Your Guide to Tube Feeding at Home

This leaflet is intended for adult patients who have a feeding tube for nutrition and/or hydration.

This leaflet aims to help you, your family or carers manage your feeding tube at home. Before you leave hospital you will be shown how to care for your feeding tube and how to manage your feed. If, after you leave hospital you are still unsure about anything, please contact your feed company nutrition nurse or community dietitian.

Useful contacts and pump details

<table>
<thead>
<tr>
<th>Name/Address</th>
<th>Telephone Number</th>
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<tbody>
<tr>
<td>Hospital dietitian</td>
<td>01895 279416</td>
</tr>
<tr>
<td>Community dietitian</td>
<td></td>
</tr>
<tr>
<td>Feed company nutrition nurse</td>
<td></td>
</tr>
<tr>
<td>Feed delivery company &amp; pump helpline</td>
<td>0800 0183799</td>
</tr>
<tr>
<td>PINNT (Patients on Intravenous Nutrition and Nasogastric Therapy)</td>
<td>01202 481625</td>
</tr>
</tbody>
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Other contacts
Pump details: (you may be given a pump instruction booklet from the hospital)

<table>
<thead>
<tr>
<th>Name of pump</th>
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<tbody>
<tr>
<td>Manufacturer</td>
<td></td>
</tr>
<tr>
<td>Supplier</td>
<td>Abbott hospital to home 0800 0183799</td>
</tr>
</tbody>
</table>

Feeding tube details:

<table>
<thead>
<tr>
<th>Type of tube</th>
<th></th>
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<tbody>
<tr>
<td>Make and size</td>
<td></td>
</tr>
<tr>
<td>Date of initial insertion</td>
<td></td>
</tr>
<tr>
<td>Balloon water volume (if applicable)</td>
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</tbody>
</table>

Replacement feeding tube details:

If your feeding tube has been replaced please provide the following information below:

<table>
<thead>
<tr>
<th>Date of replacement</th>
<th>Type</th>
<th>Make and size</th>
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<tbody>
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Additional notes:
Introduction

What is gastrostomy tube feeding?

For a number of reasons, it may be impossible or unsafe for you to take enough food and fluid by mouth to keep you healthy. A gastrostomy tube is a small feeding tube placed into your stomach. The tube allows you to be fed without using your mouth.

How long will the tube last?

Some tubes are long term and can last for a few years if well cared for. Other tubes are short term and need to be changed every 3-6 months. You will be told when your tube needs to be changed. If you notice wear and tear or cracks in your tube, it will probably need changing. Discuss this with your feed company nutrition nurse or dietitian.

How will I get my feed and equipment when I go home from hospital?

- You will be given **seven days’ supply** of your feed and equipment from hospital or it will be delivered straight to your home. Usually your hospital dietitian will contact the feed company to organise regular home deliveries of feed, feeding equipment and will inform the community dietitian that this has been done
- The hospital or community dietitian will need to request the prescription for your feed from your GP. Your GP will then need to send the prescription to the feeding company or give it to your local chemist who may organise home delivery of your feed
- Your dietitian will provide you with a feeding plan.

How should I store my feed?

- Try to keep unopened bottles or bags of your feed in a cool dry place and out of direct sunlight
- Once opened, your feed should be stored in the fridge and must be used within 24 hours. You will need to throw away any unused feed after 24 hours
Feeding Instructions

You will receive full training on the method required before discharge.

Feeds can be given by the following methods:
- pump feeding - using a pump connected to your feeding tube
- gravity feeding - using gravity
- bolus feeding - using a syringe

1. Always wash your hands before setting up your feed or flushing your tube. See the hand washing instructions on page 14 in this booklet for further information
2. Store your feed at room temperature and check the feed has not exceeded the expiry date. Shake the feed gently before using
3. Flush your tube with cooled boiled water before and after each feed and before and after giving medicines. Use the amounts given on your feeding plan.

If pump feeding:
1. Attach the giving set to the pump, prime the giving set and attach to your tube. Try not to touch any of the connecting ends directly
2. Check the flow/drip rate on your pump is the same as the feeding plan
3. Clear the volume infused from the previous day on the pump before starting the next feed.

