PARENT/CARERS’ GUIDE TO
GASTROSTOMY
ENTERAL FEEDING
<table>
<thead>
<tr>
<th>CHILD’S NAME</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>H &amp; C NUMBER</td>
<td></td>
</tr>
<tr>
<td>DATE AND METHOD OF SURGERY</td>
<td></td>
</tr>
<tr>
<td>TYPE OF ENTERAL DEVICE</td>
<td></td>
</tr>
<tr>
<td>SIZE</td>
<td>FR</td>
</tr>
<tr>
<td>CM</td>
<td></td>
</tr>
<tr>
<td>REPLACEMENT DEVICE</td>
<td>YES</td>
</tr>
<tr>
<td>NO</td>
<td></td>
</tr>
<tr>
<td>TYPE</td>
<td></td>
</tr>
<tr>
<td>DATE OF REVIEW</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CCN NAME</th>
<th>CONTACT NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>DIETITIAN</td>
<td>CONTACT NUMBER</td>
</tr>
<tr>
<td>SPEECH &amp; LANGUAGE</td>
<td>CONTACT NUMBER</td>
</tr>
<tr>
<td>REGIONAL HOSPITAL</td>
<td>CONTACT NUMBER</td>
</tr>
<tr>
<td>LOCAL HOSPITAL</td>
<td>CONTACT NUMBER</td>
</tr>
<tr>
<td>GASTROSTOMY NURSE</td>
<td>CONTACT NUMBER</td>
</tr>
<tr>
<td>OUT OF HOURS/BANK HOLIDAY/WEEKEND</td>
<td>CONTACT NUMBER</td>
</tr>
</tbody>
</table>
CONTENTS

Introduction ............................................................ 4
Why Does My Child Require An Enteral Device? ........ 5
What Are The Types Of Gastrostomy Devices......... 5
Enteral Device Essentials .......................................... 8
Training .................................................................... 9
Discharge From Hospital ........................................ 10
Handwashing ........................................................... 11
Care Of The Enteral Device Site .............................. 12
Checking Position Of Enteral Devices ..................... 16
Enteral Syringes .................................................... 18
What Is Venting .................................................... 21
Flushing Enteral Devices ......................................... 22
Enteral Feeds ........................................................ 24
Preparing To Feed Your Child .................................. 27
Oral Hygiene ........................................................ 27
Glossary .............................................................. 28
INTRODUCTION

A parent being told that their child requires gastrostomy feeding can be overwhelming especially if there has previously been no knowledge of this process. However, with sufficient support and training, it is envisaged that any anxieties will be reduced and you as a parent and carer will be able to undertake your child’s feeding confidently and competently.

This parent’s guide to gastrostomy feeding has been developed to provide essential information and support to parents and carers.

The information in this guide has been identified by parents as a result of a questionnaire and focus groups, exploring the information that parents would like to receive.

Comments and feedback from parents and staff have also been provided and used during the development of the booklet.

The Community Children’s Nursing (CCN) Team are Nurses who will provide support to your child and family within your home.
WHY DOES MY CHILD REQUIRE AN ENTERAL DEVICE?

Even if the device is required for the same reason a completely different type of enteral device may be used.

Generally an enteral device is necessary to assist your child in meeting their nutritional and/or hydration needs. It may also be used for aspiration, venting and/or delivery of medicines. Your child’s doctor will discuss and explain the reasons that your child requires an enteral feeding device.

The Gastrostomy Nurse Specialist will show and demonstrate the care and management of the type of enteral device identified for your child.

WHAT ARE THE TYPES OF GASTROSTOMY DEVICES?

A gastrostomy device is placed in the child’s stomach.

There are many different types and makes of gastrostomy devices.

It can be very confusing when professionals talk about the different devices.

Do not worry as you will be trained in the type of gastrostomy device used for your child.
Gastrostomy tube – You may have heard of the term PEG – this means the surgical method in which the device has been inserted. These tubes have an internal plate/bumper to secure it in place in the stomach which also prevents it from becoming dislodged. This is a long term device and can only be removed surgically and replaced in hospital.

Button/low profile device – It is a small device inserted through an opening (stoma) in the child’s abdomen and placed in the stomach. It is held in place by a water filled balloon. You can be trained to change/replace this device at home.

Non balloon gastrostomy – this looks like the button/low profile device- the difference is that there is no balloon. It is held in place by an internal disc/bumper in the stomach. Depending on the make of device it may only be
replaced in the hospital. You will be advised regarding the replacement of this device.

