

PAEDIATRIC HETF: SUPPORTING PARENTS AND CARERS



Emma Coates
Senior Paediatric
Dietitian, Wrexham
Maelor Hospital,
Betsi Cadwaladr
University Health
Board

Home enteral tube feeding (HETF) is the delivery of nutrients via a non-oral route within the patient's own home. Enteral feeding may be required as a consequence of a huge range of conditions, some of which are shown in Table 1.

When a patient is unable to meet their energy and nutrient requirements by regular food intake, enteral feeding is indicated. It may also be an option in the treatment of disease, for example, Crohn's disease or allergy/intolerance (1).

A variety of tubes can be used for HETF, most commonly Percutaneous Endoscopic Gastrostomies (PEG) are inserted, particularly if enteral nutritional support will be required for the long term. Nasogastric Tubes (NGTs) can be used for HETF; however, these tend to be used for short-term nutritional support. Jejunostomy tubes (JEJ) are often considered when gastrostomy feeding is not tolerated.

Home enteral tube feeding a paediatric patient can provide efficient nutrition support, however, each of the tubes have both advantages, disadvantages and complications, some of which are described in Table 2.

SUPPORTING PARENTS AND CARERS WITH A HETF CHILD

Making the decision to move to enteral feeding can be challenging for parents and carers as feeding can be an extremely emotive issue. Many parents or carers may feel scared, anxious or even guilty that they have come to the point where their child requires enteral feeding. Feelings of failure are commonly expressed by parents

Table 1: Indications for enteral feeding

Increased requirements or disrupted GI function	Reduced oral intake
Oncology Cystic fibrosis Inflammatory bowel disease Short bowel syndrome Cows' milk allergy Burns Congenital heart disease Liver disease Pancreatitis	Feeding difficulties relating to prematurity, neurological conditions, e.g. Cerebral palsy syndromes, e.g. Down's syndrome Dysphagia Feeding aversion Altered GI anatomy, e.g. Tracheo-Oesophageal Fistula (TOF) and Oesophageal Atresia (OA) Trauma to the GI tract following oncology treatment, surgery or disease, e.g. inflammation/infection Metabolic conditions

For further information please see reference (1)

Emma has been working as a Paediatric Dietitian for five years and her caseload includes HETF, disability, coeliac disease, cystic fibrosis, PKU and childhood obesity. She has been a local Coeliac UK group organiser for 18 months.

Table 2: Advantages, disadvantages and complications of various feeding tubes

Tube type	Advantages	Disadvantages and complications
Nasogastric Tube (NGT)	<ul style="list-style-type: none"> • Useful for short-term enteral feeding • Can be inserted without endoscopy and general anaesthetic • Parents/carers/patient can be training to repass the tubes at home • Easily removed 	<ul style="list-style-type: none"> • Easily pulled out or dislodged • May become blocked and require replacement • Facial or nasal irritation can occur due to adhesive tape used to keep the tube insitu, presence of a foreign body in the nostril • Obtaining an aspiration may be difficult • Highly visible - can be an issue when the child is socialising, other children or members of the public expressing curiosity/concern • Some activities are contraindicated if the tube is to remain insitu at all times, e.g. rough and tumble play, swimming
Percutaneous Endoscopic Gastrostomy (PEG)	<ul style="list-style-type: none"> • Useful for long-term enteral feeding • Discrete - hidden under clothing • Once inserted devices can remain insitu for approximately six months • Can be placed even with the presence of altered upper GI anatomy, e.g. tumours or disease of the upper GI tract • Parents/carers/patient can be trained to replace the device • Easily removed 	<ul style="list-style-type: none"> • Requires general anaesthetic and endoscopy for placement • May become blocked and require replacement • PEG site can become infected or sore due to skin irritation or leakage. Over granulation can be a problem • Tubes can migrate in to the jejunum if the fixation plate is loose. • ‘Buried bumper’, occurs when the internal bumper of the PEG tube erodes into the gastric wall and lodges itself between the gastric wall and skin (2), this may lead to further complications including wound infection, peritonitis, and necrotizing fasciitis. For more information on the management of buried bumper can be found via reference (3) • May be difficult to place if there is altered anatomy, e.g. tumours or extreme obesity • Device can be dislodged/pulled out causing trauma to the site • Replacement of the device required within 10 minutes to one hour in order to prevent site healing up • May exacerbate gastro-oesophageal reflux disease (GORD)
Jejunostomy tube (JEJ)	Many similarities with PEG tubes - see above	
	<ul style="list-style-type: none"> • Useful for long-term enteral feeding • Useful when gastrostomy feeding is not tolerated, e.g. significant vomiting/ poor feed tolerance has been a problem 	<ul style="list-style-type: none"> • JEJ extension can pass back in to the stomach Slow, continuous feeding required, which may limit activities for some patients

