Western Sussex Hospitals NHS
NHS Foundation Trust

Dietitians Department
Western Sussex Hospitals NHS Foundation Trust

Paediatric Enteral Feeding Guidance for Acute and Community Settings

[redacted]
Advanced Dietitians - Paediatrics

DATE: February 2018
Review Date: 2020

Version History:		
Version No:	Date:	Comments/Changes Made:
Final	30.07.2010	
Amended	July 2012	Minor changes to page 23, 24, 31 syringes, p32,
Amended	July 2013	Minor Changes to p31 and 32 updated syringe make used
Amended	16.04.2014	Page 13 – length of time NG tubes can be used for.
Full Review	Completed – February 2018	Grammatical amendments, addition of some details re stoma measuring devices and location of emergency equipment
Amended	20.06.2018	Amended NJT placement and position checking information, and updated reference “Guidelines for the Preparation and Handling of Expressed and Donor Breast Milk and Special Feeds for Infants and Children in Neonatal and Paediatric Health Care Settings”, BDA Paediatric Group - 2017

Paediatric Enteral Feeding Guidance

Section 1 – Introduction and Purpose of Guidance

This document provides practical advice on implementing and managing enteral nutritional support (in this case meaning enteral tube feeding) for children in hospital and at home. Children may have an NG, NJ, PEG or other gastrostomy device, PEGJ or other jejunostomy device.

The document is primarily intended for use by the Paediatric Dietitians within Western Sussex Hospitals NHS Foundation Trust (WSHFT).

It may also be used as a reference guide to support clinical practice by Paediatric Specialist Speech and Language Therapists (SALTs), Children's Community Nurses (CCNs) and Paediatric Ward Staff within WSHFT, with the support of the Paediatric Dietitians.

This document includes a "Problem Solving" guide **(See Section 8)**. If you are not confident, please contact the Paediatric Dietitians, Children's Wards or the Children's Community Nurses (CCNs).

Children who receive long term home enteral feeding usually have complex medical conditions and associated health care needs. Enteral feeding may be only one aspect of the child's special needs.

Whilst this document gives guidance on equipment and management of nutrition support, it is vital that the needs of each child and their families/carers are considered individually, with full support from a registered paediatric dietitian.

DISCLAIMER: The information in this document is correct at time of going to print. Products and guidance can change. Please check with individual companies for specific information.

Section 2 - Client Groups

New enterally fed patients:

- Any infant or child on a paediatric or neonatal ward at WSHFT requiring enteral feeding during their admission will be seen by a dietitian specialised in Paediatrics.

- Children being discharged from the wards who require ongoing enteral feeding in order to meet their nutritional and fluid needs (these patients should already be known to the Paediatric Dietitian).

- Inpatient Transfers – children who have commenced enteral feeding at another hospital, and who are transferred back to the paediatric wards at WSHFT – e.g. from Southampton, Great Ormond Street Hospital for Children, King's College Hospital etc., need to be referred to the Paediatric Dietitian.

- Neonates on NNU requiring short or long term NG feeding at home should be referred by the Neonatal Outreach Service. These patients should be referred pre discharge.

- Children who have commenced enteral feeding at a hospital outside our area and who are discharged directly home should have been referred by the transferring dietitian. They need to inform the local dietitian of the patient's requirements.

NB: If a child comes in for rehydration purposes only (e.g. gastroenteritis), they do not need to be referred to the paediatric dietitians.

Referrals can be phoned through to the Dietitian's office (ext. [redacted] for St. Richard's and [redacted] for Worthing) and/or by filling in a green referral form on the ward, and posting to the Dietitians Department - preferably alongside a phone message. It is important that the STAMP assessment has been done and recorded on the form.

Existing Community Enterally Fed Patients:

WSHFT has a paediatric dietetic community service for children on enteral feeds. This will include all children who have home enteral feeding within Coastal West Sussex CCG (Clinical Commissioning Group) area.

Children may be resident and/or attending school within our district boundary.

If these children are admitted to the ward, the ward should inform the Paediatric Dietitians. The child will be reviewed by a dietitian if deemed appropriate/necessary, or if requested by the child's family/carers.

Children Residing Within Our Area but Attending a Residential School Outside of It:

Provided the child has a local GP, the WSHFT dietitian will manage the supply of feed and ancillary items as well as the feeding devices. However, the Paediatric Dietitian based at the child's school should undertake the child's nutritional management. This should be agreed on an individual basis.

Section 3 – Indications and Contraindications for Commencing Nutritional Paediatric Enteral Feeding, Ethical and Legal Aspects and Types of Enteral Feeding

Artificial nutrition and hydration have been classified by the courts as medical treatments (BMA, 2007) and must meet the following ethical principles:

- Beneficence – treatment actively contributes to the welfare of the patient
- Non-Maleficence – treatment does not inflict intentional harm

We need to consider carefully whether we should do something just because we can.

With all methods of enteral feeding, the decision to start tube feeding, and the method of tube feeding chosen should always be discussed fully with the parents/carers and child (when appropriate) and informed consent obtained.

Identifying the need for Enteral Feeding

Before deciding whether a child should be enterally fed, it is important to clarify the reason the child requires this intervention.

Indications for Enteral Nutritional Support in Children

Enteral nutrition is required when energy and protein requirements cannot be met by regular food intake in a patient with at least a partially functional gut (ESPGHAN, 2010).

Suggested Criteria for Nutritional Support -

(Nutricia 2002, Axelrod D etal, 2006):

Insufficient oral intake:

- Inability to meet ≥60-80% of individual requirements for > 10 days
- In children older than 1 year, nutrition support should be initiated within 5 days, and in a child younger than 1 year within 3 days of the anticipated lack of oral intake.
- Total oral feeding time in a disabled child >4-6 hours/day.

Wasting and stunting evident:

- Inadequate growth or weight gain for > 1 month in a child younger than 2 years of age.
- Change in weight over 2 growth centiles on growth chart.
- Triceps skinfold consistently < 5th percentile for age.
- Fall in height velocity >0.3SD/year.
- Decrease in height velocity >2cm/year from the preceding year during early/mid puberty.

It has also been suggested nutrition support should be instigated if nutritional supplements have been tried and either weight/height <85% or weight has falling across >2 growth centiles (CF Trust, 2002).

Clinical Situations where they may be a need for Nutritional Support
(PEN Group 2004, ESPGHAN, 2010).

Indication	Examples of Clinical Conditions
Unable to suck/swallow	Critically ill ventilated patients
Unsafe swallow due to neurological impairment	Cerebral palsy
Poor suck, swallow, breathe coordination	Premature infants
Increased requirements which are unable to be met orally	Cystic Fibrosis, congenital heart disease, burns, trauma
Poor appetite secondary to illness	Cancer, liver disease, renal failure
Congenital abnormalities	Tracheo-oesophageal fistula, oro-facial malformation (cleft palate)
Disorders of Digestion and Absorption – Malabsorption, or Gastrointestinal Motility	Short bowel syndrome, IBD, Chronic Liver Disease, Intestinal Fistula, Chronic pseudo-obstruction, Hirschsprung's disease.
Growth Failure or Chronic Malnutrition (in addition to above)	Anorexia Nervosa
Unpalatability of specialised feeds	Crohn's Disease
Continuous supply of nutrients required to prevent hypoglycaemia	Glycogen Storage disease Type I, inborn errors of metabolism (metabolic disorders)

Length of intervention

It is also important to consider **how long** this intervention is likely to be required:

- A **short term** intervention - to maintain nutrition whilst a child is unable to eat e.g. due to an acute but reversible illness (e.g. dehydration due to acute gastroenteritis), side effects of treatment (e.g. poor oral intake as a result of chemotherapy) or a temporary exacerbation of an otherwise stable condition.

- A **long term** intervention - for a child with a chronic but stable illness or injury preventing them from taking adequate oral nutrition.

- A **short or long term intervention** for a child who is suffering from a degenerative condition, and because the child is unable to take sufficient nutritional intake orally, or because their swallow is unsafe and they are at risk of aspiration.

- Obviously if the child's clinical condition markedly changes, an initial short term intervention may become longer term.

Contraindications

These include paralytic ileus or mechanical ileus, intestinal obstruction, perforation and necrotising enterocolitis (NEC). Relative contraindications include intestinal dysmotility, toxic megacolon, peritonitis, gastrointestinal bleeding, high output enteric fistula, severe vomiting and intractable diarrhoea. In these circumstances enteral nutrition should be provided to the maximum extent tolerated, alongside parenteral nutrition. Even minimal quantities of nutrients in the GI tract (trophic feeding) may promote intestinal perfusion, initiate release of enteral hormone, and improve gut barrier function (ESPGHAN, 2010, Ohta K etal, 2003, Tyson JL etal, 2005).

Decision to Start Enteral Feeding

The decision to start paediatric enteral feeding may be made by ward nursing and medical staff if the child is acutely unwell, ideally in conjunction with the Paediatric Dietitian. It may also involve a (joint) assessment by the Paediatric Dietitian and Specialist Paediatric SALT (as required – if there is a concern regarding the child's ability to swallow safely). The decision to start enteral feeding should be made with the informed consent of the child's parents/carers and the child, when appropriate. This depends on the child's mental capacity.

Types of Feeding and pH Testing

Nasogastric (NG) Feeding

Whenever possible, gastric feeding is preferable to post pyloric feeding as secure positioning of gastric tubes is easier to achieve and is more physiological. Bolus feeds and hyperosmolar solutions should be delivered post pylorically with caution as they may induce diarrhoea (ESPGHAN, 2010).

Normally, a Nasogastric tube will be inserted. Initially a short term PVC NG tube will be used. This may be swapped to a "silk" (longer term) NG tube at a later stage if appropriate (see **Equipment – Section 4** for more details on length of use). Nursing staff are responsible for selecting the correct size and length of NG tube, and for passing it. The ward has a nursing NG tube placement protocol (not on intranet). Nursing care plans are instigated for enteral feeding and records of feed given and regular pH monitoring are kept.

If it is felt that the child may need long term enteral feeding, the placement of a gastrostomy tube may be beneficial. In this case, the child should be referred by the supervising Paediatrician for an outpatient assessment with a Paediatric Surgeon. It may be useful to provide the child and family with written materials, e.g. our Department Leaflet "Your child's Gastrostomy" or Company's Leaflets.

pH Testing in NG Feeding

In all cases, pH indicator strips should be used for testing nasogastric aspirates of all children, infants and neonates before each feed, medication and/or fluid flushes. (MHRA Alert (MHRA/204/026) and NPSA Patient Safety Alert 05 (2005)). Medications (and other factors) can affect pH of aspirate, especially anti-reflux medications, which increase gastric pH. pH Indicator strips used should have a resulting colour change that is easily distinguishable (particularly between the pH 5-6 range), and the colour change should happen within 10-15 seconds (NPSA, 2005). pH indicator strips must be CE marked and intended by the manufacturer to test human gastric aspirate (NPSA 2011), e.g. Merck 2-9 pH strips.

Parents/carers should be told that nasogastric aspirates of pH 5.5 or below mean it is safe to commence feeding, if aspirate of 6 or above is obtained, the child should <u>not</u> be fed. Refer to NPSA Alerts for flow charts for advice on confirming the correct position of nasogastric feeding tubes for infants and children and for neonates (extracts - NPSA Alert 05, NPSA Alert 09, 2005, NPSA 2011).

The position of the NG feeding tube should be checked:

- Following initial insertion
- Before administering each feed and/or flushes
- If on a continuous feed, tube position check advised 4 hourly
- Before administering medication via the tube

- Following vomiting, retching or coughing. However, the absence of coughing does not rule out misplacement or migration
- If there is any evidence of tube displacement – e.g. – the fixing tape is loose or the visible tube looks longer or kinked (NPSA, 2005)

pH Testing in Gastrostomy Feeding

Testing Gastric Aspirate of Gastrostomy and PEGJ Buttons
According to the NNNG Guideline 2016 Good Practice Guideline, it is recommended that pH is tested before and after change of balloon gastrostomy.
It is NOT recommended or required to test pH before and after each feed.

Jejunal/Duodenal Feeding (Post/Transpyloric Feeding)

Post/transpyloric feeding is only indicated if a child is unable to tolerate gastric feeding, or if aspiration, gastroparesis, gastric outlet obstruction, or previous gastric surgery precludes gastric feeding.

Post/transpyloric feeding should be avoided in preterm infants as no evidence of beneficial effect of transpyloric feeding has been found, but some evidence of adverse effects (GI disturbance and increased mortality) was noted (McGuire and McEwan, 2007). Presently the clinical goal of increased caloric intake and improved growth with post pyloric feeding has not been demonstrated by research in children (ESPGHAN, 2010).

Jejunal feeding may be instigated using a Naso Jejunal (NJ) tube or a PEGJ (PEG with Jejunal Extension). Nursing staff are responsible for selecting the correct size and length of NJ tube, and for passing it. A PEG-J has a G (Gastric) port and a J (Jejunal) port. It is placed under general anaesthetic.

Comprehensive guidelines on Jejunal feeding have been produced by GOSH, (2015). These can be downloaded from: http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/nasojejunal-nj-and-orojejunal-oj-management

NJ tubes are difficult to place, can easily block (as often used with powdered feed) and are also easily dislodged with the tube migrating back into the stomach. **Naso Jejunal tubes require an X-Ray at each placement** to ensure that the tube is not in the stomach. Therefore NJ tubes cannot be resited at home by parents or CCNs and the family may have to visit the ward frequently for tube replacement.
NB: Bolus feeding cannot be used with Jejunal devices – the child must be fed via a pump, often for 20-24 hrs/day.

Jejunal feeding means that the stomach's acidic pH is bypassed and therefore it presents an increased infection risk to the child. If the child cannot tolerate a polymeric feed, it may be necessary to use a (partly) hydrolysed feed. There are increased hygiene risks associated with post pyloric powdered feeds. Medication may be given by this route but it should be discussed with the child's Paediatrician and Pharmacist.

pH testing in Naso-Jejunal (NJ) Feeding

Jejunal pH is higher than gastric pH and it is **vital** that parents and ward nursing staff are aware of this.

Gastric position	pH ≤ 5.5
Bronchial position	pH 6-8
Small bowel position	pH 6-8

pH testing is used as part of confirming initial placement **ONLY**, it is **no longer used** to confirm tube position before each feed, as **aspirating the NJT can cause collapse and recoil of the tube** (GOSH, 2015).

Following confirmation via X-Ray; if the pH is 6-8, this is indicative of correct NJ tube placement (GOS, 2009).
The tube marking at the nostril and length of the jejunal tube left outside of the child's body from the nose must be checked and documented.