**Balloon Gastrostomy tube (may be called a replacement gastrostomy or G Tube)**

This is a tube placed into the stomach which is held in place by a water filled balloon.

All of these devices can be used for either bolus feeds (feed given over a short period of time) or continuous feeds (feed given over a longer period of time).

Medicines can be administered through these devices.

They can also be used for venting (removing excess air in the child’s stomach) or aspiration purposes (withdrawing stomach contents).
ENTERAL DEVICE ESSENTIALS

Before your child is discharged from hospital you will be given the following information regarding your child’s enteral device:

- The type and size of enteral device being used
- The amount of water used in the balloon if the device has a balloon.
- The reason for the enteral device i.e. feeding/medications/aspiration/venting

This is the essential information required should your child be admitted to hospital and for your CCN team.

If your child has been discharged within 72 hours after insertion of the gastrostomy device it is very important to seek urgent medical advice if your child experiences:

- Pain on feeding
- Prolonged or severe pain
- Fresh bleeding
- External leakage of gastric contents

You will be given the contact numbers of who to contact out of hours, Bank Holidays and at weekends.
TRAINING

You will be trained and deemed competent in all aspects of your child’s feeding device and feeding regimen.

Your Community Children’s Nurse will offer annual update training whilst your child has an enteral device in place.

You will be trained in:
- The importance of hand washing
- Care of entry site of enteral device i.e. where it is inserted
- Management of enteral device, rotation, fixation plate, clamp, balloon, routine replacement of device
- What to do if your child’s enteral device accidentally comes out
- Disposables required for your child’s enteral feeding
- How to store, prepare and administer your child’s feed and medicines
- How and when to check that position of enteral device is in your child’s stomach.
- How, when and what to use to flush your child’s enteral device
- How to recognise and manage complications
DISCHARGE FROM HOSPITAL

A spare enteral device will be provided if necessary – this device MUST always accompany your child.

Adequate amount of supplies will be provided until the CCN is able to organise the supplies within the community.
It is very important to wash your hands before handling your child’s enteral device and preparing and administering their feed. It is one of the most important ways of preventing and controlling the spread of infections.

You will become familiar with the 7 steps of hand washing – all health professionals use this method of washing their hands when working with their clients.

**HAND HYGIENE**

1. **PALMS**
2. **BACKS**
3. **BETWEEN FINGERS**
4. **THumbs & WeBS**
5. **KNUCKLE GRIP**
6. **FINGERTIPS**
7. **WRISTS**

**You can do it in...45 SECONDS**

- Wet hands under running water and then dispense one dose of liquid soap/antiseptic onto hands.
- Wash vigorously for 15 seconds. Following steps 1-7 without adding more water.
- Ensure hands are well rinsed.
- Dry hands thoroughly with paper towel and turn off taps with elbows or paper towel
- Dispose of towel in bin. Always use the foot operated pedal and not your hand to open bin.
- Apply hand cream regularly.
CARE OF THE ENTERAL DEVICE SITE

The enteral device site will be known as the ‘stoma site’. It can take up to 2 weeks for the site to heal and sometimes this can take longer, your CCN will support and guide you in caring for your child’s stoma site.

At the beginning you may feel apprehensive as you are frightened you will hurt your child or dislodge the device.

You will be shown and observed on how to clean the stoma site until you feel happy and confident in doing it yourself.

Clean your child’s stoma site twice daily. Use gauze/cloth that does not shed fibres as loose fibres can become entangled in your child’s device. Always ensure you dry the stoma site after cleaning. If you notice any redness, discharge, swelling and or pain contact your CCN for further advice.

Your child may have a shower following discharge from hospital. It is important that the enteral device is not submerged under water at this stage.

Once you have been advised the stoma site has healed your child may have a bath.

Swimming will be permitted at this stage and it is important to clean your child’s stoma site following
swimming and dry thoroughly as the chlorine may aggravate your child’s stoma site.

**Rotation of the enteral device**
You will be advised and shown how to rotate your child’s enteral device. You will daily rotate your child’s device 360 degrees using your fingers and thumb.

This will prevent the device adhering to your child’s stoma tract and in some devices prevent ‘buried bumper.’

Buried bumper means the part of the device inside your child’s stomach has become buried against the stomach wall. If this happens your child will need to go to hospital for the Doctor to manage. You will not be able to rotate the device if buried bumper has occurred.

