

## Colorectal Department

# What is an Ileostomy?

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The word ileostomy originates from two Greek words:

- Ileum (small bowel)
- Stoma (artificial opening)

An ileostomy is formed surgically when part of the ileum is brought out through an opening in the abdominal wall. The part of the ileum that is brought to the surface is called the stoma. Body waste can then exit the body through the stoma, and is collected externally using an ileostomy pouch.

### Why do I need an Ileostomy?

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

There are many reasons why you might require stoma surgery, but it is always done to improve your current situation.

- Sometimes it is a life saving procedure, or it is because the formation of a stoma outweighs the pain and discomfort already experienced with ulcerative colitis or Crohn's disease.
- It may be carried out to allow another part of the bowel to rest and heal because of inflammation or other surgery.
- It may be carried out because of an obstruction (blockage) or growth which can be benign (not cancer) or malignant (cancer).

Your surgeon and Colorectal Nurse Specialist will explain why you are having a stoma formed.



### **Where will the stoma be positioned on my abdomen?**

Generally an ileostomy will be sited on the right hand side of the abdomen, midway between your umbilicus (tummy button) and hip.

Your Colorectal Nurse will discuss the position of the stoma with you before your surgery. Together you will decide where it will be most comfortable and easiest to look after. Your Colorectal Nurse will ask you to sit, lie, stand and adopt various positions while deciding where to place the guide mark on your abdomen for the surgeon. The navel, hip bones, previous scars, skin creases or existing skin conditions need to 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 finally chosen, make sure you can see the mark on your abdomen clearly. It is important that the stoma is easy for you to see – and therefore easy to manage. Never hesitate to express any opinion or doubt that 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 formed usually temporarily, for example to bypass an area of large bowel that needs time to heal following 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 with the colour and texture similar to the inside of your mouth. It should protrude a few centimetres from the surface of your abdomen. It will be quite swollen immediately after the

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operation, but it will usually shrink in size over the first 6 - 8 weeks following your operation.

With little or no sensation, your ileostomy will not be painful to touch, but with a multitude 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 to see when wind (flatus) is passed. After this the output can be very loose but eventually, as your system settles down and you begin to eat again, it is likely to be less liquid, resembling a porridge-like consistency.

### **How do you feel?**

There are many reasons why you might require stoma surgery and the way you feel about this depends on why it 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?'

Having a stoma may mean making adjustments to your lifestyle and 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 various emotions which you might experience when trying to come to terms with your new situation and it is helpful to understand that 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.

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- 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. So don't be hard on yourself if that is the case.
- You might even feel anger that you have been put into this situation or you might feel resigned and occasionally depressed because you can't see how you are going to cope.
- You may be one of those people who have not had a days illness in your life and this has struck like a bolt out of the blue, so it's not surprising that your emotions might be in turmoil.

These are normal feelings, this is when talking to someone you know and trust can help.

Most people, despite knowing that the operation is in their best interest, still have confused and constantly changing emotions and take time to accept their situation.

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. 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.

Alternatively, you may prefer to talk to our hospital counsellor who is experienced in helping people who have undergone similar surgery to yourself. Your Colorectal Nurse Specialist or Ward Nurse will be able to arrange this for you.

### **Involving your family**

It can help alleviate the anxiety of close relatives or friends if they too understand what to expect following your operation. If you wish, your bowel care nurse will be happy to include a member of your family in any discussions.

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

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### 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 confronted by questions you find difficult to answer. Although you can never fully anticipate 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, and discuss who needs to know and what level of information you will give them.

### For further information:

#### Colorectal Specialist Nurses

Abby Barnwell, Sarah Taylor	024 7696 5617
Helen Taylor	024 7696 5616
Katrina Turner, Sarah Thompson	024 7696 5825
Claire Jackson, Debbie Mulhern, Caroline Ling	024 7696 5753

### Local Services

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
Bowel Clinical Trials Nurse	Hospital	024 7696 7151

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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	024 7625 2050 (appointment only)
	Rugby	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

Association of Coloproctology for Great Britain and Ireland	<a href="http://www.acpghi.org.uk/">http://www.acpghi.org.uk/</a>
Beating Bowel Cancer	020 8892 5256 <a href="http://www.beatingbowelcancer.org">www.beatingbowelcancer.org</a>
Cancer Black Care	020 8961 4151 <a href="http://www.cancerblackcare.org">www.cancerblackcare.org</a>
National Cancer Institute (American)	<a href="http://www.cancer.gov">www.cancer.gov</a>
Bowel Cancer UK	<a href="http://www.bowelcancer.org.uk">www.bowelcancer.org.uk</a>
Colostomy Association	0800 328 4257 <a href="http://www.colostomyassociation.org.uk/">www.colostomyassociation.org.uk/</a>
CORE (The Digestive Disorders Foundation)	020 7486 0341 <a href="http://www.corecharity.org.uk">www.corecharity.org.uk</a>
The Ileostomy & Internal Pouch Support Group (IA)	0800 018 4724 <a href="http://www.the-ia.org.uk">www.the-ia.org.uk</a>
Macmillan Cancer Support	0808 808 0000 <a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a>
Marie Curie Cancer Care	0800 716 146 <a href="http://www.mariecurie.org.uk">www.mariecurie.org.uk</a>

## Patient Information

The Trust has access to interpreting and translation services. If you need this information in another language or format please contact 024 7696 5617 and we will do our best to meet your needs.

The Trust operates a smoke free policy

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