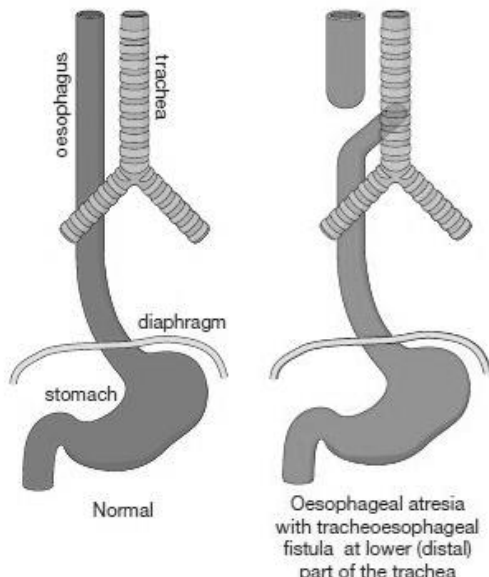


Feeding your child after oesophageal atresia and/or tracheo-oesophageal fistula repair: information for families

Oesophageal atresia (OA) and tracheo-oesophageal fistula (TOF) are both congenital (present at birth) problems. They can develop together or separately and are usually diagnosed soon after birth (or occasionally during a prenatal scan). Both conditions require repair with an operation under general anaesthetic lasting two to three hours.

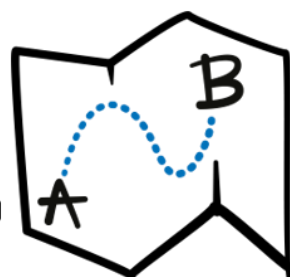
Once the repair has taken place, it can take some time for your child to completely recover. This information sheet from Great Ormond Street Hospital (GOSH) explains how best to feed your child following the repair operation and how to safely wean them onto solid foods around two years later. Suggestions contained in this information sheet are based on our extensive experience of looking after children with OA/TOF and promote safe feeding practices.

Note: Where specific foods are mentioned in this information sheet, including them does not mean GOSH is recommending them – other brands (including supermarket own-brands) may be available.



Oesophageal atresia (OA) is a rare condition where a short section at the top of the oesophagus (gullet or foodpipe) has not formed properly so is not connected to the stomach. This means food cannot pass from the throat to the stomach.

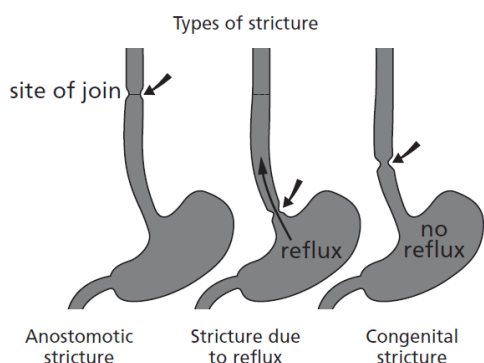
Tracheo-oesophageal fistula (TOF) is another rare condition, which tends to occur alongside oesophageal atresia. This is where part of the oesophagus is joined to the trachea (windpipe).



Why might my child have difficulty with food?

For some children with OA/TOF, weaning and feeding can be straightforward, whereas for others difficulties can occur. These difficulties can vary greatly from child to child. There are a number of reasons why children with OA/TOF might develop feeding difficulties as described briefly below:

- **Oesophageal incoordination/dysmotility** – Normally, the oesophagus squeezes food down towards the stomach using an action called 'peristalsis'. In OA/TOF this is impaired which means that food may move up, as well as down, the oesophagus, take longer to go down or get stuck.
- **Oro-pharyngeal dysphagia** – This means swallowing difficulties related to the mouth and throat. Children with OA/TOF may experience coughing with eating or drinking because of coordination difficulties in the throat that mean food or drink can more easily 'go down the wrong way'.
- **Stricture** – This is a narrowing of the oesophagus which can occur due to scar tissue from the repair or due to gastro-oesophageal reflux where the contents of the stomach flow back up the oesophagus instead of out of the stomach in to the small intestine. Very rarely, children are born with a stricture. If the oesophagus is narrowed, it may be difficult for food to pass through this section so may get stuck.



