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Section 1: Introduction

This guidance is for use by all NHS Borders staff caring for children and young people requiring enteral tube feeding. It has been developed using the *NHS Lothian Enteral Tube Feeding Best Practice Statement (2013)*¹ and *NHS Quality Improvement Scotland Caring for Children & Young People in the Community Receiving Enteral Feeding Best Practice Statement (2007)*²

The scope of this guidance covers the following areas of enteral feeding:

- Naso / orogastric feeding
- Gastrostomy feeding (Percutaneous Endoscopic Gastrostomy (PEG) and low profile buttons)
- Nasojejunostomy feeding
- Jejunostomy feeding

Developed by:

Community Children's Nursing Team and Nurse Consultant Vulnerable Children & Young People in consultation with Ward 15 and SCBU, paediatric dietitians and BGH gastroenterology team.

Section 2: Assessment prior to enteral tube feeding

Assessment should include the following:

- A multidisciplinary approach including paediatrician, paediatric dietitian, speech and language therapist, paediatric nurse, community children's nurse, paediatric psychologist and family as standard practice prior to commencing enteral tube feeding
- Nutritional assessment – ensure weight, length or height and BMI is documented and dietary assessment completed
- Most appropriate type of feeding for the child
 - A risk assessment should be undertaken prior to discharging a child to home receiving nasogastric feeding. NHS Borders Risk Assessment document below can be used by nursing or medical staff involved in the assessment



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- Most appropriate type of feeding to suit the family's lifestyle
- Consider referral to paediatric psychologist for assessment, including the psychological impact of commencing tube feeding for the child and family
 - *Recommended resource: 'How Does it Feel? Acknowledging the Emotional Impact of Tube Feeding' DVD and leaflet for parents, available from National Managed Clinical Network for Children with Exceptional Healthcare Needs*⁴
www.CEN.scot.nhs.uk

- Referral to a specialist paediatric gastroenterology team RHSC Edinburgh would be the responsibility of the consultant paediatrician

Section 3: Nasogastric /orogastric tube feeding

Short-term tubes are made of polyvinylchloride (PVC) and can remain in place for between 3-10 days. Manufacturer's guidelines should be used to determine the length of time a tube can be left in place. If a tube is accidentally removed prematurely a new tube should be used. "Single use" is usually recommended.

Long-term tubes are made of polyurethane and have a wire to aid passing the tube. The wire is removed once the tube has been passed but should be kept in a safe place in case the tube has to be re-passed. The manufacturer will provide guidance regarding the length of time the tube can remain in place, cleaning and storage of the tube.

3.1 Passing the nasogastric / orogastric tube

- Wash your hands before and after the procedure
- Collect equipment i.e. nasogastric tube, 60mls syringe, pH indicator paper or strip, water to flush, hydrocolloid dressing cut to the correct size and transparent film to secure, glass of water or juice if appropriate
- Explain to the child or young person that you are going to pass the nasogastric tube
- Babies can be wrapped in a blanket or towel to help keep them secure and laid flat on their back (unless another adult is available to assist holding the child); older children may prefer to sit up with their head tilted slightly forward
- Determine the length of tube to be inserted by measuring the tip of the tube from nose to ear and then measure from ear to stomach; note the mark on the tube or keep your fingers on the point measured
- Ensure end cap is firmly in place on the end of the tube, to prevent leakage of gastric contents
- Select nostril that is clear, where possible alternate the nostril being used
- Lubricate the tip of the tube using a water based solution and/or follow manufacturer's guidelines
- Insert the tip of the tube into the nostril and slide backwards along the floor of the nose
- If there is any obstruction, pull tube back and turn it slightly and advance again. If obstruction is felt again try the other nostril
- As the tube passes to the back of the nose, ask the child or young person to take sips of water (if allowed) to help the tube go down or in the case of a baby offer them a dummy if they have one.

If at any time the child or young person starts coughing or their colour changes stop the procedure immediately and remove the tube

- Advance the tube until you reach the point where the tube was measured
- Secure the tube in position using a barrier product such as hydrocolloid dressings to protect the skin and transparent films
- The position of the tube should be confirmed after passing it and prior to using it for administering any feed or medications
- Document the position of the tube using the markers on the tube where it enters the nostril

3.2 Checking the position of a nasogastric / orogastric tube

- Wash your hands before and after the procedure
- Explain to the child or young person that you are going to check their tube
- Note the position of the tube using the tube markers
- Remove the end cap from the tube
- Attach a 60ml syringe to the end of the tube unless contraindicated by manufacturer's instructions
- Aspirate the gastric contents from the child or young person's stomach by gently pulling back on the plunger until a small amount of fluid appears in the syringe
- Detach the syringe from the tube remembering to replace the end cap of the tube
- Test the pH of the fluid using pH indicator paper or strip. The indicator paper or strip should change colour to read a pH of 5.5 or less.

