

Colorectal Department

What is an ileostomy?

An ileostomy is when part of the ileum (small bowel) is brought through an opening in the tummy (abdomen). This is done surgically.

The part of the small bowel that is brought to the tummy is called the stoma.

Body waste can exit the body through the stoma. It is collected using an ileostomy pouch.

Why do I need an ileostomy?

There are many reasons why you might need stoma surgery. It is always done to improve your current situation.

- Sometimes it is done as a lifesaving procedure, or because the formation of a stoma outweighs the pain and discomfort experienced with ulcerative colitis or Crohn's disease.
- To allow another part of the bowel to rest and heal because of inflammation or other surgery

It may be carried out because of a blockage, or a growth which can be benign (not cancerous) or malignant (cancerous).

Your surgeon and colorectal nurse specialist will explain why you are having a stoma formed.

An ileostomy is only created when it is essential for your future wellbeing. Understanding why you need an ileostomy and what the operation involves may help you accept it more easily.



Where will the stoma be positioned on my abdomen?

An ileostomy will generally be positioned on the right-hand side of the tummy, between your belly button (umbilicus) and hip.

Your colorectal nurse will discuss the position of the stoma with you before your surgery. You will decide where it will be most comfortable and easiest to look after together.

Your colorectal nurse will ask you to sit, lie, stand and adopt various positions while deciding where to place the guide mark on your tummy (abdomen) for the surgeon.

Your navel, hip bones, previous scars, skin creases or existing skin conditions will be considered. Your weight may change after your operation, so this too will be taken into account when choosing your stoma site.

When the site is chosen, make sure you can see the mark on your tummy clearly. It is important that the stoma is easy for you to see so that it's easy to manage.

Don't wait to express any opinion or doubt you have. Your colorectal nurse will value your help and try to accommodate your preferences.

Is an ileostomy always permanent?

An ileostomy may be either temporary or permanent.

- A loop ileostomy is usually formed temporarily. This is done, for example, to bypass an area of large bowel that needs time to heal after surgery.
- An end ileostomy is formed when all or most of the large bowel has been removed and is sometimes permanent.

Your surgeon will discuss with you which type of stoma you are likely to have. It will depend on the type of surgery that is planned, along with your medical condition.

What does an ileostomy look like?

Your ileostomy will look red and moist. The colour and texture is similar to the inside of your mouth.

It should extend a few centimetres above the surface of your tummy. It will be quite swollen immediately after the operation, but usually it will shrink over the first 6 - 8 weeks after your operation.

Your ileostomy will not be painful to touch and will have little or no sensation. But with lots of small blood vessels, it can easily bleed if knocked or rubbed (when cleaning for example). This is quite normal.

What is the output like?

Immediately after your operation your colorectal nurse specialist or ward nurse will observe you to see when wind (flatulence) is passed.

After this, the output from your stoma can be very loose.

But eventually, the output is likely to be less liquid as your system settles down and you begin to eat again. The output will resemble a porridge-like consistency.

How do you feel?

There are many reasons why you might require stoma surgery.

The way you feel about this depends on why stoma surgery is being done. It can be shocking and upsetting news to learn that you need to have a stoma formed.

Even though a stoma may save your life or give you a manageable option to the pain and discomfort you already experience, it may still leave you asking, 'why do I need a stoma?'

Patient Information

Having a stoma may mean adjusting your lifestyle. You may be worried about your appearance, how to control the stoma pouches (bags), and telling other people about your surgery.

How will I feel after the operation?

There are different emotions you might experience when coming to terms with your new situation. This is normal in the recovery process.

Depending on the reason for your surgery, you might sometimes feel elated that you are going to have more freedom and will be able to do things that you couldn't do before your surgery, such as not having to constantly run to the toilet.

You may have expected this surgery and know that it will improve your quality of life. But you might not like it all of the time. Don't be hard on yourself if this is the case.

You might feel anger that you have been put into this situation. You might feel resigned and occasionally depressed as you can't see how you're going to cope.

You may have never had a day's illness in your life, so it's not surprising that your emotions are in turmoil.

These are normal feelings so talking to someone you know and trust can help.

