Children With Exceptional Healthcare Needs (CEN) Network

Emotional impact of tube feeding

Family information leaflet

This Leaflet has been prepared by NHS National Services Scotland (NSS) National Networks. Accountable to Scottish Government, NSS works at the heart of the health service providing national strategic services to the rest of NHSScotland and other public sector organisations to help them deliver their services more efficiently and effectively. Working across professional and organisational boundaries, National Networks support the delivery of safe, effective healthcare that's designed around patients, carers and families.

NSD610.022.02.V1
Leaflet Last Reviewed: May 2025
Next Review Planned: May 2028

Introduction

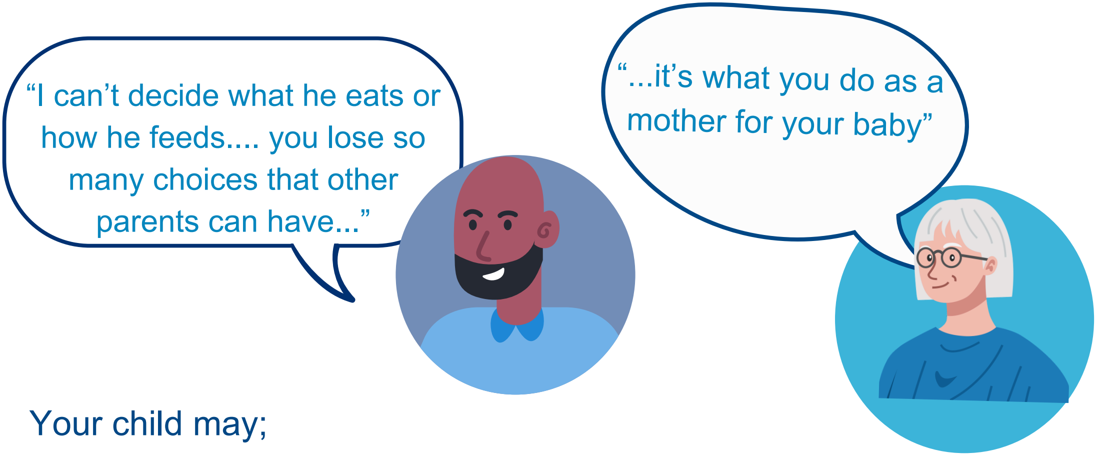
The impact of tube feeding is different for everyone. Parents' experiences of tube feeding helped with the content of this leaflet.

This information leaflet is for parents and carers whose children need help with feeding through a tube. This can be from the child's nose or through their tummy wall into their stomach. We have included both practical tips and technical information on tube feeding which may help you. CEN wants to make sure every child with exceptional healthcare needs receives the best care wherever they live in Scotland. What we mean by exceptional healthcare needs is on our website here nn.nhs.scot/cen/about-national-managed-clinical-networks/cen-criteria/. CEN brings families and health care services together to share information, improve services, develop guidance and learn from the experience of others. In Scotland, there are around 700 children with exceptional healthcare needs. If you want to read more about the CEN Network visit the Network website at nn.nhs.scot/cen/.

In this booklet we use the term 'parent' to mean the child's main carer, we know this may be different in each family.

Why is oral feeding important?

You may feel positive about a move to tube feeding and relieved that your child will get the food and liquid they need. Especially if they are not able to eat and drink enough by mouth. But you might worry what it means for your child or your family. These feelings are completely normal.



Your child may;

- never have had a chance to feed by mouth
- have managed to feed by mouth but now cannot do this safely or struggle to take all they need. Losing that ability may be a challenge
- need top up tube feeds to have enough energy for growth and health

Being aware of how your child is feeling can be helpful for you both. Each family will deal with these changes in their own way. Some parents choose not to give their child food by mouth once tube feeding has started, others do. Parents say it helps to talk with their healthcare team about what they want to do and what will work best for their family.

Moving to tube feeding can take some time to adjust, it can help to talk to all members of the family including any brothers and sisters about their feelings.

