Oxford Academic Health Science Network
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Oxford
Patient
Safety
Collaborative

Oxford Patient Safety Collaborative Specialised Paediatric Programme

Discharge Training and Information Pack for Parents and Carers

Care and use of your child's gastrostomy button

Child's name	
Date booklet given	
Contact details for your Children's Community Nurse [CCN]	

Make and size of your child's gastrostomy button:

Required amount of water for balloon:

Contents

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Introduction

This booklet contains important information that you need because your child has been fitted with a low profile balloon gastrostomy device called a gastrostomy button, or simply known as a ‘button’. This may have been changed from a Percutaneous Endoscopic Gastrostomy (‘PEG’) tube or inserted as a primary procedure (Laparoscopic primary button gastrostomy insertion with gastropexy – see the supplementary leaflet).

It also contains a set of competencies which record skills you will be trained in to care for your child and advice on where to get help if you have any problems or questions.

Its aim is to support you so that you can give safe care when your child leaves hospital.

What is a gastrostomy button?

A gastrostomy button is a feeding device, used as a connection between the stomach and the skin so your child can be fed liquid feeds. It is held in place in the stomach by a balloon filled with sterile water and fitted with a valve to prevent stomach contents leaking from the button. Feeds, water and medication can be administered directly into the stomach via an extension tube.

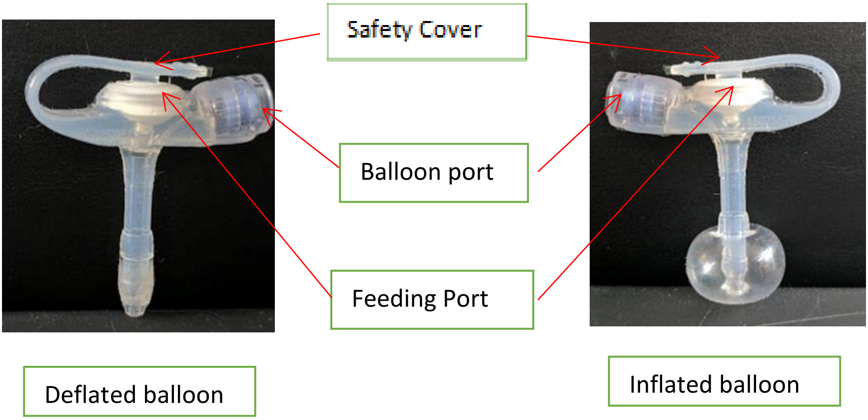
The gastrostomy button devices commonly used in the Thames Valley Region are the AMT “Mini” buttons or the Halyard/Vygon “Mickey” buttons. They have similar structures as shown in the photos on page 4, however the extension tube connectors to the buttons are different and not interchangeable so please ensure you have the correct extension tube.

Buttons come in different sizes as shown on the device itself. The devices used in children are mostly 14Fr in width of the stem (12Fr and 16Fr devices occasionally used). The length varies from 1.0cm to 5.5cm depending on the size of the child.

Occasionally, a non-standard device may be used (e.g. non-balloon buttons, gastrojejunal tubes, Monarch tubes). You will be told if these devices are used for your child and some of the information in this booklet may therefore not be applicable.

Deflated gastrostomy button

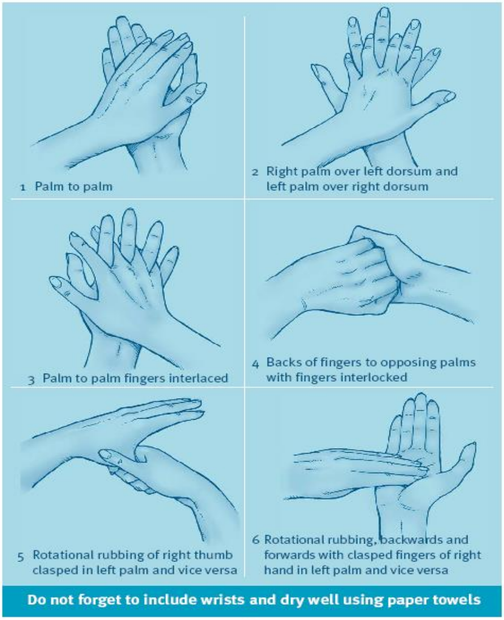
Inflated gastrostomy button



Infection Control

A good hand washing technique is essential before and after using a gastrostomy button. Hand washing for 30 seconds using the technique below ensures your hands are cleaned properly.

