





Going home with an enteral feeding tube (for children living in **Lincolnshire**)

Nutrition and Dietetic Service

Information for Patients and Parents

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Introduction

This leaflet will give you information on what to expect when your child is being discharged from hospital with an enteral feeding tube.

An enteral feeding tube gives nutrition directly into the stomach or small intestine. Your doctor or dietitian will have explained to you which tube your child has.

What should I look out for?

5 days after percutaneous endoscopic gastrostomy (PEG) insertion:

If there are leaks or fluid around the tube, or pain on feeding stop feed immediately and attend the Children's Emergency Department for urgent review.

Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

What equipment should I have when we leave hospital?

You should go home with 7 days supply (or 10 days supply if a bank holiday) of:

- ENFit syringes:
 - 60ml syringes if gravity feeding.
 - 20ml syringes if your child has a nasogastric tube (NG) to check pH.
- Feed (unless it is a standard infant formula/ expressed breast milk).

If your child has a gastrostomy button (Mic-KEY or Mini) you should also go home with:

2 extension sets, 5ml syringes for balloon water changes, a spare button.
 If your child has a PEG - you do not need extension sets or 5ml syringes.

If your child has an NG tube, you should also go home with:

• pH papers, 20ml syringes for checking pH, and a spare NG tube.

If your child needs an enteral feeding pump, your local dietitian team from Lincolnshire will supply this for home, and you will need to be trained on how to operate this specific pump (Amika pump) before your child leaves hospital. This is because the pump may be slightly different to the one you have been used to in Leicester.

How often should I change the equipment?



Amika ENFit Giving Sets:

Amika Pump Set EasyBag - these connect directly to your child's feed bag. These only need to be **changed every 24 hours.**

Amika Pump Set Varioline - your child's feed bottle screws onto this set. This needs to be changed every time you change the feed bottle.



ENFit syringes:

Syringes need to be **cleaned** in between **each use**. They will need to be **sterilised** in between **each use** as well if your child is aged 6 months or under, or feeding with a jejunal tube or if your child has problems with their immune system.



ENFit feeding tubes:

Nasogastric (NG) tubes and nasojejunal (NJ) tubes will need to be changed regularly. The type of tube will dictate how long it can stay in before being changed. NG/ NJ tubes are single use, so if your child pulls it out before they are due to be changed, then they will require a new tube to be passed. In hospital you will notice that your child's NG tube is changed every 28 days, however, once they are at home most NG tubes only need to be changed every 90 days.



Percutaneous endoscopic gastrostomy (PEG) and jejunal extensions are not routinely changed.

Dietitian follow-up after discharge

If your child was not already being fed via an enteral feeding tube before coming into hospital then they will be referred to the Lincolnshire Home Enteral Nutrition Service (also known as HENS), who are part of United Hospitals of Lincolnshire NHS Trust. HENS dietitians look after children at home who are being fed via an enteral tube. Once your child is discharged home, a member of the team will arrange an appointment via telephone or video call. This is usually within 2 weeks of discharge.

If your child is already known to HENS then the hospital dietitian will inform them of your discharge date. Your HENS dietitian may want to review your child sooner if there have been any changes to your child's feeding plan. Call them if you have any queries on 01522 597765.

How will supplies that we need be delivered?

Fresenius Kabi (FK) Homecare is a company who can deliver enteral feeding equipment and feed directly to you at home. The HENS team will register you for a delivery of all of the equipment and feed you need. Deliveries are made by the company every 28 days.

In your delivery you will usually receive 28 days supply of:

- 60ml ENFit syringes for feeds and water flushes. The quantity will vary depending on your child's feeding plan. These can be sterilised in between use.
- ENFit syringes for checking pH, for children with an NG tube. The quantity and size will vary depending on your child's feeding plan. These can be sterilised in between use.
- 28 days supply of ENFit Giving Sets for children who are pump feeding. The quantity will vary depending on your child's feeding plan and type of feed.
- Extension sets for children with a button (usually 2 extension sets per month).
- Spare NG tube(s) for children with an NG tube.
- pH papers for children with an NG tube will be delivered directly from the dietitians.
- Stickers/ tape to keep your child's NG/ NJ tube in place. These may come from the children's community nurse.
- Feed/ formula if needed.

You will not receive syringes for your child's medication from FK Homecare. These will be provided by the Children's Community Nurse Team.

If your child is fed via an NJ tube then they will not get these via Homecare because they will receive a new tube when it is placed in hospital.

If your child has a percutaneous endoscopic gastrostomy (PEG) they will not need an extension set or a spare tube.

What happens if my child's NG/ NJ tube comes out?

All children with nasogastric tubes will be referred to the Lincolnshire Children's Community Nurses (CCNs).

The CCN Team provide nursing care for children who need special care in the community. If your child is known to the CCN team then they will be able to repass an NG tube if it is within normal working hours. If your child's NG tube comes out outside of the CCN Team's working hours and you cannot wait until they start work again, or if their NJ comes out at any time, then you will need to take your child to the Childrens Emergency Department at either Lincoln County Hospital or Pilgrim Hospital, Boston. If your child has open access to the paediatric wards, call the ward first and they will advise you what to do.

Contact details

Lincolnshire HENs telephone number: 01522 {	597765
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Your ward dietitian is: / Tel: 0116 258 5400

Checklist for discharge	Tick box
7 days (10 days if bank holiday) supply of feed	
7 days (10 days if bank holiday) supply of ENFit syringes	
If your child has a feeding pump - 7 days (10 days if bank holiday) supply of ENFit Giving Sets	
If your child has NG - 7 days (10 days if bank holiday) supply of pH papers and stickers/ tape	
If your child has a MIC-KEY button - spare MIC-KEY button	
If your child has a MIC-KEY button - 2 spare extension sets for MIC-KEY button	
Feeding plan (and recipe if powdered feed) from the ward dietitian	

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔ علی هذه المعلومات بلغةٍ أُخرى، الرجاء الاتصال علی رقم الهاتف الذي يظهر في الأسفل જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ। Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk

