

Child's Name _____

Gastrostomy Device _____

French size _____ Length _____

Balloon Volume _____

Outreach Nurse _____
(Phone 364 0033)

CAAU (Phone 364 0428)

Dietitian _____

Paediatrician _____

CARING FOR YOUR CHILD'S GASTROSTOMY

Parent / Caregiver's Guide

Child Health Services



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Introduction

A gastrostomy is an opening in the skin for a tube to go through the stomach wall into the stomach and is used for children who are unable to eat or drink enough to grow properly.

Deciding to have a gastrostomy is often very difficult for parents. You will have talked about this with a number of health professionals, e.g.. paediatricians, surgeons, dietitians, nurses and speech language therapists. However, the procedure to insert the tube is relatively simple.

The purpose of this booklet is to give you information to help care for the gastrostomy. You will learn how to care for your child's gastrostomy with support and guidance from ward staff and your Outreach Nurse. You will also receive information from the dietitian about your child's feeding plan, including oral feeding.

We hope that you will find this information useful. Remember there is always someone available for advice if you need it. There is a list of names at the back of this booklet.

As you read this booklet you may come across some unfamiliar words or terms.

Below is a list of terms and their meaning.

Aspiration	- accidental inhalation of fluid into the windpipe and/or lungs
Bolus Feeds	- specific volumes of formula at various times during the day
Constipation	- difficulty in passing bowel motion or an incomplete or infrequent passage of hard motion
Continuous feeds	- small amounts of formula fed by a pump over a number of hours
Diarrhoea	- frequent loose watery bowel motions
Dilate	- to enlarge or make wider
Gastric juices	- stomach fluid
Gastrostomy	- a surgical opening (stoma) through the skin into the stomach
G-tube	- gastrostomy tube

Important Information

As well as this booklet, you should have:

- Parent's/Caregiver's Guide to Tube Feeding
- Home Tube Feeding Guidelines—provided by your Dietitian
- Specific product information about the gastrostomy device your child has.

Gastrostomy button	- a skin level g-tube
Gastro-oesophageal reflux	- a backflow of stomach contents into the oesophagus
Granulation tissue	- any soft, pink, fleshy projections which form during the healing process. Overgrowth results in flesh growing above the skin
Migration	- where the g-tube moves further into the stomach or into the small bowel
Oesophagus	- the passage in the throat through which food passes from the mouth to the stomach
Serous ooze	- clear, watery fluid from a wound
Stoma	- surgical opening through which a feeding tube may enter the body
Venting	- to allow excess air to be released from the stomach = burping.

Gastrostomy Tubes

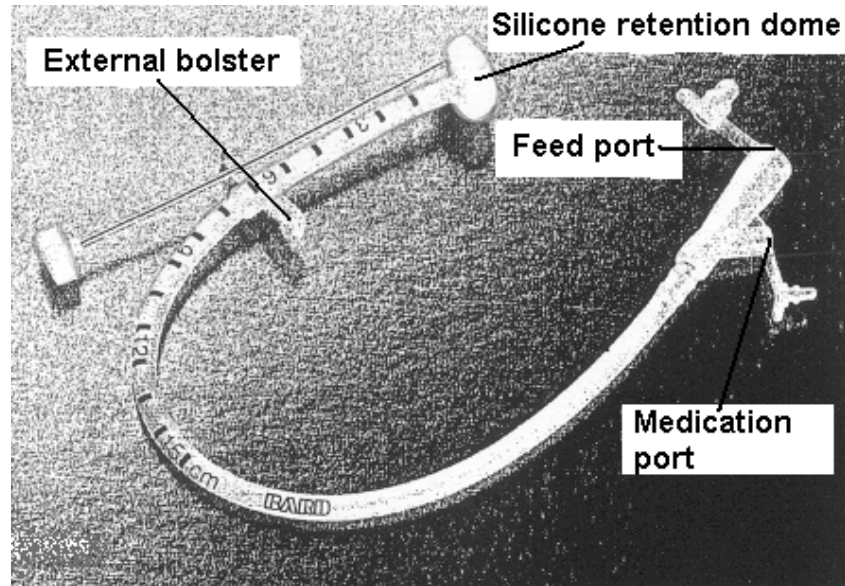
There are different types of gastrostomy tube. Your doctor and nurse will discuss with you which tube is best suited to your child's needs.

