

FACTSHEET



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Oesophageal atresia and/or tracheo-oesophageal fistula

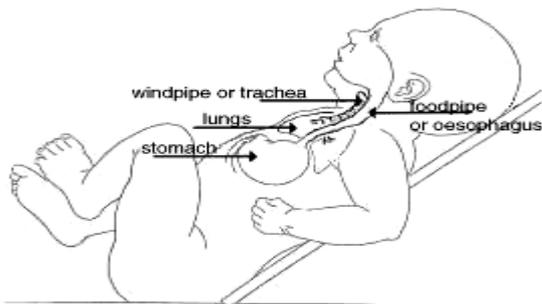
By now you will know that your baby was born with a condition called oesophageal atresia (OA). OA usually occurs with tracheo-oesophageal fistula (TOF), but not always. This fact sheet has been prepared to give you some basic information about the condition and to help you care for your child.

Basic facts about TOF

It is a rare condition. About one in 4,500 children are affected. If a baby is a reasonable size when born with OA/TOF, and if he/she is born without any other serious condition threatening his/her survival, the outlook is extremely good. While these infants may have some difficulties in the early years of their lives, it is important to remember that they will be able to lead fully normal lives.

Normal system

The **trachea** is the **windpipe** through which air passes to the lungs when we breathe. The **oesophagus** is the **foodpipe**, which carries food from the mouth to the stomach.



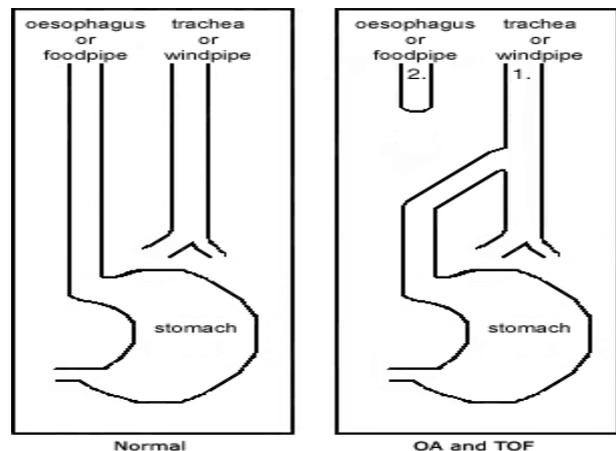
Normal digestive system

What exactly is tracheo-oesophageal fistula (TOF)?

In the common type of tracheo-oesophageal fistula there is a join between the windpipe and food pipe (see diagram OA and TOF - point 1). This causes air to pass from the windpipe to the stomach or stomach juices can pass from the stomach to the lungs. About 88 per cent of all babies born with TOF are of the common type. Check with your baby's doctor which type of TOF your baby has.

What is oesophageal atresia (OA)?

In oesophageal atresia there is a gap in the food pipe so that saliva and food cannot pass into the stomach (see diagram OA and TOF - point 2).



Generally babies with both TOF and OA are referred to as having TOF.

For the vast majority of TOF babies it is possible to repair the food pipe immediately with surgery. During the operation the connection between the windpipe and the food pipe (**fistula**) is closed off (**ligated**) and the two ends of the food pipe (**oesophagus**) are joined together. The join is called **anastomosis**. Until your baby has the operation a tube called a “**reprogle tube**” is placed in the food pipe to remove saliva so your baby does not choke. Before the operation and for about a week after the operation your baby is fed with special liquids directly into the veins (**intravenously**). Most babies with TOF need help to breathe using a machine called a ventilator.

In about five per cent of cases it is not possible to make the needed repair in one operation soon after birth. Usually this is because the gap between the two ends of the food pipe is too big to be joined together.

There are two types of treatment for babies with a "wide gap" of the food pipe.

1. In some cases the baby is nursed in hospital until the oesophagus (food pipe) grows enough to make it possible to be joined together. During this time a reprogle tube is placed in the food pipe to remove saliva so the baby does not choke. Also a special feeding tube or button (**gastrostomy tube**) is placed in the stomach so milk can be given directly into the stomach. A small operation is needed when the gastrostomy tube is first put in place.
2. In some cases the upper part of the food pipe (oesophagus) is brought out into an opening at the side of the neck. This is called an **oesophagostomy**. This opening is left for 1-2 years when another operation is then done to join the food pipe together. The opening in the neck allows saliva to drain out onto a small pad so the baby does not choke. It is important to feed the baby with milk into his/her mouth so that he/she remembers how to suck in preparation for when the feeding tube is repaired/joined. This is called "sham" feeding. The milk will also flow out the opening in the neck so the baby does not choke.

As well, the special feeding gastrostomy tube or button is placed in the stomach so milk can be given. Once you are confident with the special care needed, babies in this situation are cared for at home until the next operation.

What causes the condition?

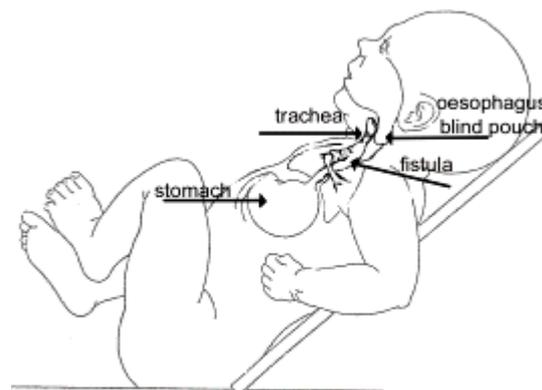
No one really knows! What we do know is that it is a fault that probably develops very early in the pregnancy - sometime during the first three to six weeks. Boys and girls are equally affected. It is believed that it is caused by a number of factors acting together, but just what they are we have yet to learn.

