

# Patient information

# **PEG** booklet

| Name:                             | MRN:                   | NHS number:                            |         |
|-----------------------------------|------------------------|--|---------|
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### **Appendices**

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- Handwashing guide
- Cleaning syringes guide by Medicina

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Puttina vou first

#### Introduction

This booklet aims to cover everything we may have discussed in your training session. You do not need to read it all, but to refer to the contents if you have a particular query.

The first two pages are personalised for you, and contain your tube details, contact details and your feeding regime. Please bring this information with you to every dietetic appointment and if you are admitted into hospital.

### What is enteral feeding?

Enteral tube feeding is used to provide hydration and/or nutrition to patients who cannot attain an adequate oral intake from food and/or oral nutritional supplements, or who cannot eat or drink safely.

# <u>ALERT</u>

For **all** patients who are discharged from hospital **within 72 hours** of having a PEG tube placed:

#### If you suffer:

- Severe abdominal pain or bloating
- Pain on feeding or flushing
- Fresh bleeding or external leakage of gastric contents
- Raised temperature
- Breathlessness (which is unusual for you)

### → Stop feed immediately

- → **Urgently contact** your GP surgery or A&E department
- → Take this booklet with you to your GP/A&E and show this page to the doctor
- → Do not put anything down the PEG tube until doctors confirm it is safe to use the tube again

#### Note to doctor:

Please consider patient for CT scan, contrast study or surgical review.

## Key contacts and tube management plan

| Fresenius Kabi Enteral Feed Company  | 0808 100 1990   |
|--|---|
| Delivers feed and equipment  24-hour helpline  Online pump training videos / troubleshooting  Patient Facebook support group (only patients have access to this, there is no input from the feeding company, Nutrition Nurses or Dietitians)   | www.fresenius-<br>kabi.com/gb/products/amika  Facebook – search: FreseniusKabi@Home |
| Nutrition Nursing Team: Monday – Friday 8.30am to 4.30pm  Maria Carpanzano – Nutrition Nurse Ria Burch and Sarah Everitt – Therapy Practitioners  We deal with all issues relating to your enteral feeding tube and site around it. We also conduct training sessions and order your equipment and feed.                   | 01284 713609<br>Maria – 07973 663 815<br>Sarah – 07973 663 907                      |
| Dietetic Team: Monday – Friday 8.30am to 4.30pm  Rachel Cooper and Clare Witcombe – Dietitians Ria Burch - Dietetic Therapy Practitioner  We will advise on your feeding regime and water quantities.  Many issues may relate to feeding, such as sickness and bowel problems, so please call us if you have any concerns. | 01284 713760<br>Rachel – 07973 663 897<br>Clare – 07973 663 883                     |
| PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy)  Charity support group for people receiving artificial nutrition   | www.pinnt.com<br>01202 481625   |

### Your feeding tube

| Tube type                           | Freka 15Fr PEG   |
|-------------------------------------|--|
| Date and place of initial insertion | at West Suffolk Hospital   |
| Management plan                     | Clean PEG site and tube daily  |
|                                     | Ensure tube is in the correct position daily.  |
|                                     | Please insert your PEG tube (about 3.5cm, or just over an inch), and rotate twice weekly.              |
|                                     | See page 8 for more details  |
|                                     | The tube is very unlikely to come out, however if it does please visit your local A&E department ASAP. |

### Personalised enteral feeding plan

# Please bring the latest copy with you to all dietetic appointments and hospital admissions

If you are admitted to hospital, please bring three to four day's supply of your enteral feed with you if possible (unless told otherwise). The hospital has pumps, giving sets and syringes, and the nursing staff are trained in using these.

| Your personalise                        | ed feeding tube plan    |              |            |
|---|-------------------------|--------------|------------|
| Name:                                   | Hospit                  | tal number:  | Tube type: |
| Date:                                   | Weigh                   | nt:          | Height:    |
| Feed                                    |                         |              |            |
| Oral intake                             |                         |              |            |
| Fluid (including                        | fluid to be used with ı | medications) |            |
| Other                                   |                         |              |            |
| Nutritional provis                      | sion from feeds and f   | lushes       |            |
| Calories:                               | kcal / day              |              |            |
| Protein:                                | g / day                 |              |            |
| Total fluid from feeds and flushes: mls |                         |              |            |
| Aim:                                    |                         |              |            |
| Next review:                            |                         |              |            |

## **Enteral feeding plastics (syringes)**

Your dietetic and nutrition nursing teams may not be aware of medication changes; however, we are responsible for ordering your syringes. Please contact us if you require more or less syringes.

