

Glossary of terms relating to OA/TOF

<https://tofs.org.uk/oa-tof-information/glossary-of-terms/>

We hope you will find this glossary of terms referenced on our website and Chew! magazine useful. If you think we've missed any useful terms out, please let us know.

We also have [OA/TOF terms in other languages](#) which can be found in the [resource section](#) of our site.

Acid reflux

This is when acid from the stomach travels back up the oesophagus causing discomfort and sometimes vomiting or choking. Also called [gastro-oesophageal reflux](#) or GOR. Reflux can make strictures worse.

Anal Atresia

A type of anorectal malformation. The anal canal does not form properly and the baby is born unable to pass meconium (the black sticky first poo). Anal atresia is very uncommon. Treatment involves a colostomy operation followed by a PSARP reconstruction operation and then closure of the colostomy.

Anastomosis

The technical term for joining to sections of bowel together, including the oesophagus.

Aortopexy

This is the name for an operation performed on infants with severe tracheomalacia. The object is to pull the front wall of the trachea forwards to prevent it from collapsing.

ARM (anorectal malformation)

Also called an imperforate anus. ARM is a general term for a baby who is born with an abnormality in their bottom which means they are unable to pass meconium properly (the black sticky first poo). There are several different types of ARM. Some have to be treated with a colostomy initially followed by a PSARP reconstruction and then closure of the colostomy. Less severe types of ARM can be treated with PSARP-type operations in the newborn period without a colostomy.

Artificial nutrition

Delivery of food in a fashion that doesn't require the patient to chew or swallow. This may take the form of milk given through a feeding tube (either a nasogastric tube or a gastrostomy). A baby can also be fed intravenously. This is called Total Parenteral Nutrition (TPN, sometimes shortened to PN)

Aspiration

The inhalation of fluid or food into the trachea or lungs. We might recognise it as a problem for us 'when food goes down the wrong way'.

Asthma

A common lung condition usually connected with an allergy that causes coughing and wheezing. It is sometimes misdiagnosed in TOF children due to their 'TOF cough'.

Atresia

The medical term for a blockage, usually in a segment of bowel eg the oesophagus

Azithromycin

Antibiotic used to treat a variety of bacterial infections. Sometimes Azithromycin is used a prophylactic antibiotic to reduce the risk of chest infections in vulnerable children.

Barium Swallow

An investigation that involves swallowing a flavoured dye (usually strawberry-flavoured barium sulphate) which shows up on x-ray.

Barrett's oesophagus

Named after the surgeon Norman Barrett, who described the condition in adults. Long-term uncontrolled reflux can damage the lining of the oesophagus. Barrett's oesophagus occurs when the lining of the oesophagus changes to become acid resistant. Eventually this can increase the risk of cancer.

Bronchoscopy

Method of viewing the inside of the Windpipe (trachea) with a telescope under anaesthetic.

Bronchiectasis

Lung damage which develops as a result of repeated infection.

Carina

The bottom of the windpipe where it splits into a tube (bronchus) going into each lung.

Choanal atresia

A congenital abnormality where the back of the nose (choana) does not form properly. Usually choanal atresia just affects one side of the nose and no treatment may be necessary. If a baby is born with bilateral choanal atresia both sides of the nose are blocked. This requires surgical correction as a baby is unable to breathe through their mouth properly.

Choking

Life-threatening emergency when food or a foreign object gets stuck in the throat or windpipe, blocking the flow of air to the lungs. If someone is choking they can't talk. They will have breathing difficulties or noisy breathing, become flushed, then pale or bluish and lose consciousness.

Chyle leak

Lymph, or tissue fluid, is the filtrate of blood after all the cells are sieved out. Lymphatic fluid passed back from the tissues through a network of delicate thin-walled vessels called lymphatics. There are many lymphatics in the abdomen which are important for absorbing fat from the bowel. These lymphatic channels join together in the back of the chest to form the thoracic duct which enters one of the big veins in the neck. Occasionally during difficult operations on the chest the thoracic duct is injured, resulting in a chyle leak. Usually this heals with a special low fat diet containing medium chain triglycerides (MCT). Sometimes a period of intravenous feeding with TPN is required.

Colonic interposition

A surgical procedure to replace a missing oesophagus with a segment of colon (large intestine).

Colostomy

A surgical procedure to create an artificial opening for the colon (large bowel) onto the abdominal wall to provide a channel for faeces to leave the body. Often the initial treatment for an ARM.

Croup

The name given to the cough associated with a viral throat infection called laryngotracheobronchitis. The 'TOF cough' is often mistaken for croup.

Dilatation

The medical name for stretching a narrowing (stricture) in the oesophagus. Oesophageal dilatation can be repeated as many times as needed.

Dumping syndrome

When food moves suddenly into the small intestine causing dizziness, tummy ache and sometimes diarrhoea.

