

# Jejunostomy tubes

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## What is a jejunostomy?

A jejunostomy tube is a specially designed tube through which your baby/child can be fed. It is inserted through the skin, and then runs either directly into the jejunum (a part of the intestines which lies a little way after the stomach) or into the stomach and then on into the jejunum.

Your child/baby will need a general anaesthetic for this procedure. The doctor will explain the operation to you, but it is important that you ask questions if you feel unsure about any aspect of the procedure, so that you fully understand what is involved.

The tube stays in place until it needs replacing or the child is eating enough that a jejunostomy is no longer required.

## What is a stoma ?

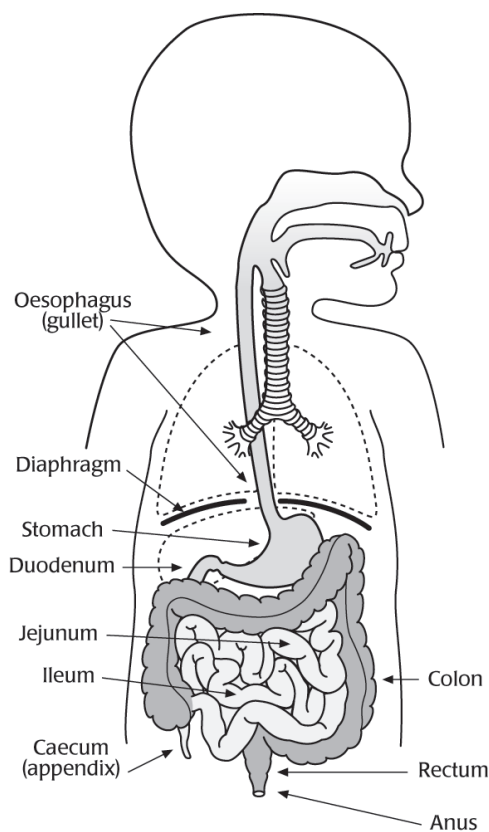
The stoma is the surgical opening in the abdominal wall through which the jejunostomy tube is inserted. The stoma is red and the size of a very small sultana.

## Why does my child need a jejunostomy?

If your doctor feels it is advisable for your child to be tube fed in this way, he/she will discuss this in detail with you.

However, there are two main reasons why a TOF child may need a jejunostomy:

- babies or children with severe gastro-oesophageal reflux (GOR) or poor gastric motility may benefit from jejunal feeding.
- babies or children who have undergone gastric transposition surgery ('stomach pull-up') cannot have a gastrostomy tube inserted (a feeding tube which runs into the stomach), so under these circumstances a jejunostomy tube is the only option.

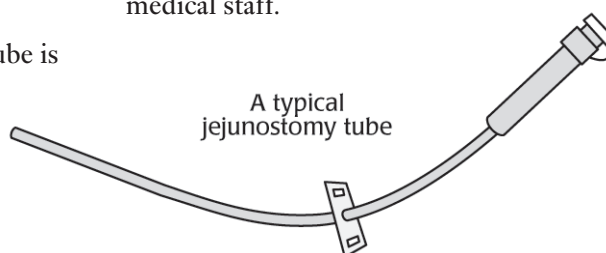


Feeds can also be administered directly into the jejunum via a tube which passes through the nostrils, down the throat, through the stomach and duodenum and into the jejunum.

## What sort of tube will my child have?

There are a variety of jejunostomy tubes available. The most appropriate tube will be chosen by the doctor after talking with you.

All tubes are all made from a soft material called silicone. Nursing staff will show you the ones available and how they are cared for. If you think it may be helpful to see the device or meet someone who has experience of a jejunostomy, ask the medical staff.



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](http://www.tofs.org.uk)

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## How do I care for my child's jejunostomy?

The principles of jejunostomy care are the same whatever kind of tube is used. Because the tube bypasses the anti-infection mechanisms present in the stomach, it is essential that a good standard of hygiene is maintained.

Before handling the jejunostomy site, whether for cleaning, feeding or anything else, wash your hands with soap and water.

Wear disposable gloves and ensure that the work surfaces where you are going to be when you handle the tube are clean and dry.

The skin around the site must be kept clean and dry; warm saline should be used for cleaning followed by careful drying with gauze swabs.

If the area becomes reddened (inflamed), seek medical advice. A bacterial swab may be taken to check for infection; if present, the child may need a course of antibiotics.

The site must be examined for leakage after feeds. If this occurs, medical advice should be sought. The surrounding area can be protected using a barrier cream and/or protective dressing; this is particularly important if the material leaking from the site is a greenish yellow colour, indicating that bile is present in the discharge.

## How do I feed my child?

Feeds to be given through a jejunostomy tube are special formulations which will initially be provided by the dietician and then prescribed by your GP.

