Feeding the TOF child

Content in association with JWL Puntis BM DM FRCP FRCPCH, Consultant Paediatric Gastroenterologist, The General Infirmary at Leeds

Although some children born with OA/TOF have no feeding difficulties, in most some problems should be anticipated – however, children vary enormously in the level of difficulty they experience and it is hard to make clear predictions when the baby is tiny as to what limitations on swallowing may emerge.

This leaflet sets out to describe:

- the child's feeding needs, and some reasons why problems may arise
- the role of medical professionals and other organisations in helping parents and children overcome difficulties
- some guidelines based on the experience of parents who have successfully fed young TOF children

Breast and Bottle Feeding

Ideally, mothers should be encouraged to breast feed as soon as oral feeding is permitted. In a survey, no mothers who did breast feed reported giving up due to difficulties related to a TOF repair.

Mothers who choose to breast feed need early advice and plenty of support from staff on the neonatal ward regarding techniques and equipment for expressing their milk, and later from health visitors. Other sources include The National Childbirth Trust (*see panel on last page for contact information*).

Many TOF children are breast fed successfully, but there are a host of reasons why mothers may not manage to breast feed – even when their children have no swallowing problems. TOF mothers should not feel guilty if breast feeding does not work for them – particularly in situations when the join up operation has been delayed.

Parents often feel apprehensive when they first take their baby home from hospital. Early feeding by breast or bottle should be unhurried; many parents find it easier to relax and gradually get to know their baby's individual needs away from the hospital routine.

Delayed Anastomosis

Babies who cannot have their oesophageal atresia joined up early on should be given a cervical oesophagostomy and receive 'sham feeds' by mouth until a join up can be performed. This gives them experience of the taste and feel of food in their mouths, and of the process of swallowing. Children who have a late join up operation are reported to have a similar frequency of feeding difficulties as other TOF children.

Weaning and Solid Foods

Many parents need support when it comes to weaning and eating. Families should be encouraged to ask to see a dietician before they start solid feeding – and at any time when they are concerned about the child's weight or eating patterns. Speech therapists can also be an important resource for the child who is reluctant to feed. Day-to-day support may be provided by the GP and health visitor.

Weaning from a totally milk diet should be started at around 4-6 months – as with any other baby. Children are particularly receptive to new tastes from around 4-6 months of age, and their preferences become more conservative if their experience at this time is limited. That said, it is important to work at the child's own pace and physical capability. Many parents report that, in spite of a slow start, their TOF child has adapted well to a varied and healthy diet in later life.

Weaning is likely to take more time for a TOF child, and should be handled in as unhurried and relaxed a way as possible. The baby should be held relatively upright to assist swallowing, and parents should introduce new flavours and textures very gradually – observing the child's response to each.

Try to distinguish between foods which the child dislikes and those with which he/she cannot yet cope.

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 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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If adapting to solid food proves problematic, make use of the fact that a child who enjoys a particular flavour or texture is more likely to be motivated to learn to eat that food rather than a possibly more nutritious, but less tasty, alternative. Remember also that children love to copy other people and will often increase their intake when they eat with others.

Young children tend to bite and swallow food, often without chewing it completely. Speech therapists can often give useful advice on encouraging TOF children to chew properly from an early age.

Finger foods can sometimes be a problem for TOF children and should therefore be closely supervised. Some suggestions are offered in the second part of this leaflet, but parents will soon discover which foods best suit their child.

Feeding is not just about correct nutrition – it is also of great emotional and social importance. It is vital to balance the TOF child's needs with those of the whole family, so that meal times are as pleasant as possible for all concerned.

Troublesome Foods

Feeding problems generally do get better with time, however some TOFs may continue even in adult life to associate swallowing problems with certain types of food which they then avoid. The most frequently identified 'problem' foods in the TOFS survey were meat (37% of children), apple (23%), bread (23%), oranges (14%) and raw vegetables (12%). These are foods which take longer to grind up when chewing and tend to be swallowed as larger lumps.

Some children have their own peculiar 'problem foods' – meaning that it is often impossible to predict whether or not particular foods will cause difficulties in any one individual.

Feeding Difficulties

Reluctance to feed can arise in any child who has been very ill and/or unable to eat, and therefore deprived of normal oral stimulation.

There are a number of other reasons why TOF children in particular have feeding difficulties, including oesophageal incoordination, stricture and gastro-oesophageal reflux.

OESOPHAGEAL INCOORDINATION

Normally, food is propelled through the oesophagus by a wave of muscle contraction which sweeps it along down to the stomach. In TOF children, this process is never completely normal (even in the child without symptoms). Coughing or choking occurs when incoordination of the oesophageal muscle means that food or fluid stays in the oesophagus and spills back into the trachea. Sometimes on a radiograph, fluid can be seen to go up and down the oesophagus like a yo-yo.