See page 7 for NHS National Patient Safety Agency 'Decision tree for nasogastric tube placements in children and infants (not neonates)'⁵

More information can be found in the embedded document below, Medicina nasogastric feeding



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NB Be aware that some medications can alter the pH. If this is the case, this should be documented in the child's record.

If it is difficult to obtain aspirate:

- Attempt to push the tube's port away from the stomach wall. Insert 3-5ml of air via syringe, down the nasogastric tube. Try again to aspirate the tube and test with pH indicator paper or strip
- Lie the child/young person on their left side and then retry aspirating the tube
- Ask the child/young person to take a small drink, if allowed, then try to aspirate the tube
- Try advancing or pulling the tube back slightly
- Ensure the tube is at the same position at the nostril, documented when passed initially
- If you are unsure if the tube is correctly positioned, remove and re-pass the tube or seek further advice from community or hospital professionals
- Once the tube is in the correct position, if using a long-term tube remove the guide wire and close the port
- Flush the tube with recommended amount of sterile water (hospital setting) or cooled boiled water (community setting).

3.3 Frequency of checking nasogastric/orogastric tube placement

Check and document the tube position:

- Following the initial tube insertion
- Before commencement of each feed
- Before medications are administered
- Following evidence of tube displacement, e.g. loose tape, the visible tube appears longer or the position mark at the nostril has changed
- Following episodes of vomiting, retching or coughing

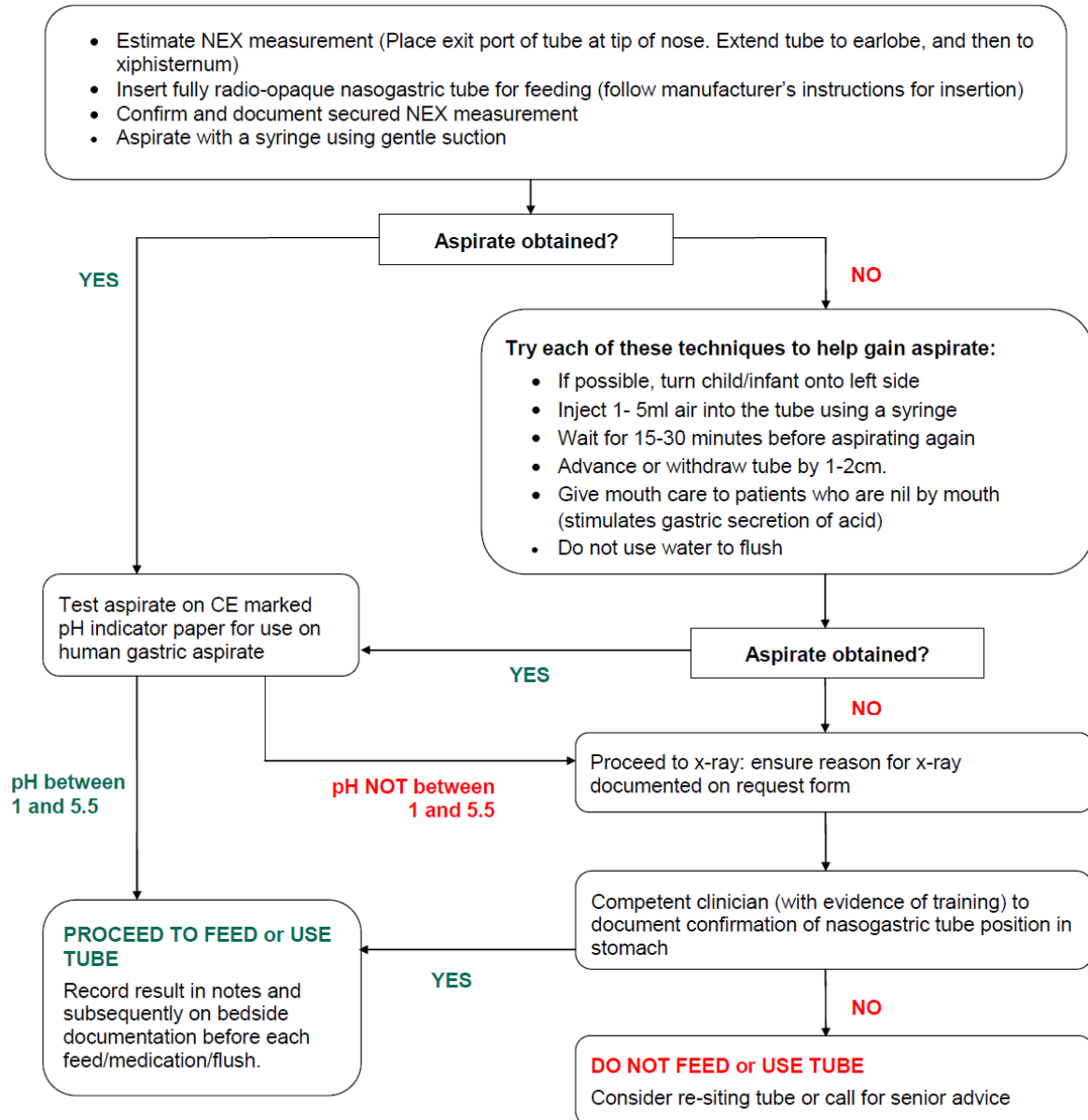
3.4 Frequency of changing nasogastric / orogastric tube

