



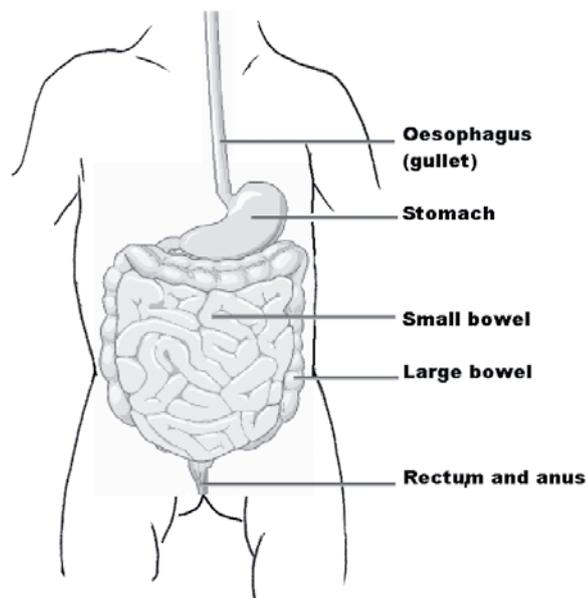
Great Ormond Street Hospital for Children NHS Trust: Information for Families

Ileostomy

This information sheet explains ileostomies: the operation, what to expect while your child is at Great Ormond Street Hospital (GOSH) and what to look out for once you get home.

What is the digestive system?

The digestive system is a very long tube. Nutrients are extracted from food and drink as they pass through this tube. Swallowed food travels down the gullet (oesophagus) into the stomach where acid begins to break it down. From the stomach, it passes into the small bowel (jejunum and ileum). Here food is digested further to form watery diarrhoea. On reaching the large bowel (colon), water is absorbed and waste products are expelled from the body through the rectum and anus as faeces (poo).

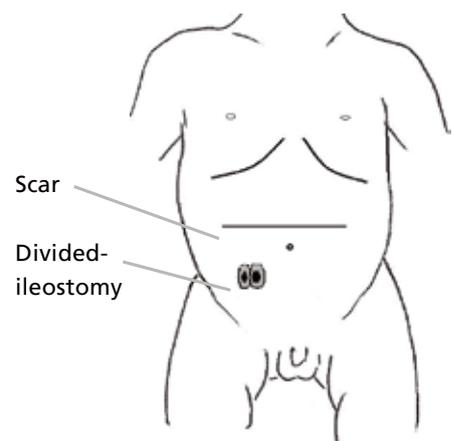


What is an ileostomy?

An ileostomy is a surgically formed opening in the ileum, which is the last part of the small bowel before it connects onto the large bowel (colon). The ileum is brought to the surface of the abdomen as an opening called a stoma. Watery diarrhoea passes through the stoma and is collected in a small plastic bag, called an ileostomy bag. An ileostomy can be temporary or permanent.

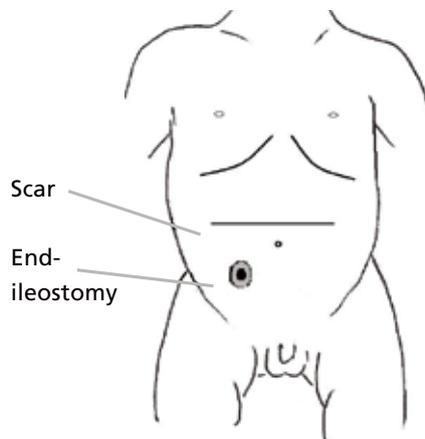
There are two types of ileostomy: a 'loop ileostomy' and an 'end ileostomy'.

'Loop ileostomy': A loop of ileum is brought to the surface and opened so that there are two ends on the abdomen as a stoma. If the stoma needs to be reversed at a later stage, the two surfaces can be joined together to form a tube once more.





'End ileostomy': If the large bowel has to be removed or there is a problem with the loop ileostomy the working end of the ileum is brought out as a stoma and the non-working end is closed and placed inside the tummy. If the stoma needs to be reversed at a later stage, the working end is freed and connected to the rest of the intestine.



When is an ileostomy needed?

There are many circumstances when an ileostomy might be useful. It tends to be suggested when a child has a bowel infection (such as for instance, necrotising enterocolitis (NEC) in premature babies), an injury to the bowel, a bowel obstruction or leak, or following removal of inflamed or diseased bowel. An ileostomy can allow surgery performed on the large bowel to heal.