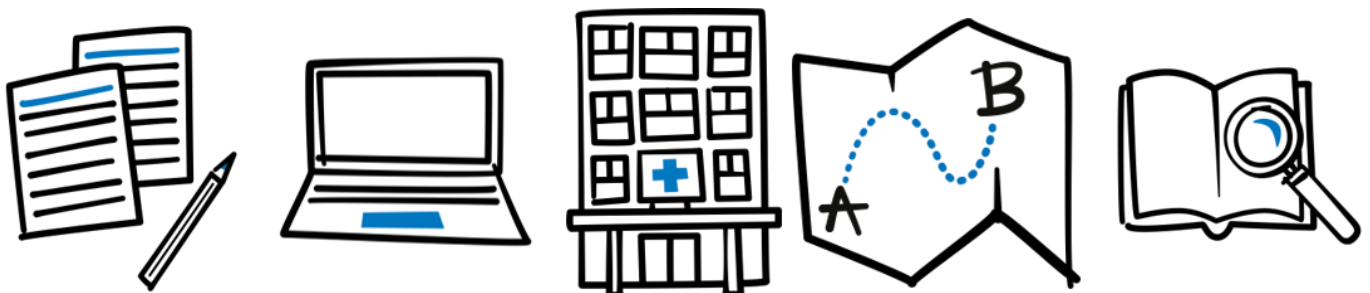
- **Delayed repair** – Children may have a delayed repair, often because the gap between the two ends of the oesophagus is too long to repair in one operation. They will usually be fed through a tube directly into their stomach which means that they might be slower to start feeding by mouth because they are not used to it or sometimes because they associate their mouth with uncomfortable procedures.
- **Gastro-oesophageal reflux** – Due to the coordination problems, reflux is also common in children following OA/TOF repair. Reflux is where acid from the stomach can travel back up the oesophagus causing discomfort and sometimes vomiting or choking. At GOSH we recommend all children with OA/TOF are treated with anti-reflux drugs.

Starting feeds

A few days after the operation, when the doctors are happy that your child's bowel is ready, they may suggest starting nasogastric (NG) feeding. A nasogastric (NG) tube is a flexible tube passed up one nostril, down the oesophagus into the stomach. You may also hear it referred to as a trans anastomotic tube or TAT. As well as 'venting' any air in the stomach, which could make your child uncomfortable, it can be used to give your child feeds directly into their stomach.

Initially, your child can have expressed breast milk which can be given slowly via the NG tube into their stomach. If you are unable to breastfeed, we will provide formula milk. Your child can continue to have NG feeds until the team feels it is time to start feeding by mouth, directly from the breast or bottle.

Your child will continue with milk feeds until they are ready to start weaning (that is, introducing food). If you have any worries about your baby's breast or bottle feeding or swallowing skills, please contact your clinical team – they will



arrange assessment with a Speech and Language Therapist and/or Dietitian if needed.

Weaning onto smooth purees

Most babies begin to develop head control and increased body strength by the age of six months indicating they are likely to be ready to start trying smooth pureed food such as baby rice.

You will see your surgical consultant in clinic around this time, this is a good opportunity to discuss weaning. We advise to wait until after this review before commencing weaning.

If appropriate you may be referred to a Speech and Language Therapist for advice and support.

A note about textures and stages of feeds

The International Dysphagia Diet Standardisation Initiative (IDDSI) was developed to make it easier to introduce foods in stages when someone has problems swallowing. Children with OATOF should aim to start weaning at stage 3 below.



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How to start

Choose a time when your child is wide awake but not over-hungry to introduce first purees. Remember that the first foods are more to introduce tastes rather than nourishment so just aim for a few small spoonfuls.

To start with, thin down the puree so it is only slightly thicker than your child's usual milk feed. Over the next two weeks gradually increase the thickness of the puree by adding less liquid. You are aiming for IDDSI level 3 (liquidised). This means that the pureed food will drip through the prongs of a fork.

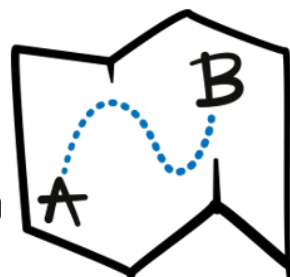
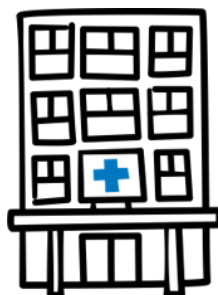
Stick to just one or two tastes for the first few days. This will help you see how your child is coping. It also means that if they have problems, you can work out which purees are more of a problem. When you know they are coping with the slightly thickened purees, you can start to introduce new tastes.