Dysmotility

When the muscles of the digestive system do not work as they should. Oesophageal dysmotility can cause dysphagia.

Dysphagia

Difficulty swallowing.

EAT

European Federation of Esophageal Atresia and Tracheo-esophageal Fistula Support Groups. (In Europe and the USA 'esophagus' is the accepted spelling of 'oesophagus'.) TOFS is a founder member of EAT.

Edwards's syndrome

A chromosomal disorder where there is the presence of all, or part of, an extra chromosome 18.

Endoscopy

A procedure to examine the lining of the bowel with a telescope or camera. Upper GI endoscopy involves using a telescope to examine the lining of the oesophagus, stomach and duodenum. Colonoscopy involves using a telescope to examine the lining of the large bowel (colon).

EoE

Eosinophilic (o)esophagitis happens when white blood cells (called eosinophils) deposit in the lining of the oesophagus. Diagnosed through biopsy, this can be the result of an allergic reaction to food or the environment.

Epithelium

The lining membrane of the bowel and also the urinary tract.

Erb's Palsy

A rare birth injury to the nerves supplying part of the arm. Usually recovers with physiotherapy. Occasionally surgery to repair the nerves is necessary.

Fistula

An abnormal connection between two tubes, eg TOF where the lower oesophagus makes an abnormal connection with the trachea.

Foker Technique

Named after Dr John Foker, a Canadian paediatric surgeon. Foker's procedure is sometimes used in babies with long gap oesophageal atresia to avoid an oesophageal replacement operation. The operation involves placing stitches in the two ends of the oesophagus and gradually pulling them together. The aim is to stretch the ends of the oesophagus to reduce the gap so that they can be joined together (anastomosed).

Gastric transposition

An operation to replace the oesophagus by moving the stomach into the chest and joining the top onto the oesophagus in the neck.

Gastrostomy

A feeding tube that is inserted directly into the stomach through the abdominal wall.

GORD (American = GERD)

Gastroesophageal reflux disease. See acid reflux.

Haemophilus influenza

Bacterium found in respiratory tract that causes chest infections

Hydrocephalus

An abnormal collection of fluid on the brain

Hypoplastic lung

Or pulmonary hypoplasia – underdeveloped lung(s).

Imperforate anus

See anorectal malformation

Jejunostomy

An operation to make an artificial opening into the jejunum (the first part of small intestine) for tube feeding to avoid problems with GOR.

Jejunal interposition

An operation to replace the oesophagus with a section of jejunum.

Laparoscopy

A method of viewing inside the abdomen and pelvis using a telescope inserted through the belly button under anaesthetic. Laparoscopy can be used to help diagnosis but it is mainly used to carry out surgical procedures (keyhole surgery)

Long gap OA

In approximately 10% of all babies born with oesophageal atresia, the gap between the upper and lower ends of the oesophagus is too long for primary repair, this is referred to as long gap oesophageal atresia.

Manometry

A test that measures the strength and muscle co-ordination of the oesophagus when you swallow.

MICKEY button

The MIC-KEY* Low-Profile Gastrostomy Feeding tube is a type of gastrostomy feeding tube which is held in place with a balloon in the stomach.

Myotomy

A surgical procedure that involves cutting muscle. Occasionally a myotomy has to be made in the wall of the oesophagus when oesophageal atresia is repaired.

Necrotising enterocolitis (NEC)

A serious bowel infection which typically affects sick premature infants. Mild NEC can be treated with gut rest and antibiotics. Severe NEC usually requires surgery.

NG Tube (naso-gastric tube)

Small feeding tube inserted through the nose down the oesophagus into the stomach.

NICU

Neo-natal intensive care unit.

Nissen Fundoplication

The procedure to reduce acid reflux by wrapping the upper part of the stomach round the base of the oesophagus.

Oesophageal atresia (OA)

The condition where the oesophagus (gullet or food pipe) has not formed properly and is not connected to the stomach. This means food cannot pass from the throat to the stomach. In the UK around one in every 3,500 children are born with OA. Tracheo-oesophageal fistula (TOF- see below) often occurs alongside OA. See [What is OA/TOF?](#)

Oesophagitis

Inflammation of the lining of the oesophagus. Usually caused by acid reflux. Occasionally caused by allergies (see eosinophilic oesophagitis)

Oesophagoscopy

Sometimes known as a 'scope', this is an examination of the lining of the oesophagus with a telescope under a general anaesthetic.

Oesophagostomy

An operation used in some babies with long gap oesophageal atresia. An opening is made into the upper end of the oesophagus in the neck to allow saliva to drain. This also allows 'sham feeding'.

Oral aversion

Fear of food or milk in the mouth.

Patau syndrome

A chromosomal disorder where there is the presence of all, or part of, an extra chromosome 13.