The position of the NJ feeding tube should be checked:

- Following initial insertion by **pH testing AND X-Ray** (as above).
- Before administering each feed and/or flushes **by checking the tube marking** at the nostril and length of the jejunal tube left outside the child's body from the nose and comparing to initial documented measurements.
- If on a continuous feed, tube position check advised 4 hourly
- Before administering medication via the tube – **check tube marking**.
- Following vomiting, retching or coughing – **check tube marking** - the absence of coughing does not rule out misplacement or migration
- If there is any evidence of tube displacement – e.g. – the fixing tape is loose or the visible tube looks longer or kinked (NPSA, 2005). **Check tube marking**.

Methods of Feed Administration

Intermittent bolus feeding is thought to be more physiological, providing cyclical surges of the gastrointestinal hormones that have a trophic effect on intestinal mucosa (Aynsley-Green, A etal, 1982). Continuous feeding has been associated with impaired gallbladder emptying in infants (Jawaheer G etal, 2001).

Using Feeding Pump to administer continuous enteral feed:

- Gives more exact feeding rate
- Need more equipment – giving set/stand/bag
- Imperative for post-pyloric feeding
- Not advised for overnight NG feeding at home – due to risk of tube displacement and potential aspiration into the lungs
- Currently, we do not advise to discharge any child on overnight unsupervised NG/NJ tube feeds – see information below

Bolus Feeding (via Gravity or Feeding Pump)

- More physiological (see above)
- Gravity feeding is more practical as less equipment is required
- Usually quicker for small volumes of feed (e.g. up to 250-300ml).
- More flexible feed "rate"
- Syringe feeds can be given via a slow 'push' to start the process and is usually used for thicker feeds and blended diets
- **Not suitable for Jejunostomy feeding**

Overnight or Continuous Unsupervised NG/NJ Feeding via Pump

This procedure has been highlighted as a risk on the official Trust SHE risk assessment register. There is Trust Risk Assessment Guidance (WSHFT/Gane H and Dicke O, 2015) for use with this method of feeding on the ward.

A risk assessment needs to be completed prior to overnight continuous NG/NJ pump feeding. This method of feeding is associated with increased clinical risks if the tube is displaced or pulled out overnight, when not supervised, due to the increased risk of aspiration, strangulation, morbidity and mortality.

If continuous overnight feeding is requested by the child's Consultant, or the Consultant on the ward, they must fully discuss the risk of doing this with the child's parents/carers; who must give informed consent. The discussion must be documented on the risk assessment document which should be filed in the medical notes. The consultant takes full responsibility should any adverse event occur.

The local CCNs **will not** take these children onto their caseload currently; therefore a child cannot be discharged on the above regime without having organised supervision (overnight carers) in place (correct at time of publishing, June 2017).

Section 4 – Equipment used in paediatric enteral feeding

The National Service Framework for Children, Young People and Maternity Services – Department of Health (2004) - Standard 8 – “Disabled Children and Young People and those with Complex Health Needs” states that local authorities and PCTs should ensure:

- That disabled children are able to use/access the equipment and assistive technology they need in all the places they typically spend time (e.g. – school, home, short term care settings (respite)).
- Equipment and assistive technology **is tailored to the individual needs** of the child and their future development.
- Parents and other carers are given training and support in the use of the equipment and assistive technology, including who to contact in an emergency and out of hours.
- Services are in place to meet the particular equipment needs of looked after children.
- Community equipment services are integrated across health, social services and education and develop multi-agency protocols that set benchmarks for the assessment and provision of children’s equipment.
- Multi-agency arrangements are in place for the provision and maintenance of equipment and supplies.
- Deliveries of bulky equipment and supplies are sufficiently frequent so that families are not required to store large amounts in the home.
- Local emergency stocks of equipment/supplies are available 24 hours a day.

This section provides:

Equipment summaries – what is required and amounts for:

1. **Baby/child bolus feeding via a Nasogastric (NG) Tube.**
   NB – Children with NG tubes should not normally be fed via a pump – unless they are an inpatient and closely supervised as this method of feeding is unsafe (see **Section 3**).

2. **Child feeding via a PEG device.**

3. **Child feeding via a Gastrostomy/Button feeding device.**

All parents will be provided with 1 or 2 spare feeding devices (replacement g-tube and button, or 2 buttons) for emergencies.

Parents should be advised to keep a spare device in the child’s school/travel/feeding bag, so that it will always be with the child, wherever they go.

This section also includes detailed information – on volumes, care and recommended length of use for the following equipment:

- Enteral feeding devices (e.g. - NG tubes, gastrostomy devices)
- Pumps, stands and carry bags
- Giving sets, gravity feed, and extension bolus sets and feed reservoirs
- Syringes and Other ancillary equipment
- Emergency equipment: this is kept in the adult community office at St Richard’s Hospital and in the Dietitians Stock Room at Worthing Hospital. At St Richard’s Hospital there is an emergency equipment box of some items in the stabilisation room on the children’s ward (Howard Ward).NB this box does not include any spare gastrostomy buttons.
- Information on pH strips and testing can also be found in **Section 3**.

ENFit

Please note that following the publication of ISO 80369-3:2016 – by the ISO (the International Organisation for Standardisation), all small-bore connectors intended to be used for connections on enteral medical devices and accessories; including enteral feeding sets, enteral drainage sets, enteral syringes, and patient interface devices including access ports must now have a new global Enteral Feeding device connector design (named **ENFit**). It was introduced in order to reduce the risk of misconnections and possible patient injury. All manufacturers have now produced ENFit compliant products.

General cleaning guidance for reusable equipment for infants.

In addition to general cleaning advice below, parents are advised to use a cold water sterilising solution (e.g. Milton) for e.g. syringes and extension sets. This may mean that the equipment needs replacement sooner as materials e.g. syringe bungs can perish and the markings on syringes can come off.

The equipment volumes offer *guidance* only. Additional volumes of equipment may sometimes be required and these may be provided if deemed appropriate by the Paediatric Dietitian following individual assessment of need and in accordance with the children’s NSF standard 8 guidelines above.

For order codes for exact sizes of equipment – refer to the Company’s Ancillary Price List.

Ancillary Supplies Guidance for Nasogastric (NG) Tube

Additional notes:

- NG feeding is a short term method of nutrition support, usually up to 6 weeks (NG must be re-sited every 4 to 6 weeks, with alternate nostrils used); patients who are expected to require longer term enteral feeding should be considered for gastrostomy tube placement
- Any patient discharged with an NG tube should have a long term plan established before they are discharged, and a documented plan for what to do if the NG tube comes out, becomes blocked or the position cannot be confirmed

Ancillary Item			**Quantity / Frequency**	
Items Required	***Comments***	***Nutricia Order Code***	***Adults***	***Paediatrics***
Flocare Infinity Giving Sets* ENFit	Use 'no medication port' to encourage disconnection & flushing before giving meds	**95349** (Standard) **86484** (Mobile)	1 set per 24 hours OR 1 set per feed pack or container	1 set per 24 hours OR 1 set per feed pack or container
60ml Syringes (or 20ml for paeds)	ENFit GBUK multi-use syringes	**113830 (113828)**	4 per 28 days (8 per 28 days if bolus feeding)	4 per 28 days (16 per 28 days if bolus feeding)
pH paper	For checking aspirate to confirm position prior to each use	**88701** (Enteral UK pH 2-9 Indicator Strips)	1 pot of 100 every 28 days	Up to 3 pots of 100 every 28 days
10 or 20ml Syringes (for Medications)	If patient already using when transferred into area or at request of patient at dietitians' discretion ENFit GBUK multi-use syringes	**113823 or 113828**	4 per 28 days (8 per 28 days if large number medications)	CCN's
Back Pack ("Go Bag") and "Go Frame"	On discussion with patient and carers. (Best to use mobile giving sets with these)	**43247** (Go Frame) **64432** (Go Bag)	If required	If required
Containers*	Where additional fluids (in excess of 500ml) are required by pump, or feed needs to be decanted (avoid wherever possible due to increased contamination risks) or reconstituted powdered feeds are being used Each container will require a giving set	**40441** (500ml Flocare container) **40455** (1000ml Flocare container)	1 container per 24 hours (water)	1 container per 24 hours (water)
Spare Replacement Tube	Ensure size is same as current tube in situ	Will vary from patient to patient	1 in red emergency wallet & 1 every 1-2 months	Up to 4 every month

- Use freshly drawn tap water for flushes and additional water – exceptions:
  - Severely immunocompromised patients: sterile water
- Syringes: Use reusable unless the patient is severely immunocompromised or there are hygiene concerns
- * Reconstituted feeds can only be hung for 4 hours; new container & giving set will be required every 4 hours
- **Other accessories maybe required in certain individual circumstances depending on clinical need**

Adapted from guidelines produced by the Nutrition & Dietetic Dept, East Sussex Healthcare NHS Trust. Ancillary Supply Guidance for NG tubes Feb 2014
Updated Jan 2017

Ancillary Supplies Guidance for PEG (Percutaneous Endoscopic Gastrostomy)

Ancillary Item			Quantity / Frequency	
Items Required	***Comments***	***Nutricia Order Code***	***Adults***	***Paediatrics***
Flocare Infinity Giving Sets* ENFit	Use 'no medication port' to encourage disconnection & flushing before giving meds	**95349** (Standard) **86484** (Mobile)	1 set per 24 hours OR 1 set per feed pack or container	1 set per 24 hours OR 1 set per feed pack or container
60ml Syringes (or 20ml for Paediatrics)	ENFit GBUK multi-use syringes	**113830** **(113828)**	4 per 28 days (8 per 28 days if bolus feeding)	4 per 28 days (16 per 28 days if bolus feeding)
10 or 20ml Syringes (for Medications)	If patient already using when transferred into area or at request of patient at dietitians' discretion ENFit GBUK multi-use syringes	**113823 or 113828**	4 per 28 days (8 per 28 days if large number medications)	CCN's Supply
Back Pack ("Go Bag") and "Go Frame"	On discussion with patient and carers. (Best to use mobile giving sets with these)	**43247** (Go Frame) **64432** (Go Bag)	If required	If required
Containers*	Where additional fluids (in excess of 500ml) are required by pump, or feed needs to be decanted (avoid wherever possible due to increased contamination risks) or reconstituted powdered feeds are being used Each container will require a giving set	**40441** (500ml Flocare container) **40455** (1000ml Flocare container)	1 container per 24 hours (water)	1 container per 24 hours (water)
Bolus Set	Allows decanting of tube feed into barrel of syringe to gravity feed. Used in paediatrics mostly	**89752**	1 set per 24 hours	1 set per 24 hours
Spare Replacement Tube	Ensure size is same as current tube in situ. Usually 16fr	**114245** (16fr ENFit Corpak Balloon G-Tube)	1 in red emergency wallet	1 on first order only
Spare ENFit Y-Adaptor (Merck Tubes)	Ensure correct size for current tube in situ. Usually 16fr	**114195** (16fr)	1 in red emergency wallet & 1 every 3-4 months	1 on first order only

- Use freshly drawn tap water for flushes and additional water – exceptions:
  - Severely immunocompromised patients: sterile water
- Syringes: Use reusable unless the patient is severely immunocompromised or there are hygiene concerns
- *Reconstituted feeds can only be hung for 4 hours; new container & giving set will be required every 4 hours
- **Other accessories maybe required in certain individual circumstances depending on clinical need**

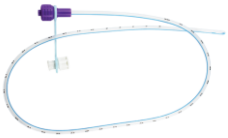
Adapted from guidelines produced by the Nutrition & Dietetic Dept, East Sussex Healthcare NHS Trust. Ancillary Supply Guidance for PEGs Feb 14
Updated Jan 2017

Ancillary Supplies Guidance for Low Profile Gastrostomy Devices (Mic-Key / Mini Button)

Ancillary Item			**Quantity / Frequency**	
Items Required	***Comments***	***Nutricia Order Code***	***Adults***	***Paediatrics***
Flocare Infinity Giving Sets* ENFit	Use 'no medication port' to encourage disconnection & flushing before giving meds	**95349** (Standard) **86484** (Mobile)	1 set per 24 hours OR 1 set per feed pack or container	1 set per 24 hours OR 1 set per feed pack or container
Extension Sets	Connected to device to allow administration of feeds/meds/water. May require straight connection (bolusing) **and** right angle connection (pump feeding)	Order same brand as brand of tube. Check with HEF Dietitian	4 per 28 days	4 per 28 days OR 8 per 28 days if at school
60ml Syringes (or 20ml for paeds)	ENFit GBUK multi-use syringes	**113830** **(113828)**	4 per 28 days (8 per 28 days if bolus feeding)	4 per 28 days (16 per 28 days if bolus feeding)
5ml Luer Slip Syringes	Required to empty and refill balloon with water once a week	**63426** (Terumo) **64773** (Becton Dickinson)	8 per 28 days	8 per 28 days
pH Paper	For checking aspirate to confirm position when tube changed	**97749** (Enteral UK pH 2-9 Indicator Strips)	1 pot of 25 on first order	CCN's Supply
10 or 20ml Syringes (for Medications)	If patient already using when transferred into area or at request of patient at dietitians' discretion ENFit GBUK multi-use syringes	**113823 or 113828**	4 per 28 days (8 per 28 days if large number medications)	CCN's Supply
Spare Replacement Tube	Ensure regular delivery order is for device of both the same length and French gauge. Tube in red wallet should be of same French gauge as Low Profile Device	Check with HEF Dietitian	1 Balloon Gastrostomy Tube in red emergency wallet & 1 Low Profile Device every 3-4 months	1 Balloon Gastrostomy Tube on discharge & 1 Low Profile Device every 3 months
Back Pack ("Go Bag") and "Go Frame"	On discussion with patient and carers. (Best to use mobile giving sets with these)	**43247** (Go Frame) **64432** (Go Bag)	If required	If required
Containers*	Where additional fluids (in excess of 500ml) are required by pump, or feed needs to be decanted (avoid wherever possible due to increased contamination risks) or reconstituted powdered feeds are being used Each container will require a giving set	**40441** (500ml Flocare container) **40455** (1000ml Flocare container)	1 container per 24 hours (water)	1 container per 24 hours (water)

- Use freshly drawn tap water for flushes, any retaining balloon water and additional water – exceptions:
  - Severely immunocompromised patients: sterile water
- Syringes: Use reusable unless the patient is severely immunocompromised or there are hygiene concerns
- *Reconstituted feeds can only be hung for 4 hours; new container & giving set will be required every 4 hours
- **Other accessories maybe required in certain individual circumstances depending on clinical need**

Adapted from guidelines produced by the Nutrition & Dietetic Dept, East Sussex Healthcare NHS Trust. Ancillary Supply Guidance for LPGD Feb 2014
Updated Jan 2017