- Follow manufacturer's guidance
- Tubes should not be re-used, except if it is a 'single patient use' tube which may be reused, if considered appropriate
- Only tubes licensed for feeding should be used

3.5 Care of the infant or child with a naso / orogastic tube

- Regular mouth care
- Use of barrier spray for skin integrity when changing tapes
- Alternate nostrils

Decision tree for nasogastric tube placement checks in **CHILDREN** and **INFANTS** (NOT NEONATES)



A pH of between 1 and 5.5 is reliable confirmation that the tube is not in the lung, however it does not confirm gastric placement as there is a small chance the tube tip may sit in the oesophagus where it carries a higher risk of aspiration. If this is any concern, the patient should proceed to x-ray in order to confirm tube position.

Where pH readings fall between 5 and 6 it is recommended that a second competent person checks the reading or retests.

Section 4: Gastrostomy Tube Feeding

4.1 Care following initial stoma formation

- Following initial formation of the stoma there may be slight bleeding from the wound.
- The stoma should be left undisturbed for 24 hours. Clean the stoma site with saline using an aseptic technique for the first 48 hours. Thereafter, use a clean cloth and water and dry thoroughly.
- During the first 14 days the patient should not have a bath or go swimming, to reduce the risk of bacterial entry to the peritoneum.
- Showers are acceptable.
- Wash the stoma site prior to rest of the body.
- Paediatric advice – no swimming for 6 weeks
- Care must be taken when adjusting the external fixator within two weeks following the tube insertion (PEG tubes only).
- To adjust - seek advice from a nutrition nurse, medical staff or a dietician. Leave at least a 2mm gap between the skin surface and the fixator.
- **If there is pain on feeding, leakage of fluid around the tube, or new bleeding within first week of insertion, STOP FEED IMMEDIATELY and CONTACT a Nutrition Nurse Specialist or Paediatric Gastroenterologist for urgent advice.**

4.2 Care of sutures following insertion of Radiological Inserted Gastrostomy

- Around the stoma there will be two to four sutures in situ.
- Please note that the gastrostomy tube is not held in place by the sutures. The sutures secure stomach wall to the abdominal wall to allow the stoma to be formed
- These sutures should be removed seven days post procedure by a ward nurse, community nurse or outpatient nurse.
- Raise the metal fastener and cut the suture, then remove the disc and sponge.
- Internal suture material will pass through the gastrointestinal tract.
- Some bleeding is normal when removing sutures.

4.3 Daily stoma / tube care

- Clean the area with a clean cloth and soapy water, rinse and dry thoroughly.
- Do not use moisturising creams or talcum powder around the stoma site.
- Reposition the external fixator after cleaning, if appropriate.
- The external fixator should not be moved for the first 2 weeks post procedure (PEG tubes or tubes placed with pull through technique). Refer to the manufacturer's guidelines.
- Once a week, the external fixator should be moved and the tube should be moved in and out by a maximum of 10mm. This prevents "buried bumper syndrome"⁶, a rare but important complication in patients with a PEG tube
- Rotate the tube 360° and reposition the external fixator daily, leaving a space of at least 2mm to allow slight movement.
- If you are unsure whether a tube should be rotated, check with the person who placed the tube or refer to the manufacturer's guidelines.

4.4 Stoma problems – infection

- Infection can be minimised by scrupulous hygiene of the stoma site.
- Avoid occlusive dressings as these can encourage and trap moisture.
- Obtain a swab for microbiology if any exudate or inflammation is present.
- Treat with the appropriate systemic antibiotic as topical therapy may not always be effective. The infection is usually within the tract and not just superficial.