Gastrostomy Procedure

Under a general anaesthetic a small cut is made into the abdomen and the tube placed in the stomach with the aid of a flexible endoscope. The tube is held in the stomach, either by a soft silicone retention dome (*Figure 1*) or a silicone balloon (*Figure 2*). An external bolster at skin level holds the tube in position. The silicone tube may stay in place for many months. If necessary, this tube is removed under an anaesthetic and replaced with an alternative tube or button.

Some children who have severe gastro-oesophageal reflux will have a fundoplication done at the same time. This involves wrapping the top of the stomach around the oesophagus to tighten the opening from the oesophagus into the stomach. This prevents food and fluid flowing back up the oesophagus.

Figure 1



Tube Position

The length of tube outside the body should be measured and noted. You may want to mark the tube with a pen where it sits just above the external bolster. The mark will wear off over time so you will need to re-mark the tube. This measurement is a guide to whether the tube is sliding in or out of the stomach. It is important to know before feeding that the tube is in the correct place in the stomach. Check the measurement before each feed. You can note the measurement on the information page in the back of this booklet.

Replacement Tubes

Depending on your child's needs, the initial tube can be replaced with the same tube, or with:

1) A "Balloon Replacement Tube" (Figure 2)

This is a silicone tube which is held in the stomach by a balloon and an adjustable external bolster at skin level.

Balloon type tubes/buttons may fall out if the balloon bursts. It is best to immediately reinsert the tube/button into the stoma and tape it in place. This will keep the gastrostomy open until the tube/button can be replaced. Make sure that any other caregivers are taught about this.

If you are not able to replace the old tube/button, cover the stoma with a clean cloth to prevent leakage and tape in place. A new tube needs to be inserted ASAP (within 1-2 hours is the ideal) to prevent the tract from closing.

You will need to come to CAAU for replacement of the tube. Please phone first – 364 0428.

You can learn to replace buttons yourself at home. Talk to your Outreach Nurse or the CAAU staff about this.

Diarrhoea

There are several causes of diarrhoea:

- Feed given too rapidly.
- Formula that is expired or incorrectly stored.
- A viral infection.

Prevention:

- Tube feed at the prescribed rate or slow the rate of the feed.
- Keep all equipment clean.
- Store formula correctly as per dietitian's advice.
- Do not mix medications with formula.

If diarrhoea persists, contact your Outreach Nurse or GP. Persistent diarrhoea may cause dehydration.

Constipation

If you find your child is having ongoing problems with constipation, contact your dietitian. It may be the result of the type of formula your child is on, their activity level or changes in their diet and feeding regime.

If your child starts choking or coughing during a feed, or if breathing becomes difficult, stop the feed and either sit them upright or lie them on their side.

Inability to breathe or turning blue is an emergency. Call for help immediately. **Ring 111 for an ambulance!**

Abdominal distension/cramps

This can be the result of:

- Formula too cold – ensure it is given at room temperature.
- Feed given too quickly – slow the rate of the feed.
- Constipation – discuss with your GP.
- Gas bloat – try venting the tube prior to feeding to release excess gas/wind.

Blocked tube/button

Prevention is the best practice. Ensure that you flush the button well with each feed and all medication. If the gastrostomy is not being used for feeding it still needs to be flushed every day.

If the the tube is blocked:

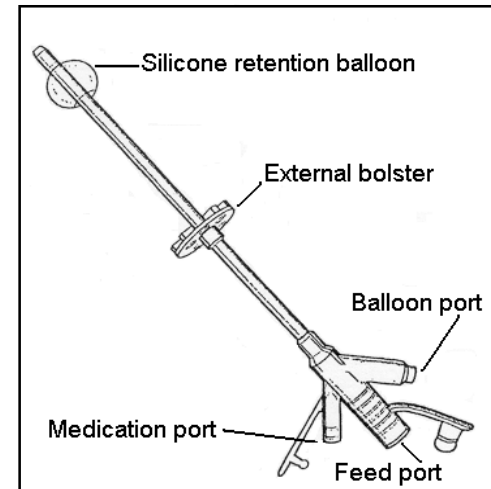
- Attach a syringe to the feeding tube.
- Gently pull back on the plunger.
- If unable to withdraw stomach contents, try flushing the tube with warm water or “fizzy” drink (eg. soda water or diet coke). You can also try pineapple juice or cranberry juice.
- If unsuccessful, contact your Outreach Nurse or CAAU. If the tube cannot be unblocked, it will need to be replaced.

