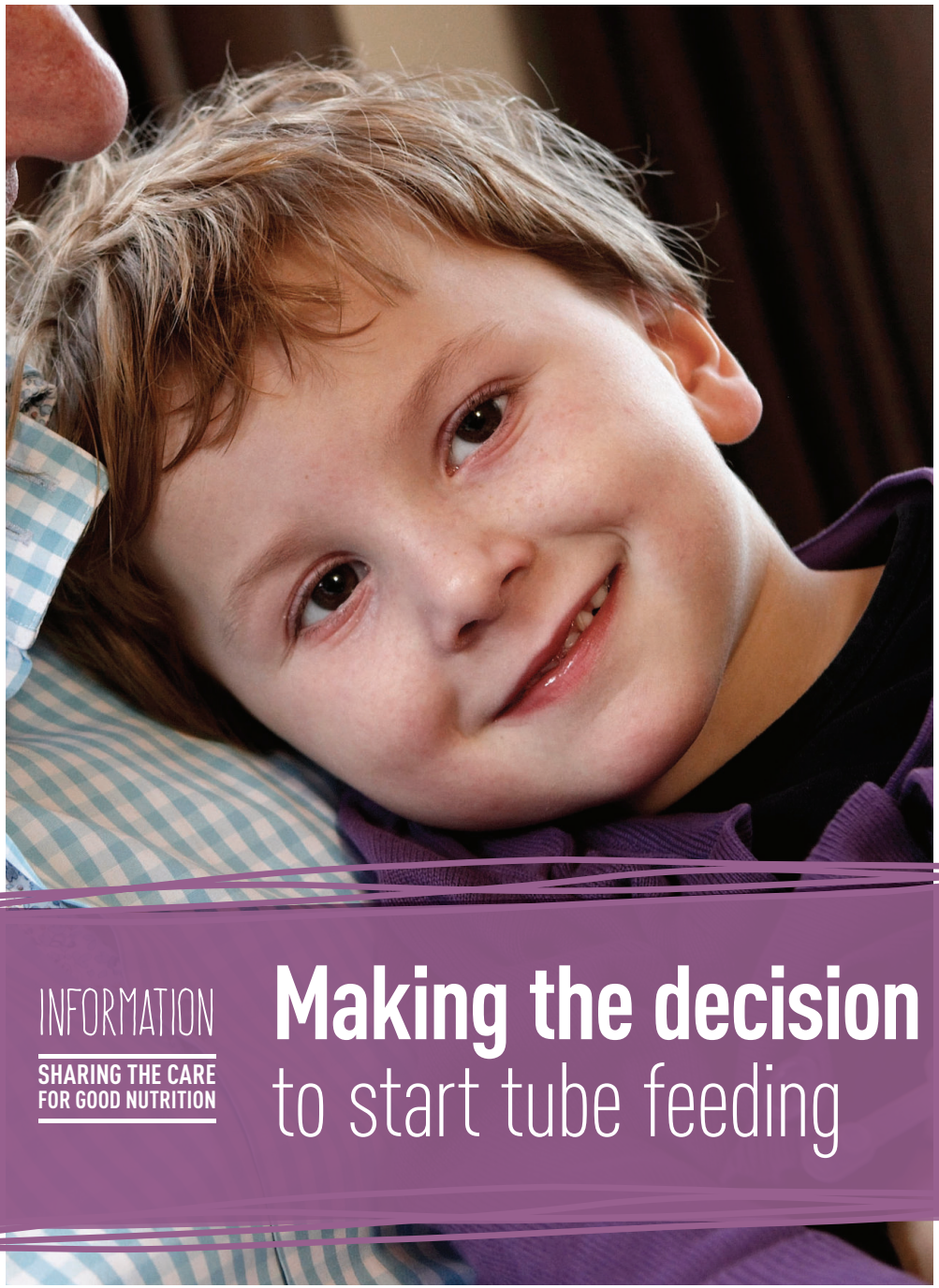


INFORMATION

SHARING THE CARE
FOR GOOD NUTRITION

Making the decision
to start tube feeding

Where can I find out **about tube feeding?**

If your child's doctor or dietitian has asked you to consider tube feeding for your child, you may be experiencing a mixture of emotions – perhaps anxiety, sadness, anger, even guilt. As a parent, of course you want what is best for your child. You want to see that your son or daughter is happy and healthy, but you may also worry that tube feeding in some way will take away the special bond created between you at meal times.

You are bound also to have a lot of questions:

How does it work?