Suitable first weaning (IDDSI level 3) foods to try initially include:

- Baby rice or cereal mixed with your child's usual milk
- Well-cooked then liquidised vegetables and fruit, such as swede, broccoli, cauliflower, apple or pear.
- Liquidised fresh fruit such as banana, strawberries or blueberries
- Fromage frais or yoghurt without 'bits'
- Stage 1 baby foods (these are those labelled as suitable for babies aged between four and six months)

Use your child's usual milk feed to thin down the liquidised food.

Children with OATOF will probably make different sounds when they are eating – this is often due to tracheomalacia. However, if your child coughs



when feeding, goes pale or even a bit blue or sounds wheezy during and after feeds, call your clinical team. They may advise a review with a Speech and Language Therapist.

Don't be surprised if your child pulls a face or is unimpressed when they first try a new taste – this is a normal reaction so try it on a few more occasions before you put that flavour aside.

Let your child play with their food – touching and spreading it around. Let them put their hands in their mouths. Give them their own spoon that has been dipped in food so they can start to feed themselves. Wait until they have finished eating and playing before you start to clean up and wipe them down.

Aim for a balanced diet with plenty of variety:

- Starchy carbohydrates such as rice, cereals, porridge
- Fruit and vegetables
- Dairy products including milk, yoghurt, cheese
- Fats such as oils and spreads
- Proteins such as meats, poultry, Quorn™, fish, eggs, beans, pulses

To make sure your child's diet is nutritious, try to include protein sources even though they may be trickier to puree to the correct consistency.

Fibrous protein foods, such as meat, are best pureed when they are well cooked and tender.

Families have told us it is often easier to batch cook large amounts of a wide range of pureed foods which can then be frozen in portion sizes.

Children may find their meals more appealing if the different foods are pureed separately and put on the plate or bowl separately too. This means the foods stay a similar colour and flavour as they would be in solid form. Mixing food together before pureeing can result in a grey stodge that is unappetising.

Investing in a blender will help make the foods very smooth. The more expensive the blender, the smoother the blend.

Introducing drinks

As your child moves from thin purees to slightly thicker ones, give them some water to drink alongside. An open cup is best as this will help your child to develop the skill of sipping. You can use sippy cups, but we advise removing the top. No spill cups are not suitable as they need to be sucked so do not encourage your child to learn to sip. When out and about a 360 cup is a good alternative to a non-spill sippy cup. There are lots of brands available online and from department stores. Learning to sip water is important as the water acts a lubricant for more solid foods as your child's weaning progresses.

Moving on

Once your child is managing thin purees and sips of water, you can reduce the amount of milk feed you add so the purees become a bit thicker. These foods hold their shape on a spoon. When the spoon is tilted, the food falls off in one dollop.

Suitable thick purees (IDDSI level 4) foods to try initially include:

- Similar foods to level 3 but with less milk feed added.
- Pureed meat and fish or pulses such as lentils and beans.

Introducing food with texture

At around the age of one year, your child may be ready to try more textured stage 2 baby foods. The clinical team will review your child and discuss this with you before giving you the go ahead.

These foods can contain 'bits' but they should be very small – about a 2mm square initially. Foods



should also be soft enough to mash easily with a fork.

Suitable (minced and moist) IDDSI level 5 foods to try initially include:

- Pureed fruit such as strawberries or raspberries leaving in a few small seeds
- Add some couscous, quinoa or crushed Rice Crispies™ to a level 4 food to add a bit of texture.
- Pureed meat and fish or pulses such as lentils and beans or egg.
- Stage 2 baby foods – make sure they are described as textured rather than lumpy. If the ‘bits’ in it are too large, you may have to mash them down a bit before giving to your child.

Typically babies move on to increasingly textured foods at eight to nine months but children with OATOF must NOT move onto solids until they are at least two years old.

