

# FACTSHEET

This fact sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: [www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form](http://www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/feedback-form).

## Your child's new gastrostomy button

### What is a gastrostomy?

A gastrostomy is an opening from the skin directly into the stomach. The opening (known as a stoma) is created by making a small cut during an operation. This opening is made on the left side of the abdomen between the ribs and the belly button. A small device called a gastrostomy button is placed in the hole to keep it open. The button and connecting tubes carry formula, fluid and medicine directly to your child's stomach.

### Who needs a gastrostomy button?

Children who are unable to eat or drink enough for their growth and/or a child who has trouble swallowing safely (dysphagia) may need a gastrostomy. The gastrostomy may be temporary or permanent.

### What to expect in hospital after the operation?

The new button will be covered with a dressing for a day or two. There may be a small tube attached to a bag for the 1<sup>st</sup> day. When the nurse removes the dressing you may notice a stitch, this is to hold the button in place. If your child has a stitch, your local doctor can take the stitch out a week after the operation.

Your child's stomach will be sore for a couple of days. The doctor will prescribe medicine for pain.

The nurse will show you how to connect the right tubes to your child's new button to give formula and medicine.

The gastrostomy specialist nurse will visit you during your stay to help you with the button and answer your questions.

When your child's surgeon is happy, your child's gastrostomy will be used to deliver small volumes of clear fluids or formula by a pump. A plan will be developed by the dietitian to slowly increase the amount of fluids and formula over a few days.

A dietitian will advise you which formula is best for your child and your options for buying this.

### How long will my child stay in hospital?

Your child will usually be in hospital for 3-5 days. You will be shown how to care for your child's button. The doctors and nurses will let you know when you can go home.

### EnableNSW

During your stay in hospital, staff will give you an application form and other paperwork to help you register your child with a NSW Health Service called EnableNSW. This form can also be used to request a budget for gastrostomy equipment if you have a National Disability Investment Scheme (NDIS) plan via your NDIS planner.

This Government service will provide you with an ongoing supply of gastrostomy buttons and equipment for feeding. If your child requires a pump for their gastrostomy feeding, the hospital staff will let you know how many feeding sets EnableNSW will give you each year or how many you can request under your NDIS plan.

## How do I care for my child's gastrostomy button at home?

- Keep the skin around the button clean and dry. If the skin is red and irritated it may need to be cleaned more often. If any leaking fluid is causing the skin to look red or sore, use a barrier cream to protect the skin around the button.
- Turn the button 360 degrees every day once the stitch is removed. If there is no stitch check with your health professional as to when it is safe to turn the button.
- Check the water level in the balloon every 1-4 weeks according to your health professional's recommendation. The amount of water to be placed in the balloon will also be recommended by your health professional.

### What to do if your child's new gastrostomy button comes out?

If your child's button comes out and you can't put it back in call your health professional immediately.

If you are unable to contact your health professional, please present to your nearest emergency department for assistance.

Ideally this should happen within 90 minutes, as a new gastrostomy opening (stoma) will start to close within a few hours.

Please seek advice before using the reinserted button.

## Call your doctor or clinical nurse consultant if...

- Your child's button appears loose. It is recommended that you first check the water level in the balloon if you have been shown how to do this.
- The skin around the button is red and sore.
- The skin around the gastrostomy hole becomes raised or starts to bleed (granulation tissue).

### Remember:

- The gastrostomy may be temporary or permanent.
- Having a gastrostomy requires surgery and your child will be in hospital for a few days.
- Your child's gastrostomy requires daily care.
- EnableNSW will supply your child with an annual allocation of gastrostomy button and feeding equipment for a minimal cost. For further information and supplies please call EnableNSW on 1800 ENABLE.