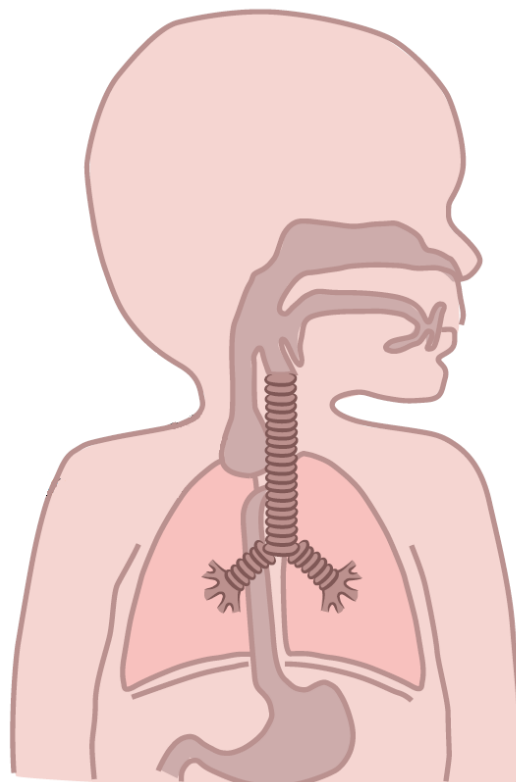




# Oesophageal atresia and tracheo-oesophageal fistula

Information for parents and carers



Your baby has been diagnosed with oesophageal atresia (OA) or trachea-oesophageal fistula (TOF). We understand this may be a worrying and stressful time for you. This leaflet aims to tell you a bit more about these conditions.

#### Key messages

- OA and TOF are conditions where your baby's oesophagus has not developed as it should
- Your baby will need an operation
- Most babies survive to become healthy adults

### What is oesophageal atresia or tracheo-oesophageal fistula?

The oesophagus (also known as the gullet or food pipe) is the tube that passes food from your mouth to your stomach. Babies with oesophageal atresia are born with a gap in the oesophagus. This means that milk or saliva cannot pass from their mouth to their stomach.

Many babies with oesophageal atresia will have an abnormal connection between their oesophagus and windpipe (trachea). This is called a trachea-oesophageal fistula. Figure 1 shows a normal oesophagus and trachea and figure 2 shows what happens if your baby has oesophageal atresia.