**Management of external fixation plate**
Some enteral devices have a visible external fixation plate which keeps your child’s device in place.

You will be shown and observed on how to care and adjust this external fixation plate.

Don’t worry as you will not have to do this until you feel confident in doing so.

This fixation plate is adjusted on a weekly basis.
Clamp on the enteral device
If your child has an enteral device with a clamp - you are advised to keep the clamp open when the device is not being used. This will prevent a weakness in the device tubing and prolong the use of the enteral device.

If the clamp is being used, change the position of the clamp on each occasion which also will prevent a weakness in the device tubing.

Management of the balloon enteral device
Some enteral devices have a balloon which is inside your child’s stomach and this balloon holds the device in place.

It is important to look after the balloon which means the water in the balloon needs to be changed on a weekly basis.

You will be trained to do this and the CCN will always support you until you feel confident in doing this yourself.

You will be told how much water to insert into the balloon.

You should change the water in the balloon in the mornings so that if you have any concerns you can contact your CCN.
Changing the water in the balloon routine replacement of enteral device
The balloon type enteral devices which are situated in your child’s stomach are routinely replaced every 6 months.

The Gastrostomy Nurse/CCN will always do the first change and you can watch how they change the button. Training and supervision will be provided at the next routine enteral device changes until you are confident to do so without the CCN present.

Every time your child’s enteral device is changed it is important that the position of the device is checked to ensure the tip of the device is in your child’s stomach.

Your child’s stoma tract will be measured at least yearly as the length of the stoma tract may change as your child grows.
The position of gastrostomy devices should be checked every time your child’s enteral device is changed and if there is any evidence of dislodgement of the device. Indications of this include unusual leakage of stomach contents around site, unusual redness or swelling around site, excessive vomiting and/or abdominal distension or pain.

How do I check the position of my child’s feeding device?

- This is done by withdrawing a small amount of stomach contents with an enteral syringe. This is called the aspirate.
- Place 2-3 drops of the aspirate onto the pH strip.
- Let any excess aspirate on the strip run off onto a paper towel.
- Within 10 – 60 seconds check the colour of the strips against the colour chart on the pH strip container. After 60 seconds the strip is not to be used as a check as the reading will be false.
- The reading should be below 5.5 which indicates that the tip of the enteral device is in your child’s stomach. **DO NOT USE ENTERAL DEVICE if pH value is above 5.5.**
- Only use each test strip once.
- You will be shown and supervised to do this check.
Storage of pH indicator strips
- Keep the pH indicator strips in a cool dry place.
- Keep the container sealed by always replacing the correct lid after every time you remove a strip.
- Check the expiry date on the container and use within the expiry date.

What if my child’s enteral device falls out?
Taking good care of your child’s enteral device will help prevent the device from falling out – very importantly you must ensure that when you are moving and handling your child that the enteral feeding tubing does not get trapped for example in your child’s buggy or chair that would pull on the device and cause it to come out.

Also ensure your child is not able to pull on the device accidently.

If there is a risk of the enteral device dislodging you will have a replacement device. You will have received training in how to replace the device – if you are unable to replace the device then you must cover your child’s stoma site with clean gauze and secure with tape.

Bring your child to the nearest hospital remembering to bring your replacement enteral device with you.

The replacement enteral device should always be with your child at all times e.g. school, respite, sleepovers.
ENTERAL SYRINGES

You will be provided with purple enteral syringes.

These come in two types
• Single use which means you dispose of them after one use. This type is always used in hospitals.
• Reusable syringes which mean you can wash and reuse the syringe up to one week. This type is most commonly used within the home and school.

Syringes come in various sizes. It is recommended that you use the largest size of syringe possible as this reduces the amount of pressure delivered when you are using the syringe for example 60ml/20ml. This will prevent damage to the internal part of your child’s enteral device.

Your CCN will explain to you the type and size of syringe identified for your child. You may be required to use a smaller size of syringe depending on the amount of flush required for your child and also your child’s medication doses.

How to care for reusable syringes
• Once you have used the enteral syringe – take the syringe apart and wash in warm soapy water and rinse.
• Leave the parts to dry
• Once dry store in a clean dry lidded container until they need to be used again.
• Dispose of your enteral syringes on a weekly basis
• Do not use the enteral syringe if
  - The markings on the syringe are no longer visible
  - The syringe is damaged in any way
  - There is stiffness when using the syringe
  - If you are unable to ensure thorough cleaning between uses.

