

After your child's low-profile balloon gastrostomy device (button) Discharge Information

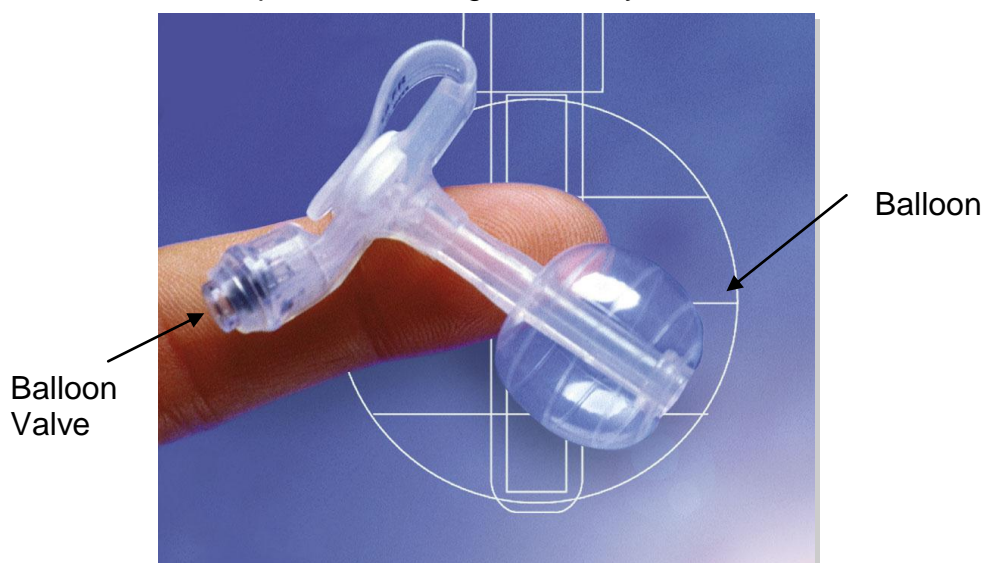
Children's services

This leaflet provides information and advice following the change of your child's initial gastrostomy tube to a low-profile balloon gastrostomy device. It is important that you are aware of what problems you may experience following discharge and when you should seek further advice. You will be shown what to do and told how to get the equipment you need.

What is a low-profile balloon gastrostomy device?

A low-profile balloon gastrostomy device is a tube that fits closely to the skin which will replace your child's first tube. This is often known as a 'button'. Unlike the first gastrostomy you will need to have an additional length of tubing that fits onto your child's button to use it. This is known as an extension tube.

Here is a picture of what a low-profile balloon gastrostomy device looks like.



How is a low-profile balloon gastrostomy inserted and how long will my child be in hospital?

Your child's first low-profile balloon gastrostomy will be inserted under a general anaesthetic when the doctor will take out the old gastrostomy tube. This will probably be done as a day case but the doctor will tell you this before your child comes into hospital to have it done. Before you go home you will learn how to care for the low-profile balloon gastrostomy device.

How is the low-profile balloon gastrostomy device kept in place?

The low-profile gastrostomy device lies flat on the surface of your child's stomach, and is kept in place by a balloon filled with water. There is a valve inside the gastrostomy to stop the stomach's contents leaking.

Changing of the low-profile balloon gastrostomy device

Your child's low-profile balloon gastrostomy device will need to be changed every 12 weeks or sooner if the balloon which holds it in place bursts. Your children's community nurse will do this. You can also be trained how to do this if you wish. Your children's community nurse will do this training.

After the low profile balloon gastrostomy tube is changed:



- If there is a leak of fluid around the gastrostomy tube
- If there is pain on feeding
- If there is fresh bleeding

Stop the feed immediately and contact your children's community nurse/ hospital

Contact details overleaf

Care of the low-profile balloon gastrostomy device

- To prevent infection, always wash your hands well, before and after touching the tube or after giving feeds and medicines.
- Turn the tube once a day in a full circle (**360 degrees**). This will stop the skin inside the tunnel from sticking to the tube. Your ward nurse will show you how to do this.
- The gastrostomy site should be cleaned with non-sterile water at least daily and checked to make sure the gastrostomy is not too loose or too tight at each feed.
- You will need to change the water in the balloon every week. Your ward nurse or children's community nurse will show you how to do this.
- Due to natural evaporation there may be less water removed than what was inserted but this should always be replaced with the recommended fill volume on the balloon valve. The water used should be cool boiled water or sterile water for babies under one year of age. This will be provided by your GP on prescription.

- Apply a dry dressing if there is oozing from the gastrostomy site. This will be provided by your GP or children's community nurse.
- If the site is inflamed, oozing blood or pus see your GP or children's community nurse.
- Your child can bath and shower as normal after having the low-profile balloon gastrostomy device inserted.
- Swimming is allowed straight away after the low-profile balloon gastrostomy device has been inserted.

