

# Gastrojejunostomy (transgastric jejunal) feeding device care: information for children and young people and their families

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A gastrostomy is a surgical opening through the skin of the abdomen to the stomach. A gastrojejunostomy device is inserted through this opening to the stomach and then on to the first part of the small intestine (jejunum). This means that liquid feed can be delivered directly into the small intestine bypassing the mouth, throat and stomach. This information sheet from Great Ormond Street Hospital (GOSH) describes the procedure to insert a gastrojejunostomy feeding device and explains the care it will need afterwards.

## Terms used in this information sheet

- Gastrojejunostomy (GJ) devices are also known as transgastric (through the stomach) jejunal feeding devices.
- The GJ feeding devices used at GOSH are sometimes known as PEG-J devices and low-profile balloon button GJ devices.

## Key points

- A gastrojejunostomy (GJ) feeding device is inserted into an opening through the skin to the stomach – this will already be in place if a gastrostomy feeding device has been used before.
- The GJ device delivers feed directly into the first part of the digestive system (jejunum).
- The feed solution contains all the nutrients needed to grow and develop. Medicines can also be given using the feeding device.
- PEG-J devices should be replaced every 18 months and balloon button devices every six months.

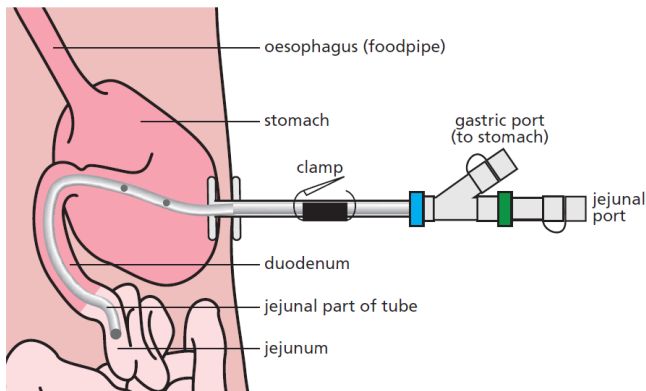
## How does a gastrojejunostomy feeding device work?

A gastrojejunostomy (GJ) feeding device is a combination of a gastrostomy device (placed into the stomach) and a jejunostomy device (placed into the jejunum, the first part of the intestines). The feeding device allows feed to be given directly into the jejunum, bypassing the mouth, throat and stomach. It also allows access to the stomach to draw off excess air, test the contents of the stomach, provide drainage, or possibly give medications directly into the stomach.

All GJ devices have two 'ports' – one ends in the jejunum and the other in the stomach. These are clearly labelled, so you will know which is which.



The nurses will show you how to access each 'port'. The advantage of having two ports is that different fluids and medicines can be given into the stomach and/or the jejunum as directed by the dietitian or pharmacist.



## Why might GJ feeding be suggested?

GJ feeding is rarely the first method of 'enteral feeding' (feeding directly into the gastrointestinal tract) used. Nasogastric (NG) and gastrostomy feeding are usually tried first. In some cases, you may need to be started on GJ feeding without trying gastrostomy feeding first, your lead team will discuss this with you if required.

A GJ device is usually suggested after gastrostomy feeding has been unsuccessful. Some people cannot tolerate feeding directly into the stomach, so a GJ device can be helpful as it bypasses the stomach. A GJ device can be helpful for people with gastric motility problems, where food does not pass through the stomach to the intestines as it should.

Children or young people with gastro-oesophageal reflux may benefit from GJ feeding as the feed is delivered directly to the jejunum rather than the stomach. This stops stomach contents travelling back (reflux) up the oesophagus (food pipe), causing pain and potentially chest infection if the liquid is inhaled into the lungs (aspiration).

The clinical team will explain why GJ feeding might be the most suitable option, and you will also be able to discuss the best feeding device for your family's needs.

## How is a GJ feeding device inserted?

Insertion of a GJ feeding device may need to be done under a general anaesthetic, depending on the type and size of feeding device a child already has in place.

