



Gastrostomy

What is a “Gastrostomy”?

This is a tube that goes into the stomach wall. It enables a person to be given food and drink if they are unable to eat all they need by mouth, by passing food directly into the stomach via the tube.

Why might I need one?

Some people with neuromuscular conditions find that they can only eat very slowly due to the shape of their mouths or weakness affecting their chewing and swallowing muscles. Mealtimes can take a long time and eating can become a chore that takes up too much of their day. It can also lead to arguments between children and their parents. Many families describe mealtimes as stressful rather than enjoyable. The use of a gastrostomy tube (g-tube) can reduce these problems and ensure that the person is always well fed without it taking too much time and effort.

Some people with neuromuscular conditions have specific problems with swallowing. Food or drink may go down the wrong way so that instead of going down to the stomach, it goes down the wrong tube into the lungs. This is called aspiration. If this happens often, the person is prone to chest infections and finds it hard to put on weight. A g-tube is a simple and very effective way of avoiding these problems as the food can go straight into the stomach.

How do they put in a G-tube?

This depends on each individual and the team will decide the best way depending on how old the person is, how good their breathing is and what sort of tube they are going to have.

Fitting the g-tube usually requires a short surgical operation that lasts about 30 minutes and usually requires a general anaesthetic. During the surgery, a hole (stoma) about the diameter of a small pencil, is cut in the skin and into the stomach. The stomach is gently attached to the abdominal wall.

The g-tube is then fitted into the stoma. It is a special tube held in place by a disc or water filled balloon that has a valve inside allowing food to go in, but nothing to come out. The hole can be made in two ways. One way uses a tube with a light on the end (endoscope). This is put into the mouth and fed down the gullet (oesophagus) into the stomach. The light shines through the skin showing the surgeon where to make the hole. The other way does not use the endoscope, instead a small opening is made in the tummy so the surgeon can see to put the tube in the right place. This results in a small scar next to the g-tube. Both of these are classed as minor operations.

Will it hurt?

There will be slight discomfort after the operation but this can be dealt with using ordinary painkillers. Once it has healed you will hardly feel it is in there.

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What is inside my tummy?

The tube needs either a disc or water filled with balloon to keep it in place. This is attached to the tube and sits just inside your tummy. The g-tube can be easily removed by a trained person.

What does a g-tube looks like?

There are various different types. The two main ones are a PEG (Percutaneous Endoscopic Gastrostomy) or a button. The PEG is a length of tubing with a valve at the end. Sometime this is put in first until the stoma site has healed well. It can then be replaced with a button. A button looks very much like the small valve that is used to inflate a child's beach-ball or a lilo. It is made of clear, soft plastic and sits right next to the skin. A length of tubing is connected at feed times to pass food in.

Can I eat some normal food or drink?

It depends on why the tube was inserted. If it was because of slow mealtimes or poor weight gain only, it is OK to continue eating and drinking as usual. In this way your mealtimes can be as long or short as you wish as you know you can top up enough calories via the tube. Some people use the g-tube mainly as "insurance" so that the person can always be sure of getting food and drink even if they don't feel like eating by mouth.

However, if the reason for having the tube is that the person has swallowing problems and aspirates on food or drinks, it is important to have advice on what is safe to take by mouth. The team may recommend that only certain amounts or types of food or drink are safe by mouth. Sometimes it is the safest option to stop taking food by mouth altogether. This is not a forever decision and the swallowing will be monitored so alterations can be made as things change.

What food can I put in the G-tube?

It is recommended that a pre-prepared commercially available feed is used. This will provide a balanced diet including all the essential vitamins and minerals needed. Some of these feeds contain fibre so that regular bowel movement can be maintained even if your are unable to eat fruit, vegetables and other high fibre foods. Specific advice with respect to the type of feed and the quantity required will be provided by a dietician.

It is advisable to stick to these feeds to avoid the tube getting blocked. Liquid medicines can also be put down the tube.

What if I am thirsty?

In some cases it is OK to drink normally. If the team has said that you cannot drink by mouth then fluids added via the g-tube will reduce thirst.

Will I use the G-tube at normal mealtimes?

The g-tube can be used at anytime that suits the individual. The feed can be given by attaching a syringe to the tube and pouring in the feed or by using an electric pump, so that feeds can be given without the person or helper needing to do anything during the

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meal. Some people choose to stick to regular mealtimes, while others use a pump and continuous feed to allow feeding to be done mainly at night. Some families find that it is nice to sit down to eat together even though one of them is getting their main meal through the g-tube. The person can sometimes be having a light snack at the same time or just a drink. Each person's routine is individual and is decided on with all their needs in mind.

Will people know that I have a G-tube?