PEG – Percutaneous endoscopic gastrostomy

This is the name given to a technique for inserting a gastrostomy feeding tube into the stomach.

Peristalsis

The muscular action of the bowel that pushes food down to the gut. Poor or uncoordinated peristalsis is called dysmotility.

pH study

A test that looks for acid reflux into the oesophagus. A pH study involves leaving an acid sensing probe (similar to a nasogastric tube) in the lower oesophagus usually for 24 hours whilst the child feeds and drinks as normally as possible.

PIP – (Personal Independence Payment)

If you have a long-term illness or disability – physical and/or mental – and you are aged from 16 to below your state pension age, then you may be entitled to Personal Independence Payment (PIP).

PPI's – Proton Pump Inhibitors

A group of drugs including omeprazole ('Losec') and lansoprazole ('Zoton') which stop stomach acid production.

Pyloric Stenosis

A narrowing of the outlet of the stomach which causes repeated 'projectile' vomiting in babies . Pyloric stenosis is treated with an operation called Ramstedt's procedure.

Polyhydramnios

Excessive amniotic fluid (the 'waters') during pregnancy. Oesophageal atresia is one cause of polyhydramnios because the unborn baby is unable to swallow the amniotic fluid.

SCBU

Special care baby unit.

Scoliosis

Abnormal sideways curvature of the spine.

Sham feeding

See cervical oesophagostomy. Sham feeding a baby with a cervical oesophagostomy means that milk (or puree) taken by mouth drains out of the neck. This can be combined with a simultaneous gastrostomy feed to help the baby associate food by mouth with feeling full.

Sphincter muscles

Circular muscles around the bowel or bladder to control flow of contents. If the lower oesophageal sphincter is weak acid reflux may occur.

SaLT

Speech and Language Therapy

'Stickies'

Term that is commonly used by TOF families for when food gets stuck! The word stickie can be used to describe the circumstances where food has been swallowed, but has got stuck in the oesophagus (food pipe) and not reached the stomach. It is not to be confused with 'choking', which is defined elsewhere in this glossary. This can cause discomfort in the chest area, drooling and a cough or gagging. The breathing is not usually affected as the food has cleared the windpipe. The person can talk and is conscious. Medical help may be needed if techniques to clear at home such as taking fizzy drinks don't work.

Stricture

A narrowing in the bowel, often at the site of an anastomosis. If a stricture is tight stretching (dilatation under general anaesthetic) may be necessary.

Stridor

Abnormal noisy breathing.

Stoma

An opening on the abdominal wall into the bowel (colostomy, ileostomy) or bladder (vesicostomy) to allow waste (urine or faeces) to be diverted..

Thoracotomy

An operation on the chest. OA/TOF is usually repaired through a right thoracotomy.

TLC

A TOFS local contact. TLCs are valuable volunteers, mainly parents, with experience of OA/TOF. They act as a point of contact for families in their area, may take posters to hospitals and help organise informal get-togethers. They welcome contact from new members and old.

TOF (Tracheo-oesophageal fistula)

The condition in which The lower oesophagus makes an abnormal connection onto the trachea (windpipe). See [What is OA/TOF?](#)

TPN

Total parental nutrition, intravenous feeding that bypasses the gut completely.

'TOF cough'

To parents of TOF children, this is that all too familiar 'honking' sound that is due to a child having a 'floppy' windpipe.

Tracheal stenosis

A rare abnormal narrowing of the main airway (trachea).

Tracheomalacia

The windpipe (trachea) is normally held open by horseshoe shaped rings of cartilage. In babies with OA/TOF these cartilages are often weak which means the trachea can flatten and close. This causes the characteristic 'TOF cough'.

Tracheoplasty

A complex operation to widen the trachea.

VACTERL

This abbreviation stands for: vertebral defects; anal atresia; cardiac defects; tracheo-oesophageal fistula; (o)esophageal atresia; renal abnormalities and limb abnormalities. Babies diagnosed with the VACTERL Association typically have at least three of these characteristic features. See [About VACTERL](#)

Vascular ring

A rare congenital abnormality with the branches of the aorta (the main blood vessel from the heart). Abnormal branches of the aorta may compress the trachea and cause stridor.

Viral wheeze

Most chest infections in young children are caused by viruses. These viruses typically cause wheezing and coughing after the fever settles.

Ventriculoperitoneal (VP) shunt

A medical device that relieves pressure on the brain caused by fluid accumulation. VP shunting is a surgical procedure that primarily treats a condition called hydrocephalus. This condition occurs when excess cerebrospinal fluid (CSF) collects in the brain's ventricles.

Glossary compiled by TOFS' member Judy Riley, with input from the rest of the Chew editorial board. With thanks to Mr David Crabbe (Consultant Paediatric Surgeon, Leeds General Infirmary) for overseeing the definitions.