### Pre-admission assessment

A pre-admission assessment before the operation either immediately after an outpatient appointment or on another day will be needed. The aim of this appointment is to check that you are well enough for the procedure, and give you an opportunity to ask questions. This visit may include taking blood samples, photographs and swabs. You may need to visit the Anaesthetic Pre-assessment Clinic as well for a check-up for the anaesthetic.

### The day before the operation

You should have a bath or shower and hair wash the night before the operation. You should remove any makeup, jewellery or nail varnish.

We will contact you to explain fasting times. You must not have anything to eat or drink after the time given in the telephone call. This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk of stomach contents entering the lungs during and after the procedure.

It is equally important to keep having food and drink until those times to keep you well-hydrated, so you may need to wake during the night. If you do not follow these instructions exactly, the operation may be delayed or even cancelled.

If the gastrostomy is being formed radiologically, you will need a drink of barium the evening before the procedure. This usually comes as a milkshake or can be given down an NG tube – it travels through the digestive system to the large intestine



so it can be seen clearly during the insertion procedure.

We will give you the barium during the pre-admission assessment, or you can collect it from the Radiology department.

We will also tell you what time to arrive on the day of the operation. Please leave plenty of time for travelling and come to the unit promptly as the surgeon and anaesthetist have to visit you before they start the operating list.

### On operation day

Before going to the operating theatre, you will meet the doctor who will explain the operation in detail, discuss any worries you may have and ask you or your child to give permission for the operation by signing a consent form.

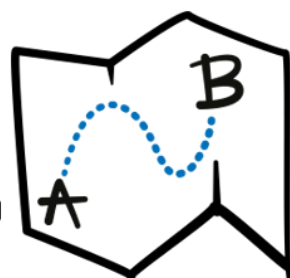
The person bringing you to the operation should have 'Parental Responsibility' for you. Parental Responsibility refers to the individual who has legal rights, responsibilities, duties, power and authority to make decisions for a child. If the person bringing you does not have Parental Responsibility, we may have to cancel the operation.

As x-rays are used to position the GJ device in the stomach and jejunum, we have to carry out a pregnancy test on any girls aged 12 or older beforehand.

An anaesthetist will also see you to explain the anaesthetic in more detail. If you have any medical problems, like allergies, please tell the doctors.

When the operating theatre is ready, you will be collected and taken there by a member of staff. You will be able to stay together until they are under general anaesthetic, and then parents will be taken to the post-operative ward. They can wait elsewhere in the hospital, but please make sure we know how to contact them.

### What does the operation involve?



The doctors will have explained which type of GJ device they are planning to use when they are talking to you before the operation.

- **PEG-J device** – While under anaesthetic, the first step is to place a new gastrostomy tube or to change their existing gastrostomy tube to one of a larger size.

Once the larger gastrostomy tube is in place, a thinner jejunal tube is threaded through it from the outside. The doctors use x-rays to guide the jejunal tube through the stomach and into the small bowel, leaving the tip in the jejunum.

They will check the tube's final position with contrast to make sure it is safe to use. The inner jejunal tube and the outer gastrostomy tube lock together within the enteral port at the end of the device.



- **Balloon GJ device** – Inserting a balloon button GJ device can usually be done while awake. However, if a tube device is already in place, or if the tract in the skin needs to be stretched to accommodate the bigger GJ device, your doctors may suggest having a general anaesthetic to take out the old device and insert the new one.

The first stage is to remove the existing device and replace it with a balloon button gastrostomy device if necessary, stretching the stoma. The balloon GJ device is threaded through the existing opening in the skin and the tube positioned into the jejunum using x-rays to guide the tube into position.

Contrast liquid is injected into this tube so that the final position can be checked using an x-ray. When the correct position of the button is confirmed, the balloon holding the device in place will be inflated using a small amount of water (three to five millilitres).



beforehand reduces this risk. If you have not had barium the night before the procedure, the consultant may cancel the operation as the risk of damaging the large intestine may be too great.