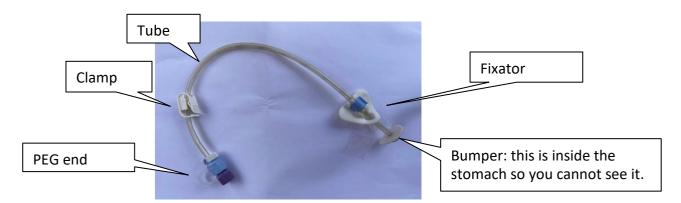
For more details on syringes for medications, see page 13

| Medication               |              |                | 0                       |   | 5               |    | Б       |
|--------------------------|--------------|----------------|-------------------------|---|-----------------|----|---------|
|                          |              |                | Syringe<br>Size<br>(ml) |   | Mid-<br>Morning |    | Evening |
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|                          |              |                |                         |   |                 | 1  | +-      |
|                          |              |                |                         |   |                 |    | +-      |
|                          |              |                |                         |   |                 |    | +       |
|                          |              |                |                         |   |                 |    | +       |
| Total syringe quantities |              |                |                         |   |                 | 1  |         |
| , , ,                    |              | N              | 41                      |   |                 |    |         |
|                          | Size         | Number per mor | ith                     |   |                 |    |         |
|                          | 1ml          |                |                         |   |                 |    |         |
|                          | 2.5ml<br>5ml |                |                         |   |                 |    |         |
|                          | 10ml         |                |                         |   |                 |    |         |
|                          | 20ml         |                |                         |   |                 |    |         |
|                          | 60ml         |                |                         |   |                 |    |         |
|                          | 001111       | <u> </u>       |                         |   |                 |    |         |

Other plastics needed

#### The PEG tube

The PEG tube made of polyurethane, is long term and should last for a couple of years. With good care, this could last longer. The Nutrition Nursing Team will monitor your tube for signs of wear.



**The bumper:** This circular disk is inside the stomach wall, and prevents the tube falling out. Please see page 8 for more details on this.

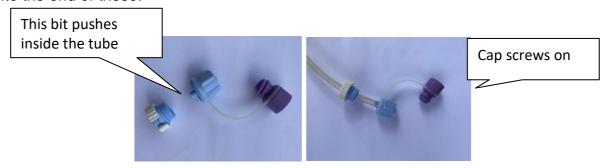
**The tube:** This clear tube is what food and fluid will travel along into your stomach. It is normal to see stomach contents within this tube as there is no valve stopping contents coming out through the stoma. Over time, the tube will become discoloured – this is normal, and there is nothing anyone can do to stop this.

**Fixator:** This could be a triangle or rectangle shape. It can be released by either flicking the blue cap up and lifting the tube out, or by twisting the white rectangle (if your tube is Corflo – the picture above is Freka) in opposite directions.

**Clamp:** This stops stomach contents leaving your PEG when the PEG end is off. The clamp 'bites' into the tube. To keep the tube in the best condition possible, we recommend:

- Leaving the clamp open when the PEG end is on
- Slightly moving the clamp to a different area on the tube each day to prevent the same area feeling the pressure.
- Keep the clamp towards the end of the tube to keep the tube nearer your stomach in the best condition possible.

**PEG ends:** These come in two parts as seen in the picture below, and simply screw onto the end of the tube. They are ENFit, which means only the purple enteral feeding syringes will be able to screw onto the end of these.



All these parts should be cleaned daily with soap and water (you do not need to remove them from the tube). If they become worn or break, the team are able to change these for you.

### Cleaning, positioning, baths, showers and swimming

### Cleaning

The stoma site is the point at which the tube enters your skin. Always ensure your hands are clean and dry before touching your PEG tube or stoma site. Please see the back sheet for a guide on handwashing instructions.

