you may need to download a QR code scanning app).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

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Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough wings (near the lift foyer).
Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health. **Web:** www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. **Tel:** 111

AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

Reference: NNU_OA_03 **Published:** March 2023 **Review date:** March 2025