

## Glossary of medical professionals parents are likely to encounter

From when your child is born with OA/TOF onwards you are likely to encounter many medical professionals who will deal with different aspects of their care. Not all patients born with OA/TOF will automatically be referred to all types of specialists, with access to some never being required and others being sought out further on in their journey. Thanks to TOFS member Roxy Cuenca, mum to Otto born with OA/TOF, the below glossary of medical professionals has been compiled in order to help parents understand the roles of the specialists caring for their child as well as potentially signposting areas of care that are missing.

TOFS is actively lobbying for more centralised and consistent care and a single point of contact to make accessing the correct help from the correct specialist much more straight forward, read more in TOFS' [position paper](#).

### Obstetrician

*An **obstetrician** is a doctor who specialises in pregnancy and delivery of babies and the health of the pregnant mother. You may see an obstetrician during pregnancy if you have polyhydramnios (too much fluid around the baby). They may also see you if they suspect your baby as OA/TOF after ultrasound scans. They would manage your care during pregnancy, labour and contact you after birth. If you are pregnant and have concerns during your pregnancy you can ask to see an Obstetrician who can help you.*

### Paediatric Surgeon

*The **Paediatric Surgeon** will be among the first medical professionals you will meet. They will have your baby in an Operating Theatre to repair your baby's OA/TOF. Sometimes the gap in the oesophagus will be too great to close, this is known as [long gap OA](#). Before the surgery, you will usually have the opportunity to ask the surgeon about what they are going to fix, what recovery will be like and what life could be like for your baby post-surgery. If OA/TOF is identified on ultrasound scans prior to delivery, you may meet with them before the birth. If you have any problems after the surgery, be sure to contact your surgical team as well as your child's consultant paediatrician.*

### Geneticist

*You may be referred to a **Geneticist** after the birth of your baby or before you have further children if your baby has other physical health problems that the paediatrician or obstetrician suspects may be part of a genetic condition. They can look at baby to see if this is the case and do any tests that will help with the diagnosis. They will also talk to you about the condition and whether any future children you have could also have a chance of being born with the same genetic condition.*

Neonatologist/ Paediatrician specializing in neonatal care

*All babies born with OA/TOF spend some time in the Neonatal Intensive Care Unit after birth and their operation. For some babies, this is just a few days, but other babies may stay there longer, particularly those born prematurely, or with long gap OA. **Neonatologists** are specialists in looking after very young babies who need extra care in hospital, and they will talk to you about your baby's health while they are staying in the NICU.*

Neonatal nurse

*You will likely see much more of the **nurses** than the neonatologist. When your baby is in NICU, they will have a nurse whose job it is to look after them, including the day to day washing, feeding, wound care and so on to keep baby well and growing big enough to leave NICU. They can answer any of your questions, and help you bond with baby in this strange environment and help you through the natural anxieties about touching and holding babies attached to so many wires.*

Consultant Paediatrician

*A **Consultant Paediatrician** will manage your child's medical needs. They will refer your child to the specialists they require. If you notice something with your child you are worried about, consult your paediatrician who can help diagnose or give medication. You can also ask them for referrals to certain specialists if you don't have them as part of your child's care or think you need it.*

ENT Consultant

*The ENT will accompany the surgeon in theatre. **ENT is Ear, Nose & Throat** and for children born with OA/TOF they will look particularly in their throat area at the trachea and the oesophagus. ENTs will help guide a camera down the throat to see down the oesophagus (OGD) and trachea (bronchoscopy). They will be looking for the fistula that connects from the oesophagus to the windpipe/trachea if your child has TOF. In this bronchoscopy they will also see the level of tracheomalacia your child, severe tracheomalacia may present itself later after birth. If you suspect your child's tracheomalacia is getting worse after surgery (e.g. blue episodes) you could ask to see an ENT specialist.*

Paediatric Gastroenterologist

***Paediatric gastroenterologists** are specially trained to perform diagnostic tests of a child's digestive system. Special instruments, such as endoscopes, are used to examine the oesophagus. A gastroenterologist may be present during oesophageal dilatations as well as the placement and management of feeding tubes if needed.*

Respiratory Specialist Paediatrician

*A **Respiratory Specialist Paediatrician** will concentrate on your child's respiratory system which is their breathing and airway. Children born with OA/TOF have particularly vulnerable airways and when children are younger, they will be more vulnerable to respiratory infections such as chest infection. Respiratory specialists will help look after your child's airway and manage them using tablet/liquid medication such as antibiotics and inhaled medication like nebulisers and inhalers. Some children born with OA/TOF may benefit from prophylactic antibiotics to help prevent serious instances of respiratory infection.*