Accidental Removal

Non-balloon tubes will not fall out, but in a few cases they have been pulled out accidentally. If this happens you will need to bring your child to CAAU as soon as possible (within 1-2 hours).

DO NOT ATTEMPT TO RE-INSERT THE TUBE.

Figure 2



- 2) Gastrostomy button. This is a skin level device. There is an anti-reflux valve to prevent loss of stomach contents. An extension tube is used for feeds.

The most common type of button used at Christchurch Hospital is the MIC-Key Button. It is held in place by a fluid filled balloon (*Figure 3*). There are two extension sets:

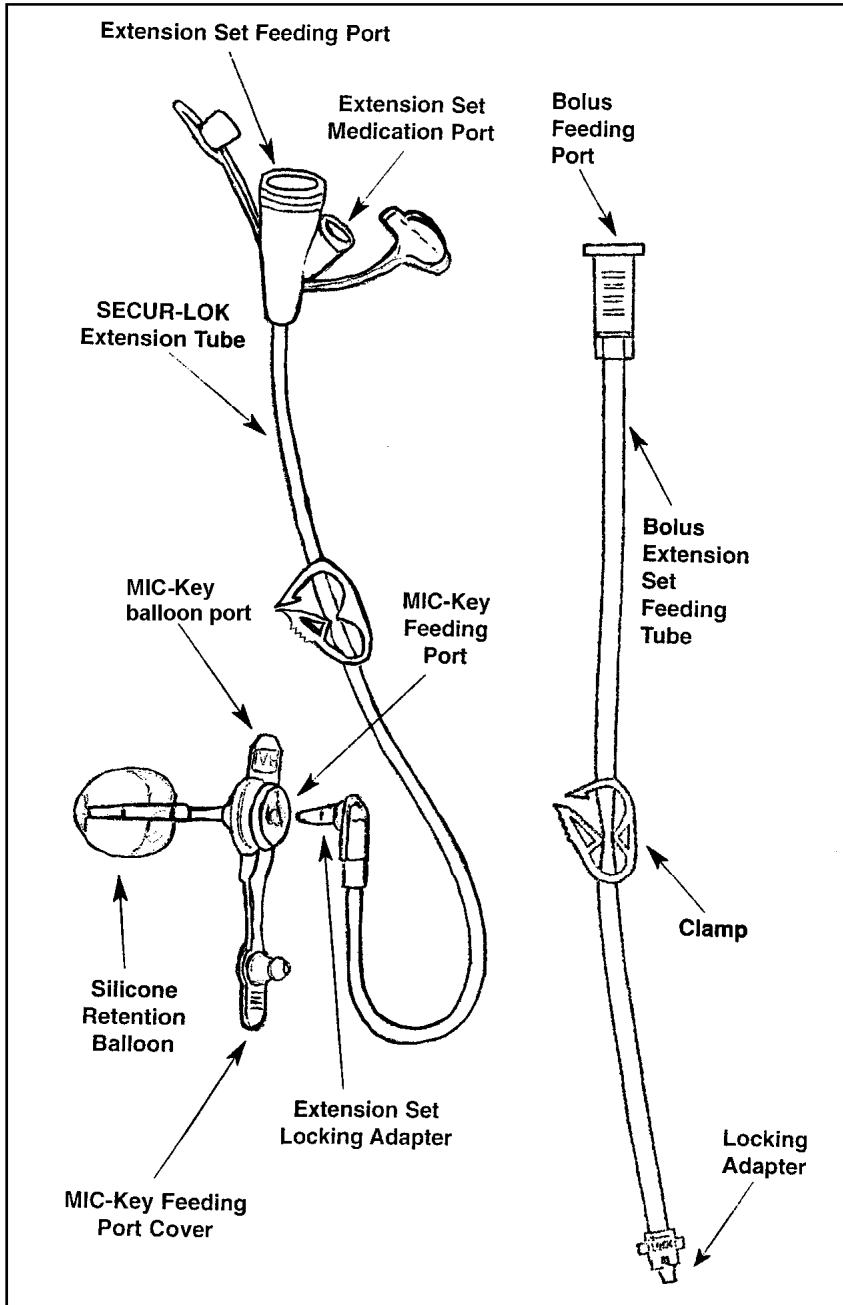
- Continuous extension set for pump feeds
- Bolus extension set used for bolus feeds and venting of the button.