Feeding Device	**Use, Advantages and Disadvantages**	**Routine Length of Use**
Naso-Gastric (NG) Tubes	• Short/long term use when button contraindicated (e.g. high anaesthetic risk) • No X Ray required • Different widths and lengths available • Width - measured by the French (Fr) or CH gauge e.g. 5fr (or CH), 6fr, 8fr, 10fr • Length measured in cm (e.g. 50cm, 92cm) Size assessed by nursing staff	
Medicina Short Term (SG tubes) **or Enteral UK Carefeed NG Tubes (PVC)** 	• Size 4-12fr and40-120cm • Tubing carries distance marks to reference tube position • All tubes have a radio-opaque stripe to confirm position with X-ray	**Up to 1 week (7 days) - in/outpatient use** (Enteral UK Guidance) (Medicina Guidelines, 2008)
Enteral UK Long Term NG Tube Nutricare (PUR) aka "Silk" Tubes 	• Fully NPSA Compliant • Fully Radio Opaque • Includes Safety Material • Unique Visi-Tip • Safety guidewire • Numbered markings every cm • NG Safety Insertion material • Size range 5fr-12fr 50-120cm	**Up to 3 months** (90 days)

Feeding device	**Use, Advantages and Disadvantages**	**Routine length of use**
Naso Jejunal (NJ) tube		
Vygon XRO Duodenal Feeding Tube 	• Short term use if vomiting with NG tube. • Difficult to place – each requires X-Ray • Frequently displaced/blocked. • Sizes as above. • Usually also need NG tube for medications • Cannot be used for bolus feeding	1 Month (manufacturers guidelines)

Feeding Device	**Use, Advantages and Disadvantages**	**Routine Length of Use**
Percutaneous Endoscopic Gastrostomy (PEG) **Fresenius Freka PEG** 	• Fresenius Freka and Merck Corflo tubes are used as **first line device**, usually a size 15Fr (Freka) or 12Fr (Corflo) is placed • Not as discrete as button device, long length tubing extends from stomach • Reduced risk of accidental removal, cannot fall out • Able to adjust shaft length as child grows by moving fixation plate. • No button changes or extension sets required • Replacement parts for retention buffer, clip, clamp and end piece available from dietitian • Useful to give 1 set of spares when device first placed • Give a one off spare balloon gastrostomy (G tube) (Merck Corflo or Flocare) (same size as PEG) when device placed, for use if tube comes out (very unlikely)	At discretion of surgeon – then replaced by low profile button – but can last 2-3 years plus
Merck Corflo PEG 		

Feeding Device	Use, Advantages and Disadvantages	Routine Length of Use
PEG with Jejunal Extension (PEGJ) Fresenius 15fr PEG with 9fr Jejunal extension 	• Used if vomiting with NG/PEG feeding • Feed via Jejunostomy (J) port or PEG (G) port • Medications only via G port • J port must only be used for continuous and not bolus feeding • Jejunal extension frequently displaced back into stomach	Not replaced unless they come out, length of use at surgeon's discretion

Gastrostomy Low Profile Balloon Button Feeding Devices		
Feeding Device	**Use, Advantages and Disadvantages**	**Routine Length of Use**
Procare Mini Compact Balloon Button (Enteral UK/AMT)  **Mic-Key Low Profile gastrostomy Button** (Vygon) 	• Discrete device • Commonly used for longer term feeding • Requires general anaesthetic to place • **Extension sets** need to be used for feeding, flushing, medication administration and venting • **Button sizes: Given as shaft width, then shaft length e.g.: 12fr 1.2cm.** • CCNs assess size required using stoma measuring device • May require introducer to put in longer shaft buttons (Mini only) • Weekly balloon water checks are required • pH testing is advised when device is changed	Changed **every 3-4 months** (manufacturer's guidelines)

Detailed Information – Button Gastrostomy Extension Sets

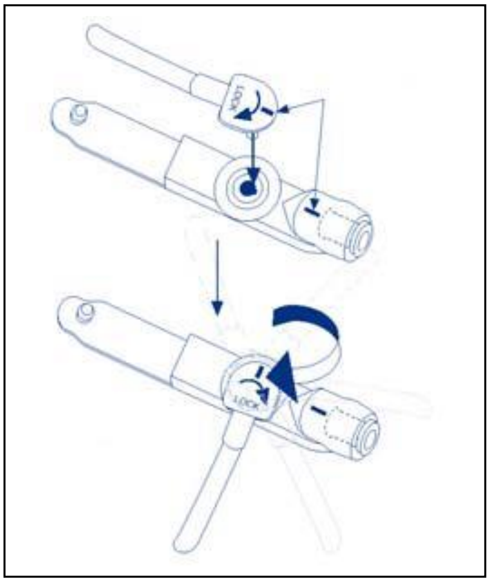
Extension Sets are required to "lock into" the child's low profile button gastrostomy to allow the administration of feed, fluid, medication and for venting. The other end of the gastrostomy extension set screws into the giving set or syringe. See table above.

Extension sets are produced by all companies who make buttons and are only compatible with the corresponding button gastrostomy e.g. Procare Mini or Mic-Key. **Ensure you know which button the child has**.

PLEASE NOTE: the TOP port of the low profile gastrostomy is for use with the extension set, the SIDE port is for balloon inflation ONLY. Touching the side port slightly will IMMEDIATELY deflate the balloon. CHECK balloon inflation after an error has occurred; otherwise the balloon gastrostomy can fall out.

Extension sets are available in 12" (30cm) and 24" (60cm) lengths. The dietitian will discuss the right type of extension set with the parents/carers.

Attaching the Extension Set to the Button



- Always wash hands and wear gloves.
- Line up the black mark on the extension set with the black mark on the gastrostomy button
- Make sure the extension set is pushed in completely and gently turn it ¾ clockwise to lock the extension set in place.
- When fully locked, the extension set will stop. Do NOT attempt to rotate the extension set past ¾ turn
- If the extension set does not rotate freely when first inserted into the feeding port, make sure the end is pushed in all the way and that there is no debris blocking the feeding port
- To remove the set, reverse the above

Use of Low Profile Balloon Gastrostomy Extension Sets			
Equipment	**Maximum Length of Use in Hospital or school**	**Maximum of Length of Use at Home**	**Recommended Monthly Order**
Mic-Key (Vygon-Halyard Health Care) or Enteral UK Mini extension sets **12” and 24” available** **Use single port sets where possible**	Up to 2 weeks - should be thoroughly washed out with warm soapy water and left to air dry, then placed in a clean plastic container labelled with the child’s name and put into the fridge – no need to normally place in steriliser unless parents prefer to do this. School: keep in labelled box in fridge		Up to 4-8/month including sets for school: Parents should be given extra sets for use at school if required

Low Profile Gastrojejunostomy Button Feeding Device	Use, Advantages and Disadvantages
G-Jet Device (Enteral UK/Procare) –   **Mic-J Device** (Vygon)  	**routine length of use up to 6 months** • Low profile button devices used for jejunal/small bowel feeding • Have 2 ports – G port (Gastrostomy) and J port (Jejunal) ports. • G port is used for medications • J port is used for jejunal feeding • Require radiologically siting. This can only be done at a children’s hospital • Lack of radiology slot can become an issue when there is a problem with the device, as it is not classed as an emergency and the child may end up on the ward on IV fluids for several days • Mutually-exclusive ports • Ports and feeding sets are colour-coded for visual differentiation • Use standard GBUK Mini button extension set for G Port • Use Mini One (or Mic-key) extension set for J port .

Feeding Device	Use, Advantages and Disadvantages	Routine Length of Use
Merck Replacement Balloon Gastrostomy Size 12Fr onwards  **Nutricia Flocare replacement Balloon Gastrostomy** Size 10Fr onwards (used for size 10Fr) 	• Short or long term measure. Some children use this as a feeding device, whilst others use as emergency device if button pulled out and no spare, and/or if stoma has started to close and usual size button will not fit • Size is given as shaft width (e.g. 10Fr, 12Fr, 14Fr, 16Fr) • Comes with an extension set	Short term emergency use in children but they can remain in situ for up to 3-4 months

Replacement Gastrostomy Balloon Tubes (G Tubes).

Replacement Balloon Gastrostomy Kits Should NOT be used:

- If the gastrostomy site is not well established (ie - the gastrostomy stoma is less than 6 weeks old) (check with parents). In this case liaise with the hospital that placed the device for specialist advice
- If there is evidence of infection.
- If there is uncertainty as to gastrostomy tract direction and length (abdominal wall thickness). In this case liaise with the hospital that placed the device for specialist advice.
- **If the child has a PEGJ or G-JET device, Seek specialist advice from the centre who placed the device before using this equipment**

Allocating a Replacement Balloon Gastrostomy Kit - Which Size to Use

To select the correct size, check the child's normal button size width (e.g. – 14 Fr or 12Fr). If the child's gastrostomy stoma has started to close down as a result of the button being out for a prolonged period then they may require a smaller gauge replacement gastrostomy to fit. (e.g. 10fr instead of normal size 12fr). The replacement gastrostomy kit can be used for a few days (or for longer) until the child receives delivery of their usual sized gastrostomy, they can tend to leak. The Paediatric Dietitian will need to place an urgent order for this.

If the stoma has closed down to such an extent that even a 10fr emergency gastrostomy will not fit; a small gauge NG tube or Foley catheter can be used to temporarily increase the size of the stoma so that the spare gastrostomy can be put back in, this would only be undertaken on the ward or under the supervision of the CCNs. The device can then temporarily be used for feeding.

If you are not confident in giving parents any of the above advice then please ask them to contact the children's ward or the Children's Community Nurses (CCNs).

Pumps and Associated Equipment

Currently, all equipment is obtained from Nutricia Homeward – if a pump is required in an emergency Homeward will deliver within 24 hours. In the Worthing area, there are spare pumps available at Salvington Lodge, Offington Ward.

The HEF Dietitians have a “pool” of pumps for enterally fed patients being discharged, within working hours.

The hospital ward pumps should NOT be taken home as these are not insured for the use at home.

All parents will receive training on how to use the feeding pump from the Feed Company Nurse.

Enteral Feeding Pump	**Stand**	**Bags**
Infinity Pump  • Small, purple, portable pump. • Comes with standard instructions, mains adapter and pole clamp. • Allow 6 hrs to charge fully for 24 hour battery life at 125ml/hr. • Run off mains when near a plug. **Optional extras:** • Pictorial Pump Instructions. • Children’s Pump Instructions • Instructions in other languages (including Polish) on request from Homeward. • Training website: "http://www.flocareinfinity.com" http://www.flocareinfinity.com **Use Period:** Homeward will recall each pump after 2 years of use for a service.	**Infinity Z-Stand** Lightweight clear plastic stand  **GO frame** Lightweight small stand suitable for putting in bag. 	**Infinity GO bag (rucksack)** • Black bag – used for mobile pump feeding and with use of GO-frame • Comes with instructions. 

Giving Sets and Associated Products

Equipment	Maximum Length of Use - Hospital and Home	Monthly Company Order
Giving Sets		
Infinity Pack Giving Set • Use with feed bags. • Longer than mobile giving sets • Cannot be used for gravity bolus feeding due to anti drip mechanism **Infinity Mobile Pack Giving Set** • Use with feed bags. • Shorter than pack giving sets • Cannot be used for gravity bolus feeding due to anti drip mechanism	Single patient use for up to **24 hours** with **sterile ready to hang feed bags**. If pause between feeds is >4 hours, the feed bag with giving set needs to be put in the fridge Can be used for more than one bag of feed during 24 hours If the child is on a powdered feed or a decanted enteral feed, a new set should be used every 4 hours day and night* * The dietitian will discuss if exceptions are acceptable e.g. hanging overnight	30/28 days (30/box) If on sterile ready to hang feeds bags. More are required if using powdered or decanted feeds and/or if child is fed at school or nursery

Bolus Feeding Sets

Equipment	Maximum Length of Use in Hospital (all sets)	Maximum of Length of Use at Home (all sets)	Recommended Monthly Order
Flocare bolus sets 60ml syringe shaped containers with short length of tubing -can be attached to end of extension set/NG tube for bolus feeding. Not always necessary as extension set and syringe could suffice.	Single patient use and single use sets for use with any sort of feed or sterile water 		1 set/feed therefore calculate for individual pt

2-Pack Connectors

These connect 2 x 500ml packs of feed (or 1 pack of feed and 1 container of water) to one giving set and allow 2 different bags of feed (and/or water) to run at once. These may be used if a child is on more than 500ml feed/fluid overnight – so that the parents do not have to get up in the night to hang the second bag. They can also be used if the child is on a combination of a fibre and non-fibre feed or a high energy and standard feed.

Equipment (order code)	Maximum Length of Use in Hospital or home	Recommended Monthly Order
2-Pack Connectors 	24 hours if used with sterile ready to hang feed See hanging time guidance below for other feed types	Normally 30/month

Feed Reservoirs

Equipment	Maximum Length of Use in Hospital and Home	Recommended Monthly Order
Feed Reservoirs		
Use if patient needs additional water/day or if on powdered non sterile feed. **Flocare 500ml and 1000ml (1 litre) Containers** Both compatible with any giving set  **Integral Reservoirs** (container + giving set attached) capacity 1500ml (rarely used)	Single patient use for up to 24 hours with water If the child is on a powdered feed or a decanted enteral feed, a new container should be used every 4 hours day and night* * The dietitian will discuss if exceptions are acceptable e.g. hanging overnight	30/28 days (30/box) If using for water only. More are required if using powdered or decanted feeds and/or if child is fed at school or nursery Maximum hanging time for container with feed is 4 hours* (Please note: 10/box)

Syringes

Following publication of the National Patient Safety Agency (NPSA) Alert 19 (2007) – "Promoting safer measurement and administration of liquid medicines via oral and other enteral routes", we only use purple *enteral luer lock syringes*, which cannot be connected to IV lines. Also following the publication of ISO 80369-3:2016, (ISO, 2016) - new ENFit syringes are now available internationally to comply with these regulations, see start of chapter for more information.

Choice of Syringe Size for Bolus Feeds and Flushes

A 20ml luer lock syringe can be used for infants, or a 60ml luer lock syringe for infants and older children, depending on the volume of fluid bolus to be given (NPSA, 2005). For neonates use a 2-5 ml syringe (Auckland District health Board, 2014, Knox and Davie, 2009). Knox and Davie also investigated this and found smaller syringe size produced less pressure. This is reflected in Great Ormond Street's Nasogastric and Orogastric Tube Management guideline (GOSH, 2014). http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/nasogastric-and-orogastric-tube-management

Review of the product literature form Enteral UK, Merck and Medicina was undertaken:

Merck investigated the effects of pressure exerted on different size syringes on their NG tubes and found evidence that although the smaller syringes produce greater pressures using less force than larger syringes, Merck concluded that in normal clinical use it is unlikely that a feeding tube would burst or collapse because typically a person would not be able to exert enough force on any sized syringe. (viewed 10.09.08 - Merck website FAQ Merck Corflo Enteral feeding tube – pressure when using syringes www. merckgastroenterology.com/faq-html).

