

Living with a transgastric jejunal feeding device

A close-up photograph of a young girl with dark brown hair styled in two pigtails. She is smiling broadly, showing her teeth, and has her hands clasped in front of her. She is wearing a white sweater with a grey ribbed collar and cuffs. The background is plain white.

Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

This information sheet explains about transgastric jejunal feeding devices (also known as gastrojejunostomy or GJ devices), how they are inserted at Great Ormond Street Hospital (GOSH) and how you will need to look after it once you return home.

Your child's device	
Size	
Date inserted	

GOSH switchboard	020 7405 9200
Gastrostomy Service	Ext 5695 or email gastrostomy@gosh.nhs.uk

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What is a transgastric jejunal feeding device?

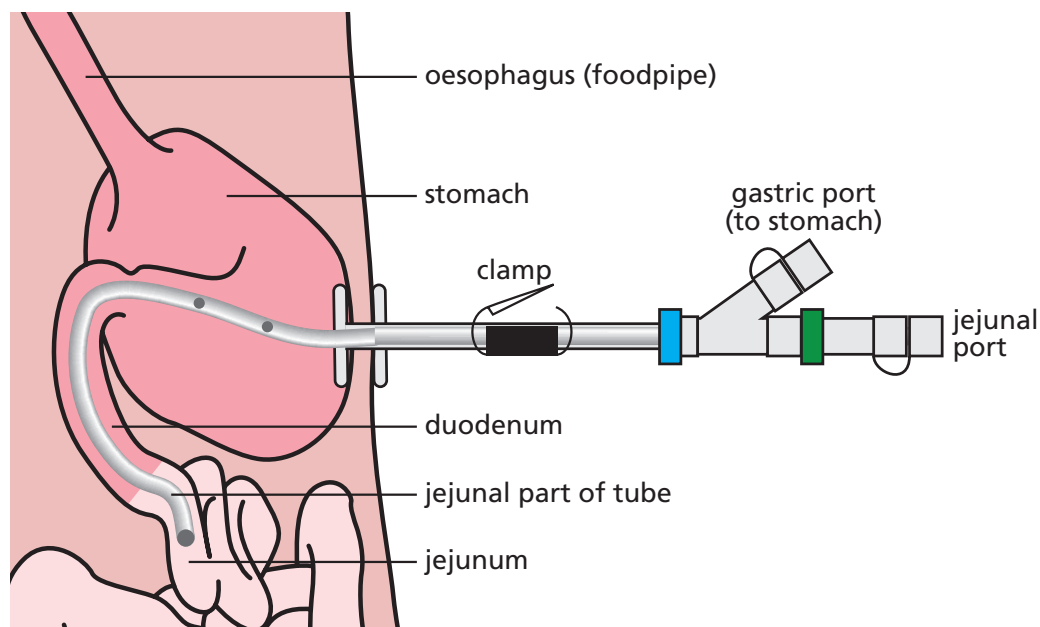
Transgastric jejunal feeding devices are a combination of a gastrostomy device (placed into the stomach) and a jejunostomy device (placed into the jejunum, the first part of the intestines). The feeding device allows your child to be fed directly into the jejunum, bypassing the mouth, throat and stomach. It also allows access to the stomach to draw off excess air, test the contents of the stomach or possibly give medications directly into the stomach. Transgastric jejunal feeding devices are also known as gastrojejunostomy or GJ devices.

There are two types of transgastric jejunal feeding device used at GOSH:

PEG-J devices and low-profile balloon button devices.

All GJ devices have two 'ports' – one of which 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 your child's dietitian or pharmacist.

GJ feeding is rarely the first method of 'enteral feeding' (feeding directly into the gastrointestinal tract) used, as naso-gastric (NG) and gastrostomy feeding are usually tried first.



Why might my child need a GJ feeding device?

A GJ device is usually suggested after gastrostomy feeding has been unsuccessful. Some children 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 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).

Are there any children for whom a GJ feeding device would not be suitable?

As mentioned previously, GJ feeding is usually suggested after gastrostomy feeding has been tried and has been unsuccessful. It is less usual for a child to be started on GJ feeding without trying gastrostomy feeding first although in some cases this may be suggested.

How is a GJ feeding device inserted?

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

The doctors will explain the procedure in more detail, discuss any worries you may have and ask you to give permission for the procedure by signing a consent form. Another doctor will visit you to explain about the anaesthetic.

Some treatments carry a risk to babies developing in the womb. These treatments include some (but not all) x-rays, scans and operations. These are called 'high risk' procedures. We have to perform a pregnancy test on any girls aged 12 or older before they undergo any of these high risk procedures. Insertion of a GJ feeding device is a one of these procedures.

PEG-J Device

While your child is 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 tube. The inner jejunal tube and the outer gastrostomy tube lock together.

PEG-J device



Balloon GJ device

Inserting a low profile balloon button GJ device can usually be done with your child awake. However, if your child already has a tube device in place or if the tract in the skin needs to be stretched to accommodate the bigger GJ device, your doctors may suggest that your child has a general anaesthetic to take out the old device and insert the new one.

The first stage is to remove your child's existing device and replace it with a low profile balloon 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 water.

Low profile balloon button GJ device



Are there any risks?

Insertion risks

If your child already has a gastrostomy tube in place, they will have a well-developed tract through the skin to the stomach, so converting the gastrostomy to a GJ tube device carries very 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 and decide to remove it using another technique on another day.

If your child has not had a gastrostomy before, there is a very small chance that the large intestine could be damaged during the insertion, but using barium beforehand reduces this risk. If your child has 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.

Your child may 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.