and carers. Discussing any concerns and anxieties pre-placement of a feeding tube or device, along with the benefits and drawbacks of enteral feeding, is extremely important. This can help to ensure that parents and carers can make an informed choice regarding the child's ongoing feeding, e.g. timings of feeds, pump or bolus feeding. Any HETF care plan should aim to suit the family's lifestyle, as well as allow parents, carers and the child, if appropriate, to be involved with any decision-making regarding the nutritional care of the child.

Parents and carers often feel quite apprehensive when moving from the hospital setting to home with a child who will be tube fed. It is often a new and unknown experience and may create a great deal of stress for some parents/carers. There can be a sense of loss of control for parents/carers/the patient, when enteral feeding is commenced. Some parents/carers may feel that feeding has become a clinical procedure and that they are taking on a nursing role. It is important to bear in mind that HETF can provide great opportunities for improving a child's nutritional status and growth; however, it can create a significant burden of care for parents/carers. Discussing these concerns prior to discharge is advisable to ensure any additional support that may be required is identified, planned and available to be provided.

It is vital to ensure that parents and carers are trained and competent in the delivery and management of the child's feeds and feeding tube. Written protocols, ward check lists and competency frameworks are useful to ensure training is robust. Empowering parents and carers to feel confident in managing the day-to-day tube care and delivery of their child's enteral feeds, should prevent the need for further inpatient care. Work-

ing as a HETF MDT, alongside specialist community paediatric nurses, company training nurses, e.g. Abbott Nutrition, Nutricia or Fresenius Kabi pump training services, gives parents and carers a valuable support network once they are at home.

Home feed delivery companies are extremely useful for parents/carers, helping to reduce the need to organise collection of feeds and equipment. However, storage of the sometimes vast amounts of feed, giving sets, flexitainers and other feeding equipment can create a headache for some parents/carers. This should be discussed before home delivery arrangements are set up to ensure that parents/carers are aware of the amount of stock about to be delivered and how best to manage this.

Further training of other carers who will be involved in the child's feeding may be required, for example nursery or school staff. Table 3 shows a summary of some of the considerations when feeding will be part of the nursery or school day. It is often very useful to visit the establishment and discuss these considerations with the staff and ensure that their queries and concerns are addressed. Once the child has settled in at the establishment it is also useful to review them with the care staff to ensure that any on-going or new concerns/queries are discussed and addressed.

There are a number of complications that can occur once the child is at home and enteral feeding has been taking place since discharge. Some of these complications have been mentioned in the article already, e.g. tube site problems, feed/equipment delivery, storage issues, or emotional concerns regarding feeding in general. Table 4 highlights some of the common physiological complications that can occur with enteral feeding.

Table 3: Considerations when enteral feeding at nursery or school

• Are there staff available to provide the support required to deliver enteral feeds at the nursery or school?
• Does the nursery or school need to apply for extra funding to obtain additional support staff for the child? The child may require a Special Educational Needs statement to ensure that this is obtained?
• Do staff require training and support regarding the use of the feeding tube and equipment?
• Is there a written care plan detailing the child's care needs and feeding regimen?
• How does the feeding regimen fit in with the timetable? Does it need to be adapted to fit in with other activities at school?
• How will feed and equipment supplies be delivered and stored at the school?
• What facilities are there for cleaning the equipment?