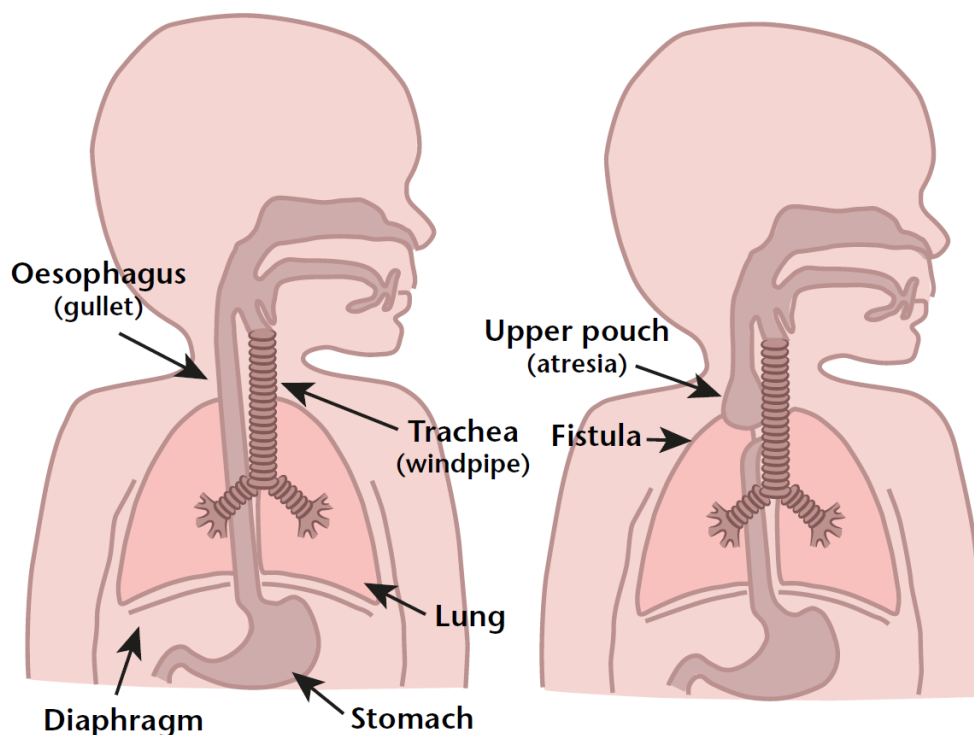


Figure 1

Figure 2

Most of the time, oesophageal atresia cannot be seen on an antenatal scan. Babies are usually diagnosed soon after birth, because of problems swallowing saliva, or after the first feed.

### **How common is OA and TOF?**

OA and TOF occur in about 1 in 3,000 babies. In Scotland, about 17 babies are born each year with these conditions.

### **Could my baby have any other problems?**

Babies born with OA or TOF may have another problem in a different part of their body. Around one in three babies (33%) will have a problem with their heart, and one in five babies (20%) will have another blockage in their bowel. A smaller number of babies will have genetic abnormalities.

Another common problem in OA or TOF is a floppy windpipe (tracheomalacia), which can cause noisy breathing but can also cause difficulty breathing. This will need further treatment.

Your baby will have a thorough examination after birth and some other investigations to check for all of these problems.

### **What will happen after the birth?**

If your baby was suspected before birth of having OA or TOF or has another abnormality, they will usually be delivered in one of the neonatal surgical centres in Scotland where babies with oesophageal atresia are cared for: Royal Aberdeen Children's Hospital; Royal Hospital for Children and Young People, Edinburgh; or Royal Hospital for Children, Glasgow.

Your delivery will be planned in the closest of these centres to where you live. If your labour starts early and there is no time to transfer you to one of these units, your baby will be transferred by a specialist neonatal transfer team soon after they are born. If you cannot be discharged from hospital, arrangements will be made for you to be transferred as soon as possible.

### **General care**

Hopefully you will be able to have a short cuddle with your baby before they are taken to the neonatal intensive care unit (NICU). Your baby will have a drip inserted to allow fluids and medicines to be given. Blood samples will also be taken.

Because your baby cannot swallow, a special tube (Replogle tube) will be passed into their food pipe to stop saliva spilling into their lungs. Most babies with OA or TOF are able to breathe on their own without any help.

### **Surgical care**

Your baby will be looked after by a team of nurses, neonatal doctors and surgeons. The surgeon will meet you to explain the operation and ask you to sign a consent form to show that you understand and agree to the operation. Surgery is usually carried out in the first few days after birth.

The surgery is performed through the side of the chest, and involves disconnecting the TOF from the windpipe and joining the two ends of the oesophagus together. Most babies will have a tube passed into their stomach after the join is made. Sometimes at the end of the operation, another tube is placed inside the baby's chest to drain any air from around the lung.

### **What happens next?**

Your baby will return to the neonatal intensive care unit. They may be able to wake up from the anaesthetic within a day or two after surgery, but some babies need to stay on a ventilator for longer. It is usual to start feeds through the tube directly into the stomach a few days after surgery.

Your baby may have an x-ray dye test (contrast study) about one week after surgery to see if the join in the oesophagus has healed properly. Most babies will be able to start feeding normally around this time. If your baby has one of the rarer types of this condition, the timing of the surgery may be different, but your surgeon will explain this to you in more detail.

### **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 OA or TOF, 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?**

Most babies with OA or TOF will make a full recovery after surgery. If your baby has another condition which will affect the outcome, your doctors will discuss it with you in more detail. Some babies may take a few weeks to feed well.

### **How long might my baby be in hospital?**

The average time that babies will spend in hospital is around four weeks, but this will be longer if they have other conditions that need treatment. Your doctors will be able to explain this to you in more detail.

### **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](http://www.scans.scot.nhs.uk). We have listed other support groups below.

### **Other useful sources of information**

[www.tofs.org.uk](http://www.tofs.org.uk) TOFS – A UK-based support group for families

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](mailto:nss.scans@nhs.scot).

You can find more information about how the NHS handles your personal information at [NHS Inform](#).