An alternative button sometimes used is the BARD Button. It is held in place by a retention dome must be replaced by a doctor under anaesthetic. There are three extension sets:

- 1) Bolus tubing set
- 2) Continuous tubing set
- 3) Decompression tube which is used for venting the stomach

If a non-balloon button or tube accidentally falls out, do not try to replace it - bring your child to the hospital.

Figure 3—MIC-Key Button



Infection around Stoma

Signs of infection may include one or more of the following:

- Skin is fiery red, hot and swollen.
- There is a thick, cloudy discharge – yellowish/green.
- Skin hurts constantly.
- Possible fever.
- Bad smell from around the stoma.

If this occurs, you should inform your GP or Outreach Nurse. Swabs may need to be taken to find the cause of the infection. Your doctor may prescribe a course of oral antibiotics or antibiotic/antifungal cream to be applied to the area.

While the infection is present, clean the stoma site with saline solution, 3-4 times per day.

Hypergranulation tissue

This is sometimes called ‘proud flesh’ and is caused by the body’s normal healing process. It may be worse after an infection around the stoma and after replacement of the tube/button.

Good skin care will help control hypergranulation tissue however, if necessary it can be easily treated. The treatment of choice at Christchurch Hospital is pimafucort cream, four times a day for five days. This must be prescribed by a doctor. This treatment will usually see the hypergranulation tissue settle down. It can be repeated if necessary, but your Outreach Nurse or GP will advise you on this.

If the hypergranulation is excessive and does not respond to pimafucort cream, the tissue may need to be treated with silver nitrate sticks by your GP or Outreach Nurse.

Check that the tube or button fits the stoma correctly. Hypergranulation can occur if the tube or button is loose.

Aspiration

Aspirating or accidentally inhaling fluid into the lungs is like swallowing something “down the wrong pipe”. It may cause pneumonia.

Some causes of leakage which you can check yourself: If you are unsure of any of these interventions, please check with your Outreach Nurse.

- 1) Balloon partially deflated – check the volume of the balloon by inserting a 5mL luer slip syringe into the balloon valve. Withdraw the fluid and note the volume. Reinflate to 5mL. **Caution:** Take care when deflating the balloon. The button or tube may easily be pulled out.
- 2) External bolster not sitting against the skin. Check by gently pulling on the tube and adjusting the bolster to sit 3mm above the skin (thickness of \$2 coin).
- 3) Migration of tube – internal bumper no longer creates a seal – check external length of tube and reposition if necessary (see page 4).
- 4) Hypergranulation tissue - apply treatment recommended by your Outreach Nurse or GP.
- 5) Excessive gas/wind – vent (burp) gastrostomy before and after feed to remove excess gas.
- 6) Constipation may slow the passage of formula through the bowel. If you think your child is constipated, talk to your GP about management.
- 7) Feeds given at too cold a temperature may result in stomach cramps. Make sure that feeds and all fluids including water flushes are given at room temperature. Cold feeds are very uncomfortable.

If leakage is a problem, discuss it with your Outreach Nurse or GP. You may be advised to use a barrier cream to protect the skin. Discontinue dressing and cream when the leakage has stopped.

Caring for the Gastrostomy

After the operation to make the gastrostomy, your child will stay in hospital for 2-3 days or until well enough for discharge home. The cut where the tube is inserted may cause mild pain for up to two weeks. Use paracetamol as prescribed by the doctor to treat this pain. If pain is severe, contact the Children's Acute Assessment Unit, 364 0428. The wound should heal in 5-7 days.

Caring for the Stoma Site and Skin

Caring for the stoma site and surrounding skin is very important. Problems may occur because the stoma is an artificial opening and the tube is a "foreign object". The body may try to "fill in" the stoma by growing granulation tissue.