**First 10 days**: you **must not move the fixator** as the tract needs to heal. We normally put a dressing over the top of the stoma. For the first two days, leave the dressing provided by hospital on, and do not touch the stoma. After this, carefully remove the dressing, and clean with cool-boiled water. As the fixator is unable to be moved to begin with, the best way of cleaning is with thin pieces of gauze. The area may feel tender. Please keep taking pain relief as directed by the doctor. The Nutrition Nursing team will support you with this.

#### After 10 days

- Move the fixator away from the skin (contact the team for advice if needed)
- Clean gently with a gentle, non-scented soap and water. It is normal for there to be a small amount of discharge – wash this away.
- Pat area dry and replace fixator, ensuring the correct position (see below).

We do not recommend a dressing, however if you would like to place a thin piece of gauze over the top, please ensure only two sides are taped down to allow air flow. Some people like to put a thin piece of gauze under their fixator, this can usually be positioned without the need for tape.

### **Positioning**

How the tube is positioned, is vital to prevent excessive stomach leakage and infections. After cleaning, gently pull on the tube to ensure that the bumper is up against the stomach wall. The fixator should then be positioned close, but not tight to the stomach. The aim is to prevent tube movement inside the stomach and to minimise leakage, but to maintain your comfort.

People have different preferences on how they like to position their tube. Some leave it to hang loose and some use tape (tape can be purchased cheaply from pharmacies. You could invest in some plaster adhesive remover if you find it a struggle to get the residue off your skin). Some people hang it from a necklace. Do whatever is most comfortable.

**Bumper** (inside the stomach) – up against stomach wall



**Fixator** – place close to skin - ensure it is comfortable but preventing tube movement

### Baths, showers and swimming

You can have a shower when you get home following your PEG placement. You may have a bath, but ensure the water does not cover your PEG tube for the first 10 days. It is advisable to use a non-fragranced soap around your PEG tube. Please do not go swimming until the PEG tube has healed (at least for the first 10 days). We would recommend asking your GP to prescribe a waterproof dressing for swimming. Always ensure your clamp is on whilst in the pool. It is advisable to wash your stoma with clean water afterwards, and pat dry

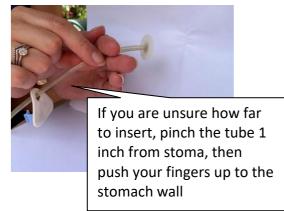
### Inserting and rotating

The PEG tube is held in place in the stomach by a bumper. If this bumper is never moved, then your skin will try to 'heal' your stoma and the stomach wall will grow over the bumper. You will find that you are unable to move the tube and eventually be unable to feed. This is called buried bumper syndrome, and requires surgery to put it right.

By advancing and rotating the tube regularly this is always avoidable! To insert and rotate the PEG:

- Release fixator
- Clean area with soap and water, pat dry
- Insert tube into stomach, approximately 3.5cm or 1 inch. Turn tube fully round, 360 degrees while inside stomach. This should be painless.





- Gently pull tube back to correct position, until the resistance of the bumper being up against the stomach wall is felt
- Replace fixator and ensure tube is in the correct position.



- This should be done twice per week. It may be done more often, but no more than once daily.

If your PEG site is, or you think may be infected, please do not insert the PEG but contact the Nutrition Nursing Team for advice.

### Equipment, storage and delivery and cleaning the equipment

#### **Equipment, storage and delivery**

You will be sent home from hospital with all the equipment needed for the following couple of days. The hospital Dietitian will write to your GP and request that your enteral feed is put on prescription (if you need this). The Nutrition Nursing Team will set you up with the enteral feeding company Fresenius Kabi.

A dedicated Fresenius Kabi coordinator will contact you to arrange delivery of all your feed and plastic equipment. Deliveries are made between 8.00am to 6.00pm, and you will be given a 4-hour delivery slot window. Fresenius Kabi will send you some paperwork to sign, to gain your permission for them to contact your GP directly to request the prescription on your behalf.

A Fresenius Kabi co-ordinator will phone you (or text / email depending on your preference), and tell you a day when your delivery will arrive. They will continue to call you monthly for a stock check and to arrange deliveries.

