

## TOFS Awareness Week, 26 February to 3 March, 2024

Imagine your child being born unable to swallow. Or imagine being unable to swallow anything as an adult. It's a scary thought. Caused by congenital conditions called oesophageal atresia and/or tracheo-oesophageal fistula, or OA/TOF for short, it's a reality for the parents of one in every 3,500 babies born annually in the UK.

Major surgery and specialised treatment at key children's hospitals in the country is necessary for survival. While some children born with these conditions experience relatively few problems (after the surgery), some are not so fortunate and can undergo numerous additional procedures throughout their childhood and into adulthood. **Life-long follow up is absolutely essential.** The journey can be a difficult one for all concerned and this is where the charity TOFS comes in.

### TOFS 2024 Awareness Week

OA/TOF are relatively rare conditions, and most people (including many healthcare professionals) have never heard of them – which is why our annual Awareness Week is so important. This year it runs from 26 Feb to 3 March, to coincide with the internationally-recognised **Rare Disease Day** on 29 February, and we aim to let as many healthcare professionals as possible know about OA/TOF and TOFS. That way, more people affected - parents, children, Adult TOFs and extended families - will be able to find others who understand just what they are going through and access the wealth of knowledge and information that TOFS and its membership have.

**We have two important aims for our 2024 campaign, to help raise awareness amongst health professionals in two distinct arenas, and with the help of our members, make the resources in our library for health professionals available to:**

1. Healthcare professionals treating those in **paediatric** care: GPs, obstetricians, nurses, paediatricians, health visitors, dietitians, speech and language therapists, gastroenterologists and respiratory specialists, and district hospitals.
2. Healthcare professionals who come into contact with **adults** born with the condition: GPs, pharmacists, and adult respiratory and gastroenterology units, amongst others.

OA/TOF are rare complex congenital conditions, and GPs, and other healthcare professionals, may only see a patient born with OA/TOF a handful of times in their career. These were once considered paediatric conditions, but as patients have grown into middle-aged adults, research consistently demonstrates that a repaired oesophagus and trachea do not function like an oesophagus and trachea that developed in normal continuity in utero. Oesophageal nerve and muscle may not function normally, and dysphagia, reflux (GORD) are common, though not universal. In addition, ongoing respiratory problems are often a challenge.

Children and adults born with OA/TOF may also have a number of mental health issues related to their experiences - PTSD from traumatic procedures as a child and their time in hospital for example. Chronic ill health is associated with increased depression and anxiety, while the need for frequent time off school can affect social relationships and school achievement. Some children live with food aversion and long-term eating issues due to their condition.

During the pandemic parents may have lost the support of face-to-face health services such as speech and language therapists, dieticians and doctors. Many children and adults with OA/TOF have long-term respiratory problems and have been especially vulnerable to the effects of Covid. Issues like school and work are a cause for worry. Covid has led to some alarm over the 'TOF cough' - it is not infectious but is loud and distinctive and caused only by a floppy trachea. Unfortunately, this cough can attract negative and unwarranted attention from strangers, and this has made many even more fearful of being in public, during these difficult times.

### About TOFS

TOFS is a UK-based charity dedicated to providing pastoral support to families of children and adults born with these congenital conditions. From the first moment that parents find out that their child has OA/TOF, TOFS is there to support them with information, experience and guidance through the everyday challenges they face, from birth onwards.

TOFS is a registered charity, no 327735 and a limited company, no 2202260.

**For more information about TOFS Awareness Week, or to discuss interview/feature opportunities please contact the TOFS office on [info@tofs.org.uk](mailto:info@tofs.org.uk) or 0115 961 3092.**

The charity relies on fundraising and donations to enable it to carry out this vital support work. The website [www.tofs.org.uk](http://www.tofs.org.uk) is packed with information to help all affected on their TOF journey, with a selection of leaflets that can be downloaded and printed to help explain the condition to friends, relatives, carers, teachers and medical professionals. There are also two thriving Facebook groups where parents and adults born with OA/TOF can share concerns, experiences, problems and progress with each other. *The TOF Book*, and *The Soft Food recipe book* are published by TOFS, and available from tofs.org.uk, as popular resources and are widely used by families and health professionals.