It is common to develop crampy stomach pains during the first few hours after the procedure. This is caused by the stomach being inflated with air during the procedure. These crampy pains usually pass in a few hours without treatment.

### **Longer-term risks of having a GJ feeding device**

All GJ devices can irritate the skin around the device, but this can usually be managed on the ward and at outpatient visits. For the first few days after insertion, there is a risk of problems developing – we will explain what to look out for and what to do if they happen later in this booklet.

At any time after the new device has been placed, the jejunal part of the device can become dislodged back into the stomach. Signs that this may have happened is an increase in reflux symptoms or jejunal feed appearing when a sample is drawn from the gastric (stomach) port.

This part of the feeding device can be replaced in a short procedure without needing a general anaesthetic. If a low profile balloon button GJ device curls back into the stomach, the entire device needs to be replaced.

### **What happens afterwards?**

You will return to the ward after the procedure so you can recover from the anaesthetic.

### **Starting to use the GJ feeding device**

When feeds and fluids can be introduced will depend on the type of device that has been inserted and whether you previously had a gastrostomy:

- If you had a low profile balloon button GJ device inserted, you will usually be able to

### **Are there any risks with insertion?**

If there is a gastrostomy tube in place already, they will have a well-developed tract through the skin to the stomach, so converting the gastrostomy to a GJ tube device carries few risks.

There is always a small risk that it might be difficult to remove the existing gastrostomy tube if it has been in a while and has become well-attached to the inner stomach wall. Trying to remove the tube might damage the stomach wall, so if the doctors are not happy to continue trying, they might leave the gastrostomy tube in place and decide to remove it using another technique on another day.

If the existing device is a gastrostomy button, which is being changed to a low profile balloon GJ device, then this can be done awake, and the risks involved in this procedure are low. They will feel the doctor or nurse changing the tube, and may not like having to stay still, but this procedure is not usually painful.

If you have not had a gastrostomy before, there is a very small chance that the large intestine could be damaged during the insertion, but using barium



start using it for fluids and feeds straightaway

- If you have previously had a gastrostomy device, which has been converted to a GJ feeding device, you will usually be able to start using it for fluids and feeds straightaway but following a new feeding plan.
- If you have not had a gastrostomy previously, you may have to wait several hours to have any fluids through the GJ device. Before the GJ is used and while the feeds are being introduced, you will have an intravenous infusion (drip) of fluids.

If this is the first time you have had jejunal feeds, they will be introduced very gradually over a period of hours, increasing the amount of feed given each time. You will need to stay overnight in hospital while the amount of feed is increased.

## Feeds and feeding plan

The dietitian will discuss with you the most appropriate method of feeding. This depends on your medical condition, the particular needs of your family, and your home circumstances. As the jejunum cannot hold feed like the stomach, feeds will be continuous given over a long period of time using a feeding pump so that the jejunum has time to absorb nutrients.

You will be prescribed a special liquid feed, which contains all or most of the nutrients you need. Please talk to your dietitian if you would like to know more about it. You may be able to also continue to eat regular food by mouth, using the GJ to 'top-up' their nutrient levels, but this depends on the reasons why it is required. Your doctors and dietitians will talk to you about this. You will need to 'flush' the device before and after giving feeds or medicines. We will show you how to do this.

Gastrojejunostomy devices are not suitable blended food, as the small size of the tubes holds

an increased chance of blockage and complications.

## Going home

Once you have fully recovered from the anaesthetic (if you have had one) and are tolerating feeds well, you will be able to go home, unless any other procedures are planned. Usually, one or two nights' stay in hospital is needed, depending on how well you get used to feeding through the device.

The feeds, equipment and other supplies should have been organised by your local team before coming to GOSH, so you should be able to start tube feeding straightaway once you return home. They will also have taught you how to prepare and give feeds, look after the gastrostomy site and spot any problems that occur. If you have any questions or problems, please contact your local team in the first instance.