4.5 Stoma problems – Overgranulation

- Insufficient rotation of the tube or movement of the tube within the tract can cause granulation tissue.
- Check that the external fixator is not too loose or too tight. Correct positioning of the external retention device can reduce the risk of overgranulation.
- Check for infection by taking a swab of the stoma site and treat accordingly.
- Consider the use of an absorptive dressing such as Allevyn Non-Adhesive, Allevyn Adhesive, Tegaderm Foam or Lyofoam. The dressing of choice should be used for a minimum of 2-weeks to determine if it has been effective.
- A Steroid-based, Antibiotic or Antifungal cream may be prescribed e.g. Maxitrol eye ointment, Fucidin H or Timodine

4.6 Leakage around Gastrostomy site

Consider the following:

- Check for infection by taking a swab of the stoma site and treat accordingly.
- Check the internal fixator is against the inner gastric wall by gently pulling the tube outwards until resistance is felt, and ensuring the external fixator is close to the skin, leaving a space of about 2-3mm to allow slight movement.
- For balloon-retained tubes, check the balloon is still patent and inflated.
- The French Gauge of the tube may be incorrect. Discuss with a specialist e.g. Nutrition Nurse or Gastro Intestinal Specialist.
- Consider the use of barrier preparation e.g. Cavilon, in conjunction with a foam dressing such as Allevyn Non-Adhesive.

4.7 Frequency of changing tubes

When a tube has been placed, document the approximate date for the next replacement. Check the manufacturers' recommendation. As a guide the following should apply:

- Gastrostomy tube with internal retention bolster: change if required or clinically indicated.
- Balloon gastrostomy tubes: 3-6 months
- Low profile devices (internal retention bolster): approximately 24 months
- Balloon replacement low profile device: 3-6 months
- The life span of a tube can vary depending on medications and stomach acidity.

4.8 What to do when a gastrostomy tube falls out

- Please refer to patients individual gastrostomy care plan
- Ensure that the child and family carry a spare feeding tube with them which is the correct type and size.
- If a gastrostomy tube falls out then it should be replaced as soon as practicable, preferably within 6 hours, or the stoma will start to close.
- Parents and carers will be trained by the CCN to replace their child's tube if they choose to do this.
- If there is any problem reinserting the tube, then the child must come to Ward 15, BGH

4.9 Frequency of checking the balloon in balloon-retained tubes

- Follow the manufacturer's guidelines (usually weekly)
- Remove old water from the balloon and replace with fresh water (according to manufacturers guidelines) using a sterile syringe.
- Ideally check the balloon on the same day each week.
- There is no evidence to suggest a preference for sterile water vs. sterile saline. Some manufacturers suggest cool, boiled water.
- Follow the manufacturer's guidelines.

- Ensure that the balloon port is kept clean.

4.10 Unable to remove water from balloon

- Check that Luer Slip syringe is attached firmly to the balloon port.
- Try again, and if unsuccessful refer to Ward 15. Possible onward referral to GI Team, RHSC Edinburgh may be required.

4.11 Other problems

- Parents / carers should be aware of the need to report problems of vomiting, diarrhoea, constipation, abdominal distension, cramps, nausea or dehydration, weight loss or rapid weight gain; these factors may indicate a need to alter the child/young person's feeding regimen, dietary intake, medication regime or may indicate that a medical assessment is required by a Paediatric Consultant or GP.
- Leakage of feed/gastric contents around the gastrostomy tube and onto the skin at the gastrostomy site will cause skin redness, excoriation and breakdown as the gastric acid contents burn the skin:
 - check balloon is properly inflated
 - pull gently on the tube until resistance is met and secure the external fixator
- Yeast infections - swab site and treat as per local policy
- If the child/young person is having problems with recurrent burst balloons or leaking valve ports a gastric aspirate should be taken and sent to check for the presence of yeasts and treated as appropriate NB. If patient takes Domperidone, they cannot have Fluconazole, but high dose Nystatin

Section 5: Jejunostomy tube feeding

The use of jejunal or post pyloric feeding, where feed is delivered directly into the small intestine, is gradually on the increase in particular for a child or young person with worsening gastrointestinal dysmotility or poor gastric emptying.

Insertion of a jejunostomy feeding tube would take place in RHSC Edinburgh by the specialist GI team. NHS Borders staff will be involved in the post operative and ongoing care.