Who to talk to about how you are feeling

Being responsible for your child’s tube feeding may feel scary or overwhelming. Over time it will become normal and easier but remember that there is a lot of support available for you. If you need support with tube feeding you can talk to the people involved in the care of your child, such as your: Children’s Community Nurse, Nurse specialist, Dietitian, Paediatrician, Health Visitor or Speech and Language Therapist.

Many parents find speaking to other parents very helpful, there are many support groups which can be found via Contact here: Local support groups | Contact.

Voluntary and parent organisations can also offer emotional support and a chance to talk about how you are feeling and learn from others’ experiences.

Building your confidence

One way to feel more confident is to think about and practise in advance. This will mean you are prepared if problems arise. Here are some tips which may help.

Tip 1

Focus on the things you can control

It can be helpful for you to think about the things you can control, rather than getting caught up in all the things you can't. For example, you can control:

- feeling prepared by having a plan
- what questions you ask and where you get your information from
- what coping strategies you use when you feel worried or anxious
- making sure you look after yourself, so you can cope with any challenges
- how you help your child cope with tube feeding
- the things you can do and enjoy when tube feeding is working well

Tip 2

Coping strategies

These strategies can help you to look after yourself when moving to tube feeding. Some of these strategies need a bit of practise so it can be helpful to try them out when things are calm.

- Relaxation exercises focus on controlling our breathing, relaxing the body or imagining a calm place or picture
- Mindfulness exercises can be a good way to slow down busy minds and shift focus from worries
- Distraction can also take our minds off worry thoughts and can help us cope with anxiety
- Doing the activities that make you feel good, give you enjoyment and help you to switch off and unwind.

There are many helpful free apps and web-based resources to support you with managing worry and anxiety. Here are some ideas:
Mood Cafe | Home
MindShift® CBT App | Anxiety Canada
Smiling Mind App — Smiling Mind
Youtube - 5 Steps to Wellbeing Animation

Tip 3 Look after yourself

It is really important to look after yourself at times of stress and worry. If you do not look after yourself, it may be more difficult to cope with any difficult situations that do come up. Looking after yourself starts with the basics of:

- good sleep
- healthy eating
- exercise or activity

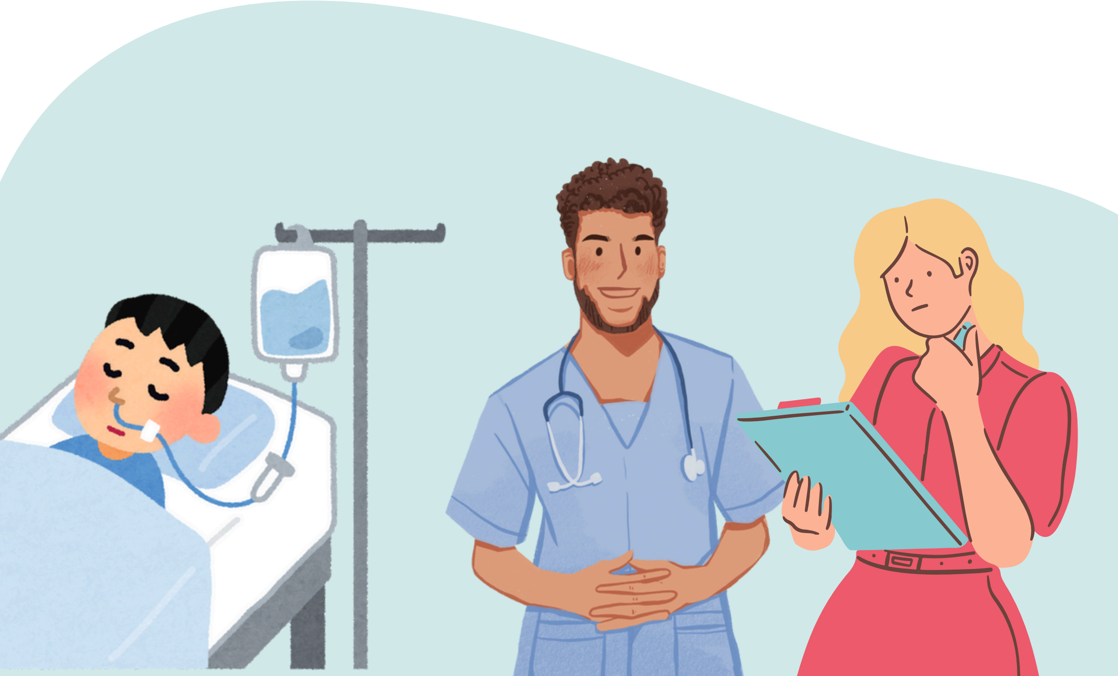
It is also important to have good support around you and make sure you have time to connect with other people. This can include family, friends, your healthcare team and other parents.
By keeping yourself well and being kind to yourself, you will be in the best place to manage any of the demands of tube feeding you are experiencing.