A computerised pump must be used to deliver the feed slowly over many hours; nursing staff will teach you how to use the pump. If given too quickly, it may cause diarrhoea, abdominal discomfort and/or distension.

The tube must be flushed with sterile water (or boiled water which has been allowed to cool) on a regular basis:

- a) after feeds
- b) before, between and after any prescribed medication which is given through the tube (only give medicines which you have specifically been told are safe to use through a jejunostomy)
- c) at least twice a day to prevent the tube blocking.

## How should I position my child when giving a feed?

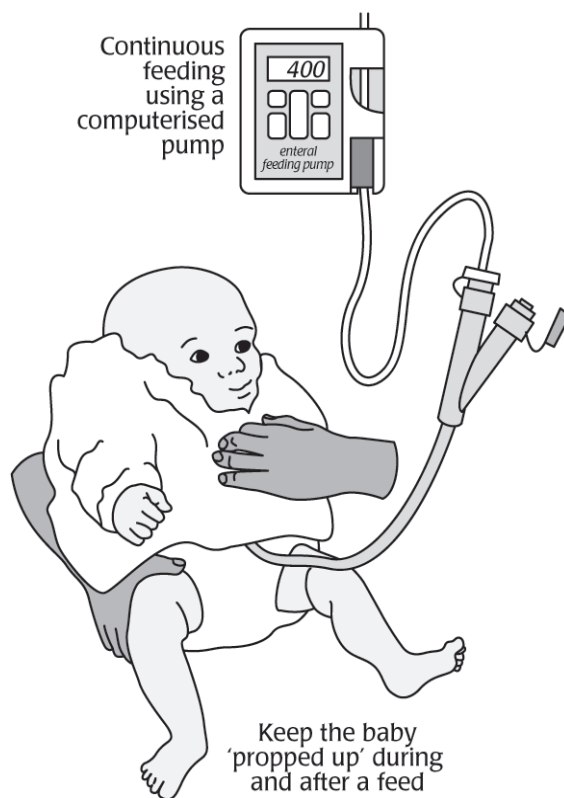
Try and make him/her as comfortable as possible. The best feeding position is sitting or 'propped up' because this helps the stomach to empty more quickly.

## Is there anything I can do while my child is having a feed?

It is important that your child has the chance to be with the family at mealtimes; mealtimes are social occasions and your child should be included. You should encourage your child to touch and taste food just like other children.

Children who have been fed by jejunostomy for a long time may develop to be poor feeders, so it's important to make their tube feeding experience as close as possible to a 'normal' mealtime so that the transition to oral feeds is as stress-free as possible:

- Let your child have something in the mouth to taste while they are being jejunostomy fed. This will enable them to associate the sight, taste and smell of food with the feeling of hunger being satisfied.
- Encourage your child to play with foods.
- Talk to your child at mealtimes.
- Offer plenty of praise and encouragement when small amounts of food are put in the mouth.
- Between meals, when your child is in the mood, encourage mouth games using the mouth and tongue e.g. blowing and kissing. This will get him/her used to having things in and around the mouth and will help them later with normal feeding. If he/she does not seem able to move food around the mouth and swallow properly, inform the doctor.



## What safety issues need to be considered?

It is important that the tube is correctly situated in the jejunum: the position can be checked by:

- a) ensuring that the length of the tube from the exit site to the cap remains the same
- b) ensuring that the tube flushes easily with water
- c) testing any fluid which flows back the tube for its acidity (pH) – it should be alkaline
- d) ensuring that the tape is well stuck down and looped correctly.

Cleanliness is essential: the equipment used to give feeds (the 'giving set') should be changed daily and the measures described previously (*under the section on caring for the jejunostomy*) should be followed whenever the tube is handled.

Make sure that the end of the tube is never inadvertently tucked into the child's nappy/pants.

### PROBLEM SOLVING

If the tube becomes stiff to flush or entirely blocked – which is usually due to a build up of fat on the inside – flush it with sterile warm water and consult medical staff.

If the tube is pulled out, it is important that it is replaced immediately if you have previously been shown what to do.

Alternatively, take the child immediately to hospital ... if the stoma is not kept open it may start to close within only a few hours.

## What about bathing or swimming with a tube?

Some types of jejunostomy tube are more flexible than others in usage, but it is possible to allow these activities for most children with a few preliminary precautions. Ask nursing staff for advice.

### Lastly...

Having a child with a jejunostomy will involve you some extra work and will inevitably be quite stressful at first, until you get used to the routines involved.

Try not to let feeding dominate your life – accept what help you are offered from friends and family, and remember that the hospital staff are there to answer queries and offer support when you need it.

Related leaflets from TOFS which you might like to read:

- 1 Nasogastric tubes
- 2 Jejunostomy tubes
- 3 Gastro-oesophageal reflux
- 4 Gastric transposition

These are all available from the TOFS web site ([www.tofs.org.uk](http://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.

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