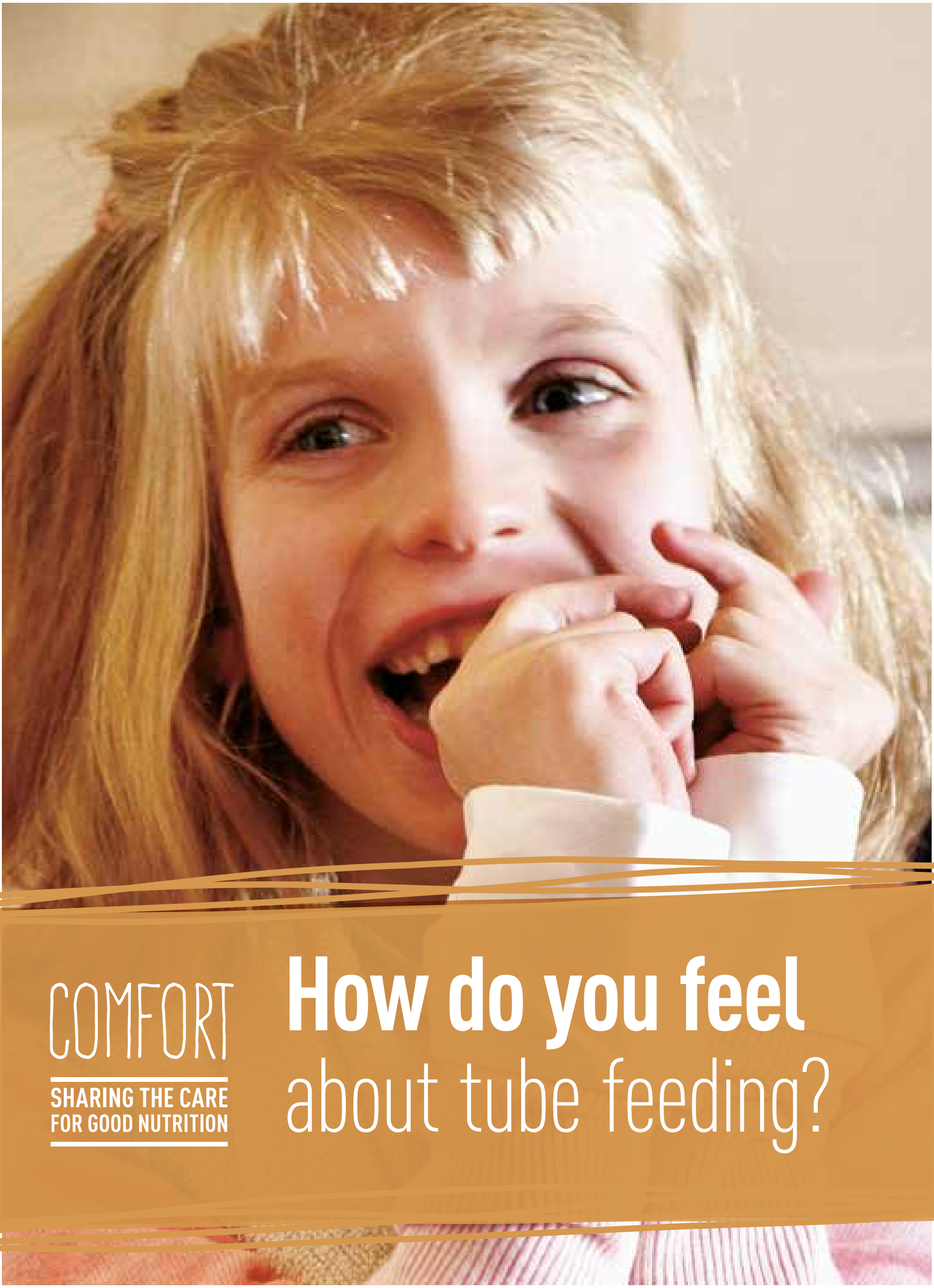


COMFORT

SHARING THE CARE
FOR GOOD NUTRITION

How do you feel about tube feeding?

carersUK
making life better for carers

Feeding the special relationship between **parent and child**

From birth, the act of feeding and caring for a child creates a strong and unconditional bond between you that is the foundation of a life-long relationship.

