Tracheo-Oesophageal Fistula (TOF) and Oesophageal Atresia (OA)

A short guide for parents, teachers and carers
“There is definitely a need for this kind of information and I am sure it will become a valuable resource for parents, teachers, and others caring for children with TOF/OA.”

Bruce Jaffray, TOFS patron and Consultant Paediatric Surgeon, Royal Victoria Infirmary, Newcastle.
A message to parents

Leaving your child in the care of someone else for the first time is a big step and can be an anxious occasion for all parents. This is especially true for the parent of a child with tracheo-oesophageal fistula and/or oesophageal atresia.

In order for your child to develop and grow up, and so that you can have some time and space for yourself, it is necessary that you are able to develop the ability to trust others fully with your child. The babysitter, carer or teacher will, of course, need to know about your child’s medical problems and needs, but they also need to understand your fears and concerns. Communication is the key – you must take the time to explain your child’s needs and to talk honestly about any feelings you have about the situation.

TOFS has produced this booklet to make it easier for you to take this step, either in your home with a babysitter, at nursery, or at school with a teacher. We have many years of experience of working with families of children with TOF/OA, and understand the issues that face parents at times like these.

In this booklet we have included *brief descriptions* of the problems children with TOF/OA commonly face, so that your child’s carer or teacher can learn about them and refer back to them when necessary. Every child with TOF/OA is different so we have included an example of a statement from a parent of a child with TOF/OA and suggested topics for you to include in your own child’s personal statement. You may wish to ‘edit’ this booklet by adding notes in the margins or crossing out paragraphs that are not relevant to your child.
Introduction

Who is this booklet for?
This booklet contains information about the congenital conditions tracheo-oesophageal fistula (TOF) and oesophageal atresia (OA). It describes what these conditions are and the kinds of problems that can be faced by children born with them. It also contains general information and practical suggestions on how to minimise these problems and what to do should they occur.

This booklet is intended as a general guide for anyone who has the role of teacher or carer for a child with OA or TOF.
This can include:
- family members
- babysitters
- nursery nurses
- lunchtime supervisors
- teachers.

The booklet contains practical information about these conditions and some of the issues that you may come across when caring for a child with OA or TOF.

Please note
Please be aware that this is a general guide. Each child with TOF/OA is different and will have developed their own individual way of coping with their condition. We suggest that this booklet should be read and kept along with a personal statement from the parents outlining their child’s specific needs (see example on page 14-15).
What are tracheo-oesophageal fistula (TOF) and oesophageal atresia (OA)?

Tracheo-oesophageal fistula (TOF) and oesophageal atresia (OA) are rare congenital conditions of the oesophagus (food pipe) and/or trachea (airway) that affect new-born babies. These conditions are nearly always diagnosed at birth and require surgical correction shortly after birth and long-term follow up. Some children have to undergo additional surgical interventions further on in their lives. Approximately one in every 3,500 babies is born with one or, more commonly, both of these potentially life-threatening conditions.

*TOFS (Tracheo-Oesophageal Fistula Support)* provides information and support to families of children with TOF/OA.

For further information on the condition, please contact us through the details listed on the back page.

**Oesophageal Atresia (OA)**

In oesophageal atresia, the baby is born with a pouch at the top of its oesophagus (food pipe), which prevents food from reaching the stomach.
Tracheo-Oesophageal Fistula (TOF)
In tracheo-oesophageal fistula, the bottom end of the baby’s oesophagus is joined to its trachea (windpipe). Without surgical intervention, this causes air to pass from the windpipe to the foodpipe and stomach. It can also allow stomach acid to pass into the lungs.

TOF and OA usually occur together but can, less commonly, occur alone.

In the vast majority of cases, both of these abnormalities can be corrected in one or more operations taking place within days of birth. After surgery, children who were born with TOF/OA vary in the difficulties they experience, but most will have feeding and/or respiratory problems of which carers should be aware.

Other problems
About 40% of children with TOF/OA also have other problems that may or may not affect the child’s day-to-day life, such as heart, kidney or limb defects. TOFS publishes a range of other leaflets dealing with these (see back page for contact details).
The TOF cough
Children with TOF/OA often have a very characteristic cough. This loud, barking cough is caused by a floppiness (tracheomalacia) of part of the trachea (windpipe). The TOF cough can get worse when a child has a cold or other respiratory problems. It can sound alarming but it does not necessarily mean that the child is ill. If a child’s TOF cough worsens, it may be advisable for parents to seek medical advice.