How will I cope?

Where do I turn to for support?

Many parents have expressed these same concerns, and have asked for more information at this stage to help them make a more informed decision about tube feeding.

This is not a decision that you have to make alone

Your child's doctor, dietitian or nutrition nurse team should be your first port of call for information and advice about tube feeding. You also may be able to discuss your concerns with a friend, or to ask for advice from another parent or carer who is going through, or has been through, the same experience.

This guide has been developed to help you find out more about tube feeding, give you information on the more practical side of things and suggest other sources of information and support (see the list of associations and organisations on page 10).

Why has my child's doctor suggested tube feeding?

If your child is experiencing reflux and/or difficulties with chewing and swallowing when eating, your child's doctor will be concerned that he or she might not be getting all the nutrients he or she needs to grow, to play and to learn.

Enteral nutrition products are designed to meet the full nutritional needs of your child, allowing them to get all the nutrients they need. Tube feeding can support your child's growth and development, and in some cases improve their recovery and response to treatments.

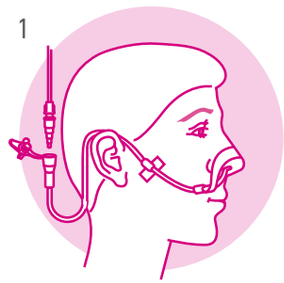
What does tube feeding involve?

If your child is experiencing feeding difficulties, tube feeding offers an alternative way of feeding that can be adapted to your child's needs.

To prevent the difficulties experienced by your child when taking food by mouth, food in a liquid form is introduced into a tube that goes directly into the digestive system. The ready to feed enteral nutrition is designed to provide all the essential nutrients and is digested as normal in the gut. Specific formulas are available, if your child has difficulty digesting and/or absorbing nutrients.

There are many types of feeding tubes, nasogastric (NG), nasojejunal (NJ), percutaneous endoscopic gastrostomy (PEG). These tubes are shown below: feeding via NG (image 1) or balloon gastrostomy (BG) tube (image 2). You and your child's doctor can discuss together which one is best for your child. There is also more information in our leaflet on the practicalities of tube feeding, which you can obtain from your child's doctor or dietitian.

1



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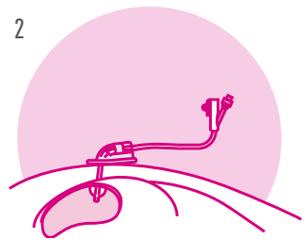

What do I put in the tube?

The decision about the type of enteral nutrition that you put into the tube will be taken by you in consultation with the other members of the team that looks after your child's health. Together you will decide what is best for your child.

Ready to feed enteral nutrition, made specifically for children who use a feeding tube, is ideal. This type of nutrition contains all the required energy, protein, vitamins and minerals your child needs at the different stages of his or her growth and development, and is designed to flow easily through the tube.

Did you know?

You may be able to give your child his or her medication through the feeding tube – a great benefit if your child has difficulties with swallowing or just doesn't like the taste of the medicine. Your doctor or pharmacist can tell you if your child's medication can be given in this way.

Your child's fluid intake can be controlled using the feeding tube. You can give water or liquid that your child would normally receive orally through the tube to avoid dehydration. It needs to be discussed with the dietitian/doctor if and how much water can be given per day via the feeding tube.

Can my child still take food by mouth once the feeding tube is fitted?

Some parents do continue to offer their child small amounts of normal food to eat in addition to tube feeding.

This not only allows him or her to enjoy the normality of eating different foods together with the family around the table, but also means he or she continues to use and develop the muscles of the mouth (e.g. whilst chewing). Remember, though, to check first with your child's doctor or dietitian in case there are any reasons why he or she should not also be fed in this way.

How will it affect family life?

When making the decision to start tube feeding, one of most parents' major concerns is the effect it will have on day-to-day family life. Typical questions include:

Can we still go out to the park?
Can we eat in a restaurant?
Can we go on holiday?
Can we still go to the seaside and swim?

Clearly these are important concerns, as sharing these and other experiences is essential to family bonding and is a key part of growing up and learning to be sociable.

The good news is that all of these activities should be achievable. In fact, the social elements of your family's life definitely can and should continue once the tube is fitted. In many ways, tube feeding can enhance relationships within the family by strengthening existing bonds and providing special moments to share. However, it is a good idea to ask your doctor for advice before undertaking outdoor activities.

Who is there to help?