**Extension sets**
These are attached to the gastrostomy device when you are feeding/flushing/administering medicines.

They can be washed in soapy warm water and rinsed and left to air dry. Once dry place them in an air tight container to ensure that they are kept clean when not in use.

Extension sets can be used up to two weeks at a time and then disposed of in the household waste.

**FEEDING SETS**

Your CCN will explain to you what type of feeding set you will use for your child.

A new feeding set will be used for each feed.
If your child is having continuous feeds – feed which is given slowly throughout the day – a new feed set will be used daily.

DISPOSAL OF ENTERAL FEEDING EQUIPMENT

When you are finished with your equipment – feeding syringes and sets – you are advised to put them in a bag and place into your household bin. Unfortunately enteral syringes cannot be recycled and must be placed in the black bin. You can check with your local council re a second black bin if you are finding you are accumulating a lot of waste.
WHAT IS VENTING?

Venting is letting the air (wind) out of the stomach by using only the barrel of a 60ml enteral syringe – remove the plunger i.e. the purple inside of enteral syringe.

This is usually performed before your child’s feed to ensure they have no excess air in their stomach which can cause your child discomfort.
FLUSHING ENTERAL DEVICES

Flushing is administering water into the feeding tube, usually with a syringe to clear feed/medication in order to keep it from blocking.

You will be trained and supervised how to flush your child’s device

• Before and after each medication administration
• Before and after feeding
• Daily if enteral device is not being currently used
• During continuous feeds the enteral device will be flushed every 4-6 hours.

What do I use to flush my child’s enteral device?
Your CCN will advise if sterile/freshly cooled boiled/tap water is to be used for the flush.

Sterile water is always used in hospital.

How much flush do I use?
Your child’s Dietitian/CCN will advise you on the volume required to flush your child’s enteral device.
How do I flush my child’s enteral device?
You will be shown how to flush using a pulsatile action. That is a push/pause technique. This technique promotes a turbulence effect within the tubing and ensures adequate flushing and helps prevent any blockages occurring.

**Hint** If you say the words “push pause” during time of flush you will remember to do this technique.
ENTERAL FEEDS

Your child’s Dietitian will prescribe the most suitable type of feed that your child requires and they will always ensure, with the support of your CCN, that you are aware of all aspects of preparation and administration of your child’s feed.

There are two types of feed
1. Ready to use feed which has been specially prepared and comes prepacked.
2. Reconstituted feeds which come in powdered form which you prepare yourself.

Ready to use feed
• Store ready to use feed in a cool, dry place out of direct sunlight. Avoid storing feeds in gardens sheds/garages and next to radiators.
• Use within expiry date
• If there is any feed not used – this can be labelled with date and time it was opened, refrigerate and disposed of after 24 hours if not used.

Reconstituted feed
• To prepare powdered feeds boil the kettle and leave it to cool for no longer than 30 minutes.
• Powdered feeds must be used within 4 hours – otherwise prepare a new feed.
Methods of administration of enteral feeds
There are two methods of enteral feeding
• Bolus feeding – this can be administered by gravity/feeding pump
• Continuous feeding – feed administered at a slower rate over a prolonged period of time.

Bolus feeding
• This is a feed given over a short period of time – usually less than 30 minutes.
• It can be given by gravity by attaching the barrel of a 60ml syringe to your feeding set and pouring the required amount of feed into the syringe barrel.
• The higher you hold the syringe above the child, the faster it will flow. Your child will be sick if the feed is given too quickly.
• To slow the rate of the feed, lower the syringe so it is closer to your child’s stomach.
• If your child coughs/retches feed may flow back up into the syringe barrel – if you raise the syringe it will reverse the flow.

A bolus feed can also be administered by a feeding pump which will be set to the length of time the feed should be delivered.

Remember to flush your child’s enteral device before and after feed.
Continuous feed
• This method of feeding is always administered by a feeding pump.
• The enteral device is flushed before and after feed and 4-6 hourly during the feed.
• Where possible your child will be prescribed a feed which can be attached for the period of time that it is required – if not possible add new feed every four hours to feeding system.

