



Information
for parents
and carers

Tube Feeding for Children and Young People in the Community

Child's Name:

NHS Number:

DOB:

Date:

Important

Please refer to this information guide as required. You are advised to bring this booklet with you to the hospital if you have an appointment/admission.

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Service	Name	Telephone
Paediatric Dietetic Office	General equipment queries Dietetic support worker	01772 522504 / 522517
Home Enteral Feeding Dietitian (Individual hours may differ) (Please leave a message if you reach the answerphone)	Paediatric Dietetic Office (Chorley & South Ribble locality) (Preston locality) (Neonatal discharges)	01772 522504 / 522517 07708 468 233 07999 048 972 07708 468 232
RPH Paediatric Assessment Unit (PAU) (24 hours)		01772 524920
Abbott Nutrition - Hospital2Home	Helpline for equipment and feeding pump	0800 0183 799
Children's Community Nursing Team (Monday - Friday 8am - 6pm)		01772 520711
GP (Please make your own note)		
Out of Hours GP Service (Please make your own note)		

Part 1 – Your Child’s Feeding Tube

Nasogastric (NG) / Nasojejunal (NJ) feeding tube

Date: _____

The type of tube your child has is a: _____ Size: _____

Date of insertion: _____

The tube should be replaced every _____ days

The position of the marker on the feeding tube is ___ at the nose for a NGT/NJT

Children with a nasogastric tube can go swimming as long as the end of the NG tube is secure and waterproof tape applied to the face, however carers must be mindful that the NG tube may become dislodged or move position.



Naso-gastric tube (NGT) is placed through the nose, past the throat and down into the stomach.

Naso-jejunal tube (NJT) inserted through the nose, down the throat and stomach and into the jejunum (small bowel).

IMPORTANT: For removable devices:

Your child should always have a spare tube in case of an emergency. In normal circumstances additional spares are **not provided** for children who attend multiple locations. The spare tube should travel with the child wherever they attend, including school. All tubes have an expiry date on them and should be checked and used in order of expiry dates to avoid wastage. If you require replacements, please contact the Dietetic department.

Percutaneous Endoscopic Gastrostomy (PEG) – fixed feeding tube

Date:

The type of tube your child has is a _____

Manufacturer: _____

Size: _____

Date of insertion: _____ at Manchester Children's Hospital/Alder Hey
(delete as necessary)

The position of the marker on the feeding tube is _____ at the top of the fixation device on the PEG.

Once the device has been in place for 3 weeks after initial placement it **MUST** be advanced and rotated weekly thereafter. (Ask your community nurse to show you how to do this if you have not been trained).

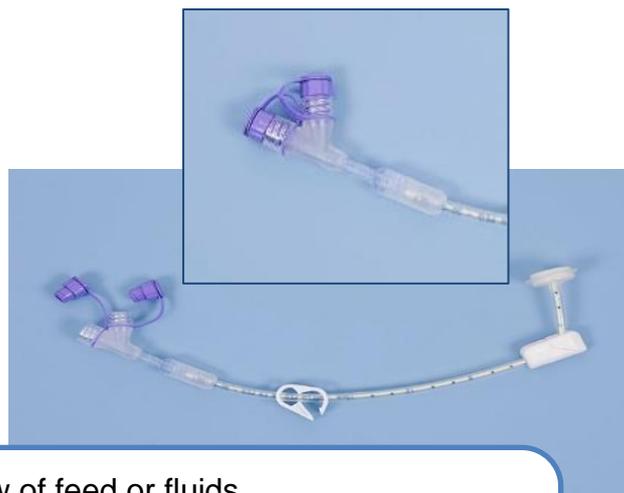
You will be able to bath your child or go swimming from **6-8 weeks** after the initial placement (follow discharge information from Alder Hey/Manchester) A dressing would not normally be applied to cover the device. (Ask your community nurse if you are concerned about the stoma).

Percutaneous Endoscopic Gastrostomy (PEG) is usually the first gastrostomy feeding tube placed. It is usually placed by a surgeon at one of the specialist children's hospitals. It is positioned through the skin of the abdomen and directly into the stomach.