What happens before the operation?

You will receive information about how to prepare your child for the operation in your admission letter and/or our *Welcome to GOSH* booklet.

Pre-admission clinic

Several days before the operation, we will invite you to come to a pre-admission clinic. This is an outpatient appointment where you will be able to discuss the operation with the surgical team. Your child will also have various tests during this appointment. This avoids any delays on the day of the operation.

One day before the operation

Your child will need to have clear fluids only by mouth for 24 hours before the operation. Sometimes your child may need to have 'bowel preparation' before surgery. This involves laxatives or bowel washouts. On the day of the operation, your child will be given 'fasting instructions', that is, he or she should not eat or drink anything from the time specified. It is important to follow these instructions otherwise your child's operation may be delayed or even cancelled.

Your child's surgeon will visit you to explain the operation in more detail and ask you to give permission for the operation by signing a consent form. You may have done this already during the pre-admission clinic. An anaesthetist will visit you to explain the anaesthetic and pain relief after the operation. If your child has any medical problems, such as allergies, please tell the doctors.



What does the operation involve?

The operation is carried out while your child is under a general anaesthetic. The surgeon will make an incision (cut) across your child's abdomen and find the last part of the small bowel. Depending on the type of ileostomy your child is having, either the free end or a loop of ileum will be brought to the surface to form the stoma.

Are there any risks?

All surgery carries a risk of bleeding during or after the operation. If there is a lot of bleeding, your child could need a blood transfusion but this is rare. There is a risk of infection but your child will have antibiotics following the operation to prevent or treat any infection. Every anaesthetic carries a risk of complications. The surgeon and anaesthetist will discuss potential risks for your child before the operation.

What happens after the operation?

Your child will return to the ward when he or she has woken up from the anaesthetic. He or she will have an intravenous infusion (drip). This enables us to give your child regular pain relief and fluids until he or she is able to eat again. Your child's abdomen will look a little red and may ooze a bit, but this settles down in a few days.

After the operation, your child will not be allowed to eat or drink until his or her bowel is working again. He or she will get all the nutrients and fluids needed through the drip. The drip will also contain a mineral called 'sodium'. This is important because sodium is usually absorbed in the large bowel, but now passes out in the watery diarrhoea from the ileostomy.

Once the stoma has been closed, sodium levels will return to normal, but until this time, your child will need to have regular appointments (initially weekly) with your family doctor (GP) or community team. They will measure your child's weight and the amount of sodium in your child's urine (wee), reporting these figures to the team at GOSH. If your child's sodium levels are low, the team may suggest a sodium supplement to put the levels back to normal.

Once your child's bowel is working well and we have taught you how to care for the ileostomy, you and your child will be able to go home.



When you get home

- Include plenty of fluids in your child's diet as this will replace the fluid lost through the ileostomy. As well as drinking plenty, jelly and other foods containing water will help.
- You should keep your child's stoma clean by washing it once a day, and then patting it dry with a towel. Do not rub the stoma site, as this will make it sore. It is best to keep a towel specifically for this purpose, as infection may spread between members of your family if you all use the same one. When you wash your child's stoma, check that it is a pink/red in colour and moist.
- Your child can continue with his or her everyday activities, such as washing, playing and swimming. Your stoma nurse specialist will guide your child's return to normal everyday life.

Support group

ia – The Ileostomy and Internal Pouch Support Group

Peverill House

1 – 5 Mill Road

Ballyclare

Co. Antrim BT39 9DR

Tel: 0800 0184 724 or 028 9334 4043

Email: info@the-ia.org.uk

Website: www.the-ia.org.uk

You should call your family doctor (GP) if:

- The stoma changes colour and looks purple, black or blue
- There is a lot of blood mixed in with the watery diarrhoea in the ileostomy bag
- The stoma starts to stick out (prolapse) or sinks inwards (retracts)
- Your child is passing more watery diarrhoea than usual and you are having to change the bag more frequently
- Your child is not passing any watery diarrhoea
- The skin around the stoma looks red and sore
- Your child is not gaining any weight

If you are concerned about any of these, please contact the Stoma Nurse Specialists (extension 5695) or the Surgical Team (bleep 0777) at GOSH on 020 7405 9200.

Compiled by the Department of General and Neonatal Surgery in collaboration with the Child and Family Information Group.

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www.goshfamilies.nhs.uk

www.childrenfirst.nhs.uk