

## Ileostomy: information for families

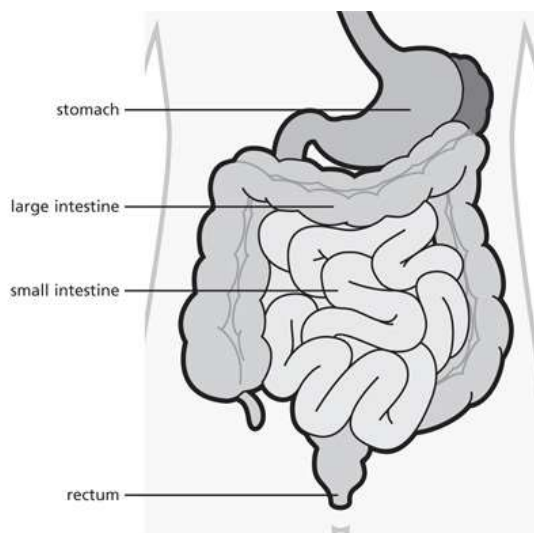
An ileostomy is a surgically formed opening in the ileum, which is the last part of the small bowel before it connects onto the large bowel (colon). The ileum is brought to the surface of the abdomen as an opening called a stoma. Watery diarrhoea passes through the stoma and is collected in a small plastic bag, called an ileostomy bag. An ileostomy can be temporary or permanent. This information sheet from Great Ormond Street Hospital (GOSH) explains the operation to create the ileostomy, what to expect when your child is recovering and what to look out for once you get home.

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).

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. The procedure to create an ileostomy may be carried out as an emergency or it may be planned in advance.

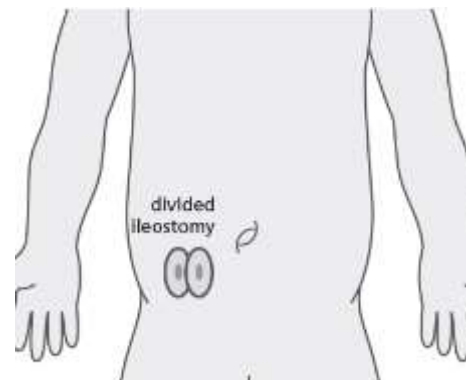
There are two types of ileostomy: a 'loop' ileostomy and an 'end' ileostomy.

- **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.

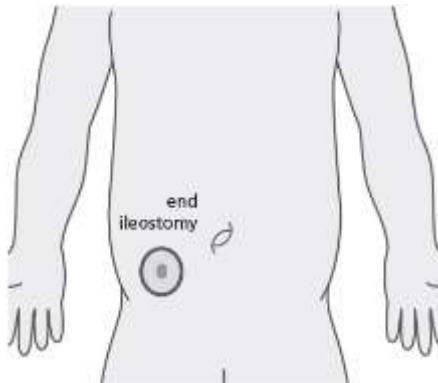


### When is an ileostomy needed?

There are many circumstances when an ileostomy might be useful. It tends to be suggested when a



- **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.



## What happens before the operation to create the stoma?

If the operation is planned, that is, not an emergency, you will already have received information about how to prepare your child for the procedure in your admission letter. You may need to come to GOSH before the operation so that your child can have a pre-admission assessment to check that they are well enough. This appointment may involve taking blood samples and other tests.

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, an enema or bowel washouts. The surgeon will advise you if bowel preparation is needed.

The operation to form the ileostomy – both laparoscopic and open surgery – is always carried out under general anaesthetic. It is important that your child does not eat or drink anything for a few hours before the anaesthetic. This is called 'fasting' or 'nil by mouth'. Fasting reduces the risk

of stomach contents entering the lungs during and after the procedure. You will be informed the night before the procedure of the time that your child should be 'nil by mouth' – in other words, have nothing to eat or drink before the anaesthetic. Fasting times are provided in your admissions letter.

It is equally important to keep giving your child food and drink until those times to ensure they remain well-hydrated and get adequate nutrition. This may involve waking your child in the night to give them a drink which we recommend.

## Operation day

The doctor will explain the procedure in more detail, discuss any questions you may have and ask you to sign a consent form giving permission for your child to have the operation.

### Important

The person bringing your child for the operation should have 'Parental Responsibility' for them. 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 your child does not have Parental Responsibility, we may have to cancel the operation.

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 surgeon will find the last part of the small bowel and check it for any damage. 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. Towards the end of the operation, they will attach a stoma bag to the opening.

## 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.

There are some specific risks to the ileostomy operation and having an ileostomy which are rare but may happen so you should be aware.

The skin around the stoma can become sore, both from the adhesive holding the stoma bag in place and from coming into contact with diarrhoea. It is important to wash the stoma and surrounding skin every day to keep it clean. Your stoma nurse will discuss which stoma bags may suit your child – there are plenty of options so if one makes the skin sore another type can be tried.

Over time, the stoma may protrude (stick out) or retract (sink inwards). This is a normal part of tissue healing and shows that the stoma is settling down but may need further treatment if severe. Occasionally a stoma can ‘prolapse’ which means that the internal bowel tissue sticks out from the stoma – this can be sore so will need checking and possibly treatment to reduce the amount sticking out. The stoma can also narrow over time, which may require further treatment to widen it again – this may involve gently stretching the stoma or having a short procedure to widen it surgically.

If your child has a loop ileostomy, the non-functioning opening will discharge mucus – there are dressings you can put over the area to stop clothes being stained. Your stoma nurse will show you how to do this.

## What happens after the operation?

Your child will return to the ward when they have woken up from the anaesthetic. They will have an intravenous infusion (drip). This enables us to give your child regular pain relief and fluids until they are 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 their bowel is working again. They 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.

While the ileostomy is in use 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. When the ileostomy has been closed (if it is temporary), your child’s sodium levels will usually return 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. Your child’s community team will liaise with you about supplies and stoma care – please call us if you have any problems.

## 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.

If your child has unusually large or very loose or different diarrhoea through the ileostomy, your child may become dehydrated very quickly. They should be reviewed by a doctor urgently as they may need to have fluid replaced through an intravenous infusion (drip).

Occasionally medicine is required to help lower ileostomy losses. This should be discussed with the surgical team if required.

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 their everyday activities, such as washing, playing and swimming. Your stoma nurse specialist will guide your child's return to normal everyday life.

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

## Further information and support

If you have any questions, please call the Stoma Clinical Nurse Specialists on 020 7405 9200 ext 5695 or out of hours, call Chameleon Ward on 020 7829 8818

Ia – The Ileostomy and Internal Pouch Support Group is the main support group in the UK for people with an ileostomy. Call their helpline on 0800 0184 724 or visit their website at [www.the-ia.org.uk](http://www.the-ia.org.uk). They also have a section for young people with an ileostomy.