*They will look at how your child breathes so if you notice any noises, or changes in your child's cough it is a good idea to consult a respiratory specialist.*

Speech and Language  
Therapist

*A **SaLT** will help your child with their swallow by reviewing them as they drink/eat, they can also provide weaning support. Children born with OA/TOF will likely have some degree of oesophageal dysmotility meaning that the oesophageal muscle contraction is often uncoordinated which can lead to food and drink travelling back up the oesophagus. This means that the swallowing process can be much slower than usual and may result in aspiration and food getting stuck.*

*SaLT may also notice other things such as reflux or laryngeal cleft. If you are worried when you are feeding your baby that they are making unusual sounds, have noisy breathing or cough frequently then SaLT can do an assessment to see what's causing this and give advice on how to feed your baby safely and give you confidence in feeding your child.*

*Some children born with OA/TOF may be reluctant to eat solid food (oral aversion), particularly those who are tube fed. SaLT will be able to help your child learn to eat.*

*SaLT cover anything around the mouth - communication, eating, drinking & swallowing and should be a part of your child's lifelong care.*

Dietitian

*A **Dietician** will be making sure your baby is putting on the right amount of weight for their gestational age, and if they're not they may suggest a fortifier or tube feeds to compliment breast feeding or bottle feeding. Children born with OA/TOF have gone through a lot at the beginning of their lives with surgeries and recovery, and they may need a little help.*

*Also, due to tracheomalacia, TOF babies will get a lot more tired feeding and may not be able to have a "full feed" so may need help getting the nutrients they need. A Dietitian will assess your baby's weight, as a drop in weight or lack of weight gain may also signal a stricture, particularly if your baby had a tight repair which would need further investigation.*

*Dieticians may also help make sure that babies and children with OA/TOF are getting all the vitamins and minerals and energy they need from food. Some with OA/TOF, particularly those born with long gap OA, are not able to absorb these as easily from their food, and dieticians can advise to correct this.*

Radiologist

*The **Radiologist** is a medical doctor present at any of your child's x-rays and ultrasounds They specialise in diagnosis during an x-ray, such as chest Xrays and barium swallows. You can ask them questions about what they see and what this means for your child.*

Radiographer

*Different to a Radiologist, a **Radiographer** doesn't make a diagnosis – they are the healthcare professional who is performing the x-ray.*

Anaesthetist	<p>The <b>Anaesthetist</b> is in charge of putting your baby to sleep and keeping them asleep during surgery. They will talk to you about fasting your child before surgery so not to complicate the procedure. If there is anything in the stomach whilst under anaesthetic, it could come back up when your baby is unconscious and cause aspiration in their lungs. Anaesthetists will be in charge of your child's intubation and breathing during surgery.</p>
Respiratory physiotherapist	<p>The <b>Respiratory Physiotherapist</b> will help you look after your child's airway. This may include giving you exercises to do with your child to manage their secretions (saliva, mucous). This is important so there is not a buildup which can make it harder for your child to breathe and also collect bacteria/infection. You may be given a PEP mask (Positive Expiratory Pressure) or be given physio to do physically on your child's chest.</p> <p>If you are worried your child struggles with their secretions, you can contact your Paediatrician who could refer you to a Respiratory Physio.</p>
Paediatric Physiotherapist	<p>A <b>Paediatric Physiotherapist</b> will help your child developmentally. If your child has spent a long time in hospital they may need help hitting their milestones. They specialise in children and will know how to encourage your child to move and play to help them learn and grow. They will be able to diagnose if your child has any difficulties that need nurturing. A physiotherapist may prescribe different exercises for your child to help tackle issues such as muscle weakness and chest wall asymmetry which can be the result of surgical intervention or be present from birth.</p>
Hospital Play Specialist	<p>A <b>Hospital Play Specialist</b> helps children in hospital to discover play in between their numerous hospital procedures and operations. They organise play times to give your child relief and fun! Providing toys or books to help with their development and learning so they can still continue while they are in hospital. The play team can also help to explain procedures to your child and provide distraction during routine procedures such as blood tests.</p>
Clinical Psychologist	<p>The <b>Children's Psychologist</b> is for children who have difficulties in more than one developmental area including learning, social interaction and behaviour. The team work closely with SaLT because both professions are interested in how a child communicates, interacts and plays.</p>
Educational Psychologist	<p><b>Educational psychologists</b> work with children and young people who are experiencing problems that hinder their successful learning and participation in school and other activities. This service may be needed for those who have extended or frequent absences due to ill health.</p>