The PEG tube can be changed for a removable device no earlier than 3 months after placement and requires a further visit to your child's consultant at Alder Hey/Manchester Children's Hospital.

Example - CORFLO PEG

End piece – for connecting syringe and giving set to for feed and fluid administration
End piece can be changed if failure occurs.



Internal fixation disk.
Once stoma established PEG must be advanced and rotated weekly.

External bumper – white clamp can be released for cleaning and changing position of the bumper for comfort.

Clamp – to stop / start flow of feed or fluids
Clamp should remain closed when feed or fluids are not being giving to prevent leakages.
Position of clamp should be changed regularly to prevent sections becoming flattened.

Balloon Gastrostomy feeding tube

Date:

The type of tube your child has is a _____

Balloon water inflated into balloon _____ mls.

Balloon water changes can occur from 3 weeks after initial placement (if first tube your child has had) and weekly thereafter. Use cooled boiled water to inflate the balloon.

Size: _____

Date of insertion: _____ at Manchester Children's/Alder Hey
(delete as necessary)

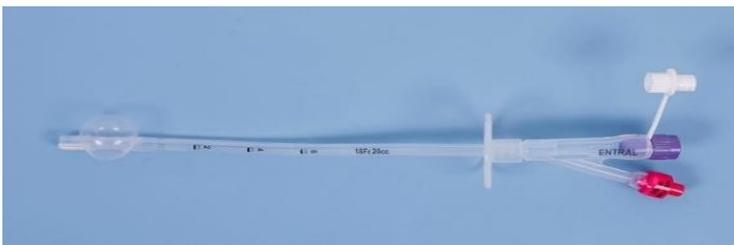
Frequency of tube changes: _____

The position of the marker on the feeding tube is _____ at the top of the fixation device for the G Tube.

Once the device has been in place for 3 weeks after initial placement it **MUST** be advanced and rotated weekly thereafter. (Ask your community nurse to show you how to do this if you have not been trained).

You will be able to bath your child or go swimming from **6-8 weeks** after the initial placement (follow discharge information from Alder Hey/Manchester) A dressing would not normally be applied to cover the device. (Ask your community nurse if you are concerned about the stoma).

Balloon Gastrostomy Feeding Tube (G-Tube) – often placed in theatre by Paediatric Surgeon as first gastrostomy tube. The device is removable and once the stoma has formed and can be changed in community for a low-profile device no earlier than 3 months after initial placement.



Device is similar to a PEG in its management, except the balloon needs to be inflated with water to hold the device in place. One port on the end piece is for feeding (purple) the other for inflating the balloon (red).

IMPORTANT: For removable devices:

Your child should always have a spare tube in case of an emergency. In normal circumstances additional spares are **not provided** for children who attend multiple locations. The spare tube should travel with the child wherever they attend, including school. All tubes have an expiry date on them and should be checked and used in order of expiry dates to avoid wastage. If you require replacements, please contact the Dietetic department.

Low Profile Balloon Gastrostomy Feeding Tube (Button)

Date: _____

The type of tube your child has is a _____

Balloon water inflated into balloon _____ mls.

Balloon water changes can occur from **3 weeks after initial placement (if first tube your child has had)** and weekly thereafter. Use cooled boiled water to inflate the balloon.

Size: _____

Date of Insertion at: _____ Manchester Children's/Alder Hey
(delete as necessary)

Frequency of tube changes:

Extension sets are required for feed, fluid and medications. These are reusable - See information below on their care.

Once the device has been in place for **3 weeks after initial placement** it **MUST** be advanced and rotated weekly thereafter. (**Ask your community nurse to show you how to do this if you have not been trained**).

You will be able to bath your child or go swimming from **6-8 weeks** after the initial placement (follow discharge information from Alder Hey/Manchester) A dressing would not normally be applied to cover the device. (Ask your community nurse if you are concerned about the stoma).



Low profile Gastrostomy tube (e.g. Mic-key or Mini button): is a feeding tube inserted through the skin of the abdomen and directly into the stomach. It is secured by a balloon inflated with water. Externally the device lies flat on the skin and an extension tube is attached to administer feed and medication.