Most people feel confused, have constantly changing emotions and take time to accept their situation. This is even though they know the operation is in their best interest.

Try to discuss your thoughts and any fears that you might have. You are not alone in this experience and other people have expressed similar thoughts.

Patient Information

It will help your colorectal nurse specialist to help you gain confidence and a sense of control if you can share your thoughts with her. The nurse is experienced and is used to helping people in this situation.

You may prefer to talk to our hospital counsellor who is experienced in helping people who have had a similar surgery to yourself. your colorectal nurse specialist or ward nurse can arrange this for you.

Involving your family

It can help to reduce the anxiety of close relatives or friends if they understand what to expect after your operation.

Your bowel care nurse will be happy to include a member of your family in any discussions if you wish.

You may find it reassuring to meet someone else who has an operation like you – proof that you can return to a normal life after your operation. Your colorectal nurse can arrange this for you.

How do I tell other people about my stoma?

It might be best to plan in advance what you want to say to whom before being asked questions you find difficult to answer.

Although you can never fully predict people's reactions, having a planned response will help you stay in control of the situation.

You might want to tell them simply that the operation has gone well and your problems have been sorted out. Or you might want to explain that you now have a stoma and what this means to you, so they have some sort of understanding.

Your nurse specialist can help you to take charge by planning and rehearsing your response to questions. They can discuss with you who needs to know and what level of information you will give them.

Patient Information

For further information:

Colorectal Specialist Nurses

Michelle Hicken, Helen Taylor, Sarah Thompson, Hannah Davies, Caroline Ling, Deepa Philips

Telephone 024 7696 5825

Local services

Service	Location	Phone number
Age UK Coventry Age UK Warwickshire		024 7623 1999 01926 458100
Bowel Screening Unit		01788 545166/667737
Cancer Information Centre	Main Entrance UHCW	024 7696 6052
Health Information Centre	Main Entrance UHCW	024 7696 6051
Coventry Macmillan Care Team	Hospital Community	024 7696 5498 024 7623 7001
Rugby Macmillan Care Team.	Community	01788 555119
GUT (Cancer Support Group for Coventry & Warwickshire)		024 7696 6475
Hospital Chaplaincy	Hospital	024 7696 7515

Patient Information

Bowel Clinical Trials Nurse	Hospital	024 7696 7151
Specialist Genetic Nurse	Hospital	024 7696 4000
Surgical Counselling Service	Hospital	024 7696 6188
Oncology Counselling Service	Hospital	024 7696 7290
Complimentary Therapies	Hospital	024 7696 7290
Psychosexual Therapy	Hospital	024 7696 7290
Citizens Advice Bureau	Coventry Rugby	024 7625 2050 (appointment only) 0844 855 2322
Coventry Carers Centre	Support for carers	024 7663 2972
Guideposts Trust	Support for carers	024 7638 5888

Also available at University Hospital:

Physiotherapy, Occupational Therapy, Dietitian Service, Social Services

National contact numbers

Service	Website or phone number
Association of Coloproctology for Great Britain and Ireland	https://www.acpgbi.org.uk/
Beating Bowel Cancer	020 8892 5256 www.beatingbowelcancer.org
Cancer Black Care	020 8961 4151

Patient Information

	www.cancerblackcare.org
National Cancer Institute (American)	www.cancer.gov
Bowel Cancer UK	www.bowelcancer.org.uk
Colostomy Association	0800 328 4257 www.colostomyassociation.org.uk/
CORE (The Digestive Disorders Foundation)	020 7486 0341 www.corecharity.org.uk
The Ileostomy & Internal Pouch Support Group (IA)	0800 018 4724 www.the-ia.org.uk
Macmillan Cancer Support	0808 808 0000 www.macmillan.org.uk
Marie Curie Cancer Care	0800 716 146 www.mariecurie.org.uk

This booklet has been developed using existing patient information, valuable suggestions from patients and contributions from health care professionals.

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Document History	
Department:	Colorectal
Contact:	25617
Updated:	December 2023
Review:	December 2025
Version:	8
Reference:	HIC/LFT/382/07