5.1 Care following initial stoma formation.

- Observe the site for swelling or bleeding - if there are concerns contact medical staff
- **DO NOT ROTATE THE TUBE**
- Use an aseptic technique when cleaning for the first 48 hours post-insertion.
- Immersion bathing should be avoided for the first 14 days post insertion.
- Showering is permitted.
- The tube is held in the stomach by a balloon which should be inflated with 3-10mls of sterile or cooled boiled water as per manufacturer's guidelines
- The water should be changed weekly as per instructions for balloon retaining gastrostomy tubes
- If the balloon bursts the tube should be taped in place if possible and medical advice sought.
- Feeds should be administered via the jejunal port of the tube
- Medications can be given via the jejunal or gastric port
- The tube should always be flushed with the recommended amount of cooled boiled water before and after feeds and before and after medications

- For care of the Balloon - see Balloon Gastrostomy advice sections **4.9** and **4.10**
- For stoma infection and overgranulation see sections **4.4** and **4.5**
- Tube migration or misplacement should be considered if the child or young person:
 - Is vomiting milk feed or milk is draining out of the gastric port
 - Is showing signs of aspiration
 - Has abdominal distension
 - Has worsening diarrhoea
- If the child or young person has problems with gastric distension a drainage bag can be attached to the gastric port to allow venting and drainage of their stomach.

5.2 Nasojejunal tubes

- A long-term nasogastric tube of a longer length than is required to feed into the stomach with or without a weighted end is passed in x-ray under fluoroscopic guidance
- The tube should be secured in position using a barrier product such as hydrocolloid dressings to protect the skin and transparent films
- The length of the tube at the nostril should be recorded, note this does not confirm the position of the tip of the tube
- Radiology is the only reliable method of confirming tube position, it is obviously not possible to x-ray prior to using the tube each time
- Tube migration or misplacement should be considered if the child or young person:
 - Is vomiting milk feed
 - Is showing signs of aspiration
 - Has abdominal distension
 - Has worsening diarrhoea
 - If fluid aspirated from the tube is testing acid on pH paper
 - If the tube appears longer or shorter than previously measured

If any of the above are observed the child or young person should be referred for an x-ray to check tube position.

Section 6: Gastrostomy or jejunostomy tube blockages

- Use a 60ml syringe to attempt to gently flush (push or pull to instil) the tube using warm water or soda water (at least 10mls)
- **Acidic solutions such as fruit juices and cola should not be used**
- Gently squeeze the tube between fingers and along its length (i.e. milking the tube)
- If the blockage persists, very gently draw back on the syringe and then attempt to flush as before
- If you are still unable to unblock the tube, consider changing the tube (sodium bicarbonate may be prescribed)
- If the tube is a PEG tube seek medical attention (sodium bicarbonate may be prescribed)
- Establish the reason for the tube blocking and check parents or carers information about flushing the tube.

Section 7: Administering enteral tube feeds

7.1 Position during feeding

- Where possible the child or young person should be positioned with their head above the level of their stomach, preferably sitting or supported at an angle of approximately 45 degrees
- If the child is unable to maintain this position, they should be well propped up on pillows at a minimum angle of 30 degrees
- If the child or young person shows any signs of shortness of breath (more than usual), sudden pallor, vomiting or coughing stop the feed immediately and seek medical attention.

7.2 Gravity Bolus feeding: this only applies to naso or orogastric and gastrostomy tube feeding (NOT JEJUNAL FEEDING)

- Allow refrigerated feeds to reach room temperature, before feeding (up to 30 minutes) to avoid stomach cramps
- Follow principles of good hand hygiene before, during and after the procedure
- Prepare feed and equipment in a clean area
- Always check the expiry date on the bottle, pack or tin and gently shake the contents before use
- Check that the pack is intact and the seal is undamaged
- Where the feed can be seen check that it does not appear to have “curdled”. If there are any signs of curdling the patient/carer must use a different pack and advise the Customer Service Team in order that arrangements can be made for the product to be returned.
- Explain to the child or young person that they are going to have their feed
- If giving feed via a nasogastric tube check the position of the tube. Further guidance on naso-gastric tube feeding can be found below.
- For powder feeds follow the dietician’s instructions regarding reconstituting the feed
- Ensure the child or young person is positioned correctly for feeding
- Attach syringe without the plunger to the feeding tube
- Flush the feeding tube with recommended amount of cooled boiled water
- Slowly pour the amount of feed required into the syringe
- If the feed is running too quickly or slowly alter the height of the syringe slightly. A feed should take between 15-30 minutes to complete
- When the feed is finished, flush the feeding tube with the recommended amount of cooled boiled water
- Remove the syringe and replace the end cap.