As you come to know and understand the needs of your child, you are driven to do everything possible to provide him or her with the very best, in particular ensuring that your child gets the nutrition required for good health.

> *"Feeding is not just a form of food, it's a way of life for me. It's a way of bonding with my child."*

The enjoyment you gain from spending time together, along with the natural instinct to do anything to help your child usually means that nothing is too much trouble; however, most parents experience frustrations with feeding their children at some time.

Seeing your child struggling to swallow or chew, or having problems with reflux or other eating difficulties, though, can be very hard and extremely upsetting. A natural response in this situation is to feel that you could be doing more at feeding time, and as a result try even harder to ensure your child is getting everything they need to grow and be happy.

*"I thought I was doing something wrong.
I tried everything, I fed him more times a day,
in a different position, in a different environment.
I tried everything, what had I done or not done?"*

Trusting your instincts

As a parent, you are aware of any small changes in your child's behaviour. You will soon notice, for example, if he or she is more tired than normal, or perhaps is not as happy as usual.

It is quite understandable in these situations for you to feel worried and concerned about your child's health and wellbeing. Similarly, it would not be surprising if you felt a little helpless if, despite doing everything you can when it comes to feeding in particular, your child's condition does not seem to change.

> *"When I noticed my child becoming more thin, pale and weak, I cannot tell you how difficult this was for me as a mother. Not being able to feed your child or even to comfort him, together with not knowing exactly how to help him was really hard to manage."*

This is, of course, another source of frustration that can make you feel worried about what needs to be done next, with the additional anxiety that your child might be suffering in some way.

Most parents will share these concerns and frustrations with a family member, close friend or other parent experiencing the same difficulties as you or a healthcare professional, who in turn has probably given you tips, advice and emotional support at this difficult time.

They also may have suggested that you think about tube feeding for your child. Although you might think that it is not necessary, tube feeding is an option that is sometimes raised when feeding through the mouth becomes too difficult and the body requires more nutrients.

This booklet has been put together because many parents with concerns about starting tube feeding for their child have asked for more support, advice and reading material after discussions with their child's doctor or dietitian.

Questions to consider when assessing your child's needs

Key questions	Red flags
How long does it take to feed your child?	More than 30 minutes, on a regular basis
Are meal times stressful to child or parent?	Yes, if one or other, or both
Is your child gaining weight adequately?	Lack of weight gain over 2-3 months in a young child, not just weight loss
Are there signs of respiratory problems?	Increased congestion at meal times, 'gurgly' voice, respiratory illnesses

Understanding your emotions at this time

The thought of introducing tube feeding for your child may cause you sadness at the thought of possibly losing the special relationship you have with your child, and concern that you may be depriving him or her of the enjoyment of different foods. You many also feel guilty about putting your child through more hospital visits.

> *"I just want to put the smile back on his face."*

It may help you to know that many parents have had these same feelings when their child's doctor or dietitian has suggested tube feeding.

Another fear you may share with other parents concerns the strain that may be put on the rest of the family.

All of these emotions are completely normal and quite understandable. Although tube feeding might seem to be the end of your special relationship with your child right now, it may in fact be a new beginning: allowing tube feeding to overcome the feeding difficulties that your child was experiencing may help you to continue to enjoy mealtimes with your child again.

The decision to start tube feeding is not necessarily straightforward and can be hard. The challenges that you and your child have already faced, however, will help to prepare you for the next step. Taking the decision to introduce tube feeding should not prevent you from continuing to share moments together and enjoying each other's company, including at meal times.

"He can do so many little things that show us that he loves us and he is happy… he has the best giggle ever."

Other parents' stories about starting tube feeding

The following (adapted from Kids with Tubes News) are stories from parents who have been in the same situation that you are now in and who have experienced the same worries and emotions about their children's welfare.