Important factors if your child requires overnight continuous feeds
• Sleep in the same room as your child
• Your child should be fed at an angle of at least 30 degrees during continuous feed.
• Never leave your child unattended if they are awake.
• Position the feeding pump at the side of your child’s bed/cot ensuring the administration set is threaded through the bars rather than dangling over the top of the cot/bed sides.
• The feed tubing should be threaded through the inside of your child’s night clothes
Preparing to feed your child

- Collect everything you need
- Feed
- Enteral syringes
- Feeding set
- Feeding pump
- Water for flushing
- Medicines if required at that time
- Wipe clean your tray with antibacterial wipe/spray.
- Set in order of use disposables required for feeding and prepare.

ORAL HYGIENE

- For children under 2 years of age – mouth care is recommended.
- Tooth brushing should be performed twice daily.
- If your child is not allowed oral fluids – additional oral hygiene maybe required to keep the mouth moist to prevent gum disease and stimulate saliva and gastric secretions.
- Your child should be registered with a Dentist
- If your child is unable to use toothpaste – speak to your Dentist about obtaining an alternative product to toothpaste.
GLOSSARY

Administration Set
Plastic tubing used to connect the container to the feeding device

Aseptic Non-Touch Technique (ANTT)
A unique and contemporary practice to reduce Health Care Associated Infections using an aseptic technique

Aspiration
A procedure used to determine the position of the end of the tube. Aspiration also refers to the accidental sucking in of food particles or fluids into the lungs

Balloon
A water filled balloon holds some gastrostomy devices securely in the stomach

Bolus/Intermittent Feeding
A prescribed volume of feed given slowly via a syringe at a specific time.

Buried Bumper Syndrome
A rare complication which occurs when the internal plate has become buried in stomach wall.

Carer (caregiver)
Someone other than a health professional who is involved in caring for a person with a medical condition.

Continuous feeding
Continuous feeds are the administration of a feed at a slower rate over a prolonged period.
Decanting
Pouring feed from the original container into the administration set container

Enteral nutrition
The provision of safe and effective nutritional support through the use of an enteral feeding device.

External Fixator
A device that holds the enteral tube in place against the skin.

Flush
Administering a small volume of water through the tube to clean it after you have used it to deliver your feed or medications.

Gastro-oesophageal reflux disease (GORD)
A common condition where acid from the stomach leaks out of the stomach and up into the oesophagus.

Gastrostomy Tube
Feeding devices which allow liquid feed, fluids and/or medicines to be delivered directly into the stomach.

Gastrojejunostomy tube
Enteral tube inserted through the abdominal wall which passes through the stomach into the jejunum for the purpose of nutrition support.

Hypoallergenic
Reduces the possibility of an allergic reaction.

Immuno-compromised
Vulnerable to infection due to having an immune system that has been impaired by disease or a medical treatment.
Jejunostomy Tube
A tube inserted directly into the jejunum (part of the small intestine)

Naso-duodenal tube
A polyurethane tube which is inserted via nose through the stomach and into either the duodenum or jejunum

Naso-gastric
A narrow tube that is passed into the nose and down the oesophagus into the stomach which allows liquid feed/medication to be delivered directly into stomach.

Naso-jejunal tube
A tube passed through the nose and down into the jejunum (the second part of the small intestine), thus bypassing the stomach and the duodenum.

Orogastric (tube) feeding
Nutrition support provided by a tube inserted through the mouth via the oesophagus into the stomach

Over granulation
Granulation tissue (natural healing process) beyond the amount required to replace the tissue loss as a result of skin injury or wound

PH Indicator Strips
Used to confirm the feeding device is in the correct position by measuring the amount of acid in the stomach contents.

Push/Pause technique
A pulsatile flushing action to promote a turbulence effect within the tube.

Single Use
Use only once and then discard
Single child use
Can be used more than once on one specific child only.

Stoma
A surgical created opening into the body from outside the body.

Venting
Venting is letting the air (wind) out of the stomach.
This booklet has been developed by Patricia Meehan & Gillian McCorkell WHSCT in conjunction with parents, carers and staff within Northern Ireland in conjunction with the Development of Gain Guidelines for caring for an infant, child, or young person who requires enteral feeding.

A special thanks is extended to all the children and their parents who consented to photographs which are used. Further support and useful links can be found at PINNT/Half PINNT at http://pinnt.com/home.aspx
Further copies of this guideline can be obtained by either contacting the GAIN Office or by logging on to the GAIN Website.

GAIN Office
DHSSPS
Room C4.17
Castle Buildings
Stormont
BELFAST
BT4 3SQ

www.gain-ni.org

ISBN Number: 978-1-906805-32-6