Medicina product literature states that the smaller syringes can be used to deliver medicines directly into the feeding tube (Medicina Product Literature – Medicina Hospital and Home Oral/Enteral Syringes and NG tubes, 2008)

In practice, a slow push can be used, ideally with 60mls syringes.

St. Richard's Paediatric Dietitians or Worthing CCNs supply:
- 20ml and 60ml luer lock syringes
- 5ml luer slip syringes for weekly gastrostomy button balloon water changes.
- Instructions for cleaning syringes (supplied via Company)

The Children's Community Nurses supply all syringes for medications and feeding (WH). In Chichester, feeding syringes will be ordered by the dietitian but medication syringes are supplied by the CCNs.

All patients require syringes for flushing their tube before and after feeding and may require additional syringes if they are administering bolus feeds. Bolus sets can also be used (these are single use – see above).

The feeding device should be flushed with cooled boiled or freshly drawn tap water prior to giving feeds or medications, between each medication and after all medications are given (NHS Quality Improvement Scottish Best Practice Statement (2007) (White and Bradnam, 2015).

For more information on giving medication via enteral syringes see Section 3

Syringes for Changing Balloon Low Profile/Gastrostomy Balloon Water

5ml luer slip syringes are required for balloon water changes. The water should be changed weekly, so 8 syringes are supplied per month; one per week to remove the dirty water and one to replace it with clean water.

Equipment	Maximum Length of Use in Hospital	Maximum Length of Use at Home	Recommended Monthly Order
Luer lock syringes - fit male luer lock ports on extension sets, NG tubes and PEG tubes. **20 or 60ml luer lock Enteral UK – use single use ones on ward and 7 day reusable syringes at home**	n/a - Single use (stocked by ward) ②	Up to 7 days use (product guidelines)	1 syringe/week x 4 = 4 syringes/month NB At the discretion of the paediatric HEF dietitian, children may be given 8 or up *to 16 reusable* syringes/month – e.g. 4 for home and 4 for school. 16 if bolus feeding. This is more practical for families and carers; and much more hygienic.

Equipment	Maximum Length of Use in Hospital and Home	Recommended Monthly Order
Luer slip syringes **Only for use for** weekly gastrostomy button balloon water changes. Terumo 5ml luer slip syringes	Single use ②	Luer slip syringes – supply 8/month (for weekly balloon water changes) one to remove the dirty water and one to replace it with clean water.

pH Monitoring Strips

Only pH indicator paper is to be used for testing gastric (NG tube) and post pyloric (NJ) aspirates in children, infants and neonates. (MHRA Alert (MHRA/204/026) and NPSA Patient Safety Alert 05 (2005). pH indicator paper must be CE marked and intended by the manufacturer to test human gastric aspirate (NPSA Safety Alert 002 (2011)

For more information on testing aspirates refer to Section 3.

Equipment	**Maximum Length of Use in Hospital and at Home Recommended Monthly Order**
ONLY USE Merck or Enteral UK monitoring strips – pH range 2-9. 100 strips/pot (1 unit) (NPSA 2011 Compliant - use with NG and NJ tubes)	1 strip/feed/medication/day (e.g. minimum of 7 x 28 =196) – 200 per month – up to 300 (3 pots) /month CCNs order pH strips for button gastrostomy testing.

Other equipment

Introducers

These can be used to assist the placement of a gastrostomy button by providing temporary tube shaft stability during insertion through a well-established stoma site (ie to stiffen up the button shaft*). **These should only be used by a Healthcare Professional and are not normally given to parents.*** They come with instructions. They are only for use with Mini buttons (Enteral UK).

Do not use an Introducer if:

- You are not competent in using one.
- The gastrostomy site is not well established (ie - stoma is <6 weeks old).
- There is evidence of infection.
- There is uncertainty as to gastrostomy tract direction and length (abdominal wall thickness).

If you are not confident in giving parents the above advice then please ask them to contact the Children's ward or the Children's Community Nurses (CCNs) or dietitians (Worthing).

Equipment	**Maximum Length of Use in Hospital and Home**	**Monthly Company Order**
Introducer Enteral UK AMT Introducer 	Single use ②	Supplied via CCNS or from office stock as a one off. Do not put on company order. In Worthing they are supplied by the Paediatric Dietitian.

Stoma measuring devices

Stoma measuring devices are tubes for stoma measuring purposes only. They are used when the current button gastrostomy seems too tight or too loose.
The devices have a balloon at the end which holds the device in place inside the stomach whilst taking the measurements. The balloon needs to be inflated after insertion into the stoma (take note of the current size to establish how far to insert) with the right amount of air (5ml) and the small disc on the outside needs to be advanced onto the skin to read the measurement above the disc. The measurements need to be taken ideally in prone and sitting position. An average of the 2 measurements will determine the size of the next balloon gastrostomy. If not sure, the longest measurement needs to be taken.

Sterile Water

Sterile water is no longer required for balloon button water changes.
If a child requires sterile water to make up feeds, it is available via the Home Delivery Company, this will be organised by the dietitian. See **Section 5**.

Location of Emergency Equipment:

SRH - Enteral Feeding Supplies Drawer in HEF Dietitians office.
WASH – Dietitians store cupboard room at Worthing Hospital.

Children's Unit (Howard Ward) SRH - Emergency Equipment Box for Enteral Feeding. This is a red spotty box – kept in the cupboard in the stabilisation room. The box is stock checked 6 monthly by the Dietitians Assistant.

WASH – Bluefin Ward Worthing Hospital: plastic box to be kept in the equipment room.

In Worthing and Chichester, the dietitians order different items via different suppliers. See the table below.

Item	**Worthing**	**Chichester**
NG/NJ	CCNs	Feed Company
Low profile device and extension sets	Dietitians	Feed Company
60mls syringes	CCNs	Feed Company
Medication syringes	CCNs	CCNs
5ml luer slip syringes	CCNs	Feed Company
pH strips	CCNs	Feed Company (CCNs for Button Gastrostomies)
Sterile water for making up feed/flushes	Feed Company/GP	Feed Company
Feed	Feed Company (occasionally GP - FP10)	Feed Company
Giving sets, pumps, stands/frames, charger, rucksack	Feed Company	Feed Company
PEG replacement kit (emergency device)	Dietitians	Feed Company or Dietitians

Feed Company – Dietitian organises these items as part of the patient's regular delivery with their feed.

Dietitians – Dietitians organise directly for items to be sent as needed by the patient.

CCNs – Do own monitoring and ordering for patients.

Section 5: Nutritional Assessment, Enteral Feeds, Supplements and Fluid

Nutritional Assessment

Considerations:

- Current Weight, Height/Length +/- Head Circumference and WHO Growth Centiles (WHO/RCPCH 2009), BMI centile chart (as appropriate), parent held growth record. Alternative measurements can be used (e.g. Knee Height, Tibial length, Arm Span, Mid Upper Arm Circumference)
- Any weight loss/faltering growth – Calculate % Weight Loss, if not known - subjective assessment using parent's comments re their child's clothing, and weight
- Recent/Current oral intake – food, feed/formula, food texture and fluid intake (thickened or normal)
- Feeding skills for age and any change in these
- Present mealtime/feeding routine
- If currently NBM, check how long for and whether the child is at risk of re-feeding syndrome (see below)
- Does the child have increased or reduced Energy, Protein and Fluid needs - e.g. – fluid restriction
- Activity level - normal or reduced (affected by illness or disability)
- Intercurrent and underlying illness or condition
- Any food allergy or hypersensitivity
- Assessment of losses/fluid balance – ie vomiting, bowels and urine output and frequency of this – use Paediatric Stool Chart
- Any blood results available (check medical notes/SemaHelix)
- Current medications - any drugs which may be affected by feed absorption (e.g. – some anti-epileptics – check with paediatric pharmacist if unsure)
- Any over the counter nutritional supplements

Assessing Nutritional and Fluid Requirements

Use "Nutritional Requirements for Children in Health and Disease", 6th Edition, (2014) - Dietetic Department – Great Ormond Street Hospital for Children NHS Trust – to calculate requirements for infants and older children.
For 10-18 year olds use BMR (Henry or Scofield) calculation.

Tips - infants
In general, the infant's formula or MEBM (calories, protein and fluid) is calculated based on their age and weight. This total volume is then divided into the number of feeds the infant normally consumes or tolerates. If the infant is unable to manage all or some orally, the remainder of the feed will be given via an NG tube.

Following pH testing the NG tube should be flushed with a small amount of water (2-5ml) before and after each feed to clear the tube and prevent blockages. This should also be done before and after any medications via the NG tube.

Exceptions - any infant on a fluid restriction due to a cardiac condition, or any preterm baby on NNU (NPSA, 2005)

Tips – older children

- Calculate nutritional and fluid needs (as above)
- Choose appropriate feed and calculate amount needed per 24 hours to meet nutritional needs. Taking into account any oral intake
- Choose timing and method of feeding (gravity or continuous)
- Divide feed over the day as required and tolerated.
- It may be useful to use a high energy feed to achieve desired nutritional/calorie intake.
- Consider osmotic load if concentrating feeds – see below.

Extra attention needs to be given to:

- Children with increased energy and protein needs required for weight gain.
- Children with reduced activity levels (due to illness or disability).
- Children who require catch up growth, as at least 8.9-11.5% energy from protein is required. (WHO/FAO/UNU, 2007).

Special Considerations for Disabled Children or Children on long term Anti-reflux Medications – Vitamin D, Proton Pump Inhibitors, Epilepsy, and Bone Health

Children and young people in the following groups are at high risk of **vitamin D deficiency** - primary prevention is therefore particularly important for them:

- Disabled children and young people who spend very little time outdoors
- Children and young people taking anticonvulsants that induce liver enzymes such as phenytoin, carbamazepine, primidone or phenobarbitone
  (National Osteoporosis Society/Arundel P and Shaw N, 2015)

MHRA (2009) reported that the available data suggests that phenytoin, carbamazepine, primidone, and sodium valproate are associated with decreased bone mineral density, which may lead to osteopenia, osteoporosis, and increased fractures in at-risk patients. Phenytoin, carbamazepine, phenobarbital, and primidone are associated with an increased risk of osteomalacia.
Vitamin D supplementation should be considered for at-risk patients who receive long-term treatment with primidone, phenytoin, carbamazepine, phenobarbital, or sodium valproate.
Uddenfeldt Wort etal (2013) found that children with GMFCS levels IV–V Cerebral Palsy had stunted growth, often a sign of longstanding undernourishment, and were associated with an increased risk of fractures. Children using standing devices had a fourfold reduction of fractures without trauma. Regular loading exercises and early adequate nutritional intake could prevent fractures in severe Cerebral Palsy.

Observational studies on a risk of fracture associated with **Proton Pump Inhibitors (PPIs)** – such as Omeprazole - suggest there may be a modest increase in the risk of hip, wrist, or spine fracture, especially if PPIs are used in high doses and over long durations (>1 year) (MHRA, 2012).

Therefore consideration regarding **Vitamin D supplements** should be made for all disabled children on tube feeds, but especially those with severe Cerebral Palsy, on anti-convulsants (as above) or/and those on PPIs. Both these drug groups are frequently in these patients' polypharmacy, and often long term.

Enteral Feeds and Diabetes

In this event, the Paediatric Dietitian would liaise closely with the child's Diabetes Dietitian and MDT.

Enteral Feed

The choice of feed is dependent on child's age, weight and medical condition and should meet their nutritional requirements. A suitable infant formula should be chosen for an infant up to 1 year of age; for children and adolescents a standard polymeric feed based on Cow's milk protein with additional fibre is usually appropriate. (ESPGHAN, 2010)

Infant Milks and Formula
Breast Milk
Breast Milk Fortifier (Nutriprem) for use with Breast Milk
Standard Infant formula and Follow on Formula or Infant Soya Formula (SMA Wysoy)
High Energy Infant Formula (Infantri Standard/Peptisorb, SMA High Energy)
Hypo-allergenic Hydrolysed Feeds (Nutramigen with LGG)
Semi-Elemental Feeds (e.g. – MCT Pepdite 1+)
Elemental Feeds (e.g. – Neocate LCP, Puramino, Alfamino).

Concentrating Infant Formula and Feeds

(cf Shaw V and Lawson M, 2007 or Shaw, 2014)

Infant formula powders should normally be made up as per the manufacturers' instructions to achieve the standard feed dilution (approximately 13% for most). This provides the correct balance of energy, protein and nutrients when fed at the appropriate volume.

Care must be taken to ensure that when concentrating feeds, guidelines on maximal additions and intake of carbohydrate, fat and protein are not exceeded as this is associated with osmotic diarrhoea, due to the increasing osmolality of the feed. Osmotic load should be kept under 500 mOsm/kg water in an infant with a normally functioning gut. If the infant has malabsorption an upper limit of 400mOsm/kg (Shaw V and Lawson M, 2007/Shaw 2014). Osmotic load for neonates should be kept under 460mOsm/kg as a strategy to reduce the risk of Necrotising Entero Colitis (NEC) (Jones and King, 2005). **For these reasons a ready to feed high energy formula should be used in preference to concentrating feed when possible**.

Powdered feeds used for older children (e.g. Modulen IBD) can also be concentrated as a therapeutic measure, **again in line with maximal additions** (see page 17). When concentrating feeds it is vital that the recipe is fully explained and understood by the parents/carers and child if appropriate.

When to consider concentrating feeds

- Infant/child on a fluid restriction for medical reasons – e.g. – cardiac/renal pts, certain premature infants
- Infant who is unable to tolerate any "ready to feed" high energy infant formula.
- Infant/child on a specialised feed where there is no suitable "ready to feed" high energy alternative – e.g. gastrointestinal problems – with milk intolerance.

How to Concentrate a Feed – see Department Faltering Growth Guideline (Gane H, 2014).

Prescribable Nutritional Supplements

Care must be taken to ensure that if high energy infant formula milks, nutritional supplements, or calorie/fat module additives are used that guidelines on the maximal intake of carbohydrate, fat and protein are not exceeded as this is associated with osmotic diarrhoea, vomiting and high renal solute load.

It is vital with calorie additives that the recipe is fully explained and understood by the parents/carers, use a "ready to feed" high calorie infant formula where possible.

Examples of Supplements used for Energy Supplementation

- **Carbohydrate Powders** (e.g. – Polycal, Super Soluble Maxijul)
- **Fat Emulsion Supplements** (e.g. - Calogen, Liquigen, Procal Shots)
- **Combined Fat and Carbohydrate Supplements** (e.g. – Super Soluble Duocal, Liquid Duocal, MCT Duocal)
- **(Protein containing supplements –** e.g. Protifar or Calogen Extra are **rarely used** in paediatrics and are **not suitable** for young children.