Respiratory problems
Some babies with TOF/OA can experience short periods when they find it hard to breathe, due to the floppiness of the trachea. This is most likely to occur when a child is breathing heavily, for example when coughing or crying. Once the child relaxes, the airway opens up. Severe respiratory problems are rare, but if they occur, may require medical attention. Children usually grow out of tracheomalacia by the age of two and then only a minority of babies suffer severely.

Asthma and chest infections
They may also experience respiratory problems such as asthma and chest infections. Preventative action such as avoiding smoky places can help. Some children may be prescribed asthma-type inhalers. For more serious infections, children may need to take a course of antibiotics. Some children may require long-term, low-dose antibiotic medication to prevent repeated infections.

“His friends think his TOF cough is great ... It’s the parents who find it difficult as they keep assuming he’s ill.”
Parent of child with TOF/OA
Swallowing
Children with TOF/OA often have abnormal swallowing mechanisms and will have had to learn, or may still be learning, to cope with their particular feeding problems. Some may require a special diet, but many cope with school dinners or a packed lunch.

Getting food stuck
Sometimes food may become stuck in the child’s oesophagus, either due to the abnormal swallowing mechanisms or due to a “stricture” (a narrowing of the food pipe at the site of the original surgery). If an obstruction occurs, it can cause the child to feel uncomfortable, choke or be sick. For many children with TOF/OA, this is quite a regular occurrence and much less alarming to them than those around them. In most cases school-age children will be able to help themselves with the help of a drink or by regurgitating the food into a napkin or the nearest lavatory or sink. Children frequently

“We took the option of giving our son a packed lunch with foods that we knew he could swallow safely with relative ease, and with the dinner ladies well briefed, the journey into eating “unsupervised” was started. We made sure that he always had a drink in his lunch box and that, if he finished first, then a dinner lady or teacher would ensure that he had another one ready.”

Parent of child with TOF/OA
develop their own particular vocabulary to describe these events, such as “stuck” or “blocked”.

Reflux

Some TOF children suffer gastro-oesophageal reflux where the contents of the stomach can wash back up the foodpipe. They are very easily sick.

Placing babies on their backs

Placing babies on their backs, as promoted by the Foundation for the Study of Infant Deaths, has significantly reduced the number of cot deaths in recent years. This practice is important when caring for babies and very young children with TOF/OA, whether they are awake or asleep.

For more information, see the TOFS leaflet *Tracheomalacia and the TOF Cough*.

“Our son is in a mainstream primary school, with his own lunches and integrated totally into his school. All the children and staff know he has a problem, but play it down magnificently. At the same time they are all prepared and trained to deal with any issue.”

Parent of child with TOF/OA
How to minimise potential problems

Don’t hurry me!
Lunchtime at nursery or school is a noisy, sociable time and most children want to wolf down their food and get outside to play. Children with TOF/OA are no different in this but they need to eat more slowly and chew their food thoroughly. Please do not try to hurry them.

Don’t distract me!
TOF children need to concentrate on the mechanics of eating rather more than other children. Whilst it is important that they are not treated differently to their peers, it might occasionally be appropriate to seat them with a couple of understanding friends on a quieter table where they will not be distracted.
**Drink up!**

Most children with TOF/OA must have access to plenty of drink with all food they eat, even snacks. The liquid helps the food pass smoothly into their stomach. They may drink more than other children when they are eating.

**I’m full!**

TOF children usually have small appetites, especially where reflux has been diagnosed. Eating little and often is easier for them than having large meals. It is inadvisable to make them eat more than they feel they can.

**Don’t embarrass me!**

Just like their peers, children with TOF/OA do not like to be made to feel different. Too much fuss can embarrass them. It is very important that as far as possible they join in with normal communal eating and that any extra supervision is low-key.
You are the experts on your child’s condition and you can ensure that teachers and carers have the best and most up-to-date information by attaching a ‘personal statement’ to your child’s school record folder and providing one to anyone who is to take care of your child. This statement should be updated regularly as your child develops.

To help you, here is an example of a real personal statement written by a parent about her son Freddie who has TOF/OA.