- Enteral feed should be stored somewhere, between 18 25°C at room temperature.
- In hot weather, try to find somewhere cool: feed should be moved from rooms that may heat up such as conservatories or sheds. Keep out of direct sunlight.
- In cold weather, if it is likely to freeze, do not place feed in sheds or garages. Do not put feed near to a radiator or fire.
- Ensure you use your enteral feed and equipment in use by date order.
- Always check that the name of the enteral feed matches what you have been prescribed.

### Cleaning the equipment

**Amika pump**: This should be wiped down regularly (do not submerge in water). The door can come fully off for easy cleaning.

**Syringes**: The Nutrition Nursing Team will talk to you about syringe use. Please see the last page for a guide produced by Medicina on how to clean your syringes. We try to ensure that all of our patients receive reusable syringes. If this sign it means the equipment should be for single use only, please let us know if you receive any of these.

**Syringes for water**: Please use one syringe per week

**Syringes for enteral feed**: Please use one syringe per day

**Syringes for medications**: Please use for one week, or up to 40 uses, whichever comes first.

### Feeding and flushing

### **Feeding**

People have a PEG tube for a variety of reasons. Some will just need it for water and medications, some will need it to top up their oral diet, and for many it will be their sole source of nutrition. Your enteral feed will be prescribed by your dietitian. There are a wide variety of enteral feeds and your dietitian will calculate which is best for you.

As each person is different, the Dietetic team will consider what enteral feed you have, the quantity and how you should have it on an individual basis. Our aim is to provide you with everything you need nutritionally, while helping you maintain the best quality of life. We have many different options, but not everything is suitable for everyone. Please discuss any barriers you are facing with us.

Whenever using your tube, important points to remember are:

- To wash your hands
- To ensure you are sitting at a minimum of 30 degrees whilst feeding, and for a minimum of half an hour afterwards.
- Avoid touching the ends of syringes or giving sets with your hands.
- Always check the name of the feed, how the feed looks, and the expiry date.

#### Flushing / fluid

We use the term 'flushing' for when we syringe water into your tube. We recommend that **cool boiled water**, at **room temperature** is used. The easiest way to do this is to boil the kettle the night before, pour it into a jug with a lid and use throughout the next day. If you have forgotten to do this, run the tap for a minute, and then use fresh tap water. **As with feeding, it is important to be at least 30 degrees while having flushes, for the duration of the flush and for half an hour after.** 

Your dietitian should have told you how much water you need to have. Some people like to measure the water out exactly, so this can be used throughout the day and not measured each time. Other people like to measure at each flush. As long as you get the required amount of water, it normally doesn't matter when you have it. Most people prefer not to have a large amount of water before bed. The water should be used for all flushes before and after feed, as well as with medications.

Even if you are no longer using your tube, we would recommend it be flushed daily to keep it clean and prevent infections.

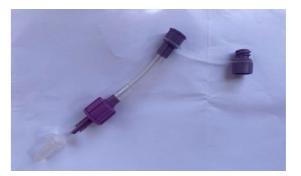
### **Bolus feeding**

We use the term bolus feeding for when we syringe liquid food into your tube. Your food will be prescribed for you, and you will be given a feeding plan stating the quantity and frequency you need. Give your feeds at regular intervals throughout the day. Different individual's will be able to tolerate different quantities of feed.

### Step by step guide on water flushing or bolus feeding via syringe

If you are bolus feeding bottles, these can be poured into a clean cup. If you are bolus feeding from an EasyBag, a bolus adapter will need inserting into the top of the bag each day. The bolus adapter can stay in place for 24-hours, if using more than one bag of feed in a day, it will need to be removed from the used bag, rinsed with water and replaced into the new bag of feed.

- Water or feed from a cup: Submerge your syringe into the water or cup of feed, and slowly pull the plunger up to the desired amount.
- Feeding from an EasyBag: snap off the cap on the EasyBag, push and screw on the bolus adapter. Unscrew cap from bolus adapter end and push and screw on a 60ml syringe. Lay the bag down and draw back required amount of feed. Stand bag up before unscrewing the syringe.