Table 4: Common physiological complications of enteral feeding

Complication	Possible causes	Management
Diarrhoea	<ul style="list-style-type: none"> Malabsorption Osmolality of feed too high 	<ul style="list-style-type: none"> Consider any other cause of the diarrhoea, e.g. infection, antibiotics, medication related Check hygiene practice when delivering feeds, e.g. hand washing, hang times for decanted feeds Reduce rate of feeds and monitor tolerance Consider smaller feeds - frequent or continuous feeding may be better tolerated Reduce concentration of feed and gradually build up to 'full strength' Check fibre content of feed - consider reducing or alternating with a non-fibre feed Hydrolysed feeds may be useful if standard feeds are not tolerated
Constipation	<ul style="list-style-type: none"> Inadequate fluid intake or fibre content of feed Medication related 	<ul style="list-style-type: none"> Calculate fluid requirements and ensure feed and flushes provide appropriate amounts Increase fibre content of feed Discuss medication related causes with pharmacist or consultant - consider alternatives or possible laxatives, e.g. Lactulose or Movicol
Reflux and regurgitation	<ul style="list-style-type: none"> Weak gastric sphincter Slow gastric emptying; gastric pressure; scoliosis - causing pressure in the abdominal area Possible cows' milk intolerance 	<ul style="list-style-type: none"> Ensure cows' milk intolerance is excluded Consider reflux medications, e.g. ranitidine, domperidone, Gaviscon +/- thickener, e.g. Carobel, Nutilis, Thick n Easy Positioning in an upright (30 degree angle) may help to reduce symptoms during and after feeds JEJ feeding may be appropriate if not resolved
Nausea and vomiting	<ul style="list-style-type: none"> Limited gastric capacity Delay gastric emptying Constipation 	<ul style="list-style-type: none"> Rule out any infection or allergy/intolerance Consider reducing feed rate, increasing gradually. Try pump feeding if bolus feeds aren't tolerated Smaller more frequent bolus feeds may be better tolerated but may not be practical for parents/carers Prokinetic medications may be indicated Consider any psychological factors Check timings and volumes of medications Ensure constipation is managed

HETF is crucial for the growth and development of children who require enteral nutrition support. It requires a holistic approach by all healthcare professionals involved; giving

the patient and their family substantial support to ensure that safety, nutrition and quality of life are optimised.

References

- Braeggar C et al (2010). Practical Approach to Paediatric Enteral Nutrition: A Comment by the ESPGHAN Committee on Nutrition. Available at http://espghan.med.up.pt/pdf_files/EN.practical%20approach.2010.pdf <accessed 08/09/14>
- Saptarshi B (2014). Case Report - Buried Bumper Syndrome Revisited: A Rare but Potentially Fatal Complication of PEG Tube Placement. Case Reports in Critical Care, Volume 2014, Article ID 634953, 4 pages Available at www.hindawi.com/journals/cricc/2014/634953/ <accessed 08/09/14>
- BAPEN - Percutaneous Endoscopic Gastrostomy - Management of buried bumper syndrome. Available at www.bapen.org.uk/pdfs/decision-trees/buried-bumper-management.pdf <accessed 08/09/14>

Questions relating to: Paediatric HETF: supporting parents and carers

Type your answers below and then **print for your records** or print and complete answers by hand.

Q.1 What is home enteral tube feeding (HETF) and when is it required?

A

Q.2 Describe the three main tubes used for home enteral tube feeding.

A

Q.3 Outline the advantages of PEG feeding in paediatric nutritional care.

A

Q.4 What are the disadvantages of using nasogastric tubes in paediatric HETF?

A

Q.5 What are the likely concerns of parents/carers when moving a tube-fed child from a hospital setting to home?

A

Q.6 What training is required to ensure that parents/carers can manage a child's tube feeds at home?

A

Q.7 Give four considerations to bear in mind when a HEFT child is at nursery or school.

A

Q.8 When diarrhoea occurs as a complication of HETF, what are the common causes and how should this be managed?

A

Q.9 Describe the management of reflux/regurgitation in a HETF child.

A

Please type additional notes here . . .