Hand washing technique



Daily Care of the gastrostomy button

Following your child’s PEG to button procedure the gastrostomy button can be cleaned and turned straight away.

Wash your hands before and after touching and using the button, using the techniques on page 4.

Make a visual assessment of the stoma site and surrounding skin. If there are any changes for example redness, irritation or moisture please call your CCN; they may ask you to take a photo to send to them for review and provide advice

For the first seven days after insertion of the button, clean the stoma site with gauze and tepid, cooled boiled water and dry thoroughly with gauze.

Once healed, usually 7 to 10 days later, the stoma site can be cleaned using a washable face cloth. So long as the safety cover is closed, your child can now be bathed or showered as part of their normal routine, remembering to dry the stoma site thoroughly with a clean soft towel.

Once the stoma site has been cleaned and dried the button needs to be turned 360 degrees daily to prevent it sticking to the stoma.

Weekly care of the gastrostomy button

Over a period of time water can leak out of the balloon and the balloon will shrink in size. The amount of water needs to be checked to ensure the button stays in place and the sterile water in the balloon should be changed weekly.

For this procedure you will need:

- 2 x leur slip syringes
- Sterile water

The size of your child’s button will dictate the size of syringe and volume of water you will require. This information is on the front of this booklet

Method

- Wash your hands
- Into syringe 1, draw up the required volume of sterile water
- Hold the button securely in place until the procedure is complete
- Attach the empty syringe 2 to the balloon inflation port and withdraw all of the water from the balloon. Make a note of the amount of water you have removed to ensure check for leakage.

- Disconnect syringe 2
- Insert syringe 1 containing the sterile water and push all the contents in being careful to hold the plunger in until you disconnect
- One final check, gently pull upwards on the button to make sure the balloon has been inflated.

Using a gastrostomy button

To access the button an appropriate extension set is required. This should always be primed with tap water (cooled boiled water if your child is under 1 years old or immunosuppressed) before use to avoid unnecessary administration of air.

Attach a syringe of water to the extension set, unclamp and flush through to the end, then re-clamp.

You can now attach the extension as follows:

1. Lift off the safety cap.

2. Line up the black line on the feeding set connector with black line on top of the button.

3. Hold the button firmly either side of the centre feed port.
4. Push extension set into the white valve and turn clock-wise until it stops (3/4 turn).
5. The feeding extension is now locked in place.

6. Once the extension set has been attached you are able to administer water, feed and medication via the button. Feeds can be administered as a gravity bolus or via a pump.

7. Cleaning: each extension set can be washed out and reused. Manufacturers recommend changing extension sets every two weeks but refer to your CCN for local guidance.

   Wash the extensions in hot soapy water rinse and air dry, then store in a small plastic box with a lid. For babies under one year, or a child who is immune-suppressed, please wash out with soapy water and then sterilise with your usual method.

Administering a feed

You will have a feeding plan/regime for your child from your dietician, so that you know how much feed and water to put down the tube.

Gather all the equipment you will need:

- Feed (check that it is in date and not spoiled)
- Water for flushing tube (cold, cooled boiled water if under 1 year or as advised)
- Clean 20 ml or 60 ml syringe
- If fed with a feeding pump, feed pump and feed giving set. Check that the giving set packet is intact and the paper circle on the back is white and not discoloured or wet
- Extension set flushed with water [primed]

Method

1. Wash your hands
2. Ensure that your child is in an optimal upright feeding position
3. Attach the primed extension set to the button.
4. Connect the water syringe, unclamp and administer.
5. Administer a bolus feed by putting the recommended amount of feed in the syringe, unclamping the tube then holding the syringe upright above the level of the gastrostomy stoma, give feed over 15 to 20 minutes
6. For feeds via a feeding pump, prime the feeding set and attach to the extension set