The NHS Five Ways to Wellbeing Resource may be helpful- https://www.nhs.uk/mental-health/self-phelp/guides-tools-and-activities/five-steps-to-mental-wellbeing/

Moving on with tube feeding

After your child has needed naso-gastric feeds (a feeding tube through their nose into their stomach) for some time. The next step may be to get a more permanent gastrostomy (a feeding tube directly into the stomach through a tiny opening in their tummy wall) put in place. When deciding to get a gastrostomy you should consider the pros and cons, with your healthcare team.

Having a gastrostomy put in can be a 'straight forward' surgical procedure that can be done in a day. However, you might need to stay in hospital for a few days while a feeding plan is started. In this time, you will be trained on how to care for the tube.

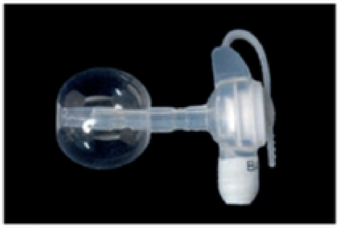


There is some detailed information on the different types of gastrostomies below. The pictures used are examples and might be different to what is used for your child.

Corflo PEG tube

Freka PEG tube

Mini Button



Mic-Key® Button

Note: These are example pictures of devices – slight changes may occur in local Boards.

Tube displacement

Naso-gastric (a feeding tube through their nose into their stomach) or naso-jejunal (a feeding tube from the nose which goes through the stomach and into the intestine) tubes can become displaced (pulled out or the position moved) accidentally. These can be replaced, and it is good to have a plan in place for this.

Gastrostomy tubes can also be displaced. If this happens, it is important to keep the track open from the skin surface to the stomach. Your specialist nurse can help you practise this to give you confidence and reassure you about how to get help.

Types of Gastrostomy tubes

1 PEG (percutaneous endoscopic gastrostomy)

Insertion of a feeding tube is a surgical procedure (an operation). The tube is passed into the throat and down into the stomach using an endoscope (thin tube and camera down the throat). The gastrostomy tube exits through an opening (stoma) between the stomach and the abdominal (tummy) wall that has been surgically created. A small disc at one end secures the tube inside the stomach. An external fixator device, a clamp and a feeding connector, are then fitted to the outside part of the tube. PEG tubes generally last around 18 months, dependent on manufacturers' guidelines and healthcare professionals' guidance. Change of a PEG device usually requires another endoscopy under general anaesthetic (child will be fully asleep) and is often done as a day case admission (in and out in one day).

2 Balloon inflated /gastrostomy

A balloon gastrostomy device has a balloon under the skin filled with water to hold the device in place. This can either be inserted into an established gastrostomy (after a change of PEG device) or as a first procedure (primary button) through a new incision using an endoscopic or laparoscopic (small tube and camera through openings in the tummy) technique. There are two types of balloon device.

3 A button or low-profile device

This is a smaller balloon gastrostomy device, which is held inside the stomach with a balloon filled with water. An extension set (plastic tube) is required to access the device for feeding and medication administration. This extension set can be removed when the gastrostomy button is not in use.

There are different types of button device and care must be taken to ensure that the right extension set is used to prevent damage to the button.