If gravity feeding:
1. Prime the gravity set with feed
2. Attach the gravity set to your tube
3. Loosen the roller clamp on the giving set and allow the feed to run through with gravity
4. The roller clamp will be adjusted depending on the drip rate stated on the feeding plan.

If bolus feeding (using a syringe):
1. Draw up the feed into the syringe
2. Attach the syringe to the tube with the clamp closed on the tube. Remove the plunger from the syringe
3. To allow feed into the stomach, release the clamp fully and allow the feed to flow into the tube with gravity
4. Top up the syringe with the correct amount of feed as per plan. Try not to touch any of the connecting ends directly
5. If your feed does not flow into the tube with gravity then you can use the plunger on the syringe to slowly and gently push the feed into the tube.
Taking medicines through your feeding tube

1. If you are using a pump, turn this off
2. Flush your tube with at least 30ml water using a syringe
3. Give medicine through your feeding tube
4. Flush your feeding tube again
5. If a number of medicines are given at once, flush with at least 10ml of water between each one.

Notes:

Ideally your medicines should be in liquid form so it can be flushed easily down the tube.

If you have been advised to crush your tablets it is important that they are crushed and dissolved with water. Flush the tube with at least 30ml water before and after medicines. If you are having several medicines at the same time flush with at least 10ml of water between each.

There are some medicines which cannot be crushed. Please ask your pharmacist if you are unsure.

Some medicines may interact with the feed and therefore the feed may need to be stopped for a few hours before or after. Please ask your pharmacist or doctor for advice.
Caring for your feeding equipment

<table>
<thead>
<tr>
<th>Equipment</th>
<th>How to clean it</th>
<th>How often does it need changing</th>
<th>Tick item</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single use syringe</td>
<td>Re-usable: clean after each use. (See page 7 for cleaning instructions).</td>
<td>After 7 days or 30 uses.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Re-useable: single use only.</td>
<td>Throw away after every use.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The symbol above indicates that it is ‘single use’.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gravity set</td>
<td>Single use only.</td>
<td>Throw away after each use.</td>
<td></td>
</tr>
<tr>
<td>Giving set (for pump)</td>
<td>24 hour use only (Do not clean)</td>
<td>Change every 24 hours or if you have had to change to bottle of feed.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Each giving set will have a cap in the package. If you have a break in feeding; put the cap back on the giving set. Place the giving set and feed in the fridge inside a clean lidded container until ready to be used again.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>The giving set must be discarded after 24 hours of opening the package.</td>
<td></td>
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</tr>
<tr>
<td>Feed reservoir (Flexitainer)</td>
<td>Single use only</td>
<td>Throw away after each use (hanging time 6-12 hours depending on feed).</td>
<td></td>
</tr>
<tr>
<td>Extension set for your gastrostomy (if used)</td>
<td>Re-useable: Immerse in warm water with washing up liquid. Remove all traces of debris. Rinse under running tap water. Shake off excess water, wipe dry with a clean paper towel and store in a clean dry, lidded container.</td>
<td>Change every 10 days.</td>
<td></td>
</tr>
<tr>
<td>Adaptor/connector</td>
<td>Re-useable: discuss with your dietitian.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pump</td>
<td>Wipe with clean damp cloth. Do not soak in water.</td>
<td>Clean between each use.</td>
<td></td>
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</tbody>
</table>
Washing your re-useable equipment

1. Wash your hands.

2. Fill a clean sink with warm water and washing up liquid.

3. Pump the plunger in and out several times, then separate the barrel and plunger.

4. Use a soft brush to remove any debris.

5. Soak under the water for 1 minute.

6. Rinse well under running water.

7. Dry excess water off with a clean paper towel.

8. Place on a clean paper towel and allow to air dry.

9. Store in a clean, lidded container.

10. Dispose of the paper towel.

11. Hang the brush up to dry.

12. Wash your hands.
Caring for your feeding tube

There are various types of gastrostomy tubes, the main two gastrostomy tubes which are used for adult patients are:

- Percutaneous endoscopic gastrostomy feeding (PEG) tube
- Balloon gastrostomy feeding tube, usually inserted radiologically (RIG)

The method recommended for cleaning your tube site, caring for your stoma site and flushing your tube will be the same for either type of gastrostomy tube.

Cleaning your tube site daily
The tube site (also called the stoma site) is the point at which the feeding tube enters the body. A dressing is not required once your stoma site has healed.