Feed Hanging Times	
Type of feed	**Length of time to be used**
Sterile Ready to hang feed	24 hours then discard
Sterile feed which has been decanted into a sterile container	24 hours and then discard if decanted, using a clean technique
Reconstituted powdered feed or non-sterile feed.	Ideally 4 hours and then discard. (<u>and change giving set and reservoir)</u> In practice it may be necessary to feed for longer than 4 hours- and impossible for carers to keep changing i.e. overnight. Risk assess as necessary

(Information taken from Oxford Health Shared Care Protocols October 2016)

7. Flush the extension set with the recommended amount of water after administering feed and clamp
8. Dispose of the giving set after feed as directed /per manufacturer’s guidelines. Syringes that can be reused need to be washed after every use, dried and stored in a clean area (if your child is under one year of age or immunocompromised, follow manufacturer’s guidelines). Follow manufacturer’s guidelines on storage and disposal of the opened feed container.

Administering medication via a button extension

- Wash your hands before and after using the button.
- Draw up medication doses as prescribed and recommended volume of water for flushing.
- Flush and clamp the extension tube before attaching to the button to prevent air being pushed into the stomach
- Flush with recommended volume of water before and after administering medication, this will keep the tube clean and stop the tube from blocking.
- Medicines should be given separately and flushed with the recommended amount of water each time to prevent any possible interaction.
- It is important not to add the medicine to the feed at it can cause tube blockage.

Troubleshooting: if the button or extension becomes blocked

Try the following:

- Flush with warm water or fizzy water, using a 50ml syringe with a push/pause technique this creates turbulence to try and move the blockage along. Your CCN will demonstrate this during training.
- Massage the extension tubing to try and break up any debris.
- Replace the extension tube
- Replace the button

Changing a gastrostomy button

Gastrostomy buttons should be changed as frequently as recommended by the manufacturer, if your child requires a different size or if it becomes faulty.

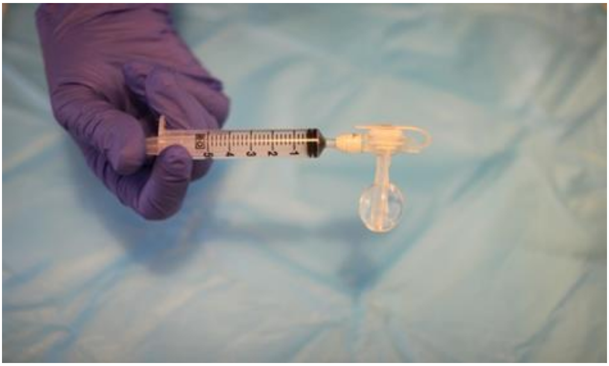
Your child's first button change at home will be done with your CCN who will support you to be able to complete this task independently, although it may take more than one button change for you to feel confident in carrying this out on your own.

Gather all required equipment:

- New Button
- 2 luer slip syringes size depending on size of button used.
- 1 x ampoule of sterile water
- 2 x 20ml Enteral syringe (purple)
- Extension
- pH strips
- Lubricating gel
- Introducer [if advised by your CCN]
- Gloves

Method

1. Wash your hands, and put on gloves
2. Establish a baseline pH prior to button change: attach an extension tube and using a 20ml syringe, withdraw some stomach contents [aspirate] and test with correct pH paper to check the pH level. This should be below 5. If it is above 5, then it is not safe to feed your child using this button until an aspirate of 5 or below is obtained. Contact your CCN team for advice
3. Check the patency of the new balloon by drawing up the correct amount of sterile water. Attach the syringe to the balloon valve and fill the balloon to check the whole balloon inflates and does not leak. Then withdraw the water and leave in the syringe for inflating the balloon once the button has been inserted.



