

TOF/OA Discharge Advice

Children with an OA and TOF on their own and with no other associated problems have a good outlook with the majority growing up to live normal lives. The outlook for children with OA and TOF who have other difficulties varies depending on how severe these other problems are.

However, there are a couple of problems which may occur and which you should know about. They tend to happen most often in the first few years after the operation and improve as the child grows older. Chest problems can occur, which are sometimes serious enough to need a stay in hospital. These tend to improve with age, and have little effect on the child's breathing when older. Some children however, continue to have a distinctive 'TOF cough' but this is not at all serious.

The area of the trachea which was repaired may become floppy (tracheomalacia) which can cause breathing problems. If your child's breathing is very noisy or he/she is having 'blue spells', please take your child to your local hospital and contact the team at RACH.

Feeding problems may also occur due to the oesophagus narrowing where it was originally repaired (strictures). Sometimes it needs widening (dilatation) and this will be done in an operation under general anaesthetic. Some children also complain of problems with swallowing and need to have a drink with all food. This is often caused by the oesophagus not being coordinated but it can be investigated by a speech and language therapist, who can suggest treatment and exercises.

Some children who have had OA and TOF develop a problem with gastrooesophageal reflux. This is where the contents of the stomach flow back up the oesophagus causing pain and irritation. We start babies on an anti-reflux medicine after the operation to reduce the risk of this developing.

Weaning onto solid foods can also be more problematic for children who have had OA and TOF. It can take longer for children to adapt to food with chunks and certain foods, such as white bread, can cause problems. Children should remain on Stage 2 foods (puree with soft lumps) for longer than usual to reduce the risk of choking. Feeding should also be done under close supervision to reduce the risk of coughing and choking.

For more information about all aspects of TOF/OA issues see the TOFS Association website.

www.tofs.org.uk

You should seek urgent medical help from your family doctor (GP), local hospital or team at the RACH if your child:

- is coughing or choking when feeding
- has difficulty in swallowing saliva or feeds
- is failing to gain weight

PLEASE TELEPHONE TMBU FOR ADVICE, YOU MAY NEED TO COME TO THE ROYAL ALEXANDRA CHILDREN'S HOSPITAL TO BE SEEN.

01273 696955, Ext 4377/3450.