- Wash your hands with soap and water and dry well before touching the stoma site. You can refer to the hand washing instructions on page 15
- Move the external fixation plate (shown on page 9) along your tube away from the skin to allow access for cleaning. If you are unable to move the fixation plate, please contact the feed company nutrition nurse or dietitian who can arrange for someone to show you
- Gently clean the skin around the tube with mild soap and warm water
- Dry the area thoroughly.

Caring for your stoma site

- Try to avoid using powders or creams on the skin area unless advised by a healthcare professional
- Try to avoid using a dressing around the site unless advised to do so by a healthcare professional
- Contact your feed company nutrition nurse, GP or community dietitian for advice if there is a problem, for example:
  - The tube site is red and sore
  - There is leaking from around the tube
  - The tube is loose or tight

Flushing your tube

- Always flush your tube with cooled, boiled water before and after feeds and medicines to prevent your tube from blocking. See your feeding plan for details on the amount of water to flush
- You should only put feed, water and liquid medicines down the tube, unless otherwise advised by a healthcare professional
- Try to make sure that your tube does not get pulled or kinked. To avoid kinks along your tube, try to avoid closing the clamp at the same place on your tube.
- Move the clamp along the tube, and if possible try to keep the clamp open when not in use.
If you think the tube has dislodged, do not feed and contact your feed company nutrition nurse or visit A & E if out of hours.

If you have a PEG tube

This is a PEG tube. All PEG tubes are held inside the stomach by an internal plate/disc and on the skin by an external fixation plate. Your PEG tube may look slightly different from the one shown below if it is from a different manufacturer.

Rotating your tube

Some people may be prone to the skin inside the stomach growing over the internal plate. Rotating your tube may help to prevent this from happening

- Always check with your feed company nutrition nurse or dietitian if and when to start rotating your tube and how to rotate it
- To rotate it, once a week loosen the external fixation plate. Gently push the tube into the stomach by 2-3cm, and then rotate the tube 360 degrees. Finally pull back the tube gently to feel resistance and replace the fixation plate approximately 1cm from the skin
- Do not rotate your tube if there is discharge, if the stoma site has not healed or looks infected
- Do not rotate your tube if you have stitches in place.

Tube breakage

If the end of your PEG tube breaks (this is called the Y adapter or luer lock adaptor), contact your community dietitian immediately as it may be replaced at home. It is useful to always keep a spare end for your PEG tube.
If the tube comes out

If your PEG is pulled out accidently you must go to A & E immediately otherwise your stoma site will close over. Do not wait to make an appointment to see your GP. If you have an emergency pack and have been trained, place the emergency tube in the stoma to keep it open.
If you have a balloon gastrostomy feeding tube

These tubes are held in the stomach by an internal balloon and usually last between 3-9 months.

The balloon contains cool boiled water and the water needs to be checked every 7 days. You will be shown how to do this by your feed company nutrition nurse.

Checking the balloon water:

- Prepare new cool boiled water in a new syringe
- Hold the tube gently near the stoma site
- Move the fixation plate about a centimetre away from the stoma site
- Gently push tube into the stomach until the fixation plate rests on the abdomen
- Remove all the water from the balloon via the balloon port using a 10ml Terumo syringe
- Discard water from the syringe. Repeat the procedure to ensure the balloon is completely empty
- Replace the water in the balloon with the expected volume (depends on type of tube)
- If the water in your balloon is regularly less than the expected volume, then contact the company nutrition nurse as the balloon may be damaged and the tube may need to be changed.

If the tube falls out

- If the tube falls out within normal working hours, contact your feed company nutrition nurse. If you have been trained please put one of your emergency tubes in the stoma site to keep it open.
- Out of hours you will need to go to A&E (take your emergency equipment/spare tube).
Other types of feeding tubes

If you have a jejunostomy feeding tube

This type of feeding tube ends in the jejunum (small intestine) rather than the stomach. It is held in place by an internal disc or stitches. If you feel that the tube end may have moved into the stomach, you may need to visit your nearest A & E. It is important that you do not remove the stitches or advance and rotate this type of tube unless you have been advised to.