4. If using an introducer: Remove the safety cover from the new button and attach the white clamp from the introducer and place into the white valve in the feeding port. Feed the blue introducer through the port to the tip of the button and close the white clamp.

5. Put lubricant on the tip of the button and leave in the packaging until ready to use. Put the leur slip syringes - one empty and one containing correct amount of water in the packaging. Place on a clean surface within easy reach plus an extension, 20ml enteral syringe and a pH strip and pH pot.
6. Deflate the current button by placing a leur slip syringe into the balloon valve, withdrawing the water from the balloon, then remove the old button from your child’s stoma.

7. Take the new lubricated button and insert it into the stoma using a corkscrew technique.

8. Once inserted, open the white clamp and remove the blue introducer. Remove the white clamp from the gastrostomy by pulling upwards.

9. Using the syringe with sterile water inflate the balloon via the balloon port.

10. Attach the extension set with the 20ml enteral syringe and withdraw some stomach contents. Check the pH - this should be 5.0 or less. If it is higher, contact your CCN further advice.
11. Remove the extension set and close button cover. Wash your hands and dry thoroughly.

Troubleshooting: what to do if the button falls out

You should keep an emergency gastrostomy pack which should contain the following:

- 1 x gastrostomy button in your child's current size
- 1 x leur slip syringe of the correct size for that button (either 5ml or 10ml)
- 1 x ampoule of sterile water
- 1 x introducer
- 1 x lubricant
- 1 x pH pot
- 1 x 20ml enteral syringe (purple)
- 1 x extension
- 1 x temporary gastrostomy tube ['G tube'] pack contents include a gastrostomy tube one size down from current Fr size, 5ml leur slip syringe and lubricant.
- 1 x small packet of gauze
- 1 x piece of white Hypafix tape
- 1 x packet of 'Enplugs' [optional].

These items should all be kept in a bag or a sealable plastic box and be carried with your child at all times.

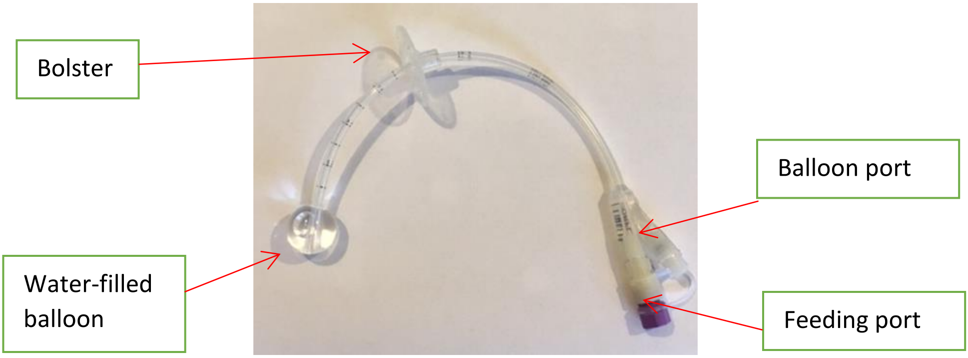
If the button falls out, cover the site with clean gauze or tissue as it may ooze. A new button or other device needs inserting within 1-2 hours to keep the tract open.

If the button falls out **before 6-8 weeks**, if possible follow the procedure below to place the smaller emergency G tube (or an 'Enplug' if supplied to you) into the tract.
DO NOT FEED through the catheter. Take your child to the nearest hospital with and Emergency Department. Remember to bring the old button and the emergency pack equipment with you

If the button falls out **after 6-8 weeks**, you or your CCN may be able to reinsert a new one following the procedure described on page 10; if this is not possible, you should try and insert the temporary G tube from the emergency pack which is a size smaller than the current size your child has fitted.