Sip feeds (nutritional supplements)

Some Examples of High Energy Feeds and Supplements and Age Ranges

Stocked by Pharmacy Stocked by Catering
NB - other brands are available, WSHFT pharmacy can order any in with 24 hours' notice.

Infant Milks and Formula (in order of preference)		
Preterm Human Milk Fortifier	**Preterm Infant Formula**	**High Energy Infant Formula Milks (up to 8kg)**
Nutriprem Gold Prem Pro	Nutriprem 1 and Nutriprem 2 Nutriprem Hydro, Gold Prem Pro 2 - 90ml bottles and 900g packs (Nutriprem 2) and 200ml bottles (community only)	Infatrini Infatrini Peptisorb SMA Pro High Energy Similac High Energy

Paediatric and Adult Complete Nutritional Supplement Drinks		
8kg to 20kg	**From 3yrs of Age**	**6 years and Above**
Fortini, Fortini Multifibre Fortini Multifibre Compact Fortini Smoothie Multifibre Fortini Creamy Fruit Dessert Paediasure, Paediasure Plus+/- Fibre Paediasure Plus Juce Frebini Resource Junior	Fortisip Compact Fortisip	Fortisip Compact Multifibre Fortijuce Fortisip Yoghurt Style Forticreme Complete Dessert

Standard Paediatric Polymeric Tube Feeds on Current Contract:

From 8-20kg: Nutrini, Nutrini Multi Fibre, Nutrini Energy, Nutrini Energy Multi Fibre, Nutrini Low Energy Multi Fibre.

From 21-45kg: Tentrini, Tentrini Multi Fibre, Tentrini Energy, Tentrini Energy Multi Fibre.

Above 45kg: Use adult feeds.

Specialist Paediatric Feeds - If there are tolerance issues - consider:
Nutrini Peptisorb (1kcal/ml), Nutrini Peptisorb Energy (1.5kcal/ml, small amount of fibre), Peptamen Junior Advance (1.5kcal/ml, added fibre).
Metabolic feeds/supplements – these are usually initiated by the tertiary referral centre.

Feed Presentation Choice
The preferred feed would be a **RTF (Ready to Feed) feed pack** as no preparation is necessary and the feeds are sterile.
Decanting feeds into a feed container will increase the risk of cross-contamination and bacterial and microbial proliferation which therefore reduces the hanging time of a feed and giving sets, from 24 to 4 hours. (See Feed and Fluid Hanging Times on the Ward – **Section 5**)
When using a **PIF (Powdered Infant Formula)**, extra care needs to be taken as these products are not sterile. There is an inherent risk of infection with pathogenic bacteria (e.g. Salmonella and Enterobacter sakazakii) with neonates, preterm, low birth weight and immunocompromised infants who are most at risk.

Blended Diets for use with Enteral Feeding Tubes

Recently there has been an increase in the use of blended diets via the enteral feeding route in the UK. Parents are hearing and reading a lot about this practice on social media and there may be a growing desire by parents to have a more involved role in their child's care including the provision of family foods.

The support of these families poses a professional issue for dietitians as using blended diet via enteral feeding tubes is not supported by current BDA best practice guidance. This is however under review. The dietitian has an over-riding duty of care to their patient and their emotional needs and preferences should be taken into account when supporting the family.

For decades now, dietitians have been using commercially prepared feeds which give clear and concise information on nutritional content. Using blended diets can pose a risk for microbial contamination, difficulty in achieving the necessary consistency, tube blockage and achieving nutritional adequacy. It is important to assess the family situation to help establish the best way forward in supporting them.

The BDA (BDA 2015) has produced recommendations via the "Practice Toolkit" for dietitians to guide them through the process with parents who wish to partially or wholly feed their children with blended diet.

This document includes risk assessment forms from the PEN Group which dietitians should use in discussions with the family about blended diet. These documents should be used when care planning; and copies of the completed risk assessment filed in the patient's notes. The toolkit is available on the BDA website.

Crawley dietitians ([redacted]) have also put together practical guidance for blended diets.

Fluid

Fluid Choice for Flushes and Making up Feeds

Flushes

The advice in the table below should be followed **unless** the child is immunocompromised, when sterile water is indicated in all locations. Occasionally, Dioralyte or other Oral Rehydration Solutions (ORS) are given as flushes or boluses to aid the child's electrolyte intake if required.

	Feeding Type – Infant (under one year of age)		
Location	**NG Tube**	**PEG/Gastrostomy Button**	**Post Pyloric Feeding**
Hospital	Sterile Water only		
At Home, Nursery or Respite	Cooled boiled water		

	Feeding Type - Child (above one year of age)		
Location	**NG Tube**	**PEG/Gastrostomy Button**	**Post Pyloric Feeding**
In Hospital	Sterile Water only		
At Home, School or Respite	**cooled boiled water** (Worthing area) *or* **freshly drawn tap water** (Chichester area*)		Cooled boiled water

*Reflects advice given at Southampton hospital.

Making up Feeds

Manufacturers' guidelines should always be followed.

Location	**Advice**
In Hospital	All powdered feed should be made up with sterile water, and each bottle feed should be made up individually before feeding the baby[1]. (see exceptions[2])
At Home, School or Respite	Cooled boiled water can be used to make up powdered feeds for most patients. However sterile water should be supplied at home for the following: • Patients with a Nasojejunal (NJ), Jejunostomy or Percutaneous Endoscopic Gastrostomy with Jejunal Extension (PEGJ) tube. • Patients who are immunocompromised. • Patients who are under 1 year of age. (ICNA, 2003).

[1] Information taken from: Guidelines for the Preparation and Handling of Expressed and Donor Breast Milk and Special Feeds for Infants and Children in Neonatal and Paediatric Health Care Settings, BDA Paediatric Group - 2017.

Do not heat or warm sterile water used for enteral feeding/flushes.

[2] For modified feeds with multiple ingredients; making up individual feeds may be less accurate, more time consuming, impractical and susceptible to errors as the different ingredients need to be measured down to the correct quantities required for each individual feed. Therefore, some feed recipes should be made up in bulk quantity (usually 24 hour volume) and decanted into several bottles using aseptic technique (The BDA Paediatric Group, 2017) . All left over feed should be discarded after 24 hours of making up.

Feed and Fluid Hanging Times

Feed Type	Maximum Hanging Time in Hospital and home
RTF bags sterile until opened and stored at room temperature (8-25ºC)	24 hours – If a break in between feeds is >4hours, the feed pack (with attached giving set) should be put in the fridge. Then taken out 30 minutes before the next feed. Discard any leftover feed after 24 hours (ICNA, 2003)
Feed or Non Sterile reconstituted powdered feed or **water decanted** into a Sterile Feeding Reservoir	Maximum hanging time of 4 hours in Hospital and at home (at dietitian's discretion). When made up, store at <8ºC for a maximum of 24 hours (ICNA, 2003) until ready to use. Take out of fridge 20 minutes beforehand. Change giving set, container and feed every 4 hours (Anderton A, 1986a and1986b). Do not refill or top up feed reservoirs due to increased risk of microbial contamination (Kohn, 1991), Patchell et al 1998).

Water for Gastrostomy Button Balloon Water Changes

Patients with a Gastrostomy Button (or Transgastric Gastrojejunostomy) should have their balloon water changed weekly. **Cooled boiled water** is used. In an area with extremely hard water; the dietitian may advise sterile water if problems with the balloon longevity.

Amount of Water for Gastrostomy Button Balloon Water Changes (follow manufacturer's guidance)

For Enteral UK (Mini) Buttons:

French Size	Minimum	Recommended	Maximum
12F	2ml	**2.5ml**	3ml
14F	3ml	**4ml**	5ml
16F	4ml	**6ml**	8ml

For Vygon (MicKey) Buttons:

French Size	Minimum	Maximum
All	3ml	5ml

For MIC-J or G-Jet Transgastric Gastrojejunostomy Devices

Liaise with the hospital that placed the device, and follow manufacturer's guidelines.

Ordering Sterile Water

If sterile water is used, it will need to be prescribed by GP and then dispensed via a Home Delivery Company.

Equipment	Maximum Length of Use in Hospital and home	Recommended Monthly Order
Sterile Water for Gastrostomy Button Balloon Water Changes, if used: Braun 10ml sterile water vials	Single use ②	4/month (1/week) comer in packs of 20 – therefore have one box 5 monthly
Sterile Water for Making Up Feeds at Home, if used: Cow and Gate Sterile Water 90 ml bottles/1litre		Calculate volume amount water required/day for making up feeds and for flushes x by 28 = amount/month

Giving Medication to children via an Enteral Feeding Device

Medications should be given in a liquid formulation whenever possible; the syringe used should be of appropriate size to the dosage of medication given. Small syringes are acceptable for measuring and administering small doses of medications via an enteral feeding device (Dept. of Health 2004) National Service Framework for Children Young People and Maternity Services – Standard 10: Medicines for Children and Young People). The feeding device should be flushed with water prior to medications, between each and after all medications. (NHS Quality Improvement Scottish Best Practice Statement (2007) (White and Bradnam, 2015) and pH tested in the case of NG/NJ tubes before administration of medicines. The paediatric pharmacist should advise on the correct dosage and administration of all drugs given via an enteral feeding device. Community nurses supply medication syringes.

Feeding Regimen/Plan

The dietitian will liaise with the child and family and other people involved (e.g. schools and respite) to devise an individualised feeding plan to meet the child's nutritional and fluid requirements - taking into account family routine, meal times, any oral intake and any medications which may affect feed absorption.

The dietitian will provide a typed feed plan for everybody involved.

The feed plan should include: nutritional requirements and possible intake from feed/food (energy, protein, fluids, fibre etc.), name of the feed being used, volume, feeding method (ie bolus or continuous) timing of feed, rest periods and hanging times of the feeds as well as volume and timing of flushes to be given. In some cases, medication will be added to the plan. Advice on modified consistency food and oral fluid textures may be given after SALT involvement.

If the child is on a specialised feed then a clear "feed recipe" needs to be included – recorded in useable measures e.g. correct size/colour of scoops with correct dilution.

The dietitians provide correct size scoops for recipes for some products which do not come with scoops or have multiple scoop size options (e.g. – Maxijul/Duocal).

Section 6 - Infants and Children on Enteral Feeds on the Ward

Assessment of an infant or child starting a tube feed on the ward

Following initial assessment, the infant/child should be reviewed daily until stable when reviews may be reduced to 2-3 times per week, or as requested by ward MDT.

Assessment of a child already known to us for enteral feeding

The ward should inform the dietitian that a child on enteral feed is in hospital, so that the child can be reviewed if required (see Community Paediatric Home Enteral Feeding (HEF) section 7).

Dietitian Responsibilities – Ongoing Care

- Feed tolerance – vomiting, diarrhoea, and other symptoms – pyrexia
- Review of general medical condition from medical notes
- Review intake from feed and any oral intake versus calculated nutritional and fluid needs
- Review of weight gain/growth
- Review of practicalities of feeding plan for child and parents/carers
- Review of any medications which could affect feed or vice versa
- Bloods review (FBC, UandEs, LFTs, Calcium. Magnesium, Phosphate – if available)
- If the patient is complex/longer term then it may be useful to attend the daily ward round to review the child with the MDT
- Joint review with the Paediatric Specialist Speech and Language Therapist (SALT) may also be useful - especially to review progress with eating and drinking or safety of oral intake
- If plan is for long term feeding at home – check discharge planning meeting date and pending discharge date. It is essential that the paediatric dietitian attends these regarding children being discharged with tube feeds
- Liaise with the Children's Community Nurses (CCNs) and/or Neonatal Outreach Nurse to ensure they are aware of the child's pending discharge – as they will visit the child regularly at home to provide support with enteral feeding. They will change NG tubes post discharge and will provide syringes for medications and nursing products
- If an enteral feeding pump is being used, the dietitian should ensure the parents/carers and child (if appropriate) are fully trained on setting up the pump and feeds and using the basic pump functions. This training will be undertaken by the Feed Company Nurse
- All changes to the feeding plan should be discussed with the child, family/carers and named nurse and fully documented on the feeding plan, in the nurse's kardex, in the medical notes and in dietetic record card. This should include powdered feed recipe and guidance for nursing staff on the hanging time of powdered feed and plastics (see **Section 5 Nutritional Assessment, Enteral Feeds, Supplements and Fluids** for details)
- Continuous unsupervised NG/NJ feeding should be avoided on the ward if possible. If no alternative is available, a risk assessment should be completed with the Consultant. Currently, the CCNs do not support children at home on overnight continuous NG/NJ feeds so cannot discharge on this

Dietitian Responsibilities – Prior to discharge on an Enteral Feed

For all patients:

- Discuss feed plan as above and provide written copy.

For new patients:

- Discuss the Enteral Feeding Home Delivery Service with the family
- After consent, register the patient on the feed company system (see Appendix 1), so that parents do not have to organise their own feed prescriptions and collection
- See **Section 4** for summary tables of quantities of feed and ancillary items to provide – ensure the ward send the patient home with sufficient (1 weeks) supplies

- Send prescription request to GP and ask that this is to be sent to Home Delivery Company, NOT local pharmacy. Use proforma letter on shared drive
- Ensure that the above is done as soon as possible prior to discharge as it takes a minimum of 2 working days for the home delivery company to organise and dispense feed for the first delivery
- Organise pump training by the Feed Company Nurse. The Home Delivery Company will also send out a welcome pack with useful phone numbers
- Complete home enteral feeding discharge checklist and file in dietetic notes (SRH).
- Book follow up with parents/carers – either in next scheduled clinic or occasionally home visit
- Add child to Paediatric Home Enteral Feeding register
- Ensure family have dietitian and feed company contact details

For existing patients:
- Make any required changes to feed company order
- Update GP prescription request via letter as above
- Update patient's feed on Paediatric Home Enteral Feeding register if required
- Ensure patient has follow up appointment scheduled

Chichester only:

Discharge pack
Register child on E-BANS [redacted] (see Appendix 2 for information)
Add child to Ward open access list

Nursing Staff Responsibilities – Ongoing Care
- Accurately weigh the child on the days/at the frequency agreed and record weights in the bed end kardex
- Ensure the child is receiving the correct feed as per feed regime, according to tolerance. Highlight any concerns regarding this to the Paediatric Dietitian
- Make up any powdered feeds as per the "feed recipe" on the feed regime
- Change powdered feeds and plastics as per the feed regime (**Section 5**)
- Ensure NG tubes are correctly sited and securely taped, with size of NG tube used and all tube related measurements (eg NEX measurement, tube nostril position measurement) clearly documented in nursing/medical notes
- Ensure gastric pH and tube position is monitored and recorded following initial insertion, before administering each feed, before giving medication via the tube and following vomiting, retching or coughing. (however, the absence of coughing does not rule out misplacement or migration) and if there is any evidence of tube displacement – eg – the fixing tape is loose, the marker has moved or the visible tube looks longer or kinked (NPSA, 2005)
- Change NG tubes as per these guidelines (**Section 4**)
- Accurately record oral intake and enteral feeds/other fluids intake, or agree with the child and/or parents/carers to take this on if appropriate

Nursing Staff Responsibilities – Prior to Discharge on an Enteral Feed
- Fully train as competent and sign off the child (if appropriate) and/or parents/carers on enteral feeding, administration of medications and tube management (including checking tube position and troubleshooting) using the ward gastric feeding training pack and parent/nurse signed off competency record. This document is produced by and kept on the ward
- Ensure that the child is not on a continuous unsupervised/overnight feed when discharged
- If required, ensure the parents/carers are trained to safely make any powdered feeds as per the "feed recipe" in preparation for discharge
- If pump feeding is used, pump training should be requested via, and organised by, the Paediatric Dietitian
- Organise the provision of one week's supply of enteral feed TTOs and interim equipment if required prior to the patients' first Home Delivery of feed/equipment

- Advise parents/carers on how frequently their child’s NG tube should be changed (**Section 4**). Usually the parents/carers will not be trained to replace NG tubes – this will be done by the Children’s Community Nurses (CCNs)
- Refer the child to the CCNs
- Ensure parents/carers are aware their child will have open access to the ward for any problems with their feeding device which cannot be resolved by the CCNs, dietitian or if out of normal working hours

Section 7 – Community Paediatric Home Enteral Feeding (HEF)

The Service

Many children with feeding devices have complex health needs and life limiting or life threatening conditions, and HEF may only be one aspect of the child's day to day care that the parents/carers have to manage.