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

Longer term risks of having a GJ feeding device

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 your child's 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?

Your child will be taken back to the ward to recover from the anaesthetic and the procedure. When feeds and fluids can be introduced will depend on the type of device that has been inserted and whether your child previously had a gastrostomy.

- If your child has had a low profile balloon button GJ device inserted, they will usually be able to start using it for fluids and feeds straightaway
- If they have previously had a gastrostomy device, which has been converted to a GJ feeding device, they will usually be able to start using it for fluids and feeds straightaway but following a new feeding plan.
- If your child has not had a gastrostomy previously, they 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, your child will have an intravenous infusion (drip) of fluids.

If this is the first time your child has 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.

GJ feeding

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

Your child will be prescribed a special liquid feed, which contains all or most of the nutrients he or she needs. Please talk to your dietitian if you would like to know more about it. Some children can 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 dieticians 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.

Going home

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

Your child's 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 your child straightaway once you return home. They will also have taught you how to prepare and give your child feeds, look after the gastrojejunostomy site and spot any problems that occur. If you have any questions or problems, please contact your local team in the first instance.

If any of the following occur, do not give any feed or medicine and contact the stoma and gastrostomy team at GOSH.

- Your child is 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

Changing the device

Both types of device will need to be replaced, as the plastic tubing becomes worn. It may need to be replaced sooner if it breaks, blocks or gets dislodged. It may also need replacing as your child grows. Generally, the outer part of a GJ device can stay in place for one to two years but the inner part will need replacing more frequently. Low profile balloon button GJ devices need to be replaced every three to six months. The type of GJ device your child has will influence whether they need a general anaesthetic for the device change, along with their individual needs.

Follow up appointments

As children having a GJ inserted can be under the care of a number of different teams at GOSH, they may not need a follow up appointment with the team that inserted the device. Follow up appointments and care will usually be with your child's original team.

On-going care of the GJ

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 stoma and gastrostomy 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.

If your child has trapped wind, you can 'vent' the GJ device by attaching an empty syringe to the stomach port and releasing the wind. We will show you how to do this.

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.

Medicines

When medical staff are prescribing medication, remind them your child has a 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.

Support at home

Your local community health care team will be able to help you. This may be your local paediatric community nurse, if your area has one, your school nurse, the dietitian at the local hospital or your local GP surgery. If you have any worries you can always ring your community team for advice and support.

Equipment and supplies

If the device falls out, you will need to insert the spare tube into the stoma straight away, otherwise the stoma will close. The nurse will advise you about when it is safe to do this.

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 could harm your child.

Your child's GJ supplies do not need any special requirements for waste disposal. They can be put in your usual household rubbish, although we advise that giving sets and syringes are put in a plastic bag before putting in the bin.

Getting back to normal

Mouth care

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

Showers and baths

Until the site has healed, you should clean it as shown by the nurse. After the site has healed, your child can shower and bath as normal. Check that the button is fully closed or the tube is clamped before your child has a shower or bath. Always make sure that you dry around the GJ, as any dampness can breed bacteria and develop into an infection.

Nursery and school

Your child should be able to go to school as normal. Your community team, social worker or the special needs co-ordinator (SENCo) at the

school will be able to advise you further about this. If necessary, staff at the school can be taught what to do if the device falls out.

Swimming and PE

Your child 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 your child gets in the water. You might want to coil the clamped tube under a large waterproof dressing. If your child particularly enjoys contact sports, ask the medical team for advice.

Holidays

It is fine to travel with your child. However, if your child has complex needs you should discuss your travel plans with the doctor. Remember to take extra supplies with you, in case you end up staying longer than you planned. If you are planning a beach holiday, cover the GJ device with a large dressing to stop sand getting into it. Sand can irritate your child's skin near the stoma site, cause an infection or damage the device itself.

If you want to travel abroad with your child, please contact PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy) – see Useful numbers for

details. They can provide you with information on how to arrange insurance, get supplies abroad if necessary and other useful information.

It may be helpful, particularly if your child has other complex needs, to take a letter from the relevant consultant at GOSH explaining your child's medical history. This will help if you need to seek medical advice locally.

If you are planning to fly to your holiday destination, remember to carry some equipment in your hand luggage, in case your suitcases go missing. You should also carry a letter from your consultant explaining that you are carrying medical equipment because of your child's feeding needs. This should prevent any problems with airport security.

Trouble shooting

If any of the following occur, contact your community team for advice.

What if	Action
My child feels sick and has stomach cramps	<ul style="list-style-type: none"> ■ 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. ■ The feed may be too cold. Let the feed reach room temperature before giving it to your child.
My child has diarrhoea	<ul style="list-style-type: none"> ■ Check the rate of feeding. You may need to slow down the feeding rate. ■ If diarrhoea continues, contact your family doctor (GP).
My child's stomach is swollen and hard after feeding or they are vomiting milk	<ul style="list-style-type: none"> ■ 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	<ul style="list-style-type: none"> ■ 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 my child has a temperature	<ul style="list-style-type: none"> ■ Check the site around the GJ tube or button daily. ■ Clean if the feed or medication comes into contact with your child's skin. ■ If the site remains irritated, you may need to use a soft dressing to absorb ooze and act as a barrier. ■ If your child has 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	<ul style="list-style-type: none"> ■ Insert a spare tube or gastrostomy button device to stop it closing up. ■ Take your child to your local hospital. ■ They will arrange for your child to be admitted to GOSH to have the device replaced.

Notes

Notes

Useful telephone numbers

Gastrostomy Service – 020 7405 9200 ext 5695

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.

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