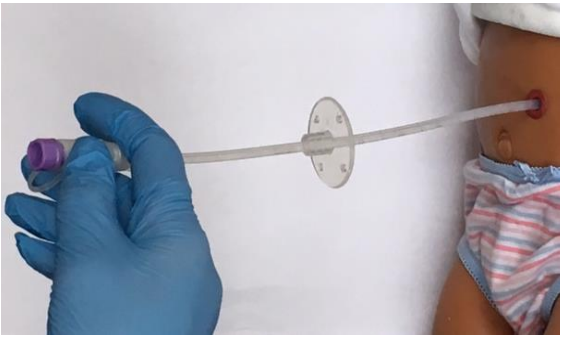
1. Gather all required equipment:
   - 1 x temporary G tube pack contents include a gastrostomy tube one size down from current Fr size, 5ml leur slip syringe and lubricant.
   - 1 x ampule of sterile water
   - 1 x piece of white (Hypafix tape)
2. Wash your hands and put on gloves
3. Check the patency of the new balloon by drawing up correct amount of sterile water. Attach to the balloon inflation port and fill the balloon to check the whole balloon inflates and does not leak. Then aspirate the water back out and leave in the syringe for post gastrostomy insertion.
4. Gather all required equipment:
   - 1 x temporary gastrostomy tube pack contents include a gastrostomy tube one size down from current fG size, 5ml leur slip syringe and lubricant.
   - 1 x ampule of sterile water
   - 1 x piece of white (Hypafix tape)

5. Wash your hands
6. Check the patency of the new balloon by drawing up correct amount of sterile water. Attach to the balloon inflation port and fill the balloon to check the whole balloon inflates and does not leak. Then withdraw the water back out and leave in the syringe for post gastrostomy insertion.



7. Lubricate the balloon end.
8. Push the balloon end into the stoma 3 cms past the current length of the low profile button. Inflate the balloon with the sterile water.

9. Pull the gastrostomy tube upwards until you feel resistance.



10. Push the retention bolster down so it sits flat against your child’s skin.

11. Attach two strips of tape to secure the bolster in place.

9. Using a 20ml enteral syringe withdraw some stomach contents [aspirate] to test the pH. If this is 5.0 or below it is safe to feed. You should then contact your CCN to arrange for a suitable low profile button to be inserted at a time they advise.

10. If you get a pH reading of 5.5 or above leave the tube in place, do not feed, and contact your local CCN team urgently for advice. If it is out of CCN working hours, and you remain unable to obtain a pH of 5 or below you will need to attend your local hospital for review and re-insertion of a button.

Managing your child's distress

Your child may find some of the procedures you have to carry out distressing or upsetting. Here are some strategies that may help you to manage in these situations.

Preparation

- **Equipment:** Have all the necessary equipment ready in advance, this can help reduce the build-up of anxiety. When equipment is not being used keep it out of sight.
- **Environment:** Wherever possible, avoid carrying out procedures your child finds distressing in areas that you want your child to think of as safe, such as their bedroom.
- **Explain:** If your child is able to understand, explain honestly what needs to be done, why it needs to be done and how it may feel. Avoid giving false reassurances like 'this won't hurt'. Dolls and story books about children undergoing similar procedures can be helpful when explaining procedures to younger children.

During the procedure

- **Distraction:** Distractions can be useful in reducing distress. You might want to have another person in the room to help with distraction or play some music as this can reduce distress. Younger children in particular may find the use of touch comforting and it can be a good distraction, e.g. holding their hand.
- **Control:** Giving your child a sense of control can reduce feelings of helplessness and uncertainty, e.g. you could get your child to give a signal when they feel ready to start by raising their hand, or let them choose which distraction, activity or incentive they would like to use.

- **Parental distress:** If you look distressed as the parent, this is likely to impact on your child's anxiety. Give yourself a few minutes to run through the procedure in your head and try to keep calm in front of your child.
- **Language:** Try to avoid using negatives such as 'don't move'. Saying 'this is the time to hold still' is much more supportive.
- **Praise:** Use phrases such as 'well done' and 'you're doing great' to help reassure your child.
- **Breathing**: Breathing techniques can help reduce your child's anxiety. Games like pretending to blow bubbles or pretending to blow the candles out on a cake can help your child to slow their breathing down.
- **Relaxing:** Your child may find relaxation techniques like pretending to be a rag doll helpful. Holding your child in a comfortable position can be helpful.