The Children's NSF Standard 8 "Disabled Children and Young People and Those with Complex Health Needs" (2004) states that: "It is vital that the child and family receive co-ordinated high quality child and family centred service…which enable them and their families to live ordinary lives".

Aims of the Service (reflecting ESPGHAN, 2010):

- Work closely together as an MDT holistically to manage different aspects of the child's needs regarding HEF, according to respective professional expertise to provide effective nutritional support

- Take into account the preferences of the child, their family and carers regarding route of feeding and feed plan, ensuring safe and trouble-free maintenance of nutritional support, and maximising the potential for improved lifestyle and optimal disease management

- Promotion of patient and family autonomy - provide the child, family and carers with adequate information, assistive equipment and support to empower them to manage as many aspects of their child's enteral feeding as they are confident and competent to do at home (e.g. – some parents are happy to change feeding devices, whilst others may not wish to undertake this aspect of their child's care)

- Minimise unnecessary hospital attendances/admissions related to enteral feeding

- Liaise with other health professionals (e.g. medical and ward staff, school and (short stay) care settings) to ensure that all are kept updated on the child's enteral feeding needs

- Ensure child, family, carers and hospital and community based health professionals are kept updated on any necessary changes to nutritional support/feeding practice (e.g. NPSA), via informal and formal training routes in liaison with paediatric ward managers, paediatricians and the paediatric training coordinator

Local Paediatric Home Enteral Feeding Service Standards (2017)

Standard 1

For any new paediatric HEF referrals – make contact with the family/carers within two working days of receipt of referral, or if on the ward within one working day of referral.

Standard 2

Organise provision of home equipment and feed within 2 working days of referral for new patients, or for inpatients in good time for discharge if this is not imminent.

Standard 3

Arrange initial review face to face within 1 week of referral, if appropriate.

Standard 4

Liaise regularly with the child, family and carers, every 3 months by telephone, according to individual need. For new patients this may be more frequent - initially weekly. For stable well patients the onus is also on the parents/carers to contact the dietitian.

Please note - Some patients will be reviewed monthly or more frequently. If a child has been tube fed for a long period of time and is very stable then there may be less frequent contact and the responsibility will lie with the parent/carers to telephone between clinics if they have concerns.

Standard 5
Review the child regularly (at least every 6 months) in an appointment at convenient location (e.g. - CDC or hospital clinic, school clinic or occasionally at home).

Standard 6
Liaise closely with others involved in the child's care, e.g. CCNs, SALT, Health Visitor, school and school nurses, (short stay) respite care, named acute and community paediatricians, ward, social workers - and maintain close liaison with these HCPs/agencies.

The Responsibilities of the Paediatric Dietitian looking after these children:

General:

- Ensure each child receives optimal enteral nutrition (according to tolerance) to meet their changing needs for optimal health, growth and development
- Organise the child's Home Enteral Feeding registration and ongoing supply of feed and equipment
- Provide ongoing clinical management of the child's home enteral feeding including feed plans for the child's family and other services involved
- Review the child preferably in school or other setting (e.g. CDC, home) with relevant other health professionals e.g. Consultant Paediatrician, CCN/school nurse, SALT, Physio, OT, Social Worker, School staff etc
- Maintain a department paediatric HEF patient register
- In Worthing, the HEF Paediatric Dietitian is able to place replacement low profile balloon buttons

In clinics:

At each clinic use clinic proforma sheet to undertake regular monitoring of home enteral feeding patients (**Appendix 5**). The sheet includes assessment of:

- Anthropometry – Weight and Length/Height - plot on appropriate centile chart
- Nutrition (at minimum energy, protein, fibre and fluid) requirements appropriate for age and weight – using GOS (2014) – ensuring these meet the child's changing needs for optimal health, growth and development
- Nutritional intake from feed (commercial and blended) and any oral intake versus calculated nutritional and fluid needs
- Acknowledgement of mobility/activity level and changes in this
- Food and fluid texture (alongside SALT)
- Feed tolerance – reflux, vomiting, diarrhoea, constipation, and other symptoms
- Practicalities of feeding plan for child and parents/carers including position and safety of child during feeding, feed rate and volume
- General health, and changes in clinical condition e.g. reflux, chest infections, seizures
- Please note presently blood tests are not undertaken in clinic and would only be reviewed/requested if there was a specific concern. E.g. Vit D
- Any medications which could affect feed or vice versa
- Gastrostomy site and condition as appropriate – alongside CCN
- Balloon integrity – water being checked and changed weekly
- Location of spare devices (e.g.. kept in school bag and with child at all times)
- Check if any issues with enteral feeding pump (if used)
- Feed and equipment order; to check supplies, delete any unused items and check patient satisfaction with service.
- Agree new or ongoing feeding regime to meet nutritional and fluid needs
- Agree any changes to Feed Company order
- Agree date for next clinic review.

Following Clinic appointment, the dietitian will action any changes that have been agreed in clinic (e.g. – to feeds, prescriptions and ancillaries order), book the next clinic review on SemaHelix, and produce a report of the clinic appointment, including updated feed regime etc.

Working together with the Children's Community Nurse (CCN) or Special School Community Nurse (SSCN):

The CCNs are very important in the management of children on home enteral feeds. Their role is to:

- Manage nursing aspects of paediatric HEF including practicalities of tube feeding, providing additional training regarding this as needs be to family and carers, school and (short stay) care
- Provide initial advice and ongoing feeding device care management in addition to what parents should have received at the hospital that placed the device. This may include training parents/carers to replace these if they wish to learn
- Providing training to schools/nurseries as required
- Providing routine replacement of feeding devices and urgent replacement when possible within normal working hours, when required
- Regularly reviewing size/length of feeding device (using stoma measuring device in the case of button gastrostomy changes) in line with child's growth
- Managing feeding device site infections
- Provision and management of some home enteral feeding equipment (syringes for medications, duoderm, hypofix fixative tape, pH strips for testing pH during button changes)
- Management of the administration of medications via the device and possibly changing dosage in liaison with child's paediatrician/paediatric hospital pharmacist
- Aiding in managing the general health of the child and liaising with other Health Care professional (e.g. paediatrician) as needs be
- Liaising with tertiary centre colleagues as required – e.g. – Gastroenterology Specialist Nursing Team at Southampton Hospital

Section 8: Other General Information and Trouble Shooting

Oral Hygiene

This is extremely important whether the child is orally fed or not. The child should be encouraged with tooth brushing twice a day. See also "Homeward for Kids" advice sheet. Parents are encouraged to take up free NHS dental care.

Post Feeding Device Placement care

General:

Refer to manufacturer's guidelines for advice on cleaning and care of the device. The CCN's will have discussed this with the parent/child.

Bathing

The child can have a bath with an NG tube in situ. Parents should ensure it is kept out of the water and that the end is kept closed. For PEGs and Low Profile Devices, the stoma should not be immersed in water until the stoma is fully healed. This is usually 4-6 weeks post placement.

Swimming

Swimming is permitted with an NG tube. Parents should ensure it is kept out of the water and that the end is kept closed. It may be best to go swimming before a feed is due, and not immediately after a feed.

The child can swim 4-6 weeks after their initial PEG/Low Profile Device (Button) has been placed – provided that the stoma site has healed. Parents should ensure the cap on the device has been closed to prevent leakage. A normal waterproof plaster should be used to cover the Low Profile Device/PEG. The child should not go swimming if the skin around their stoma is broken or inflamed.

Holidays

Families may request our support to enable them to go on holiday with enteral feed and all the equipment required. There are 2 options here:

1. **Rumble Trunk**

- A rumble trunk is a large plastic trunk used for transporting and storing pump, enteral feed and ancillary equipment. The Feed Company will send this directly to the patient's home
- The family are thus taking their *own supplies* on holiday with them. They are responsible for liaising with the airline regarding weight and volume

2. **Feed Company Travel Service**

- Used for longer holidays (more than 1 week)
- The Feed Company ship the ancillary equipment and feed *ahead* to the holiday destination airport (many but not all world destinations)
- Family must liaise *directly* with the Feed Company travel coordinator via the patient phone line to organise this
- The Feed Company require ***at least 6 weeks' notice*** prior to holiday departure to organise this, as they have to liaise with the airline and customs
- The family must provide the travel coordinator with details of their airline, dates and destination of their holiday, copies of their tickets and up-to-date passports (even if previously supplied) for each holiday
- The feed company should organise additional feed prescriptions with the child's GP should this be required

In either case the family should take some feed with them in their hand luggage to enable feeding during the trip, in case of delays on-route or in case of problems with the feed delivery if it is being sent ahead

Holidays – Paediatric Dietitian's Role

- Support family in informing them about the Feed Company Holiday Service and the above options, as well as the family's responsibilities – particularly the need for them to liaise with the Feed Company at least 6 weeks before their planned departure date, to see if their feed can be delivered ahead (ideally before booking flights) and to agree destination of delivery (e.g. – airport or hotel).
- Provide a free travel and flight letter if requested. The family must keep the letter with them during their flights and at the airport as it provides official documentation allowing them to carry the feed, powder or liquids, pump and ancillary equipment onto the flight and in their hand luggage. The letter is also evidence for customs. The Feed Company will also provide documentation if the feed is being sent ahead.
- Inform the family that they must also obtain an official letter from their named Consultant Paediatrician (or GP) to enable them to carry prescribed medications onto the flight and through customs. (Please Note: some GPs charge for these).
- Ensure the family are aware of the need to take sufficient feed and ancillary items with them for their outward and return flights, plus extra in case of delays to flights or problems with feed delivery – even if the Feed Company are sending the feed and ancillaries ahead.
- Advise the family to take at least a week's supply of feed and ancillaries with them in case of damage, supplies being lost in transit or if the return flight has to be postponed. It may also be possible that the child requires additional feed during their holiday.
- Advise the family that they should take their spare low profile device and emergency replacement kit or NG tube with them.
- If the child is nil by mouth and fed by pump it may be prudent for them to take a spare pump with them in case of pump failure.
- Ensure family take a country appropriate travel plug adaptor with them to allow pump charging whilst abroad.

Transition to Adult Services

The Paediatric Dietitians usually manage the care of all children who are enterally fed until they are 18, or 19 years of age (if in full time education at a Special School). Each child with a feeding device has open access to the Children's ward until they are 18 years old. The Paediatric Dietitian will refer the children to the Adult HEF Specialist Dietitian. A joint transition appointment will be organised to hand over the care, before the child reaches 19 years of age.

Discontinuation of Home Enteral Feeding

Child No Longer Requires Enteral Feeding as on Full Oral Nutrition

- If it has been agreed by the clinic team, e.g. Paediatrician, Dietitian and child/family that enteral feeding can be discontinued, and that the child is able to swallow all medications orally; the CCNs will be asked to remove the child's feeding device when the child has had a period of adequate oral nutrition and growth, e.g. 6 months for a permanent feeding device.
- In the interim, the feeding device should be flushed once or twice daily with 10ml cooled boiled water and normal cleaning care and tube maintenance should be continued.
- After removal, the CCNs liaise with the family regarding stoma care and will provide sterile dressings for the stoma site, which should be kept covered whilst it is healing over. If the site does not fully close down, the CCNs will liaise with the child's Paediatrician to organise a review. In some cases, surgery is required to aid healing.

Dietitian Responsibilities

- Contact Feed Company to put deliveries "on hold" until further advice, or remove child from their records.
- Parents may keep some emergency feed and ancillaries initially whilst "on hold".
- The Feed Company can arrange to collect all feed and equipment from the family.
- Take child off current patients HEF Register. Record on it the date of and reason for discontinuation (Chichester).

- Complete discontinuation of HEF on E-BANS if registered (Chichester).
- Monitor nutrition, hydration and growth for at least 6 months before discharging the child from dietitian's service.

End of Life Care

When a child is receiving end of life or palliative care, enteral feeding may continue for some time depending on the child's feed tolerance, as it will provide hydration and help prevent constipation and UTIs. The dietitian will liaise with the family directly, or with the CCNs where appropriate to help support the child's nutritional intake to keep them comfortable, but not necessarily to meet full nutritional needs if the feed is not well tolerated. If the child can eat and drink – they should eat or drink whatever they wish to.

"Clinically Assisted Nutrition and Hydration (CANH) is legally regarded as a medical treatment (Airedale NHS Trust v Bland, 1993) and one that sustains or prolongs life. It may be used for symptom relief and may increase quality of life, but it also carries risks. There may be concerns that withdrawal of CANH in semiconscious or unconscious children may unwittingly increase their suffering. On the other hand, attempts to provide CANH when its intended benefits cannot be achieved may also fail to promote the interests of the child" (RCPCH, 2015).

Withdrawing Enteral Feeding

Any child with a complex medical condition should have an Advanced Care Plan in place. This is written by the Paediatrician in conjunction with the parents and it will support health care professionals in making decisions about the use of artificial nutrition and hydration. The focus of care changes from attempting to prolong life to keeping the child as comfortable as possible until death occurs. In these final stages active treatment and the provision of artificial nutrition and hydration may become unnecessarily intrusive and merely prolong the dying rather than offering a benefit to the patient. Basic care should however always be provided.