STRICTURE

Less commonly, there may be a narrowing (stricture) at the point in the oesophagus where the surgeon has joined the two ends together, which simply doesn't open up to let food through. This is usually caused by a natural process of scarring as the wound heals, and is treated using dilatations (stretching).

OESOPHAGEAL OBSTRUCTION

This can be either 'functional' (due to incoordination of the oesophageal muscle, so that food is not propelled down to the stomach) or 'mechanical' (due to a stricture i.e. a physical narrowing of the oesophagus due to scar tissue such that solids cannot pass through).

Sometimes food – or an object swallowed by a child ('foreign body') – may get stuck in the oesophagus and cause a blockage (obstruction). Whatever caused the blockage, an obstruction may mean that swallowing even saliva from the mouth is impossible.

If the child becomes very distressed or the blockage fails to clear within an hour or two despite taking sips of water, hospital assessment will be necessary. You should telephone your local paediatric unit and arrange to go to the ward. This kind of problem is more common in the early years after surgery and rare beyond ten years.

GASTRO-OESOPHAGEAL REFLUX

The unpleasant symptoms of reflux can be sufficient to put a child off eating. *See separate leaflet on reflux.*

Summary

Most children, once they have been 'joined up', have some degree of swallowing difficulties – although some seem to have no problems at all.

Experienced nursing staff, dieticians, speech therapists and occupational therapists may be able to give useful advice. Much practical and emotional support for parents struggling with feeding difficulties has come via support groups such as TOFS, from parents who have seen their children get over their problems and grow into strong and healthy adults.

The following pages offer a selection of tips provided by TOF families.

Feeding tips

The main thing to remember is to take things slowly and not to worry too much. All TOFs are different and you may find you have no problems at all.

A child with ongoing swallowing problems can however be very time-consuming and disruptive. Each family has its own cultural expectations, attitudes and preferences when it comes to choice of food and the way mealtimes are conducted. It is important to adapt feeding advice to your family's needs and habits, and to your child's tastes. Eating is very personal and only you know what is likely to work for your child in your home

Some of the following ideas – which have come from TOF parents – may be conflicting. There is no single solution to any TOF feeding problem, so finding the right solution for you may take time and a little experimentation. Observe your child carefully and you will become the expert in his/her needs. See also the TOFS Recipe Book, available from TOFS office.

Babies

SOLID FOOD – WEANING

- The hospital dietician or health visitor will advise on suitable 'first foods'. These can be adapted to suit the child's ability to swallow.
- Seek encouragement and support from other TOF families, who will be only too pleased to share their experiences.
- You know your child best. Take each day as it comes. Don't worry if weaning takes longer than usual - your child has had major surgery!
- To begin with, always puree then sieve food using lots of liquid such as fruit juice, tomato juice or gravy. Gradually offer slightly thicker food and observe how your child copes. Allow more time between spoonfuls to allow the food to go down; sips of drink may help to push the food down.
- Some parents advocate feeding the TOF child separately from the family to ensure that there are no distractions. Swallowing solid food can be hard work and the child needs to be able to concentrate and have his/her parent's undivided attention.
- Other parents integrate their TOF child's feeding patterns as far as possible into those of the family in the belief that meal times should be social occasions and the child will be able to learn more from imitating other family members .
- Work slowly at the child's own pace and do not allow distractions such as TV when feeding.
- Keep lists of 'easy' and 'problem' foods. If a new food is difficult, go back to something easy and re-try the problem food after a week or so.
- Eating can be exhausting for both baby and parents. Find out when your child is most alert and introduce new tastes and textures at those times of day. Perhaps there are times when the child is too tired to eat, in which case there is no harm in substituting the comfort of breast or bottle, or relying on favourite foods – even if the diet seems monotonous to you.
- You may find that your child's ability to cope varies from day to day. Eating ability always deteriorates when a child is unwell. Do not be afraid to go back a stage if this is the case. Any noticeable regression over a period of days, which is not obviously related to a specific problem such as a chest infection, should be investigated by your consultant.
- If you are concerned about slow weight gain, your health visitor or dietician can advise on higher calorie foods or dietary supplements.
- If the child chokes on pureed food or textured food such as baby rice at first, offer tastes of liquids such as fruit juice and meat juice. Use a small quantity of instant powdered food to very slightly thicken a normal milk feed or mix with expressed milk. This way the child will experience new flavours even if he/she cannot manage new textures.
- Get to know your child's taste preferences. Some children (and adults!) have strong preferences for sweet or savoury, soft or crisp, wet or dry foods, and the TOF child will be most motivated to learn to eat the type of food he or she prefers.
- Many young TOF children cope better with small but frequent amounts of food. Eating may take far more effort for a TOF child so he or she may simply feel too exhausted to eat normal portions and will lose interest. It is both frustrating and tiring to persist when the child has given up.
- Introduce new textures gradually. Most TOFs have difficulty swallowing foods which do not disintegrate readily, such as bread, meat, vegetables, fruit, grains of rice and cheese. These can be pureed and later mashed or chopped to the right consistency, but whatever the consistency of the food, you should encourage your child to chew at every mealtime. Ask your medical adviser for a referral to a speech therapist for advice on teaching your child how to chew.
- Beware – second stage commercial baby food often contains lumps, such as whole peas, which are too large for some TOFs to swallow.