If your child has a gastrostomy tube, it is important that it is secured well to help stop the tube moving out of position. Make sure the external bolster is sitting approximately 3mm above the skin (the thickness of a \$2 coin), loop the tube loosely and tape it to the tummy. Don't pull the tube or try to tape it flat across the tummy as this may stretch the stoma. Use suitable clothing to prevent your child pulling on the tube (see Tube Position on page 3).

If both the tube and external bolster are dry, friction prevents the bolster sliding. The skin around the stoma needs to be kept clean and dry to prevent skin irritation.

When the stoma is first made, it may bleed slightly and have some watery discharge until the wound has healed. Until the stoma is healed, it should be cleaned **daily** or more often if necessary with saline, your nurse will show you how to do this before you go home. If there is a lot of ooze, the stoma can be dressed. Your nurse will discuss the most suitable type of dressing with you. It is important to keep the skin as clean and dry as possible, so do not use a dressing unless absolutely necessary as they tend to keep the skin moist. Exposing the site to the air is the best way to heal the skin and keep it in good condition.

Daily Care:

Once the stoma has healed, wash the site with warm water and a mild soap daily. This is best done in the bath or the shower. Some parents find that a few drops of lavender oil added to the bath water helps the skin. Ensure that the skin around the stoma is dried well, pat dry but do not rub.

Buttons and tubes need to be turned daily to help the stoma form properly. It also stops pressure on the skin from the external bolster and stops the tube or button sticking to the stomach lining.

Feeding Methods

Your child's feeding plan will depend on their medical condition and their ability to tolerate fluid volumes. The decision on feeding plans will be made by you and the Dietitian or Enteral Feeding Team. The aim is to try and fit feeding times into your lifestyle.

There are a variety of commercially prepared formulas available to meet your child's individual needs. Other food should not be put down the tube as it can block the tube.

The feeding plan will change over time depending on your child's growth and will be reviewed by the dietitian or at the Enteral Feeding Clinic.

Keep mealtimes as normal as possible. If recommended by the Dietitian or Enteral Feeding Team give your baby, a pacifier/dummy, or older children something to taste, so they associate food and/or sucking with the feeling of hunger being satisfied.

- **Continuous Feed (Pump Feed)**

This method is used when there are problems managing a large volume of formula at one time or if overnight feeding is required.

- **Bolus Feed (Gravity Feed)**

Used when children are able to tolerate larger volumes of formula. The formula is delivered by gravity over 15-30 minutes using a catheter tip syringe and tube.

If your child is having continuous feeds, stop the feed, flush with water before and after giving medication through the medication port and then restart the feed.

Never put syringes directly into the button as it may affect the anti-reflux valve.

Troubleshooting

When the feed is not tolerated

This may be due to illness or the stomach being slow to empty. Your child's feeding regime needs to be reviewed if there is:

- Discomfort or bloating during or after a feed.
- Nausea or vomiting during or after a feed.
- Diarrhoea or constipation.

If your child has severe diarrhoea and/or vomiting because of an illness, stop the feed. Discuss with your nurse or doctor. Your child may require rehydration solution instead of formula. Contact your doctor again, if these symptoms last for longer than 24 hours.

Leaking around tube or button

A small amount of clear fluid will not need treatment. However, if there is a significant amount of fluid or formula leaking around the tube or if the skin becomes red, please contact:

☎ 364 0033 – Children's Outreach Nurse (CORN)
Monday to Friday, 8.00 am – 4.30 pm.
(Except for Public Holidays)

☎ 364 0428 – Children's Acute Assessment Unit for advice outside CORN hours.

☎ Your own GP

☎ 364 0730 – Paediatric Outpatients Department
Monday to Friday, 8.00 am – 4.30 pm

Avoiding Dehydration

In warm weather, or if your child has a fever, additional water may be necessary to prevent dehydration. Your dietitian will give you guidelines about this.

Venting (Burping or decompression)

This allows air to escape from the stomach. Not all children will need this done but it is important for children who have had a fundoplication and may not be able to burp easily. A good time to vent the tube is before a feed or between feeds.

Mouth Care

Your child should continue to eat and drink as recommended by your doctor and dietitian.