This issue is covered with regard to infants and children in depth in "End of Life Care of Infants, Children and Young People" (NICE, 2016), and in the RCPCH/Larcher et al (2015) document "Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice". It is also covered in the General Medical Council (GMC) reference – "Treatment and care towards the end of life: good practice in decision making" (GMC, 2010), which replaces "Withholding and Withdrawing Life Prolonging Treatment" (BMA, 2007).

The child's named Paediatrician will lead any such decision making process, and should inform the dietitian so they can make any appropriate changes to the feed plan and any prescriptions/deliveries.

Dietitian's actions when a child on Home Enteral Feeding passes away.

- Phone the Feed Company as soon as possible to inform them that the child has passed away. Ask them **not** to contact the family. This is to ensure that the Feed Company doesn't contact the family with queries and cancels any pending delivery.
- The feed company should be told to await our instructions as to whether they should collect all the feed and equipment from the home or whether the CCNs should do this as they would have been in close contact with the family. If the CCNs are collecting all feed and equipment they will keep any new ancillaries that they feel they can use, and return pump to dietitians for collection by Homeward, or the dietitian will arrange Homeward to collect it directly from CCNs.
- Send confirmation Change of Regimen via online system with change of status to feed company.
- Cancel any appointments on SemaHelix (the hospital update the patient's record to show they are deceased when they receive official confirmation from a Dr/GP).
- Take patient off current patients HEF Register list. Record on it the date of and reason for discontinuation. Add to "the off list" at the end of the register (Chichester).
- Complete discontinuation of HEF on E-BANs if registered (Chichester**)**.

Problem Solving

Pump Breakdown

- Parents/Carers can telephone the feed company discuss pump problems as they may be able to resolve it on the telephone or via an visit from the feed company nurse, who will request a new pump if needed. A new pump should be sent within 24 hours.
- If the parents do not have a spare pump and the feed company are unable to supply one quickly enough, they can be given a pump from HEF dietitian's pool pump supply (Chichester and Worthing) or Worthing have a community pump supply in Salvington Lodge, on Offington Ward. The serial number of the pump supplied should be recorded by the Dietitian in dietetic notes and with admin and feed company.
- The feed company should be notified of the issue so they can uplift the broken pump and replenish the pool pump.

Nasogastric/Naso Jejunal Tube cannot be aspirated

Please Note - If parents telephone for advice regarding this and you are not confident to advise them – please ask them to speak to the CCNs or Children's Ward.

Nasogastric aspirates of pH 5.5 or below mean it is safe to commence NG feeding, if aspirate of 6 or above is obtained, the child should not be fed, advice should be sought from the ward or CCN and the tube may have to be repassed.
Following this the CCN should check the parent's technique to ensure best practice is being followed.

Nasogastric or Button Gastrostomy Tube Blocked

Please Note - If parents telephone for advice regarding this and you are not confident to advise them – please ask them to speak to the CCNs or Children's Ward.

Suggest using *warm* (not hot) water or soda water using a "milking action" with a 50ml syringe and tube manipulation (rolling between thumb and forefinger).

- **Do not** use cola or acidic fruit juices as these can exacerbate tube occlusion by causing feed to coagulate or protein to denaturise (Frankel, etal 1998).
- If tube remains blocked, "Clog-Zapper" (Merck) can be used, which should be administered by a CCN or ward nurse. However, if the blockage is caused by medication and not feed it is unlikely to work (White and Bradnam, 2015).

Leaking Around Gastrostomy Stoma Site

This can happen within first 2-3 weeks of device insertion. The CCNs will liaise with parents to suggest appropriate management.
Leakage can occur if the child is too full of feed, or by wind. This can be relieved by "venting" or "decompression", by opening the tube or attaching extension set and syringe.

Leakage of balloon containing device may suggest that the balloon is partially deflated:

- Check volume of water in button is correct for device. (See section 5)
- If ongoing problems occur, liaise with CCN to measure stoma length as this may have changed.
- Balloon gastrostomy may be near the end of its life and need replacing.

Balloon Gastrostomy Will Not Deflate

Please Note - If parents telephone for advice regarding this and you are not confident to advise them – please ask them to speak to the CCNs or Children's Ward.

- **This should NOT be attempted by parents at home.**
  Button Manufacturers advise inserting a clean paper clip into the balloon insertion valve to release it, or alternatively using sterile scissors to cut across the top of the button just before the point where the balloon inflation port channel descends down the side of the balloon shaft, to release the shaft. **On doing this the**

button shaft should be held in place by an “artery clamp” to prevent any risk of it falling into the stoma.

- If the balloon still will not deflate it can be removed whilst still containing water with a sharp tug if the parents and healthcare professionals present agree.

Accidental Removal of NG tube

Please Note - If parents telephone for advice regarding this and you are not confident to advise them – please ask them to speak to the CCNs or Children’s Ward.

- Parents/carers should have a spare NG tube; if they are trained as competent to replace this they can do so.
- If they have not been trained do so, the parents should liaise with CCNs in the first instance.
- If it is out of office hours they should visit the Children’s ward (they should telephone ahead first) and take their spare NG tube and guide wire (if applicable). If they do not have a spare NG tube the ward should be able to supply one.

Accidental Removal of Button Gastrostomy Device

Please Note - If parents telephone for advice regarding this and you are not confident to advise them – please ask them to speak to the CCNs or Children’s Ward.

- Some parents are trained by the CCNs to replace their child’s gastrostomy tube (unless the gastrostomy is very new)
- All patients should have a spare button gastrostomy device
- If they do not have a spare they should contact the paediatric dietitian or the CCNs as soon as possible
- If parents cannot reinsert the button gastrostomy device they should liaise with CCNs in the first instance. They may ask the Worthing Paediatric Dietitian to replace the button in hospital too during office hours if he/she has the competency to do this
- Out of hours the parents should contact the Children’s ward
- The CCNs and/or ward may use an Introducer to aid button replacement – these are available in the ward gastrostomy emergency box (Chichester); the CCNs and Dietitians have them in stock.
- Introducers are only to be used by healthcare professionals and should not be given to patients, unless they keep them with the buttons for health professional use or have been trained to use them.
- Gastric pH should be checked before first using the new device.

Accidental removal of NJ and PEG-J Tube

- Parents should liaise with Children’s ward at their local or tertiary Hospital. Placement should always be confirmed by X-ray.
- PEGJs cannot be replaced at Western Sussex Community Health NHS Trust as this needs to be done under a general anaesthetic. The ward should insert an emergency balloon gastrostomy tube to ensure that the stoma tract is kept open. If the child cannot tolerate gastrostomy feeds and/or is NBM, IV fluids may be required.

Child Runs out of Enteral Feed

- Parents should contact their Paediatric Dietitian as soon as possible in the first instance.
- Dietitian to check the reason for running out of feed and to organise new delivery as soon as possible via the home delivery company.
- It may be necessary for the dietitian to organise a very short term interim supply of feed via own stock (Worthing) or hospital pharmacy. If the child’s exact feed is not in stock, the nearest suitable alternative should be used.
- Out of hours parents should contact the Children’s ward.

Child Runs Out Of Enteral Feeding Equipment

- Parents should contact their Paediatric Dietitian as soon as possible in the first instance.
- Dietitian to check which equipment is required and the reason for running out of equipment and will organise new delivery as soon as possible via the feed company, or for parents to collect items from the office.
- Dietitian may need to supply small amount from department stock or ward. Please Note – Chichester do **not** stock spare gastrostomy buttons. Parents will need to use an emergency balloon gastrostomy device in the short term.
- Spare NG tubes are kept on the ward.
- Out of hours, parents should contact the Children's ward – emergency equipment is kept in the ward emergency box.

Stoma Site Infections

- Parents should liaise with the CCNs in first instance for advice.
- Parents should continue to ensure that the stoma is cleaned twice daily (more if advised by the CCN), and rotated as required.
- If child has an infected stoma site (red, inflamed, sore, purulent, patient generally unwell), the CCNs then request a swab to be taken of the site.
- If the CCNs are not available the child should see their GP.

Venting

If the child on a PEG or balloon gastrostomy device appears to be in abdominal discomfort, it may be useful to vent the child before feeding commences, especially if they are known to swallow a lot of air. Venting allows air out of the child's stomach. The extension set and syringe need to be attached and it will be obvious when air escapes from the stomach. The amount removed may be variable. It should come out of its own accord and should **not** be "drawn out" by pulling back on the syringe plunger.

Section 9 - Useful Contacts

Dietitians:

[redacted]

[redacted]

[redacted]

[redacted]

Children’s Community Nurses:

[redacted]

[redacted]

[redacted]

[redacted]

[redacted]

Homeward Patient Line (Number to give to Parents/Carers)

[redacted]

Wards:

Howard Ward - St Richards Hospital - [redacted]

Neonatal Unit - St Richard’s Hospital - [redacted]
([redacted])

Bluefin Ward - Worthing Hospital - [redacted]

Beeding Ward - (Neonatal Unit WASH) [redacted]
([redacted]

Paediatric SALTs:
Paediatric Speech and Language Therapists Chichester
[redacted]

Paediatric Speech and Language Therapists Worthing
[redacted]

Dentist:
Jubilee Dental Unit, St Richard's Hospital [redacted]

Pharmacy:
[redacted]

Section 10 -Appendices

Appendix 1: Using a Feed Company in WSHFT – who orders which items

Western Sussex Hospitals NHS Foundation Trust currently use Nutricia Homeward home delivery service for feeds, ancillaries and nursing support for patients on home enteral feeds. The Paediatric Dietitians register the child on Nutricia Connections (with parent/carer consent) and organise volume and type of feed and ancillaries, and will amend orders when needed. They will contact the Homeward Specialist Nurse who will undertake pump training as required.

Nutricia deliver on a 28 day cycle basis, but can deliver more frequently if there is a storage issue. The initial delivery will be done within 2-5 working days of patient registration, provided this has been done by 12 noon.
Each patient will have a monthly scheduled delivery date and a calendar for future deliveries.
Homeward perform a monthly stock check, 2 weeks before the next delivery date is due, to avoid stock piling of unused items.
Patients or parents can also choose to do this online. They are not able to request additional items; this will have to go through the dietitians first.
Nutricia have their own line of feeds and supplements – but they also supply third party items if required.

Worthing and Chichester dietitians order items via different suppliers:

Item	Worthing	Chichester
NG/NJ	CCNs	Feed Company
Low profile device and extension sets	Dietitians	Feed Company
60mls syringes	CCNs	Feed Company
Medication syringes	CCNs	CCNs
5ml luer slip syringes	CCNs	Feed Company
pH strips	CCNs	Feed Company (CCNs for Button Gastrostomies)
Sterile water for making up feed/flushes	Feed Company/GP	Feed Company
Feed	Feed Company (occasionally GP - FP10)	Feed Company
Giving sets, pumps, stands/frames, charger, rucksack	Feed Company	Feed Company
PEG replacement kit (emergency device)	Dietitians	Feed Company or Dietitians

Feed Company – Dietitian organises these items with the patient’s regular feed delivery.

Dietitians – Dietitians organise items to be sent directly to the patient.

CCNs – Do own monitoring and ordering for patients.

Appendix 2: E-BANS
Using E-BANS (electronic BANS) – Chichester only

E-BANS (electronic BANS) – the British Artificial Nutritional Survey, is a method by which national data on enteral feeding in adults and children is collected by BAPEN (British Association of Parenteral and Enteral Nutrition). The data is used to produce national reports on trends in enteral feeding. It is important (following informed consent) to register patients on E-BANS, so that BAPEN can collect accurate data.

NB – There are printable guidelines on how to use E-BANS on the E-BANS log on page if required.

Registering a Child on E-BANS

1. Go to [redacted]
2. Log into E-BANS with Username: strichards, Log in: Richard210
3. Click on register patient and follow the online instructions.
4. Print off completed registration and file in dietetic notes.
5. Log out when finished.

Confirming Patient Status on E-BANS

E-BANS automatically produces a list of patients whose status has not changed for a while from time to time – to remind you to check and update their status if required.
1. Follow step 4 as above to log in.
2. Check list confirm or amend patient status as needs be
3. Log out when completed.

Removing a Child from E-BANS

1. If a child stops home enteral feeding follow step 4 above to log in.
2. Click “view patient” button to find existing patient and click “update episode” button.
3. Amend information on part 14 of online form.
4. Print off amended information and file in dietetic notes.
5. Log out when amendments completed.

Appendix 3

Western Sussex Hospitals NHS
NHS Foundation Trust

Your Child's Tube Feeding Equipment

Name: **Hosp No:** **D.O.B:**

This sheet provides a summary of what tube feeding equipment your child requires, & the amount of equipment you will receive each month via homeward.
It also provides a summary of how you should care for this equipment. More advice on tube & skin care cleaning can be found in your child's information folder.

Contact Numbers:

[redacted] [redacted]

YOUR EQUIPMENT	NUMBER PER MONTH	CLEANING INSTRUCTIONS	HOW OFTEN DO I NEED TO CHANGE THIS?
NG TUBE **NAME:** **SIZE:**		Single Use	PVC tube — once a month. Silk Tube – Once every 3 months
pH Paper **NAME:**		Single Use	Single Use Use a new strip for each feed.
SYRINGES **NAME:** **SIZE:**		Wash out with warm soapy water after each use and rinse thoroughly, store in a clean dry container in the fridge.	Use 1 syringe a week.
FEED **NAME:**		N/A	N/A
EXTENSION SETS **NAME:** **SIZE:**		Wash out with warm soapy water after each use and rinse thoroughly, store in a clean dry container in the fridge.	Use a new extension set each week.
GASTROSTOMY BUTTON **NAME:** **SIZE:**		Clean site and turn button daily, remove button and flush out with warm water if blocked.	Change button every 3 months.
Giving Sets		Single Use	Single use—use a new one every 24 hours
OTHER EQUIPMENT			

Please note your community nurse will provide you with medication syringes and any tape you need (e.g. To hold your child's NG tube in place).