The tubes are measured in diameter (FR size) and in shaft length (e.g. 2.3cm). The details can be found on the top of the device.

Right angled extension sets are most frequently used and are 12 inch long.

The button devices **MUST** be monitored for signs they are becoming too tight. A longer shaft size may be required as your child grows. The Children's Nursing Team can measure the stoma so a new device can be requested.



Extension set is required – either straight or Right angle, 12/24-inch tube.

Line up and rotate to connect and secure to button.



IMPORTANT: For removable devices:

Your child should always have a spare tube in case of an emergency. In normal circumstances additional spares are **not provided** for children who attend multiple locations. The spare tube should travel with the child wherever they attend, including school. All tubes have an expiry date on them and should be checked and used in order of expiry dates to avoid wastage. If you require replacements, please contact the Dietetic department.

Other types of feeding tubes

Low profile Trans-Gastric Jejunostomy tube (G-J tube) is a button top tube which goes through the skin of the abdomen and directly into the stomach, with an extension that passes into the jejunum (small bowel). The device lies flat on the skin and is secured by a balloon filled with water. These devices **MUST NOT** be rotated.

Most buttons have a locking mechanism to securely connect the extension set. The extension set can be attached to the gastric and/or jejunal port to administer feed, water and medication. Most commonly medications are administered into the gastric port but please seek advice from your nursing/medical team if you are unsure.

Jejunostomy tube (JEJ) is a tube which goes through the skin of your abdomen, directly into your jejunum (small bowel).

There may be other types of specialist feeding tubes used and not covered in this information. The hospital that placed the tube will provide all necessary information. Please ask your Community Nurse or Dietitian if you require further information.

Part 2 – GIVING FEED, FLUIDS AND MEDICATIONS

Feeding methods

Pump feeding

A pump feed can be continuous e.g. over 16 hours or intermittent e.g. three feeds each lasting 2 hours. Your child's feed is delivered at a set rate using a feeding pump, e.g. Abbott FreeGo. The pumps are very easy to use, and training is provided by the Abbott representative or community nurse. Pump feeding requires a drip stand/backpack and giving sets to be provided. You may also require bottle hangers or bottles (flexitainer/sterifeed bottle). These items are provided for you on the Hospital 2 Home delivery service.

If you have a problem or concern with your pump, please contact Abbott on 0800 0183799 for troubleshooting advice.

Bolus feeding

Bolus feeding is a method of gravity feeding using a 60ml syringe. This is attached to your feeding tube/extension set to administer the prescribed feed volume at intervals throughout the day. The speed of delivery is controlled by the positioning of the syringe; a raised position will flow quicker than a lowered position.

Combination feeding

Combination feeding is when your child is tube fed using both methods; pump and bolus methods are used. For example, they may have 3 bolus feeds during the day, e.g., breakfast, lunch, and tea with an overnight pump feed.

Water flushes and additional water

For infants under 12 months, jejunostomy feeds or immuno-compromised children:

Flush all feeding tubes or give additional boluses using **cooled boiled water**.

For children over 12 months:

Flush all feeding tubes or give additional boluses using **freshly drawn tap water**.

Important

Always follow your child's feed and fluid regimen to ensure you are giving the correct amount of fluid.

Syringe Provisions

Bolus feeding and water flushes

60ml feeding syringes should be used.

Syringes for testing the pH of aspirate for Nasogastric tubes

20ml syringes should be used.

Medications

Medication syringes are available in 1ml, 3ml, 5ml, 10ml and 20ml sizes.

Balloon syringes

5ml leur slip syringes should be used.

Balloon gastrostomy tubes require weekly water changes. 10 syringes per month are provided (one to draw out stale water; one to replace with fresh water, discard after use).

Equipment provision

All equipment will be delivered monthly with the exception of low-profile gastrostomy tubes which will be delivered on a quarterly basis (every 3 months). You will be contacted by Abbott Hospital2Home prior to your monthly delivery. They will do a stock check to ensure that they do not send you items that are not required. **Please note**, if you miss their call or do not return their call you may not receive your delivery on time.

