

Going home from hospital

Content provided by JM Beck, Consultant Paediatric Surgeon, and Penny Seymour, Neonatal Surgical Outreach Sister, The General Infirmary at Leeds.

Leaving the hospital

Taking your baby home is a big step which feels very scary – but is something that you will also be looking forward to.

Planning and preparing for discharge will help to give you the confidence you need to handle any difficulties which may arise. You will then know where to look for support, help and advice in case of problems and what to do in an emergency.

VACCINATIONS

It is important that your baby is protected from the common infectious diseases of childhood, so the full standard vaccination programme is essential.

Despite the fears and worries periodically raised about vaccination, it is beneficial – and for TOF babies the prevention of whooping cough is particularly important.

Preparing for discharge

Babies born with OA/TOF can develop further problems after they have been discharged from hospital. It is important that you have the opportunity to learn as much as possible about these potential problems before you go home.

The most common problems to be aware of relate to feeding, gastro-oesophageal reflux and respiratory difficulties.

INCREASING CARE RESPONSIBILITIES

As the time to go home approaches you will be encouraged to become increasingly involved in your baby's care.

If your baby is not being breast fed you will need to learn to make up and give feeds, either by bottle or tube. You will also have to measure and administer any medicines accurately and provide all the normal day to day care your baby needs.

There may also be 'add on' bits of care that you will have to be familiar with, like the management of tubes and stomas. If physiotherapy, suction or oxygen are still required in hospital by the time you are thinking towards discharge, then it is likely that your baby will continue to require this at home and such treatments will need to become part of your normal routine.

Medical and nursing staff will be spending time talking to you about your baby and what extra care, if any, you will need to learn about and continue at home.

Discuss your home circumstances and the level of support available to you with hospital staff; if there are problems they are there to help.

MAKE SURE YOU UNDERSTAND

When you are given explanations in hospital, do not allow professionals to get away with jargon that you don't fully comprehend. If terms are used that you don't understand, do not hesitate to ask for the advice to be repeated in simple language. Many parents report that nursing staff are far better at explaining problems and techniques in simple language than the medical or surgical staff.

BE PREPARED

The thought that you may one day need to resuscitate your baby is a very frightening one. The need very seldom arises, however it will increase your confidence enormously 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.

The transition period

On the day of discharge you will be leaving an environment where there is a team familiar with the care of babies with TOF/OA and associated problems.

The neonatal surgical outreach nurse, where there is one, provides an invaluable link between the hospital, the primary health care team and yourself.

Your GP and health visitor have, in all probability, never looked after a TOF baby before. The emphasis of their interest in your baby is on general well-being and child health issues, and they can offer a vast amount of experience of common childhood illnesses.

The surgical unit will contact your doctor before you go home to tell him or her about the problems which might be anticipated.

This information has been written for the parents of TOF children by TOFS (Tracheo-Oesophageal Fistula Support) – helping children born unable to swallow.

If you have any feedback on this leaflet, please use our leaflets feedback form which is available from either the TOFS office or our web site.

TOFS relies on money from membership fees, voluntary donations and other sources of charitable income to fund its activities.

Web site

www.tofs.org.uk

Address

TOFS,
St George's Centre,
91 Victoria Road,
Netherfield,
Nottingham NG4 2NN

Telephone

0115 961 3092

Fax

0115 961 3097

Email

info@tofs.org.uk

TOFS does not offer specific medical advice to parents.

We work only in a supportive role, offering emotional and practical support to meet the needs of parents and providing a source of information which complements that given by the specialist hospital.

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"On the day we left hospital I was very apprehensive as to what may lie ahead for him. I am pleased to be able to tell you, however, since bringing Craig from hospital that day, we have never looked back. I was always careful in the early days to ensure food was kept in small portions or reasonably mashed down to be on the safe side.

He is not under the hospital any more. The consultant has not seen him since he was nine and when we did see him it was always a happy event telling him how well Craig was."

Related leaflets from TOFS which you might like to read:

1. Feeding the TOF child
2. Communicating with medical professionals
3. Your TOF child in the care of others
4. TOF and the family
5. Looking after the TOF child (for babysitters and teachers)
6. TOF and the primary care team (for GPs and clinic staff)
7. Gastro-oesophageal reflux
8. Tracheomalacia and the TOF cough
9. Chest infections and 'wheeze'
10. Strictures
11. TOF: long term follow up
12. Conditions occurring with TOF/OA
13. VACTERL: an overview

These are all available from the TOFS web site (www.tofs.org.uk) or from TOFS office.

TOFS also publishes a book, 'The TOF Child,' which is suitable for both parents and medical professionals. Details are available from TOFS.

Equipment

If your baby needs a feed pump, suction or oxygen at home, this will be provided and you will be taught how to use it.

Ensure that you know who is responsible for the equipment – how to obtain fresh supplies, replacements and repairs. When you leave hospital you should have sufficient supplies to last you at least 2–3 weeks because it takes time for fresh supplies to be organised.

All these arrangements need to be planned in advance. You may find it useful to write down lists of the things you will need when you go home; you can then discuss them with staff on the ward. The more preparation you do before you go home, the less you have to worry about when you get there.

Feeding

The normal oesophagus is a coordinated muscular tube which actively passes swallowed drink and food from the mouth to the stomach. Such coordinated action is not present in TOF babies because of the lack of continuity between oesophageal segments. They are therefore liable to choke, splutter and inhale feeds.

TOF babies tend to take longer to feed. They may need more breaks during their feed, and suck more slowly to allow time for the feed to reach their stomach. Small, frequent feeds are often better tolerated.

Some babies seem more able to suck and swallow if the feed is made a bit thicker.

Feeding babies in an upright position helps milk to reach the stomach more easily.

Difficulty with feeding will be aggravated if there is a narrowing (stricture) due to scarring at the join between the upper and lower parts of the oesophagus. This problem may only become obvious when weaning to solids starts, so solids should be introduced into the diet with caution. If your baby has any problems with feeding, you should contact the surgical unit.

Medicines

If your baby is going home on medication, find out what it is, why they need it and how long for. Practise measuring it out and giving it before you leave the hospital.

Physiotherapy

Chest physiotherapy is used to encourage drainage of secretions from the lungs in babies producing excessive secretions and/or tending to inhale or aspirate feed or saliva. It may be needed by some TOF babies at home.

Additional problems

A number of TOFs have associated problems which may add to their care. These considerations will have been described to you if your baby is affected, and any care procedures fully explained.

Follow up

Prolonged hospital follow up will be necessary; its purpose is twofold:

- i) to check on your baby's progress – both the particular medical problem(s) and general growth and development
- ii) to allow you to discuss problems that have arisen at home and to try to answer any questions that you have.

The dosage of any medications may need adjusting to allow for the baby's growth, which is best assessed by routinely weighing the baby at each check-up.

Advice on weaning and the introduction of various foods may be given, including advice on types of food to avoid. If any problems are being experienced, arrangements for further investigations and treatment may be made.

If you are worried, the neonatal unit or ward where your baby was nursed will be happy to speak to you over the telephone, or to make arrangements to see your baby if necessary. Keep a record of important telephone numbers next to your phone.

It is not always possible to predict which babies will develop problems, so it is wise to be prepared. The more complicated your baby's surgery, the more likely they are to have difficulties with swallowing or feeding at some stage.

If your baby does have problems, be reassured that they will diminish with time.

**IF YOU'RE NOT ALREADY
A MEMBER OF TOFS,
WHY NOT JOIN US?**
Information available
from either TOFS office
or the TOFS web site.

