

Information leaflet for Parents

Oesophageal atresia (OA) and Tracheo- oesophageal Fistula (TOF) repair Discharge Advice



Congratulations on having your new baby. It is a daunting task taking any baby home from hospital especially if they have had surgery. We at Birmingham Women's and Children's Hospital will always be here to help and support you. Below are some of the areas that you may need to look out for over the weeks, months and years ahead.

Common Problems:

- Reflux
- Stricture
- Respiratory (breathing) problems.

Reflux: Many babies have frequent milky vomits (reflux). However TOF/OA babies are particularly prone to it. They may have been started on medication as treatment for their symptoms. It may also help to keep your baby upright after feeds for at least 30 minutes.

Stricture: A stricture is the commonest problem requiring surgical treatment after TOF/OA repair. It is a narrowing in the oesophagus, usually due to scar tissue, at the join between the two ends of the repaired oesophagus. Occasionally, a stricture develops lower down in the oesophagus, in this area it is usually due to reflux. Strictures are believed to be worsened by reflux. Acid from the stomach can damage the join in the oesophagus and leads to more scarring.

If a baby has previously coped well with feeds and then starts to have problems with swallowing, this may suggest a stricture.

Respiratory problems: Your baby may develop a characteristic cough, often referred to as 'the TOF cough'. This is due to a weakness in the wall of the trachea (breathing pipe) at the site of the tracheo-oesophageal fistula repair, and usually causes no problem to the baby.

Some babies however do have more problems with their breathing and may need help in an emergency.

What to look out for.

- Difficulty swallowing, refusing feed
- Drooling/dribbling of saliva
- Choking and spluttering
- Pain, that doesn't get better with pain relief.
- Difficulty breathing

If any of the above symptoms happen suddenly or your baby has any difficulty breathing, call 999 or take your baby to the nearest emergency department immediately. We would expect your local hospital to contact our on-call surgeon if there are any concerns.

If you notice your baby has a gradual change in their reflux or the amount or way they are feeding then contact your baby's consultant secretary during office hours via BCH switchboard (0121 333 9999) or contact your GP.

Treatment of stricture:

A stricture can be successfully treated by stretching the narrowing (called a dilatation). The procedure is performed under general anaesthetic. The baby is able to feed within a few hours and is often able to go home the same day or soon after. When you go home you will be given a discharge advice leaflet.

Basic life support: TOF babies are more likely to cough, splutter and inhale their food. The thought that you may one day need to resuscitate your baby is a frightening one. The need very rarely arises, however it will increase your confidence if you can learn some basic first aid techniques. Many units have 'dolls' on which you can practice resuscitation and videos demonstrating what to do.

Follow up: Following discharge home, your baby will have regular check-ups in the Outpatient Department in order to monitor their progress and to answer any questions you may have. We will send you details of your outpatient appointment in the post, soon after you leave hospital.

Long term outlook: Some TOF children will go home and have very few problems following surgery, however others may experience feeding difficulties and chest problems, and a few may require further surgery. The problems are usually at their worst in the first two years of life, and problems after five years of age are uncommon.

Further information and support: The surgical unit will contact Your GP and Health Visitor before you go home to provide information about any potential problems and any medicines, equipment or special supplies needed.

The team looking after your baby will be happy to answer any further questions you may have before discharge.

For more information and support you may find the following websites useful:

Web site www.tofs.org.uk TOFS offers a range of leaflets about aspects of TOF, OA and VACTERL. These may be useful to you, your doctor and anyone involved in the care of your baby as he or she grows up.

Contact a Family: www.cafamily.org.uk

Contact numbers: If you have any concerns after discharge you can call for advice.

Neonatal Surgical Ward, Birmingham Children's Hospital Tel. 0121 333 9022

Looking after and sharing information about your child

We have a duty of care to help patients and families understand how information about them is kept and shared and we include the following information in all our patient leaflets:

Information is collected about patients relevant to their diagnosis, treatment and care. We store it in written records and electronically on computer. As a necessary part of that care and treatment we may have to share some patient information with other people and organisations who are either responsible or directly involved in the patient's care. This may involve taking the patient's information off site. We may also have to share some information for other purposes; such as research etc. Any information that is shared in this way will not identify the patient unless we have the patient's and parent's/carer's consent. If you have any questions and/or do not want us to share that information with others, please talk to the people looking after your child or contact PALS (Patient Advice and Liaison Service) on 0121 333 8403.

Birmingham Women's and Children's NHS Foundation Trust
Steelhouse Lane Birmingham B4 6NH
Telephone 0121 333 9999
Fax: 0121 333 9998
Website: www.bwc.nhs.uk

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By your side