Mouth care is very important for a child who is not eating or drinking. Clean all surfaces of teeth and gums at least twice a day with a toothbrush and toothpaste. If your child is not able to tolerate this, talk with your nurse.

Use a moisturising lip cream to moisten lips and prevent cracking.

Giving medication

If possible, give medications by mouth. If necessary, the gastrostomy may be used for medications.

Liquid medications are the best and easiest to give via the gastrostomy. If the medicine is very thick it may need to be diluted with a small amount of water. **Always flush the tube with water before and after giving medications.**

When a medication is only available in tablet form, it will need to be crushed to a fine powder and mixed with water. **Check with the pharmacist to make sure it may be crushed.** Do not mix medication with formula.

Many children will use a combination of continuous and bolus feeds and may feed orally as well.

Continuous Feeds:

- 1) Wash your hands well with soap and water.
- 2) Gather all equipment.
 - Formula
 - Feeding bottle
 - Feed-pump tubing set
 - Feeding pump
 - Pump pole
 - 10mL Syringe of water
 - Extension tubing for G-buttons
- 3) Add the prescribed amount of formula to the feed bottle following the dietitian's instructions.
- 4) Attach screw top of pump tubing set to bottle. Attach button extension set.
- 5) Prime the pump set with formula following the instructions for the pump. When fully primed, clamp the tube.
- 6) If necessary, vent (burp) the stomach by removing the cap from the end of the gastrostomy tube or by attaching venting tube to the button to allow excess air to escape.
- 7) Check position of tube (see page 4) and flush with recommended volume of water.
- 8) Connect the pump set to the gastrostomy tube or button. To attach extension set to MIC-Key button, match up the black line on the extension set with the line on the button. Insert the extension set and rotate it clockwise until you feel a slight resistance to lock into place.
- 9) Set the desired rate on the pump, unclamp the tubing and select RUN to commence feeding.



- 10) The desired position during feeding is (a) sitting, (b) head elevated if lying, (c) standing. These positions help the stomach to empty. If possible, maintain one of these positions for 20 minutes after the feed is completed. Where possible, hold your baby in your arms as for a breast or bottle feed as this provides important physical contact for you and your baby.
- 11) At the completion of feeding, flush the tube or button with the recommended volume of water to prevent tube blockage and close feed port.
- 12) Disconnect extension set from button, rotate counter-clockwise until black lines match up and remove. Close button cap.
- 13) Wash the feeding equipment well in warm soapy water. Rinse well and dry. Soak the equipment used for babies in Milton or Presept solution. Equipment for older children should be rinsed after use and stored in a plastic bag in the refrigerator between feeds. Replace with a new set every 24 hours. Syringes can be cleaned in the dishwasher.

Bolus Feeds

- 1) Wash your hands well with warm soapy water.
- 2) Gather all equipment.
 - Formula – at room temperature
 - 60mL catheter tip syringe
 - Button extension tubing if required
 - Syringe with water for flushes
- 3) The best position for feeding is sitting as this helps the stomach empty. Alternatively raise the head of the bed/cot. This will help prevent aspiration if reflux occurs. Maintain this position for 20 minutes after the feed is completed. Where possible, hold your baby in your arms as for a breast or bottle feed as this provides important physical contact for you and your baby.



- 4) Vent the stomach as necessary (see page 11).
- 5) Attach the syringe to the gastrostomy tube or for a gastrostomy button use the bolus feeding tube to link the syringe to the button. **Never put a syringe directly into a button.**
- 6) Fill the syringe with formula and slowly allow formula to flow into the stomach. You can control the speed that the feed is given by raising or lowering the syringe. For babies, the feed should take as long as a breast or bottle feed.
- 7) Refill the syringe as required when 5-10mL of formula remains in the syringe. This will prevent air from entering the stomach.
- 8) When the feed is completed, flush with the recommended volume of water and close feed port.
- 9) After feeding wash the extension set and syringes in warm soapy water, rinse well and dry. Equipment for infants must be soaked in Milton or Presept solution between feeds as for babies bottles or teats.

Before discharge from hospital, your dietitian will give you a pamphlet called “Home Tube Feeding Guidelines”. This will give you information on your child’s feeding plan including care of equipment and formula and the volume of water needed for flushes.