General care - for all types of tubes

- Try to avoid immersing your tube in water. You can shower after the site has healed (normally about 2-3 weeks after tube has been placed) and you can have a shallow bath. Ensure your feed is disconnected from the pump and check that the clamp on the tube and the end of the tube is closed. Dry the area thoroughly afterwards

- If you are swimming, cover the stoma site with a water proof dressing. Remember to check that the clamp on your tube and the tube ends are closed

- Refer to your community dietitian for further advice.
What to do if other problems occur

1. What do I do if my tube blocks?
   - Firstly check to ensure all clamps are opened and there is nothing blocking the end of the tube
   - Check for any kinks or bends in the giving set or tube
   - Flush your tube with 30ml lukewarm water. You can use a gentle push and pull motion on the plunger of the syringe to help dissolve the tube blockage.
   - Sometimes massaging the tube with fingertips may help
   - Avoid using juices, or other sugary fizzy drinks. Never try to unblock the tube with sharp objects or excessive force as this may damage the tube
   - If at first you do not succeed, try once more. If the blockage persists, contact your community dietitian or feed company nutrition nurse. If you are unable to contact the dietitian or it is outside of normal working hours, you may need to go to your local A & E department.

2. What if I have constipation or diarrhoea?
   - When tube feeding is started it can lead to either fewer or more bowel movements than normal. Antibiotics and some medications may also cause diarrhoea for a short while. This should settle down as your body adjusts to the feed and you are taken off the antibiotics
   - If you continue to suffer from diarrhoea or constipation, contact your community dietitian.

3. What should I do if I’m feeling sick?
   - Temporarily stop feeding and try to sit in an upright position. If the symptoms are gone in one hour try a syringe full of water through your tube
   - When starting your feed again, make sure you are sitting upright or if you are in bed, your head is raised at a 30-45 degree angle
   - Re-start the feeding rate at a slower rate than normal. Gradually increase the feeding rate back to the original. If you are constantly feeling full or uncomfortable, contact your community dietitian who can advise you further
   - If you are unable to tolerate water or the vomiting continues, contact your GP. If you have diabetes and you start vomiting, contact your GP immediately.
4. How do I know if I am getting enough fluids?

- Your dietitian will have calculated your estimated fluid requirements and included this in your feeding regimen
- You may need to increase the amount of water you need in hot weather or if you have a temperature or if you have diarrhoea by giving additional flushes of water
- Common signs of dehydration to look out for are; feeling thirsty, dry mouth, cracked lips, headaches, constipation and dark or concentrated urine.

5. What happens if I run out of giving sets and the company cannot deliver in time?

You can give bolus feeding (see page 6) until the giving sets arrive. Please speak to your dietitian who can advise you further if you are unsure.

If you are unsure about any of the information in this booklet please contact your community dietitian or feed company nutrition nurse who will be able to advise you further.

If you have any questions out of hours, please contact the feed company’s helpline for advice on 0800 0183799.
Washing your hands

To help prevent any infection, it is very important to wash your hands thoroughly before and after touching any of the equipment. Liquid soap and either a clean dry towel or a disposable paper towel should always be used.

1. Wet your hands thoroughly and apply liquid soap.
2. Rub your hands together palm to palm.
3. Rub the back of your hands with the palm of your other hand.
4. Rub your palms together with your fingers interlocked.
5. Interlock fingers as close to the palm as you can and rub your fingers together.
6. Rub the backs of your fingers with the palm of the other hand.
7. Clasp your thumb with the palm and rotate your thumb.
8. Rub your fingers in a circular motion.
Languages/ Alternative Formats

Please ask if you require this information in other languages, large print or audio format. Please contact: 01895 279973

Fadlan waydii haddii aad warbixintan ku rabto luqad ama hab kale. Fadlan la xidhiidh 01895 279 973

Jeżeli chciałbyś uzyskać te informacje w innym języku, w dużej czcionce lub w formacie audio, poproś pracownika oddziału o kontakt z biurem informacji pacjenta (patient information) pod numerem telefonu: 01895 279973.

Per quanto riguarda l'acquisto di questa informazione in altre lingue, in caratteri grandi o in formato audio, contatta il personale del servizio informativo (patient information) al numero 01895 279973.

如果没有您需要的其他语言版本、大字体、或音頻格式，請致電01895 279 973查詢。

Adapted from Community Children’s Nursing Team and Community Paediatric Dietitian, Laurel Lodge Clinic, Harlington Road, Uxbridge UB8 3HD

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