7.3 Pump feeding: this applies to nasogastric, gastrostomy and jejunostomy tube feeding

- Wash your hands before and after the procedure
- Prepare feed and equipment in a clean area
- Always check the expiry date on the bottle or pack and gently shake the contents before use
- Check that the pack is intact and the seal is undamaged
- Where the feed can be seen, check that it does not appear to have “curdled”. If there are any signs of curdling the patient/carer must use a different pack and advise the Customer Service Team in order that arrangements can be made for the product to be returned.
- Ensure the pump is positioned according to manufacturer’s guidelines
- Explain to the child or young person that they are going to have their feed

- If giving the feed via a nasogastric tube **always** check the tube position before feeding
- Ensure the child or young person is positioned correctly for feeding
- Flush the feeding tube with the recommended amount of cooled boiled water (or sterile water where applicable)
- Set up the feed, ensuring that air is expelled from the giving set and set the feeding pump according to the manufacturer's instructions either for a continuous ongoing feed or set the time/volume limit for continuous bolus feed
- Where necessary decant the required volume of sterile feeds (i.e. pre-packed feeds) at the beginning of a pump feed and do not top up feed containers until the container is almost empty
- When the feed is completed, flush the feeding tube with the recommended amount of cooled boiled water and replace the end cap.

7.4 Infection control, storing feed and equipment

- Avoid touching any internal part of the feed container and giving set, such as the spike with your hands by using a non-touch technique
- Pre-packed liquid feeds are sterile until opened so they can be used for up to 24 hours, if good hand hygiene is employed. Pour any unused feed down the sink after the container has been open for 24 hours
- Powdered feeds and feeds that have extra ingredients added should not be used for more than 4 hours
- It is good practice to encourage parents or carers to make up each bolus of powdered feed immediately before tube feeding at home during the day. For overnight continuous pump feeds at home, using powdered or decanted feed, the maximum hang time should be 12 hours or less. The hang time of non-sterile feeds should be agreed for each individual.
- Feed containers should not be topped up with sterile feed once feeding has started.
- Feed and containers should be changed every 4hrs in hospital settings. Hang time for non-sterile feeds is longer in the community for practical reasons.
- Any unused feed should be discarded after the above time periods.
- Giving sets should be changed after 24 hours and not reused
- Change extension sets every two weeks
- Rotate stock so that it does not go out-of-date
- Store equipment and powdered feeds in a dry place as per manufacturer's instructions
- Avoid stacking feed next to radiators or in direct sunlight
- Avoid storing feeds or equipment in garden sheds or garages during the winter when there is a risk of supplies freezing
- Discard feed that is out-of-date by pouring it down the sink
- Opened packages of feed can be kept covered in the fridge for 24 hours.

Tubes not used regularly should be flushed daily to prevent them becoming blocked

Section 8: Giving medication via feeding tubes

- Discuss with a pharmacist the medication requirements for any child or young person who will have to receive regular medication via nasogastric /gastrostomy tube

- The prescription should state the route by which the medication is to be given; the absorption of some medicines can be adversely affected by the presence of enteral feeds
- Use liquid medications wherever possible
- Flush tube with the recommended amount of cooled boiled or sterile water before administering medications, between each medication and after all medications have been given
- If medication is only available in tablet form check this can be crushed as the efficacy of some formulations can be impaired or lost by crushing

Section 9: Oral Hygiene

- Ensure that the patient/carer has been advised on the importance of oral hygiene and regular dental checks.
- Explain to the patient/carer the importance of keeping the mouth, teeth and gums clean and free from infection.
- The frequency and methods of oral hygiene and care will depend on the advice given by the Speech and Language Therapist, GP or Dentist as the patients mouth care needs must be assessed on an individual basis.

If at any time the child complains of a sore mouth, bleeding gums or blistering inside the oral cavity, medical advice should be sought.

Section 10: Discharge planning and teaching guidelines for parents/carers

- Prior to discharge careful consideration should be given to ensure patients can be discharged home safely on enteral tube feeding. This includes identifying who will be responsible for daily care of the tube and set up of the feed. Relevant training should be provided for patients, parent, carers and care staff
- The multidisciplinary team should be informed of the patient's discharge
- All paediatric patients will have a Children's Community Nurse
- A multidisciplinary discharge planning meeting may be required including the appropriate community staff
- All children having home enteral feeding will have a named dietitian and if required a speech & language therapist
- A written feeding regime should be provided
- Children discharged to home on enteral tube feeding should have an NHS Borders Individual Health Care Plan for Enteral Feeding ⁷