Balloon devices should be changed every 3 to 4 months, depending on healthcare guidance and the individual patient. This should be carried out by someone who is trained and competent to do so, this is not a surgical procedure.

Tube Problem Solving

PEG tube displacement	Seek immediate medical advice at local Accident & Emergency department.
Gastrostomy button displacement	A replacement device should be fitted within 1-2 hours by someone who has completed appropriate training. If trained, the appropriate EN-PLUG-s should be inserted into the stoma if a spare gastrostomy tube cannot be inserted. If a primary button device (first one put in) dislodges within 3 months of being put in the patient should attend A&E for review by the surgical ream. No button device or EN PLUG-s device should be inserted into the gastrostomy until review in this case
Leakage of milk or feed from around the gastrostomy	stop feed and seek advice from appropriate professionals.
Discharge from gastrostomy site	Contact your healthcare team.
Skin breakdown around stoma site	Contact your healthcare team.

Tube Problem Solving

Redness irritation at gastrostomy site	Use Prontosan gel or wound wash to cleanse gastrostomy site instead of water.
Overgranulation (red, spongy flesh which may bleed easily)	Contact your healthcare team.
Repeated troublesome problems at the gastrostomy site (regular issues)	Please refer to specialist gastrostomy nurse by phone or email referral.
Tube Blocked PEG	Gently try to flush with warm water using push and pull motion with a 20ml syringe, to try and aspirate or remove the blockage, then try and flush as before. You may have to open the PEG fixator device to help unblock the device. If tube remains blocked, seek medical attention.
Button	Prime and change extension set and gently flush the button with new set. If the tube remains blocked, the button must be changed by someone competent to do so.

Your notes and Questions

After reading this booklet if there are any questions or worries you have, please list below and ask the clinician at your next visit.

Support Organisations

PAMIS - Provide support for people with profound and multiple learning disabilities (PMLD), their family and carers and interested professionals.

Contact - A national charity for families with disabled children.

Family Fund - The Family Fund is the largest provider of grants to low-income families raising disabled or seriously ill children and young people across the UK.

Sibs - For brothers and sisters of disabled children and adults.

SOFT UK - For UK families affected by Patau's syndrome (trisomy 13), Edwards' syndrome (trisomy 18) and related disorders.

Carers Trust - Carers Trust Scotland is the largest provider of comprehensive carers support services in Scotland.

Together for Short Lives - UK charity for all children with life-threatening and life-limiting conditions.

The Office for Rare Conditions offer information and support to those affected by conditions that are not common or may not yet even be diagnosed.

Children's Health Scotland - Dedicated to informing, promoting and campaigning on behalf of the needs of ALL sick children and young people within our healthcare system.

Kindred - provide advocacy and information on services to children with additional support needs and their carers.

ALISS (A Local Information System for Scotland) - is a service to help you find help and support close to you when you need it most.

A number of further support organisations can be found on the CEN website .

Glossary

- CEN – Children with Exceptional Healthcare Needs National Network.
- Intravenous feeding – means having nutrients and fluid directly into the bloodstream. sometimes known as Parenteral nutrition.
- Ventilation/ventilator/CPAP/BiPAP - Ventilatory support refers to the use of a ventilator or breathing machine to support the process of breathing. A tube is put in through the nose or mouth into the trachea (windpipe) and attached to a ventilator.
- Exceptional needs – CEN Criteria – Children with Exceptional Healthcare Needs (nhs.scot)
- Complex needs - If your child has been diagnosed with an illness, disability or sensory impairment and needs a lot of additional support on a daily basis, they're described as having "complex needs". A child might have complex needs from birth, or after an illness or injury.
- GIRFEC – Getting it Right for Every Child is Scottish Governments commitment to providing all children, young people and their families with the right support at the right time. This is so that every child and young person in Scotland can reach their full potential.
- The United Nations Convention on the Rights of the Child (UNCRC) - is a legally binding international agreement that sets out the civil, political, economic, social and cultural rights of every child, regardless of their race, religion or abilities.