### Problems can develop in the first few days after insertion, such as:

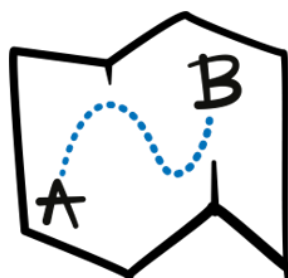
- **You are in pain when a feed or medicine is given through the GJ**
- **There is any bleeding from the GJ**
- **The feed or stomach contents are leaking from the GJ**

**Call the team at GOSH (or the On-Call Surgical Registrar out of hours) for urgent advice. Do not give any feed or medicine until you have spoken to the team.**

**You may need to go come back to GOSH for the device to be moved in another operation under general anaesthetic. The team at GOSH will advise you whether to go to your nearest Accident and Emergency (A&E) department.**

## On-going care

The device will need some extra care to keep it working well and reduce the risk of infection. We



will talk to you about this before you go home and your community team will also be able to help.

### Care of the device

Check that the button is fully closed or the tube is clamped before having a shower or bath. Always make sure that you dry around the GJ, as any dampness can breed bacteria and develop into an infection.

Unlike gastrostomy tubes and buttons, GJ devices should not be rotated as this could move the position of the tube in the jejunum and cause kinks in the tubing.

You should not need to check the position of the GJ device before each feed, but if you are concerned that it might have moved, you can use pH paper to check a sample from the jejunal port. If this shows 'acid', please contact the Gastrostomy and Stoma nursing team at GOSH.

You should flush the device as you have been shown before and after feeds and after giving medicines.

- If the stomach port is not being used, you should flush this every 24 hours.
- If the jejunal port is not being used, you should flush this more frequently, between six and twelve hourly.

Button devices are held in place by a water-filled balloon inside the stomach, and you should change the water every week. Remove the water by attaching a syringe to the balloon port and replace it as you have been shown.

### Equipment and supplies

We may give you a spare nasogastric tube or gastrostomy device to take home with you. If the device falls out, you will need to insert the spare tube or device into the opening straight away - otherwise, it will close. The nurse will advise you about when it is safe to do this.

Otherwise, you must go to your nearest Accident and Emergency (A&E) department for them to maintain the opening. You will receive further supplies from your community health care team, your local paediatric community nurse (if your area has one), your dietitian or your GP. If you have any problems getting hold of further supplies once you are at home, please ring the hospital.

You should remember to order new supplies in good time before you run out and only use equipment for the length of time specified by the manufacturer. Using or re-using equipment against the advice of the manufacturer could lead to infections, diarrhoea and vomiting, which cause could harm.

There are no special requirements for disposing of gastrostomy supplies such as giving sets and enteral syringes – they can be put in your usual household rubbish, although we suggest you put them in a separate plastic bag before putting in the bin.

### Giving medicines

When medical staff are prescribing medication, remind them about the GJ. Tablets may block the tube, so liquid medicine would be better. If you need to give medicines in tablet form, make sure they are finely ground and mixed with cooled boiled water. You can buy a tablet crusher from your local community pharmacy to make this easier.

Most medicines should be given into the stomach port. However, if medicines cannot be tolerated by the stomach, they can be given into the jejunum, but you should discuss this with your doctor or pharmacist first to ensure that the medicine can be absorbed properly by the jejunum and that the volume of medicine is not too large. Some medicines can also block the GJ, so again, check with the pharmacist if you have any concerns.

Always flush the GJ with sterile or cooled, boiled water after giving the medicine (you will have been shown how to do this by the nurses on the



ward). If you are giving two types of medicine, flush the GJ between each type.

### Mouth care

You should still continue to clean your teeth twice a day and visit the dentist regularly. If your mouth feels dry and you cannot safely have a drink, a fine water spray bought from the chemist can make your mouth more comfortable. Lip balm can help dry cracked lips.