You may also be able to register with the H2H App to help co-ordinate your deliveries. Please speak to a H2H advisor.

Please contact the Dietetic department should you have any equipment queries.

Care of syringes

For infants under 1 year of age:

Feeding

The quantity of syringes you receive will depend on the number of feeds administered in a day.

Caregivers are not expected to sterilise syringes after each feed, they should be washed in hot soapy water, rinsed in clean water, air dried and sterilised at the end of the day, for reuse the following day. **They can be used for 3-4 days and then should be discarded.**

Medications

For infants under 1 year of age, medication syringes will be provided based on the number of medicine doses administered in a day i.e. **use clean syringe for each medication dose daily, washed as above and discarded after using for 3-4 days.**

For children over 1 year of age:

With nasogastric tube or gastrostomy devices/who are not immuno-compromised:

Feeding

The quantity of syringes you receive will depend on the number of feeds administered in a day.

The 60ml syringes provided are **reusable for 30 uses or 14 days**, whichever is the sooner, and should be washed in hot soapy water, rinsed with cool clean water and air dried on a paper towel. Once dry they should be stored in a plastic box with a lid.

To ensure they last the required length of time syringes should not be washed in the dishwasher or steam sterilisers or stored in cold water sterilisers.

Medications

Medication syringes will be provided based on the number of medicine doses administered in a day i.e. use a clean syringe for each medication dose daily, washed as above and discarded after 30 uses or 14 days, whichever is the sooner.

Some medications are thick/sticky which can make cleaning more difficult. Graduations can degrade due to having high fat (Keto) feeds or are using Blended Diet (family foods), therefore additional supplies can be provided. Please discuss any concerns with your Dietitian.

Infants or Children who are Jejunally fed or are immunocompromised:

Feeding and Medications

As general guidance all syringes should be changed daily but can be used several times in the day if washed between uses. Discuss your child's individual requirements with your Dietitian.

Medications

Medication syringes will be provided based on the number of medicine doses administered in a day i.e. use a clean syringe for each medication dose daily, washed as above and discarded after 30 uses or 14 days, whichever is the sooner.

Some medications are thick/sticky which can make cleaning more difficult. Graduations can degrade due to having high fat (Keto) feeds or are using Blended Diet (family foods), therefore additional supplies can be provided. Please discuss any concerns with your Dietitian.

For Infants or Children who are no longer using their gastrostomy feeding tube

If your child no longer requires feed, fluid or medications via their gastrostomy/jejunostomy feeding tube you must make sure the tube remains in the patient by flushing with water twice daily and rotating in the usual way until they are referred to the consultant for the device to be removed.

Part 3 – Problem solving

Problem - Unable to obtain aspirate from NG tube

Do not feed until aspirate has been achieved and pH tests less than 5.5.

You can try the following to help you obtain an aspirate:

1. Advance/withdraw the tube 2-5cm
 2. Give mouth care to patients who are nil by mouth (this stimulates gastric acid secretion)
 3. Lie patient on left side and retry
- **If problem persists** - DO NOT USE THE TUBE. See **Useful Contacts Information, page 3**, to reach either the Children's Community Nursing Team or Paediatric Assessment Unit.

Problem - pH of NG aspirate greater than 5.5

Do not feed until aspirate has been achieved and pH tests less than 5.5.

- Some medications may alter the pH of the aspirate, e.g. Proton Pump Inhibitors (PPI's) **Omeprazole/Lansoprazole**
- Ideally the PPI should be given in the morning after the aspirate testing or after first feed administration to not alter the stomach pH
- If Problem persists - DO NOT USE THE TUBE. See Useful Contacts Information, page 3, to reach either the Children's Community Nursing Team or Paediatric Assessment Unit

Problem - Feeding tube has fallen out

Have you been trained by Community Nurses to replace the feeding tube?

If **NO**, (if yes see below).

This is an **urgent** matter and needs to be dealt with immediately. See Useful Contacts Information, page 3, to talk to either the Children's Community Nursing Team or Paediatric Assessment Unit.