We do know it is not hereditary in the strict sense, though one of the contributing factors may be hereditary, but this is not certain. It is highly unlikely to happen in following pregnancies or in the future children of your child.

An important point to keep in mind is that it is in no way your fault. The good news is that the majority of TOF children grow up to be normal young people if they are born with no other major problems.

Children with TOF have a floppy windpipe known as **tracheomalacia** that may cause noisy breathing and occasional "**blue spells**". If these are a problem they will be discussed with you before your baby is discharged.

Care of your TOF baby



OA and TOF digestive system

Caring for your baby does not begin when you take him/her home - you are encouraged to share in your baby's care while your baby is still in hospital. Don't be afraid to ask questions, even the same question over and over again. It is often difficult to fully understand things when you are worried or anxious. People caring for babies and children in hospital understand that all parents are worried and anxious when their child is not well and needs medical attention. Confused feelings are common at this early time.

Many parents speak of their deep disappointment that they were unable to take their baby home from the maternity hospital in the usual way. Sometimes people can feel bewildered and angry. Most parents feel frightened to see their baby connected up to tubes and machines. Some parents may not want to see the baby

until they are well on the road to recovery and free of equipment. If that is the way you feel, remember that these feelings are perfectly normal. The sooner parents are involved with their baby the better. The more you know your child and deal with him/her while in hospital, the easier it will be when you take your child home. Parents are the real experts in the care of their child. Every TOF child, like every other child, is different. Though you need the assistance of other experts for a time, you are really the most important people in the team caring for your child.

Problems you may encounter in the early years

It is important to emphasise that you may experience problems but these problems can vary with every child. Problems include swallowing difficulties and a higher number of normal childhood coughs and colds. It is important to keep in close touch with your baby's doctor about anything that is causing you concern. The following gives you an idea of problems that can occur:

Swallowing problems

The majority of babies where the TOF is repaired in the newborn period do not have swallowing problems. When you take your baby home you will be given a feeding program suitable for your baby to thrive on.

As your baby grows you will need to add solids and increased varieties of foods. It is at this stage that problems may occur. It is important that your baby has as normal a diet as possible - this will depend on trial and error. There really is no reason to delay the introduction of solids (always in consultation with your baby's doctor) but with some TOF children, close observation is often needed and "mushy" foods may need to be given. A blender or small mincer is really helpful when preparing "mushy" food.

The sorts of foods that most often cause problems in the early years are meats (steak, chops, chicken), fresh bread and at times hard fruits like apples. Most of these can be prepared to suit your child. Meat can be minced, or at first only the meat juice can be given, apples or other hard foods can be stewed and mashed.

A helpful hint from a "TOF mum" for feeding toddlers

When you introduce new foods, always blend, mince or chop finely. When the child gets used to eating the new food, gradually make the sizes bigger. Also let your child watch you cut it up. Give them a nibble while you are doing it. As the years go on the child won't be afraid to eat new things if you gradually build them up to it.

Try to ensure that meal times are quiet and peaceful (this is not always easy with a young, energetic family). When children are in a hurry or excited, swallowing problems are most likely to occur. During social occasions, when you have a lively, energetic, curious child, extra observation is necessary. Things like nuts and potato crisps left at the child's level can be a problem. People are usually helpful if you explain the need to put these things out of reach (nuts should never be given to any children under five years). Many parents also suggest that the child be encouraged to drink during meals.

Stricture

Sometimes the oesophagus becomes narrow at the site of the join - this is called a **stricture**. Babies with a stricture have problems swallowing. The first sign might be that your baby becomes fussy with feeds. Stricture is treated with **dilation** (stretching the food pipe). This is a procedure where an instrument is passed through the mouth, under a general anaesthetic. The purpose is to widen the narrowed oesophagus. It is often needed where there has been a period of swallowing difficulties.

Reflux

When milk/food moves up from the stomach to the oesophagus it is called **gastro-oesophageal reflux, also known as GOR**. This may cause a baby to vomit, but not always. Reflux is treated using a combination of practical procedures and medicines. Practical procedures include:

- keeping the baby upright after feeds,
- giving small frequent feeds,
- thickening the feed.

Babies who are troubled by reflux often cry and may be difficult to settle. It is important to tell the surgeon or nurse about this behaviour as reflux can irritate the oesophagus and increase the chances of stricture.

Respiratory problems

Many TOF children are more likely to get coughs and colds in the first few years. However, it is likely to improve by the early school years. Close contact with your doctor will help you cope with your child's needs. Physiotherapy exercises may help and can be taught at the hospital by a trained physiotherapist. These can be done at home quite easily and help when your baby has a cold. Many, but not all TOF children suffer from what has become known as the TOF cough. This is a harsh, brassy cough, which sounds as if the child is very sick. Remember, this does not mean that your child is sick. Sometimes swallowing difficulties remain but usually children learn to cope with this on their own.

Acknowledgments

Some of the information for this fact sheet was gathered in a long-term study of TOF children undertaken at The Children's Hospital at Westmead in conjunction with the [Children's Medical Research Institute](#). Sixty-two children over the age of ten who were successfully operated on when they were babies were interviewed along with their parents. We are very grateful to these young people and their parents for giving us the benefit of their experience to help others in similar situations.

Remember:

- Most cases of TOF are normal by the time children get to school.
- As your baby grows you will need to add solids and increased varieties of foods. There really is no reason to delay the introduction of solids (always in consultation with your baby's doctor). TOF children may take longer than usual with the introduction of solids into their diet