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- It is essential that all patients and carers are fully aware and have written information regarding the procedure to follow if the feeding tube is displaced
- The following teaching guidelines for parents and carers are recommended:
 - NHS Lothian Royal Hospital for Sick Children Teaching Guidelines on Skin Level Gastrostomy Tube (Button) ⁸
 - NHS Lothian Royal Hospital for Sick Children Teaching Guidelines on Care and Use of a Percutaneous Endoscopic Gastrostomy (PEG) Tube ⁹

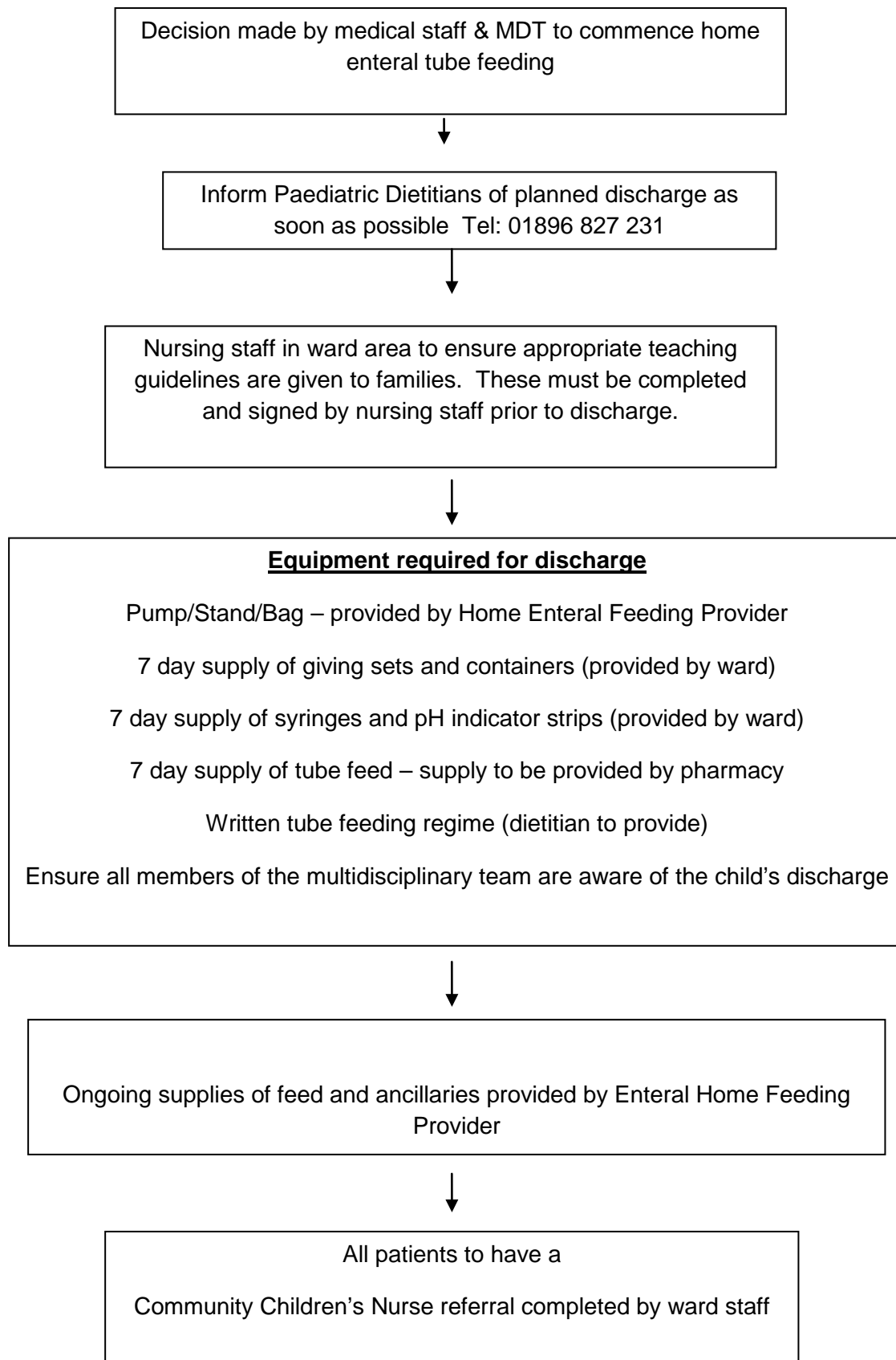
- NHS Lothian Royal Hospital for Sick Children Teaching Guidelines on Changing a Low-Profile Roux-ENY Jejunostomy Tube 10
- NHS Lothian Royal Hospital for Sick Children Teaching Guidelines on Passing and Caring for a Nasogastric tube¹¹
- NHS Lothian Royal Hospital for Sick Children Teaching Guidelines on Administration of Nasogastric feeds¹²
- Enteral UK Ltd Instructions for home care of syringes 13
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These teaching guidelines are a general guide to be used in conjunction with an explanation and a practical session with a qualified healthcare professional



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PAEDIATRIC DISCHARGE PLANNING FOR HOME ENTERAL TUBE FEEDING PATIENTS



Section 11: Nutritional monitoring and ongoing assessment and support for home enteral nutrition

This will be provided by the Community Children's Nursing Team and paediatric dietitian.