### **So what exactly is oesophageal atresia and tracheo-oesophageal fistula?**

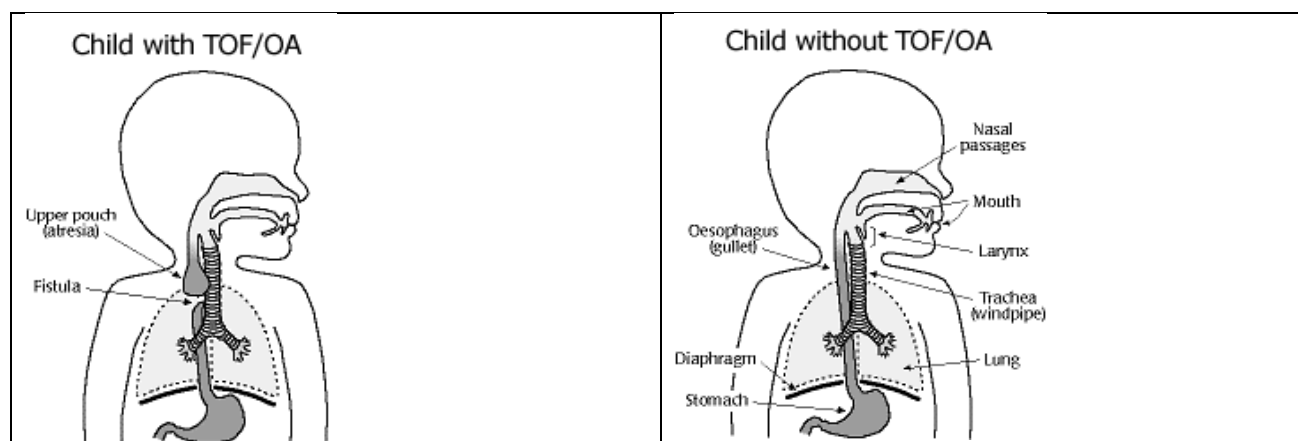
Oesophageal atresia (OA) and tracheo-oesophageal fistula (TOF) are rare congenital malformations of the oesophagus (food pipe) and/or trachea (airway) that affect one in every 3,500 babies. Babies born with OA/TOF need to have intensive neo-natal care prior to corrective surgery, normally within days of birth in order to survive.

### **Oesophageal Atresia (OA)**

In oesophageal atresia (OA), the baby is born with an incomplete oesophagus (food pipe) - a top part (usually ending in a pouch) and an unconnected bottom part. This prevents food from reaching the stomach. Prior to surgery, this pouch can fill up with food and saliva, which can eventually overflow into the baby's trachea (windpipe), entering the lungs and causing choking.

### **Tracheo-Oesophageal Fistula (TOF)**

In tracheo-oesophageal fistula (TOF), the bottom end of the baby's oesophagus is typically joined to its trachea (windpipe). Without surgical intervention, this causes air to pass from the windpipe to the food pipe and stomach. It can also allow stomach acid to pass into the lungs.



Some children may also have to undergo additional surgical interventions later on in their lives. Whilst many children born with OA/TOF will experience only a few problems, others may have difficulties with swallowing and digesting food, gastro-oesophageal reflux (where the acidic stomach contents pass back into the lower oesophagus) and respiratory problems. The effects of surgery and associated health problems can add a great deal to the usual challenges of parenthood.

Currently nobody knows what causes the vast majority of cases of OA or TOF. For the new parent this is extremely important to know - it is no-one's 'fault', it just happens. However, with the benefits of modern medical intervention and the active support of TOFS, the outlook for children with OA/TOF is very positive.

For more information, please visit [www.tofs.org.co.uk](http://www.tofs.org.co.uk)