When the decision has been made to start tube feeding, you will have a discussion together with your child's doctor and specialist care/support team (see below) to decide on the best options for your child. The team may include the following healthcare professionals:

Occupational and physical therapists focus on all aspects of your child's movement, including control of the mouth.

A speech-language therapist will assess and help your child's mouth control focusing particularly on speech, language and feeding.

The pharmacist supplies the medication and nutritional products that have been prescribed for your child and can give you advice on how it is to be taken.

A surgeon may be required to fit your child's feeding tube (but not all tubes require surgery).

Specialist nurses or members of tube feeding associations may carry out home visits to help you and your child with the feeding tube and to provide support and advice.

A dietitian is a specialist in food and nutrition and will be able to give you advice about the best feeding plan for your child.

School nurses may also be involved and will know what happens when the child is at school and potentially feeding, but may also put you in touch with other families who are already tube feeding.

Information, advice and support about **tube feeding**

www.pinnt.com
www.cafamily.org.uk
www.nutricia.co.uk
www.tubefeeding.co.uk

For more information please contact your **healthcare professional.**

Reading materials

The following are additional sources of information about tube feeding which you may find helpful:

How do you feel about tube feeding

Practical advice on the signs that may indicate that your child is ready to tube feed.

A practical guide to tube feeding

For a more step by step approach focusing on the more practical aspects of tube feeding.

Glossary of terms

Bolus feeding	A feed that is volume-dependant given over a short period of time
Clamp	A small device which, when closed, prevents leakage from the feeding tube
Continuous feeding	A feed that is given at a pre-set rate, continuously for many hours via pump
Endoscope	A thin and flexible tube that is passed through the mouth, and down towards the stomach (for investigation and tube placement)
Enteral feeding	Liquid nutrition that passes directly into the stomach or intestines
Extension set	Plastic tubing that can be attached between the feeding set and the feeding tube
Feeding set	A plastic tube that is attached to the bag with the feed on one end and the tube or extension set on the other
Flush	Water given to clear the feeding tube/extension tube
Gastric	Anything related to the stomach
Gastrostomy	An opening through the abdominal wall into the gastric cavity
Gastrostomy tube, G-tube	A device through which formula, fluids and/or medication can be given. A G-tube is placed directly into the stomach through an opening in the abdominal wall (stoma) and has a balloon end
Gravity feeding	Liquid nutrition that enters the stomach by force of gravity (i.e. placing the feed above the height of the stomach)
Nasogastric tube, NG-tube	A device through which enteral feed, fluids and/or medication can be given directly into the stomach. An NG-tube is inserted through the nose, passed down the oesophagus and enters directly into the stomach
Oesophagus	Referred to as the 'swallowing' tube – the path through which food and drink are moved from the mouth to the stomach
Oral	Anything related to the mouth
Overnight feeding	Liquid nutrition that is typically given during night-time, often by pump
Port	A capped opening at the end of the feeding set or extension set sized to fit a certain syringe
Pump	A device that delivers liquid nutrition through the tube at a rate and volume set by you
Pump feeding	Liquid nutrition that is given using a pump
Stoma	A surgical opening in the abdomen
Syringe	A medical device used to administer or remove fluid
Trachea	The 'wind-pipe' that carries air from the mouth to the lungs
Tube feed, formula	Specifically formulated liquid nutrition that can be tailored to individual needs
Tube feeding	Liquid nutrition through a special tube that enters directly into the stomach or intestine
NJ	An NJ tube is placed usually in hospital and can't be replaced in community. The tube is passed through the nose down the oesophagus and into the small bowel
Button	A low profile gastrostomy that sits at skin level, and is retained by a small balloon inside the stomach. These devices are usually changed every 3-6 months at home by a healthcare professional or yourselves if this is something that you want to learn to do
PEG	A Percutaneous Endoscopic Gastrostomy tube that is placed under general anaesthetic. There is a bumper inside to prevent it from coming out. The tube outside the body is approx 20-25cm long

Your notes...

Your notes...

Your notes...

About Carers UK

This guide has been produced in partnership with Carers UK, who work to make life better for carers.

- We're the UK's only national membership charity for carers
- We give expert advice, information and support
- We connect carers so no-one has to care alone
- We campaign together for lasting change
- We innovate to find new ways to reach and support carers

Visit our website to sign up for free membership and access our 24/7 forum, read our detailed help and advice, or support us: **www.carersuk.org**

Call our Helpline for expert information and advice about caring: **0808 808 7777** (open Monday to Friday, 9am-6pm) or email **advice@carersuk.org**

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