The tube is very small and is hidden by clothing, so nobody will notice it unless you show them. When a person is undressed, for example for swimming, the tube may be seen and people have come up with a variety of methods to help conceal it. For children, especially girls, a one-piece swimsuit is enough to cover the tube. For older children and adults, a slightly larger than usual sticking plaster will disguise the tube quite well.

Can I have a bath and go swimming?

Yes. You can return to normal activities. In fact, swimming is encouraged. Just make sure the feeding port is closed.

Will it catch on my clothes and fall out?

This is unlikely as the tube is secured either by a little water filled balloon or a small plastic disc. As the hole is only a fraction of this size, the tube cannot pull out until the balloon is deflated, which is only normally done to renew the tube. If the tube ever does come out – don't panic. Place a clean dry towel over the stoma to absorb drainage. Contact nursing staff to help you or change the tube if you have been shown what to do. If in doubt go to casualty and get them to put in another tube. The stoma can close up quite rapidly so it is important to get it replaced relatively quickly to avoid another general anaesthetic.

It is worth having a plan of action before the event so you know what to do if it happens.

Will it be there forever?

This is a decision that the person and their medical team should make together depending on the person's weight, health and eating abilities including swallowing. A g-tube can just be there as a back-up and does not have to be used every day.

If a g-tube is removed, the hole in the stomach will heal over extremely rapidly – as fast as 45 minutes, so the fitting of the g-tube can be reversed very quickly with just a small scar remaining.

How much time will I need to spend taking care of my gastrostomy?

Usually g-tubes need very little maintenance. They need to be kept clean but a bath or shower does most of this for you. They will need to be replaced if the balloon inside the stomach gets old and punctures – this can happen every 6 months or so, but varies with different types. The tube can be replaced by a professional helper, such as a district nurse, but many parents or carers quickly learn to do it themselves. Replacing a g-tube takes about a minute and is not as messy or unpleasant as many people fear.

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Will it leak?

Most g-tubes leak a small amount but this is easily taken care of with a little damp cotton wool. The fluid that leaks out from the stomach can irritate the skin around the tube so it is important to clean any leaks and to apply a little protective cream.

Normally, the degree of leakage is very small and it will not be enough to mark or stain clothes. A tube that leaks more than a little, probably needs replacing because the balloon is leaking or it is not the correct size. In either case, the doctor or district nurse will give advice and help solve the problem.

What other complications might there be?

Occasionally, the skin around the stoma can become sore or infected or it can get a bit hardened. It is therefore important to look at the stoma when cleaning it and let your nurse/doctor look at it if you are concerned.

Tummy ache, bloating or diarrhoea can occur if too much food is put into the tummy too quickly. This may happen if the stomach is not used to large volumes. A feeding regime should be discussed with a dietician or community nurse so that tolerance can be gradually built up.

What stops the food coming back out?

The g-tube has a one-way valve fitted to keep stomach contents in and air etc, out.

Will I taste anything?

A person's taste-buds are on their tongue, so they will not taste food that is given via the g-tube, although some say they can taste food a bit if they burp after a feed. Some people will still be able to take food and drink by mouth so will still taste food, though, perhaps, in smaller quantities.

One advantage of a g-tube is that unpleasant tasting medicines can be taken via the tube instead of by mouth and in case of children, this can ensure they always get a full dose of medicine on time.

What will it feel like while I'm being fed?

Most people don't notice anything at all. If an attempt is made to feed a person too quickly they will soon complain of feeling sick, just as they would if they ate too much, too quickly. If this happens, then the rate of feeding is easily reduced or stopped.

Will I still feel hungry, and then full after a feed?

Yes. The stomach will still fill and empty in the normal way, giving the usual sensations of hunger and satisfaction.

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Can I still be sick?

Yes. In most cases a g-tube will allow a person to vomit as they normally would and this can be a useful reaction when they are unwell and their body needs to reject something from their stomach.

In some cases, the doctor may recommend an operation called a Nissen's fundoplication to tighten the muscles at the top of the stomach to make it harder for food to flow back up from the stomach into the food pipe (gastro oesophageal reflux). This is usually done when there is a risk of refluxed food coming up and going into the lungs.

To determine if a person needs a fundoplication, the doctor may ask for a pH study, which will show how prone they are to acids coming up from the stomach. A person with fundoplication finds it harder to vomit so, if you have a gastrostomy, stomach contents can be emptied out through the gastrostomy when you feel sick.

Occasionally, the placement of s gastrostomy can cause gastro-oesophageal reflux and some children may have to return to have a fundoplication later.

If you have any other questions or would like to discuss any of this information, please contact a member of your Medical Team or your Care Adviser.

If you have feedback about this factsheet please email info@muscular dystrophyuk.org.

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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or info@muscular dystrophyuk.org from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.muscular dystrophyuk.org

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