May's story

"We agonised about whether or not to go ahead with the feeding tube, it sounded so invasive and scary. The doctor talked to us patiently, and finally we decided to go ahead with it. May was 7 months old, and weighed just under 9 pounds.

May gained weight well with the tube. In the first month, she gained 2 pounds. After a few months, she hit the growth chart for the first time.

Getting used to it was hard to start with, but the medical implications of weight gain and full nutrition were obvious."

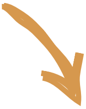
Jessica's story

"We were at a crossroad. The decision to start tube feeding seemed so obvious but we were still reluctant, we were not happy about it. We tried everything to avoid this step, part of me felt like a failure.

Although we were not happy about this decision we knew it was the right thing to do. Jessica had to have the calories in order to grow, and we could no longer watch her get dehydrated with each illness. We didn't want our child to be different. We didn't want our child to experience any pain, physical or emotional. So after talking with the doctors, and being assured that Jessica would still be able to lead an active life, we decided to have the tube placed.

I can honestly say that this was the best thing we could have done for Jessica. She has gained weight steadily. After a year I can also say how difficult it was to make the decision. There were times I was mad. There were times I wept at night for my daughter. There were times I felt guilty because all in all we are blessed with a relatively healthy and happy child."

Dealing with day-to-day experiences



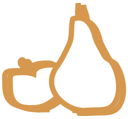
Tube placement

"After Zack was fitted with his feeding tube we asked him all the time if he was feeling any pain or discomfort. He never once said that he was; other than feeding time it's almost like it isn't there."

Please note that the feeding tube should not hurt your child; however, it is important to take care of the tube as complications can occur that can cause your child discomfort or pain.

Visibility

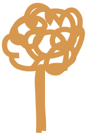
"We worried that the tube might get in the way and that Sara might play with it and pull it. In fact it's pretty well hidden and you can't even see it when we go out. We have taught Sara to be careful with the tube but to be honest it has never been a problem."



Other foods

"I like to give Tom a little bit of food at mealtimes when the whole family is around the table. It's social time and allows him to enjoy the taste of different foods. Tube feeding is something we can do overnight or during the day when he is watching TV."

Please note that it is best to ask the doctor or dietitian if it is OK for your child to have foods by mouth before offering them.



Outdoors

"It took us a while to get used to going out after the tube was fitted but now we do everything that we used to. She loves it. I think it was more a question of confidence."

Please note that it is a good idea to seek advice from your child's health care team before undertaking any outdoor activities.

Support

"I found most of my support through parent associations and different tube feeding organisations. I speak to other parents online all of the time. Plus, any questions I might have there is an entire team of specialists who I can ask."

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

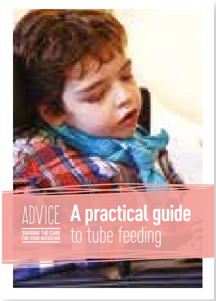
The following are additional sources of information about tube feeding which you may find helpful:

Making the decision to start tube feeding

For information about the range of tube feeding products available.

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 pressed 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	Feed that passes directly into the stomach or intestines
Extension set	Plastic tubing which 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	Feeding 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 balloon end
Gravity feeding	Feeding that enters the stomach by force of gravity (i.e. placing the feed above the height of the stomach)
Nasogastric tube, NG-tube	A feeding 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	Feed 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 feed through the tube at a rate set by you and volume
Pump feeding	Feeding 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	Supplemental 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 it is 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 which 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...

About Carers UK

Carers UK makes 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 us at our website to join us, help us, or access more resources:
www.carersuk.org

Call our advice line for expert information and advice about caring:
0808 808 7777 (open Monday to Friday, 10am-4pm) **advice@carersuk.org**

We warmly thank all parents and children who contributed to the elaboration of this guide.

Carers UK

20 Great Dover
Street, London
SE1 4LX

Visit:
carersuk.org

Carers NI

58 Howard Street,
Belfast
BT1 6PJ

Visit:
carersni.org

Carers Scotland

The Cottage
21 Pearce Street,
Glasgow G51 3UT

Visit:
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River House
Ynys Bridge Court,
Cardiff CF15 9SS

Visit:
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