Freddie’s statement
Freddie was born with a rare condition called tracheo-oesophageal fistula/oesophageal atresia (TOF/OA for short). In brief this means that his oesophagus (food pipe) was not formed properly and stopped in a pouch, restarting a little further down. The problem was diagnosed shortly after birth and he had surgery to join the two ends together.

   Because of this surgery, Freddie has a ridge of scar tissue around his oesophagus. This means that food can easily become stuck; it also means that his swallowing mechanism is not as effective as it should be. For these reasons Freddie cannot always manage to swallow foods that do not break down easily - chunks of meat, hard raw vegetables, some fruit, doughy bread and ‘cloggy’ foods such as large bits of cheese. He also needs to drink plenty of fluids.

Signs to watch for
If Freddie gets food stuck he stops eating, shudders and may look distressed. He is aware of what has happened and, if able, will tell you that something has got stuck. If
he is coughing and/or gagging he will usually bring the food up. More often now it will eventually go down. He will then cheer up and tell you whether it has gone.

What to do
A serious choke requires normal first aid procedures; otherwise calm reassurance until it passes is the best thing to do. If he is in a room with lots of other children it would be a good idea to take him somewhere more private where no one is staring at him. Not only may Freddie become distressed when he gets food stuck, it can be alarming for other people to watch. He may refuse to drink anything while the obstruction is there but should be encouraged to drink as soon as he is able. If fluid goes down normally then no further action should be taken. The main thing is not to make a fuss and, once you are sure he is ok, to carry on as normal.

General
Freddie needs to sit down and eat slowly. He understands his condition but still needs to be reminded to chew his food properly and drink plenty. Even though I am providing his lunch and it will consist of foods he is normally able to eat, he can still choke if he bolts his food or cram too much in at once.

Note
We try our best to treat Freddie as a normal child and not to build up too much anxiety about meals and eating. Although it is always a possibility he may have a choke while at school, it is not likely. If you do have any queries or worries please don’t hesitate to mention them to me.
My child’s personal statement

What to include
A personal statement like Freddie’s can act as a useful reminder for others when they are taking care of your child.

Whilst there are some common issues experienced by children with TOF/OA, every child is different and has individual needs and habits. Developing your child’s personal statement for use with schools, play groups and baby sitters, will depend very much on your knowledge of your child.

However, there are some common themes you may want to cover:

Basic description of the TOF/OA condition:
“(Child’s name) was born with a rare condition called oesophageal atresia (OA for short) / tracheo-oesophageal fistula (TOF for short)”.  

OA
“This means that he/she was born with a pouch in his/her oesophagus (food pipe).”

TOF
“This means that at birth, the bottom end of his/her oesophagus (food pipe) was joined to his/her trachea (windpipe).”

“Because of his/her condition, my child has had to have serious medical interventions and continues to have specific health needs.”
(If appropriate) “He/she continues to have medical attention and may need to visit specialist medical centres, during school holidays or term time.”

Other aspects to include:
• Respiratory problems - the TOF cough, asthma
• Feeding - preferred and problem food/drink, mealtime routines
• Placing babies and children on their backs
• Activities - sports, P.E. and break time games
• Who to contact in case of problems - contact details
• Medication (if appropriate) - which medications, timings, where they’re kept and implications if missed.

Keeping up to date
Obviously, your child’s needs will change as they grow up, so include a date for review on the statement (e.g. six months / a year) and note this in a diary or calendar. This will act as reminder for you to review and update the information and send out the new version.

Further help and support
For help or support with writing your child’s statement, please contact the TOFS office. Details are on the back of this leaflet.
General information

TOFS (Tracheo-Oesophageal Fistula Support) is a charity that provides support and information to parents of children born with the medical conditions tracheo-oesophageal fistula (TOF) and oesophageal atresia (OA).

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Other brochures in this series include:
About TOF, OA and VACTERL
Information for GPs about TOF, OA and VACTERL

TOFS also provides information sheets on a wide range of topics. These are available free through our website, www.tofs.org.uk or from the office.

Our publication, The TOF Child, is available to buy from the office.

TOFS needs funding to keep producing information for parents, hospitals and carers. Please remember us when you are organising fundraising events.

Company registration number 2202260
Charity registration number 327735

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