CONSIDER THE FOLLOWING

If this has happened within 4 weeks of initial placement (i.e. the first tube your child has ever had) then **DO NOT** attempt to re-insert the tube. Attend Paediatric Assessment Unit as soon as possible, **WITH YOUR SPARE DEVICE**, where your child's tube will be replaced.

If this has happened with an established stoma, insert your replacement gastrostomy tube to keep the tract open until tube can be secured. Attend Paediatric Assessment Unit as soon as possible to ensure device is correctly positioned.

Have you been trained by Community Nurses to replace the feeding tube?

If **YES**,

This is an **urgent** matter and needs to be dealt with immediately. Replace the feeding tube according to your training, using your spare device. If required, request support from Children's Community Nursing Team or Paediatric Assessment Unit.

In both cases, notify the Children's Dietitians who will request delivery of another spare device

Part 3 - PROBLEM SOLVING

Problem - The position of my child's tube has changed (PEG/Balloon Gastrostomy)

If you have concerns about the position of your tube and/or if the tube has moved then **DO NOT USE THE TUBE**. See Useful Contacts Information, page 3, to reach either the Children's Community Nursing Team or Paediatric Assessment Unit.

Problem - The feeding tube is blocked

Should the tube become blocked, try to flush the tube with warm water (not hot) using a gentle push and pull "swishing" motion with the syringe plunger.

If this fails See Useful Contacts Information, page 3, to reach either the Children's Community Nursing Team or Paediatric Assessment Unit. If your child has a removable device and you are trained on how to replace the gastrostomy device you may proceed as if "tube has fallen out" section above.

Never try to force water into the tube as this may cause it to split.

Problem - The feeding tube / stoma is leaking

If leakage occurs within 72 hours of primary tube placement contact Paediatric Assessment Unit and **DO NOT USE THE TUBE**.

At all other times: Causes for leakage include: poorly fitting device, over or under inflation of the balloon, tension at stoma site or device valve (from extension sets during continuous pump feeding) and abdominal distension. Please contact your Children's Community Nurse if problem persists.

In the event of device failure, please do not discard the device. Contact Abbott Hospital 2 Home who will request return of the device for analysis.

Notify the Children's Dietitians who will request delivery of another spare device from Abbott.

Problem - The stoma or surrounding skin is red / sore

- Once the stoma is established the device in place must be advanced (slight push inwards) and rotated a full circle before being fixed back into position
- It is important to look for signs of infection – sore to touch or attach extension set, redness, warmth or child running a high temperature, pus or cloudy/smelly discharge from the area
- See Useful Contacts Information, page 3, to reach either the Children's Community Nursing Team or your GP to arrange for the area to be swabbed

Part 3 - PROBLEM SOLVING

Problem – My child’s button device appears too loose or too tight

- Button gastrostomies may appear tight or loose after rapid weight gain/loss.
- Growing children will need their devices reviewed regularly
- Discuss your concern with your Children’s Community Nurse / Dietitian
 - Either the next size (shaft length) device will be requested **OR**
 - Your Dietitian will request a measuring device from Abbott Hospital 2 Home

Problem - My child is vomiting

- Check use by date of feed
- Check the feed is being made up correctly, if not ready prepared
- Ensure you are feeding in an appropriate position (i.e. not lying down too flat, recommendation 45 degree minimum elevation)
- Check the feeding rate is correct. Try slowing the rate by 10-20ml/hr
- Contact your GP in the first instance for advice if the problem persists
- Contact your Dietitian as the feeding regimen may need to be altered

Problem - My child has diarrhea

- Check use by date of feed
- Check the feed is being made up correctly, if not ready prepared
- Check the feeding rate is correct. Try slowing the rate by 10-20ml/hr
- Contact your GP in the first instance for advice if the problem persists
- Contact your Dietitian as the feeding regimen may need to be altered
- Diarrhoea may be caused by taking antibiotics. Do not stop taking the antibiotics

Problem - My child is constipated

- Check sufficient fluid is being taken (refer to your feeding regimen)
- Check the feed is being made up correctly, if not ready prepared
- If your child has prescribed medication for constipation contact your GP to discuss their dose
- You may wish to contact your Dietitian to review the feed plan

Problem - My child seems thirsty

Ensure your child is getting the fluid advised by the Dietitian on their feeding regimen. If so, contact your Dietitian for further advice.