What if my child is too distressed to do the procedure?

If your child is so distressed that it is not possible to do the procedure, stay calm and give yourself and your child some time out. Praise your child for what they have managed to do and if you are able to, try to do the procedure later in the day – just because something hasn't worked on one occasion, don't rule it out for the future.

If you need further support, your CCN should be able to help you with the procedure. If you continue to experience problems, ask to be put in contact with a play therapist who can work with your child to reduce their anxiety.

Looking after yourself

Managing your own emotions

Providing medical care for your child can be emotionally draining for you as the parent. It is important for you to know that you are not alone. Many parents feel anxious and stressed particularly when they are learning to do a new procedure for their child.

Below is some advice from other parents:

- **Ask questions:** Ask lots of questions of your healthcare professionals and take your time learning. If you're not confident carrying out a procedure, ask for more opportunities to practice under supervision. Don't be afraid to ask for more support.
- **Share your feelings:** Explain how you're feeling when people ask. It is normal to feel anxious.
- **Look after yourself**: It does get easier and you will feel overwhelmed at times. Looking after yourself is just as important as looking after your child.
- **Trust your instincts:** You know your child better than anyone else. Never feel bad questioning the "experts".
- **Talk to other families:** It can be really helpful to talk to other parents in similar situations, this can be done in person or online such as through Facebook groups, although advice from these sources can be conflicting and should always be checked with your CCN.

  Here are some charities that can also provide helpful information and support:

  - PINNT
    https://pinnt.com/Home.aspx
  - TOFS
    https://www.tofs.org.uk/home.aspx
  - WellChild
    https://www.wellchild.org.uk/
  - ROSY
    http://www.rosy.org.uk/

Gastrostomy Button Competencies for parents/carers

Child’s name	
Date of birth	
Learner’s name	
Name of professional delivering training	

For each skill described in the table below, the Learner [L] and Trainer [T] must each initial the appropriate columns to record training given and competency achieved.

When all the skills are signed off, the Learner should sign the declaration at the end.

Skills:- appropriate knowledge and practical demonstration required	**Date shown/ discussed**		**Date practiced**		**Dates practiced**		**Learner is confident and safe to deliver care**	
	L	**T**	**L**	**T**	**L**	**T**	**L**	**Assessor**
Anatomy of the digestive system								
Equipment required and how to ensure supplies are available								
Safe use and storage of feeds								
Hand washing technique								
Correct positioning of child for feeding								
Weekly balloon water change								
Priming the extension with water								

Skills:- appropriate knowledge and demonstration required	Date shown/ discussed		Date practiced		Dates practiced		Learner is confident and safe to deliver care	
	L	T	L	T	L	T	L	Assessor
Use of the feeding pump								
Water flushing by syringe								
Giving a bolus feed by gravity and/or by a feeding pump								
Giving a continuous feed								
Safely administering medicines								
Daily assessment and care of the skin around the stoma site, with escalation process								

Learner’s declaration

I believe I am competent and am willing to take on these tasks.

If I feel I need additional support at any time, I will seek advice from the relevant Healthcare Professional:

Learner’s name and signature(s):

Date:

Notes

This booklet was originally produced by the Children's Community Nursing Team, Oxford Health NHS Foundation Trust.

It has been further developed as part of a partnership project led by the Oxford Academic Health Science Network Patient Safety Collaborative to improve the safety of children with complex medical needs who are technologically dependent and cared for by their families in the community.

In addition to the Oxford Health CCN team, parents of children with gastrostomies and healthcare professionals from the following Trusts and organisations have been involved in compiling and reviewing it:

Berkshire Healthcare NHS Foundation Trust

Buckinghamshire Healthcare NHS Trust

Central and North West London NHS Foundation Trust

Frimley Health NHS Foundation Trust

Great Western Hospitals NHS Foundation Trust

Milton Keynes University Hospital NHS Foundation Trust

Oxford University Hospitals NHS Foundation Trust

Royal Berkshire NHS Foundation Trust

Helen and Douglas House