- Wipe syringe nozzle with a clean piece of damp kitchen roll (if needed).
- Check that there are no large air bubbles. If there are air bubbles, holding the syringe upright, pull the plunger further out to allow more air in, all the air will go to the tip of the syringe. Push the plunger upwards slowly to expel all the air.
- Clamp your PEG tube and unscrew the PEG end.

Continued over page

- Push and twist the syringe onto the PEG end, undo the clamp on the PEG tube. Very slowly
  push the plunger on the syringe into the PEG tube. A 60ml bolus should take on average
  about 20 seconds to administer. Some people may be able to tolerate it faster, and others
  may need to take longer.
- Once all the water / feed has gone, click the PEG clamp shut, unscrew the syringe and replace the PEG end. The last flush should always be water. Always remember to open the clamp afterwards.

### **Gravity feeding**

As the name suggests, gravity feeding is when you are fed through a tube using gravity. This is another type of bolus feeding, as feed is given in set quantities throughout the day.

- Prime the gravity set first, to ensure there is no air in the tube.
- Connect the gravity set to your PEG end (shut the PEG clamp, open the PEG end, attach
  the gravity set and open the PEG clamp).
- Adjust the roller clamp on the gravity set depending on the drip rate recommended by the dietitian.

### **Pump feeding**

You will have received pump training by one of the nutrition nursing team if you require it.

- The Fresenius booklet, which you should have received at your training session has step-bystep instructions.
- Fresenius Kabi also have a youtube video: www.fresenius-kabi.com/gb/products/amika
- Please call the Nutrition Nursing Team, or the 24-hour Fresenius Kabi helpline if you have any problems.

### Intermittent feeding

Intermittent feeding is when feed is provided via a pump a couple of times per day, normally over a period of 20 - 60 minutes at a time. This can also be called bolus feeding, however it is administered via a pump rather than s syringe.

#### Medication

The majority of medications are not licensed to go through enteral feeding tubes, however for many people there are no other options.

#### **Administering medications**

- As with feed and flushes, you must be sitting at 30 degrees minimum when having anything through your tube.
- ALWAYS administer medications one at a time, never mix different medications together in a syringe.
- ♦ A water flush (cool boiled water) needs to be given before, after and in between each medication this can be as little as 30ml before and after, with 10ml between each medication. Afterwards the tube must be clear to prevent blockages, if it is not, flush with more water. Try not to exceed the total amount of water recommended by your dietitian.
- If feeding via a pump, medications can be given through the medication port on the giving set (stop the pump first). Otherwise, medications can be given directly into the PEG, your team will explain this to you before you are discharged.
- If you are having a lot of medications, it may be easier to measure them all out in your syringes before starting. Keep in mind that some medications, such as Fybogel, thicken on standing, and so will need to be given immediately after preparation.

| Liquid<br>Medications | If the medication comes in a liquid form, then this should be prescribed. Look at the consistency of the liquid, if it is too thick to go through the PEG it will need diluting with water.   |
|-----------------------|---|
| Pills                 | Always check with your doctor or pharmacist that your medications are suitable for crushing.  |
|                       | If the medication needs crushing, then a pill crusher can be purchased from a pharmacy cheaply, or two metal spoons could be used. Ensure an adequate amount of water is used to flush the medication to prevent blockages.   |
|                       | Sustained-release tablets or capsules must not be crushed as this would cause the whole dose to be given at once.   |
|                       | Enteric-coated medications are supposed to be released in your small intestine, therefore these must not be crushed.  |
| Dispersible tablets   | Ensure these are fully dissolved before administering. These can either be mixed in a cup or you could pull the barrel out of the syringe, put the tablet in, replace the barrel and draw up some water. Put your thumb over the end of the syringe and shake until all is dissolved. |

Please note that some medications react with enteral feeds. When you initially start with an enteral feed, the team will look at your medications and check with pharmacy. If you have any medications added without the dietetic or nutrition nursing team knowing, please ensure that the pharmacist is aware if you are enterally fed.

#### **Mouthcare**

Mouthcare is very important, regardless of whether you are nil by mouth or not. Not cleaning your mouth is unpleasant, but can also cause adverse effects, such as soreness and infections within the mouth. If saliva goes into the lungs, it is much more likely to cause illness without regular mouthcare.