### Nursery and school

You should be able to go to school or nursery as usual. Talk to your community team or school staff for further advice – they may be able to teach what to do if the device falls out.

### Sport and swimming

You will be able to go swimming once the GJ site has healed, as long as they do not have any other problems which prevent this. Your nurse will advise you when it is safe to start swimming.

Check that the button is fully closed or the tube is clamped before getting in the water. You might want to coil the clamped tube under a large waterproof dressing. If you particularly enjoy contact sports, ask the medical team for advice.

### Holidays

Most children and young people can travel within the UK and abroad when they have a GJ device. If you have additional needs, it may be wise to discuss your travel plans with your doctor before making any bookings. Carrying a letter from them will be helpful for getting through security and if you need to seek advice when you are away.

If you are flying, always carry some equipment in your hand luggage, in case the hold luggage goes astray. The support organisation PINNT – see details later – can advise about holiday insurance and foreign travel.

### Device changes

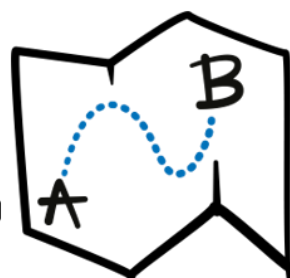
Both types of device (PEG-J and balloon button) will need to be replaced, as the plastic becomes worn. It may need to be replaced sooner if it breaks, blocks or gets dislodged. It may also need replacing as you grow.

At GOSH, we aim to change PEG-J devices every 18 months and balloon button devices every six months. The type of GJ device you have will influence whether they need a general anaesthetic for the device change, along with their individual needs.

### Trouble-shooting

What if

- You feel sick and have stomach cramps
  - Check that you are using the correct port on the device.
  - Check the rate of feeding. You may need to slow down the feeding rate. Consider if the feed can be slowed down to put less pressure on the stomach but still meet daily targets.
  - The feed may be too cold. Let the feed reach room temperature.
- You have diarrhoea
  - Check the rate of feeding. You may need to slow down the feeding rate.
  - If diarrhoea continues, contact your family doctor (GP).



- Your stomach is swollen and hard after feeding or you are vomiting milk
  - Check that you are using the correct port on the device
  - The jejunal part of the device may have moved back into the stomach. Ask your community team to check its position.
  - 'Vent' (or remove wind) in the way you have been shown. Attach an empty syringe to the tube to allow air to escape.
- The GJ tube or button seems to be blocked
  - This may be due to inadequate flushing or a very thick feed or medication.
  - Try flushing the tube with warm water or fizzy soda water.
  - If this does not help, contact your community team.
- The exit site seems red or is bleeding, oozing, irritated or swollen and you have a temperature
  - Check the site around the GJ tube or button daily.
  - Clean if the feed or medication comes into contact with your skin.
  - A barrier cream can be useful to protect the skin from small amounts of leakage.
  - If the site remains irritated, you may need to use a soft dressing to absorb ooze and act as a barrier.
  - If you have a temperature, contact your community team to arrange for a swab and a prescription for antibiotics or antifungal treatment if necessary.
- The tube or button falls out
  - Insert a spare tube or gastrostomy button device to stop the tract from closing up.
  - Go to your local hospital.
  - They will arrange for you to be admitted to GOSH to have the device replaced.

## Further information and support

The Gastrostomy and Stoma nursing team are available Monday to Friday on 020 7405 9200 extension 5695 or email [gosh-tr.stoma.nurses@nhs.net](mailto:gosh-tr.stoma.nurses@nhs.net). You can also contact them using MyGOSH once you have registered. Further details are available at [www.gosh.nhs.uk/your-hospital-visit/mygosh](http://www.gosh.nhs.uk/your-hospital-visit/mygosh). Out of hours or in an emergency, call Chameleon Ward on 020 7405 9200 extension 5593.

PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy) is an organisation for anyone receiving tube or intravenous feeds. They have a special section for children and young people called Half PINNT. Visit their website at [www.pinnt.com](http://www.pinnt.com).