Flushing and Feeding:

- The gastrostomy should only be used for prescribed feed, water or medication.
- Always attach an extension set on the low-profile balloon gastrostomy device to allow you to put anything down it. Your ward nurse will show you how to do this.
- Extension sets should be washed with warm water and soap after each use and left to air dry.
- Extension sets can be used for two weeks then should be replaced.
- Aspirate the tube before giving anything down it and test the pH of this on pH paper. Your ward nurse will show you how to do this.
- Make sure the prescribed amount of water (at least 10mls of water) is flushed through tube using a stop/start action after feed and medications.
- Medicines given should always be in liquid form (as prescribed).
- Tap water should be used unless otherwise indicated.
- If tap water is not used, you should use water that has been boiled and cooled to room temperature. This water should be stored in a lidded container/bottle in the fridge for no longer than 24 hours.
- Unopened bottles of feed may be stored in a cool dark place, away from direct sunlight. Once opened, bottles should be stored in the fridge.
- Any opened feed that has not been used within 24 hours should be thrown away.
- A feeding set cannot be used for longer than 24 hours.
- Keeping your child upright when feeding will help prevent acid coming up from your child's tummy which could cause pain and also reduce the risk of your child vomiting.
- Your child should not lie flat for 30 minutes after feeding has finished.
- If the tube blocks, water (cold or warm) can be used to try and unblock the tube. Use a push/pull action with a 60mls syringe to try and unblock the tube.
- A smaller gauge syringe can be used to try and unblock a tube – reasonable caution needs to be taken when applying pressure with a smaller gauge syringe to prevent any tube damage.
- If unable to unblock the gastrostomy tube contact your children's community nurse for advice on numbers provided.

NB It is recommended that 60mls syringes are used when flushing and aspirating the tube. Sterile water is not necessary.

Unable to get water out of the balloon

- Ensure that you have put the syringe on the balloon port correctly. If still unable to get any water out, contact your children's community nurse for advice.

Unable to get water into the balloon

- Ensure that you have put the syringe on the balloon port correctly. If still unable to get any water in, contact your children's community nurse for advice.

Low-profile balloon gastrostomy falls out

If this happens, the hole in your child's tummy will start to close within 1-2 hours.

- If possible, pour cooled boiled water over the low-profile balloon gastrostomy device, to clean it, before putting it into your child's tummy. Secure it in place with a dressing. This should only be done if the gastrostomy falls onto an area such as your child's stomach.
- If you are unable to replace the old low-profile balloon gastrostomy device or have not been shown how to replace it, insert a nasogastric tube into the hole, put a dressing over the hole and get help as soon as possible, because within 1-2 hours the hole will begin to close up. Contact your children's community nurse or attend your local paediatric emergency department.
- Only if you have been taught to do so, replace it with a new low-profile balloon gastrostomy device.

How to get supplies

Feeds/Delivery sets/Pump and other equipment:

- When your child leaves hospital you will be given the equipment you need to feed and your nurse will explain how you get equipment in the community. This will be from a home delivery company.
- If required, a feeding pump will be supplied by the hospital. You will be taught how to use the pump by your nurse on the ward.
- The GP should send the prescription for the special feed to the company, so that the feed can be delivered each month.
- If you choose to continue to collect feeds from a local chemist, then the other equipment can still be delivered by the company.
- If your child is on a bolus feed discuss with your local Community Services how this equipment will be ordered for your child.

Waste Disposal at Home

- Ask your children's community nurse how you get rid of used equipment and any feed that is left.

What to do if you have you any questions?

- If you have any questions these can be answered by the nurse on the ward. After you go home, these can be answered by your children's community nurse. It is sometimes a good idea to write them down.

Checklist for healthcare professionals and parents for minimising risk of overnight gastrostomy feeding:

- The child should sleep in the same room as the parents/carers **or** a suitable alarm or monitor should be fitted in child's room.
- The child needs to be positioned at a minimum of a 30 degree angle, preferably using a wedge or sleep system as recommended by an Occupational Therapist or Physiotherapist.
- Feeding regimes should be reviewed regularly as the child grows and develops, especially at the stage where movement during the night is likely to change.

- The feeding pump should be positioned at the top end of the cot or bed with the giving set threaded through the bars of the cot, not dangling over the top.

Contact Details

Monday to Friday between the hours of 9am to 5pm

Please contact your child's community nurse or telephone the ward that you were discharged from.

Contact number community nurse:

Contact number ward:

Outside the hours stated above:

Please telephone the ward that you were discharged from **or** please attend your local paediatric emergency department

Contact number:

The Patient Advice and Liaison Service (PALS) can offer on-the-spot advice and information about the NHS. You can contact them on freephone 0800 032 02 02 or email northoftynepals@nhct.nhs.uk

Useful websites

If you would like further information about health conditions and treatment options, you may wish to have a look at the NHS Choices website at www.nhs.uk. On this website there is an information prescription generator www.nhs.uk/ips which brings together a wealth of approved patient information from the NHS and charity partners which you may find helpful.

Patient Name (Print)

has had a low-profile balloon gastrostomy device inserted

Gastrostomy Manufacturer:

Gastrostomy gauge:

Gastrostomy length:

Date of Insertion:

See dietitian's plan for feeding regime

Discharge Nurse (signature).....

Discharge Nurse (print).....

Parent/carer (signature)

Parent/carer (print).....

Date.....

Information produced by Nurse Specialist (CYP Gastroenterology and Nutrition)
September 2014
Updated February 2015
For review February 2017