We realise that this seems like a very long time to be eating just pureed food but we believe that it is safer – unfortunately we are aware of children who have choked after introducing solid foods too soon. A pureed diet can still give your child all the nutrients and vitamins required for growth.

Introducing bite and dissolve foods

Your child will only learn to chew when they move on to firmer food textures. We advise trying ‘bite and dissolve’ finger foods at around eight months or age.

As well as eating skills, these will help your child develop hand/eye coordination – picking up foods and putting it in their mouth. The aim of bite and dissolve foods is that they ‘melt’ in the mouth so your child can swallow them easily but they still learn how to bite and chew. There are lots of different types of bite and dissolve foods available,

so try them yourself to judge how easy they dissolve before you give to your child. Many of these foods are available in the baby food aisle in a supermarket. Packets labelled “from six months” will melt most easily.

Bite and dissolve foods are usually snack foods, so should not form a large part of your child’s diet. See our *Bite and dissolve foods* information sheet for ready-made snacks.

Introducing more texture

When the clinical team is happy for you to introduce more textured foods to your child, we suggest taking this in stages as follows:

- Smooth thick puree – such as mashed potato or Weetabix® with less milk
- Well-mashed foods – mashed banana or avocado work well but remember to mash them just before you feed them to your child, otherwise they will go brown
- Small soft lumps in food – for example, mashed potato with small pieces of soft cream cheese.

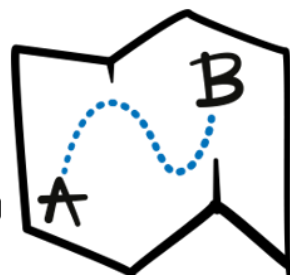
Suggestions

- Add sauces and gravy to foods to provide extra moisture to help swallowing
- Adding water to food before pureeing can dilute the goodness contained in it – try using milk, fruit juice, sauces, soup or gravy instead

Problem foods

Some foods are particularly problematic for children following OATOF repair as they tend to get stuck and cause blockages so you should avoid them:

- Doughy foods such as bread, doughnuts, pastries and thick crust pizza
- Raw apples and raw vegetables



- Citrus fruits, due to the pith (white stringy substance)
- Hot dogs, frankfurters and sausages
- Lumps of meat, poultry or Quorn™ that need a lot of chewing or are stringy – we advise you continue to puree meat even if your child is eating non-pureed vegetables or pasta. You can introduce non-pureed meat but it should be minced or chopped very finely and mixed with a sauce.

The following foods may be difficult for other reasons:

- Slippery food that might be swallowed too quickly – such as peaches or grapes
- Rusks – although they are soft when chewed they can form a difficult-to-swallow lump
- Fibrous or stringy foods such as some cooked vegetables

If you have any worries about your child’s feeding or swallowing skills or if their feeding with textured food changes or gets more difficult, this could be an indication of stricture or other problem. Please contact your clinical team immediately – they will arrange assessment.

Dealing with reluctance

Children who struggle to eat (or have rarely eaten by mouth) can show reluctance to try new foods. This is particularly problematic with children who have had an OA/TOF repair as one bad experience with food can put them off for a long time.

Further information and support

Talk to a member of the team if you have any questions.

You may also want to contact TOFS, the national support group for anyone affected by OA/TOF. Call them on 0115 961 3092 or visit their website at www.tofs.org.uk

The key is to carry on trying but to ask for help if you feel you are getting nowhere. There are plenty of people at GOSH who can help – dietitians, speech and language therapists and we also have a specialised feeding disorders team.

Good days and bad days

Every child – whether they have OA/TOF or not – will have good days when they enjoy food and taste and days when they seem to go backwards towards comforting foods they know well. Children with OA/TOF may struggle if they are unwell, for instance, with a cold or snuffles, or are teething, so don’t be disheartened.

You may worry that a setback means something more serious, such as a stricture. If you are concerned, contact your clinical team for advice.

Otherwise, it is fine to go back a step when your child is unwell and then reintroduce the next stage when they feel better.

We recommend parents keep a supply of ‘easy to eat’ foods in such as soups and milkshakes for these times.

Causes for concern

If your child is coughing or choking or food seems to get ‘stuck’ while eating and drinking, you should contact your clinical team for further assessment.

In an emergency, use the basic life support skills we have taught you while someone dials 999 for an ambulance.