If you are suffering with a dry mouth, there are different options such as artificial saliva and mouth sprays which may help.

Please speak to the Speech and Language Therapy Team if you have any questions about this.

### **Holidays**

Having an enteral feeding tube does not stop you from enjoying holidays. The enteral feed company are often able to deliver your enteral feed to your holiday destination. If you are considering a holiday, please get in touch with one of the team for more information. Fresenius Kabi require at least 7 weeks' notice to arrange delivery. We are happy to write you a letter to carry onto an aeroplane explaining why you need to carry large amounts of liquids if needed.

### Troubleshooting and who to call if ...

We hope that you do not experience any problems, however we are all here to help if you do.

We work Monday to Friday 8.30am to 4.30pm. Should you experience problems out of hours, and wish to speak to someone sooner, please contact Fresenius Kabi's 24-hour helpline, where a trained nurse will be able to assist you.

#### Please call your Dietetic Team if you experience:

#### Diarrhoea / constipation / urgency

When first having enteral feeding, you may notice that your stools are looser than they used to be. This is because you are now having a liquid diet and is normal. Please call us if you are concerned.

Antibiotics are known to cause bowel problems. It might be useful to use a probiotic when starting antibiotics, your dietitian will be able to advise you on this.

#### Vomiting / nausea

Treatment for this depends on the cause. Please call your dietitian for advice.

Reflux: always call the team about this.

A few steps which can be started straight away:

- Bolus feed or flush water slower
- Sit up further whilst feeding, the minimum recommendation is 30 degrees, however some people prefer to sit more upright.
- Leave a longer gap before feeding and laying down.

#### Weight change

Your aim may be to gain weight, lose weight or to stay the same. If your weight is not doing what you expect, call us. You may notice a change in weight by looking at the clothes you wear or by your jewellery or watch. The dietetic team will probably weigh you at most visits. We have stand on scales, hoist scales and wheelchair scales available. If you are able to keep a log of your own weight this is always helpful.

#### **Please call your Nutrition Nursing Team if:**

- Your PEG tube is damaged
- Your stoma site feels or looks sore
- You are experiencing a change in discharge around your PEG tube: Some discharge is normal, and will be fine if cleaned daily. If the discharge begins to smell, looks a different colour, the quantity increases, or any other concerns please call.
- There is any change to what equipment or feed you need to be ordered.
- The tube is blocked
  - Never use excess force or a sharp instrument to unblock, as this could permanently damage the tube.

- Check that the tube is not kinked and the clamp is open.
- Gently massage the tube with your fingers (be careful not to pierce the tube if you have long nails)
- Syringe warm water into the tube and leave for a few minutes to dissolve the blockage.
- Try first with a 60ml syringe, however if it doesn't work revert to a 10ml syringe, half fill the syringe with warm water, connect to PEG end and **pull back** (aspirate) the plunger of the syringe. Debris will be seen floating in the syringe. If you let go of the barrel it will 'pop' back, applying pressure to the blockage. Discard any water with debris in and continue until blockage is cleared. Once cleared, flush well with cool-boiled water.
- If the above doesn't work, dissolve 2 teaspoons of bicarbonate of soda in 50ml of warm water, or carbonated water, repeat the above step using this. Once the blockage is cleared, try not to syringe this water into the PEG tube, flush with cool boiled water.
- Call the Nutrition Nursing Team if you are unable to unblock the tube.

#### Problems with feeding pump

If a red light is visible, contact Fresenius Kabi directly for an urgent delivery of a new pump. If a yellow light is visible, please refer to your pump booklet. You can press the top left button with a crossed-out bell sign to silence the alarm while you read the instructions. If you are unable to deal with the pump alarm, call Fresenius Kabi on 0808 100 1990 (24-hour helpline) or the Nutrition Nursing Team.

#### **Appendices**

Handwashing instructions (PDF – print separate)

Cleaning syringes (PDF – print separate)

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<sup>\*\*</sup>Never use boiling or too hot water – only use water of a temperature which you would be comfortable drinking.