Appendix 4 - HEF Discharge Checklist (for children starting HEF)

[redacted]

Western Sussex Hospitals NHS
NHS Foundation Trust

Dietitian's Check List for Starting Home Enteral Feeding

Child's Name: **DOB:** **Hospital Number:**

Date Commenced Form:

Item	Date
Button or NGT discussion	
Feed Regime Options (pump/bolus) discussed	
Pump Training (see also pump training checklist)	
Request for CCNs review re button care & mgt	
Initial Homeward Equipment Order (feed, pump & adapter, stand, carry bags, syringes, pH strips, giving sets, ext sets, NGT or button/PEG)	
Homeward 4 Kids written information pack given	
Initial Prescription faxed to GP	
"Having a Gastrostomy" SRH leaflet given	
"NAF clinic" SRH leaflet given	
Initial nutritional needs calculated	
Initial written feeding plan (regime) & recipe (if required) discussed & given to pt, HCPs, School, respite care	
EBANS Registration	
NAF clinic follow up date	
Add to Paed HEF Register & Give copy of updated list to ward	

Appendix 5 – NAF Clinic Proforma (2 pages)

HEF Review Sheet

Date, time & location: ____________________	Name ______________________________ DOB________Hosp No:___________		Attended by: ____________________
Weight: ________kg Centile: : ________	Height:_______m Centile:________	BMI:____________ Centile:_________	Age:____________

Comments

Daily Nutritional Requirements

BMR/EAR : ______________________	Activity factor (% / PAL)_______________
Weight gain / loss _______________________________ Stress ____	TOTAL Energy (Kcal) _________________________
TOTAL Protein (g)_______________	TOTAL Fluid (ml)____

Fibre	**Calcium**	**Iron**	**Vit D**	**Other**

Daily Nutritional Intake

Oral Intake **Y:N** Food Texture___________________________	Oral Fluids **Y:N** Consistency ____________________ Thickener **Y:N**____________________

Energy (Kcal)_________	Protein (g)_______	Fluid (ml)____	Fibre (g)_________
Calcium	Iron	Vit D	Other

Food, Fluids and Enteral Feed

Breakfast Mid-morning Lunch Mid-afternoon Tea Bedtime	Feed Regimen Flushes

Tube Information

Tube type ____________________

Tube size / length _____________

Issues with tube? _________________________________
Condition ____
Date inserted _____________________________________

Balloon integrity ___________

Checked weekly? **Y:N**

Advance and Rotate

____

Fixation Device

____

Pump service date ___________

Pump serial number __________

Pump clean? **Y:N**

Information sheets and spares
Advice sheets **Y:N**
Spare tube **Y:N**
Spare accessories **Y:N**

Delivery review

Stoma site Condition ___________________________

Dressing **Y:N**
Over-granulation **Y:N**
Exudates **Y:N**

Medications

General Health Review

Skin integrity

Bowels

Urine output

Vomiting

Biochemistry

U's & E's		Trace Elements	
L F T's		Micronutrients	
FBC			

Assessment

Plan

Letters	Report	Feed plan	Outcome	Review Date

Section 11 – Abbreviations

BDA – British Dietetic Association
BMA – British Medical Association.

CCG – Clinical Commissioning Group.

CCN – Children’s Community Nurse/s.

M/EBM – Maternal/Expressed Breast Milk.

EBANS – Electronic British Artificial Nutrition Survey.

ESPGHAN – European Society of Paediatric Gastroenterology, Hepatology and Nutrition

GOS/H – Great Ormond Street Hospital for Children.

MDT – Multi Disciplinary Team.

NEC – Necrotising Enterocolitis

NG/NGT – Nasogastric (Tube).

NJ/NJT – Naso-Jejunal (Tube).

NNNG – National Nurses Nutrition Group

NPSA – National Patient Safety Agency.

PEG – Percutaneous Endoscopic Gastrostomy.

PEG-J - Percutaneous Endoscopic Gastrostomy with Jejunal Extension.

PEN – Parenteral and Enteral Nutrition Group of the BDA.

RTF – Ready to Feed.

RCPCH – Royal College of Paediatrics and Child Health.

SALT – (Paediatric Specialist) Speech and Language Therapist/s.

TTOs – To Take Out/s (items organised in readiness for discharge from hospital)

WHO – World Health Organisation.

WSHFT – Western Sussex Hospitals NHS Foundation Trust.

Section 12 - References

Afzal NA etal (2002). Re-Feeding Syndrome with enteral nutrition in children: a case report, literature review and clinical guidelines. Clin Nutr 2002, 21: 515-20.

Agostoni C, Axelson I, Colomb V etal (2005). The Need for Nutrition Support Teams in Paediatric Units: A Commentary by the ESPGHAN Committee on Nutrition. J Paediatric Gastroenterology and Nutrition. 2005 41, 8-11.

Airedale NHS Trust V Bland [1993] 1 All ER 821
http://www.bailii.org/uk/cases/UKHL/1993/17.html (accessed 07.03.2017)

Anderton A (1986a). Microbiological Quality of Products used in Enteral Feeds. J. Hosp. Infection. 7, 68-73.

Anderton A (1986b). Microbial adhesion: a source of infection in patients fed by enteral feeding. J. Hosp. Infection. 7 171-176.

Auckland District Health Board (2014) Newborn Services Clinical Guideline, ADHB New Zealand cited in http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/nasogastric-and-orogastric-tube-management (accessed 28/02/2016)

Axelrod D etal (2006). Paediatric enteral nutrition. JPEN J Parenteral Ent Nutr: 2006; 30: S21-6.

Aynsley-Green, A etal (1982). Feeding and the development of enteroinsular hormone secretion in the preterm infant: effects of continuous gastric infusions of human milk compared with intermittent boluses. Acta Paediatrica Scand. (1982); 71: 379-83.

British Dietetic Association (BDA) Practice Toolkit. Liquidised Food via Gastrostomy Tube, BDA, 2015 (incorporates PENG risk Assessment in Appendices).

BDA Paediatric Group (2017). Guidelines for the Preparation and Handling of Expressed and Donor Breast Milk and Special Feeds for Infants and Children in Neonatal and Paediatric Health Care Settings, BDA Paediatric Group - 2017.

BDA Paediatric Group/Nutricia (August 2008). Enteral Feeding in Infants and Children – A Practical Step by Step Guide.

BMA (2007) Withholding and Withdrawing Life Prolonging Medical Treatment – Guidance for Decision Making. 3rd Edition, Ed English, V, Blackwell Science.

British Inherited Metabolic Disease Group (BIMDG) http://www.bimdg.org.uk

CF (Cystic Fibrosis) Trust (2002).Nutrition Working Group. Nutritional Management of Cystic Fibrosis, London 2002.

Dept. of Health (2004) National Service Framework for Children Young People and Maternity Services – Standard 10: Medicines for Children and Young People.

Dept. of Health (2004). National Service Framework for Children, Young People and Maternity Services – Standard 8. Disabled Children and Young People and those with Complex Health Needs

E-BANS https://www.e-bans.com

ESPGHAN (European Society of Paediatric Hepatology, Gastroenterology and Nutrition) (2010). Practical Approach to Paediatric Enteral Nutrition: A Comment by the ESPGHAN Committee on Nutrition. Braegger C, Decsi T, Dias JA etal. J Paed Gastroenterology and Nutrition. Jul; 51(1)110-22.

Frankel EH etal. (1998) Methods of restoring patency to occluded feeding tubes. Nutr Clin Pract. 1998, 13: 129-131.

Gane H, (2014) Dept. Nutrition and Dietetics, St Richard's Hospital. Paediatric Growth and Faltering Growth Guideline, Helen Gane - Specialist Paediatric Dietitian, June 2014.

GBUK Leaflets "Your Child's Gastrostomy" and "Changing a Mini Button" (2010) GBUK.
http://www.gbukhealthcare.com/patient-caregiver-enteral-products/patient-caregiver-advice-books/

General Medical Council (GMC) (2010). Treatment and Care towards the End of Life: Good Practice in Decision Making. http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life___English_1015.pdf_48902105.pdf (accessed 07.03.2017)

GOS Guidelines - The Dietetic Department Great Ormond Street Hospital for Children NHS Trust. Nutritional Requirements for Children in Health and Disease, 6th Edition (2014)

Great Ormond Street Hospital for Children NHS Trust (GOS) (2015) Clinical Guideline – Naso-jejunal and Oro-Jejunal Management. http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/nasojejunal-nj-and-orojejunal-oj-management (accessed 26.02.2017 & 20.06.2018)

Great Ormond Street Hospital for Children NHS Trust (GOS) (2014) Clinical Guideline – Nasogastric and Oro-Gastric Tube Management. http://www.gosh.nhs.uk/health-professionals/clinical-guidelines/nasogastric-and-orogastric-tube-management (accessed 26.02.2017).

Infection Control Nurses Association (ICNA) (2003). Enteral Feeding - Infection Control Guidelines. Skipper L, Cuffling J and Pratelli N. Infection Control Nurses Association in Partnership with Nutricia Clinical Care.

International Standardisation Organisation (ISO) (2016). Small-bore connectors for liquids and gases in healthcare applications — Part 3: Connectors for enteral applications. https://www.iso.org/obp/ui/#iso:std:iso:80369:-3:ed-1:v1:en (accessed 26.02.2017).

Jawaheer G etal (2001). Continuous enteral feeding impairs gallbladder emptying in infants. J Paediatr. (2001); 138: 822-5.

Knox, T. and Davie, J. (2009). **Nasogastric tube feeding--which syringe size produces lower pressure and is safest to use?** *Nursing Times,* 105 (27): 24-26.

Kohn CL, (1991) The relationship between enteral formula contamination and length of enteral delivery sets usage. JPEN 15, 567-571

McGuire W and McEwan P (2007). Transpyloric versus gastric tube feeding for preterm infants. Cochrane Database Syst Rev (2007); 3: CD003487.

Medicina Product Literature – Medicina Hospital and Home Oral/Enteral Syringes and NG tubes, 2008

Merck website FAQ Merck Corflo Enteral feeding tube – pressure when using syringes www. merckgastroenterology.com/faq-html

MHRA (Medicines and Healthcare Products Regulatory Agency) (2009). Antiepileptics: adverse effects on bone. https://www.gov.uk/drug-safety-update/antiepileptics-adverse-effects-on-bone (accessed 26.02.2017).

MHRA (Medicines and Healthcare Products Regulatory Agency) (2012). Proton pump inhibitors in long-term use: increased risk of fracture. https://www.gov.uk/drug-safety-update/proton-pump-inhibitors-in-long-term-use-increased-risk-of-fracture (accessed 26.02.2017).

National Osteoporosis Society/ Arundel P and Shaw N (2015). Vitamin D and bone health: a practical clinical guideline for management in children and young people. https://nos.org.uk/media/2074/vitamin-d-and-bone-health-children.pdf (accessed 26.02.2017)

NHS Modernisation Agency/Dept. of Health (2003). Essence of Care: Patient Focussed Benchmarks for Clinical Governance, Dept. of Health, London.

NNNG (National Nurses Nutrition Group) (2016). Changing of a balloon gastrostomy tube (bgt) into the stomach for adults and children.

NPSA (National Patient Safety Agency) (2005) Alert 05 (21.02.2005). Reducing the harm caused by misplaced nasogastric tubes, and How to confirm the correct position of nasogastric feeding tubes in infants, children and adults. NPSA, 2005.

NPSA (National Patient Safety Agency) (2005) Alert 09 (18.08.2005). Reducing the harm caused by misplaced naso and orogastric feeding tubes in babies under the care of neonatal units, How to confirm the correct position of naso and orogastric feeding tubes in babies under the care of neonatal units. NPSA 2005.

NPSA (National Patient Safety Agency) (2007). Alert Number 19 (28.03.2007).
Promoting Safer Measurement and Administration of Liquid Medicines via Oral and Other Enteral
Routes. NPSA, 2007.

NPSA (National Patient Safety Agency) (2011). Alert Number NPSA/2011/PSA002 10.03.2011. Patient Safety Alert. Reducing the Harm Caused by Misplaced Nasogastric Feeding Tubes in Adults, Children and Infants. NPSA 2011.

NICE Guideline 32 (2006). Nutrition Support in Adults
(www.guidance.nice.org.uk/CG32/niceguidance/pdf/English)

NICE Guideline (NG61) (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management.
https://www.nice.org.uk/guidance/ng61 accessed 07.03.2017

Nutricia (2002). Topical Review. Nutritional Support in Children. Nutritional Communications. Nutricia Healthcare, 2002.

Ohta K, etal. The effect of small amounts of a low residual diet against total parenteral nutrition. Am J Surg. 2003; 185: 79-85.

Oxford Radcliffe Hospitals NHS Trust (2007) Guidelines for the prevention and management of the Refeeding Syndrome.

Patchell CJ etal (1998). Reducing bacterial contamination of enteral feeds. Arch Dis Child, 78, 166-168.

Royal College of Psychiatrists (2005). Report CR130 (July 2005), Guidelines for the Nutritional Management of Anorexia Nervosa. pages 17-24. (www.rcpsych.ac.uk/files/pdfversion/cr130.pdf).

Royal College of Paediatrics and Child Health/Larcher etal (2015). Making decisions to limit
treatment in life-limiting and life-threatening conditions in children: a framework for practice Larcher V, et al. Arch Dis Child 2015;100(Suppl 2):s1–s26. doi:10.1136/archdischild-2014-306666
http://www.londonneonatalnetwork.org.uk/wp-content/uploads/2015/09/RCPCHMakingdecisions-to-limit-treatment2015.pdf (accessed 07.03.2017)

RCN (Royal College of Nursing) (2006). Malnutrition – Position Statement: What Nurses Working with Children and Young People Need to Know and Do. August 2006.

Shaw V and Lawson M. Eds. (2007) Clinical Paediatric Dietetics, 3rd Edition, Wiley.

Shaw V Ed (2014) Clinical Paediatric Dietetics, 4th Edition, Wiley.

Solomon SM and Kirby DF (1990). The Refeeding Syndrome: A review. Ann Clin. Biochem. 28, 19-26.

Tyson JL etal. Minimal enteral nutrition for promoting tolerance and preventing morbidity in parenterally fed infants. Cochrane Database Syst Rev. 2005, 3:CD000504.

STAMP (Screening Tool for the Assessment of Malnutrition in Paediatrics). Central Manchester and Manchester Children's University Hospitals NHS Trust (2008). http://www.stampscreeningtool.org/stamp.html

Uddenfeldt Wort etal (2013). Fractures in children with cerebral palsy: a total population study Developmental Medicine and Child Neurology 2013, 55: 821–827. http://www.rehabmart.com/pdfs/wort_et_al-2013-developmental_medicine__child_neurology.pdf
Accessed 26.02.2017.

Western Sussex Hospitals NHS Foundation Trust (WSHFT)/Gane H and Dicke O (2015) Risk Assessment Protocol for Continuous or Overnight Nasogastric/Nasojejunal Tube Pump Feeding – for Infants and Children on the Ward and in the Community.

White R and Bradnam V, on behalf of the British Pharmaceutical Nutrition Group (2015). Handbook of Drug Administration via Enteral Feeding Tubes, 3rd Edition, Pharmaceutical Press, Royal Pharmaceutical Society Publishing, London.

WHO (World Health Organisation). Management of Severe Malnutrition: A Manual for Physicians and Other Senior Health Workers. WHO, Geneva, 1999.

WHO/FAO/UNU – Protein and amino acid requirements in human nutrition, WHO technical report series 935, 2007

WHO/RCPCH (2009) New Growth Charts
http://www.rcpch.ac.uk/Research/UK-WHO-Growth-Charts