Problem - My child seems hungry

Ensure your child is getting the feed advised by the Dietitian on their feeding regimen. If so, contact your Dietitian for further advice.

Part 4 – REFERENCES

References

Bischoff et al (2022) ESPEN practical guideline: Home enteral nutrition

https://www.espen.org/files/ESPEN-Guidelines/ESPEN_practical_guideline_Home_enteral_nutrition.pdf

British Association for Parenteral and Enteral Nutrition (2017) Administering medicines via enteral feeding tubes.

<https://www.bapen.org.uk/nutrition-support/enteral-nutrition/medications>

European Society for Paediatric Gastroenterology, Hepatology and Nutrition (2021) ESPGHAN An Update to the Position Paper on Management of Percutaneous Endoscopic Gastrostomy in Children and Adolescents

https://journals.lww.com/jpgn/Fulltext/2021/09000/Percutaneous_Endoscopic_Gastrostomy_in_Children_.28.aspx

Our thanks to the Medical Illustration Department at Royal Preston Hospital for all photographs contained in this information booklet.

Contact details

Should you require further advice or information please contact Paediatric Nutrition and Dietetics:
Telephone: 01772 522517.

Sources of further information

www.lancsteachinghospitals.nhs.uk

www.nhs.uk

www.accessable.co.uk

www.patient.co.uk

All our patient information leaflets are available on our website for patients to access and download:

www.lancsteachinghospitals.nhs.uk/patient-information-leaflets

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Lancashire Teaching Hospitals is a smoke-free site. Smoking is not permitted anywhere on any of our premises, either inside or outside the buildings. Our staff will ask you about your smoking status when you come to hospital and will offer you support and advice about stopping smoking this will include Nicotine Replacement Therapy to help manage your symptoms of withdrawal and the opportunity to speak to a nurse or advisor from the specialist Tobacco and Alcohol Care Team.

If you want to stop smoking, you can also contact the Quit Squad Freephone 0800 328 6297.

Please ask if you would like help in understanding this information. This information can be made available in large print and in other languages.

Gujarati:

આ માહિતીને સમજવામાં સહાયતા જોઈતી હોય તો કૃપા કરીને પૂછો. આ માહિતી મોટા છપાણામાં અને અન્ય ભાષામાં ઉપલબ્ધ કરી શકાય છે.

Romanian:

Vă rugăm să întrebați dacă aveți nevoie de ajutor pentru înțelegerea acestor informații. Aceste informații pot fi puse la dispoziție în format mare și în alte limbi.”

Polish:

Poinformuj nas, jeśli potrzebna jest ci pomoc w zrozumieniu tych informacji. Informacje te można również udostępnić dużym drukiem oraz w innych językach

Punjabi:

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਸਮਝਣ ਵੱਲੋਂ ਮਦਦ ਲੈਣੀ ਚਾਹੋਗੇ ਤਾਂ ਕਰਿਯਾ ਕਰਕੇ ਇਸ ਬਾਰੇ ਪੁੱਛੋ। ਇਹ ਜਾਣਕਾਰੀ ਵੱਡੇ ਪ੍ਰਿੰਟ ਅਤੇ ਹੋਰਨਾਂ ਭਾਸ਼ਾਵਾਂ ਵੱਲੋਂ ਮੁਹੱਈਆ ਕੀਤੀ ਜਾ ਸਕਦੀ ਹੈ।

Urdu:

دوسری زبانوں اور بڑی اگر آپ کو ہی معلومات سمجھنے کے لئے مدد کی ضرورت ہے تو
یہی چھپا میں یہی ابی دست ہو سکت ہے براے مہر بیان پوے چھہی۔ معلومات

Arabic:

مطبوعة بأحرف كبيرة وبلغات إذا كنت تريد مساعدة في فهم هذه لمعلومات يُرجى أن تطلب
أخرى يمكن تو فير هذه المعلومات

Department: Nutrition & Dietetics – Child Health

Division: Surgery

Production date: November 2022

Review date: November 2025

JR 908 v1