FINGER FOODS

Finger foods are important in all children's development, but can represent a minefield for TOF children. No absolute recommendations can be offered and parents are advised to experiment to find out their child's abilities.

For many TOF children, the earliest finger food they can manage is what would otherwise be classified as

Related leaflets from TOFS which you might like to read:

1. Gastro-oesophageal reflux
2. Strictures

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.

Additional resources:

The National Childbirth Trust offers information and support related to breastfeeding.

National Childbirth Trust
Alexandra House
Oldham Terrace
London W3 6NH

Tel: 020 8992 8637
Fax: 020 8992 5929

Website:
www.nct-online.org

'non-food' – such as puffy crisps (e.g. Wotsits), meringues or sponge fingers, which dissolve in the mouth and do not have a tendency to swell in the gullet if swallowed whole by accident (such foods are often referred to as 'bite and dissolve' foods). They are important in giving the child an early experience of 'solid' food in the mouth.

Foods to treat with caution include:

- Slippery foods such as bananas and slices of ripe pear or peach – they can be difficult to control in the mouth, so may slide down and get stuck.
- Rusks – which may soften easily in the mouth, but which may still contain lumps when swallowed.
- Fibrous foods e.g. cooked vegetable.
- Doughy foods such as bread and toast; shop around for substitutes such as CrackerBread/toast type crackers.
- All types of meat unless pureed.

Toddlers

Once a child becomes more mobile, supervision is needed to ensure that 'unsafe' foods are kept out of the child's reach; older children need to be trained not to share food with the TOF child without permission. Unsuitable foods may also be offered by well-meaning adults – to whom it may be difficult to explain that your child can cope with some foods but not others. Some parents find the 'Do not feed me' badge available from TOFS is helpful.

Many children find eating easier if food is accompanied by a suitable smooth sauce e.g. gravy, cheese sauce, mayonnaise, ketchup, French dressing, salad cream.

Generally, soft or processed meats (such as chicken or sausages) are easier to eat than fibrous meats (such as pork and beef) unless well cooked, and minced or finely chopped.

Some parents have found that fizzy drinks can help clear 'stuck' food.

DRINKING PROBLEMS

A few children, especially those who are not joined up soon after birth, experience difficulties swallowing fluids and a little experimentation may be needed to find out what will work best for the individual child. Some parents report that babies who never mastered the techniques for sucking from a bottle take easily to a 'feeder' cup with a spout (such as Tommee Tippee) or to a plastic drinking straw – probably because they can then control the flow of liquid.

Older Children

Many TOF children in their first years at school need mealtime supervision and suitable provision should be made by the school. For further advice on obtaining support, contact the TOFS Education Officer (*tel. no. from TOFS office*).

Young school age children may still benefit from the 'little and often' pattern of eating. They should also be allowed plenty to drink while they are eating. Discuss this with the school so that staff are fully aware of the child's needs.

If low weight is an issue, study food labels to find higher calorie alternatives. The calorie content of food for older children can be boosted by adding butter, olive oil, cheese, cream, evaporated milk or fromage frais – or supplements such as Build Up and Complan. Your dietician or GP may also be willing to prescribe high calorie supplement drinks.

An older child may feel frustrated by his/her inability to eat as fast as the rest of the family and these issues should be discussed openly. Snacks between meals may be an option and permission to eat alone occasionally may be a welcome treat.

Eating in Public

With forward planning and imagination, the family need not be deprived of treats such as eating out. Some families feel more relaxed if the TOF child eats beforehand and is given a 'safe' snack at the table; others prefer to choose 'safe' food from the menu and mash or cut it as required. If sticking food is likely to be a problem, many parents take a small box with a lid to catch anything which is regurgitated, and choose a table with easy access to toilets for mopping up.