Additionally all children who are enterally tube fed will be reviewed every 6 months at the Children's Home Enteral Feeding Clinic (CHEF) and seen by a Community Children's Nurse, Paediatric Dietician and Speech and Language Therapist.

Monitoring of growth parameters and nutritional requirements of paediatric patients on home enteral nutrition is based primarily on individual patient need. There are no evidence-based guidelines regarding biochemical, growth and clinical monitoring in this patient group.

10.1 Growth parameters

Infants less than 2 years

- Naked weight, length and head circumference should be measured and accurately plotted on a standardised centile chart, and corrected age for prematurity should always be used for infants born at less than 37 weeks gestation until 2 years.
- As a minimum standard, growth parameters should be obtained and considered at 2 weeks post tube placement and then every 6 months as above.

2 years – adolescence

- Weight and height should be measured and accurately plotted on a standardised centile chart 1 month post tube placement and then every 6 months.
- Anthropometry such as mid upper arm circumference (MUAC) and triceps skin fold thickness (TSF) may be a valuable tool to monitor specific patients where more detailed information is required.

10.2 Clinical monitoring

The following points should be discussed and considered at all reviews:

- Nutritional assessment
 - intake from enteral feeds and oral diet
 - nutritional requirements adjusted for weight/age/stress factors/physical activity
- General condition, appearance, energy levels
- Gastrointestinal function
 - Presence of vomiting or reflux
 - bowel frequency/consistency
 - presence of abdominal distension or pain
- Check fluid status -include feed, water flushes/boluses, oral diet, medicines
- Infusion rate and pump
- Feed regimen- consider amendments to tolerance and timing of daily activities
- Home delivery service
- Medicines and drug / nutrient interactions
- Check feeding tube and stoma site
- Ensure adequate support in community
- The key goal with any aspect of enteral tube feeding should be, wherever possible, to improve quality of life by working feed regimens and cares around normal social activities to compliment lifestyle.

10.3 Biochemical monitoring

Any child receiving at least 50% of their daily nutritional requirements as enteral tube feeds should have blood collected for the following biochemical tests as a baseline:

- Urea and electrolytes, creatinine, glucose, liver function tests
- Calcium/Phosphate/Magnesium
- Albumin/Protein
- C-reactive protein, full blood count
- Zinc, copper, selenium (2ml LiHep in tube with push-on cap)
- Vitamins A/D/E (2ml LiHep)
- PTH (1ml EDTA)
- Vitamin B12/folate (1ml plain)
- Ferritin (0.5ml LiHep)

It is recommended that the above bloods are repeated at 6 months after the baseline blood tests and then annually thereafter. The request for the nutritional blood test should be made by the Consultant Paediatrician responsible for the care of the child.

If biochemical imbalances, deficiencies or excessive levels of individual nutrients are identified, then closer intervals for reassessment may be appropriate.

Urinary sodium and creatinine will often be a useful measurement in infants with stomas, short bowel syndrome, gastroschisis and cystic fibrosis. The frequency should be based on individual patient need.

Section 12: Transition from child to adult health services

The coordination of care for transitions will be discussed at the young person's CHEF clinic appointments. The NHS Borders 'Transition of Young People with Complex Needs from Children to Adult Health Services Policy'¹⁴ should be followed.

Care by the Community Children's Nurses will be transferred to the District Nurse Team. Information regarding the young person's care plan will be shared; this includes details re ordering supplies. The Community Children's Nurses will provide training regarding changing the gastrostomy tube and provide details about training re feeding pumps from feeding companies.

References:

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3. NHS Borders Risk Assessment for Overnight Tube Feeding Infants and Children (2017)
4. National Managed Clinical Network for Children with Exceptional Healthcare Needs: *'How Does it Feel? Acknowledging the Emotional Impact of Tube Feeding'* DVD and leaflet for parents. Available at: <http://www.cen.scot.nhs.uk/>
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7. NHS Borders Individual Health Care Plan for Enteral Feeding updated 2017
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11. NHS Lothian Royal Hospital for Sick Children Teaching Guidelines on Passing and Caring for a Nasogastric tube
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