

How will an ileostomy affect me?



**Ileostomy & Internal Pouch
Association**

Registered Charity

- Providing support and guidance
- Helping you with your concerns
- Local support

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Introduction

You have probably just been advised that you, or someone you care for, needs to have an ileostomy. Understandably this may have generated many different emotions such as fear or worry, perhaps anger or even relief, following a difficult illness. Whatever your thoughts, you are not alone.

This booklet provides an introduction to living with an ileostomy or 'bag', and answers many of the questions that may be of concern. Your surgeon or specialist nurse will also be available to answer any questions you may have both pre and post-operatively.

Alternatively, you are welcome to make use of IA's visiting service and speak to one of our volunteer visitors who has been through similar surgery and is now living with an ileostomy.

"Anyone faced with the prospect of having an ileostomy must react with dismay, even horror.

Fortunately, as so often in life, reality proves better than the prospect - and much better than the imagination."

Professor Bryan N Brooke MD, MChir, FRCS
Founder president of IA

What is an ileostomy?

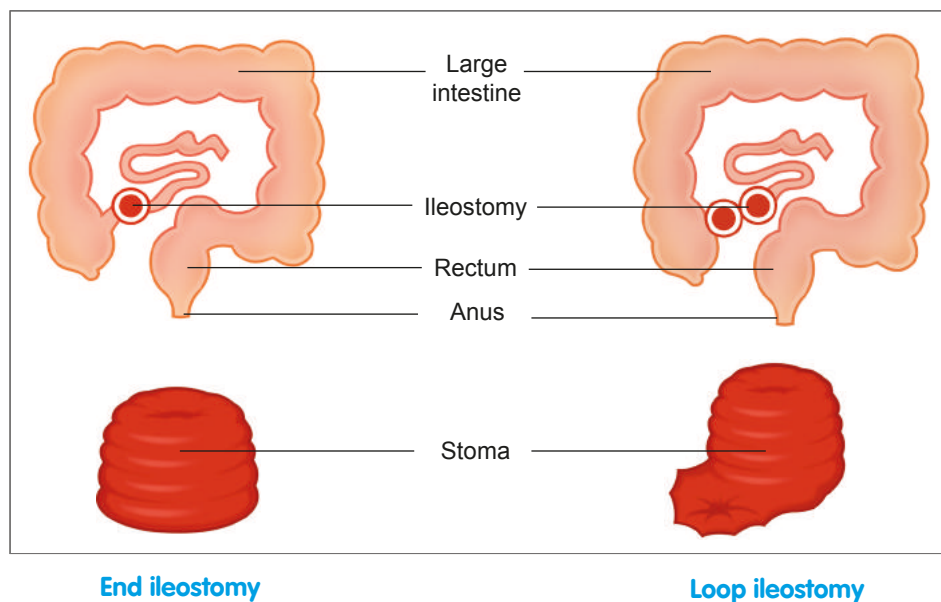
An ileostomy is part of you. Your bowel needs to be diverted away from its usual route and out on to your abdomen. This will mean that your bowel motion and any wind will pass into the stoma bag.

The consistency of the bowel motion can vary, and you can still become constipated or have diarrhoea. However, you should still be able to pass urine in the normal way. Because of the type of surgery, bladder and sexual problems can be a risk, although your surgeon will take care to try to avoid these problems.

What will it look and feel like?

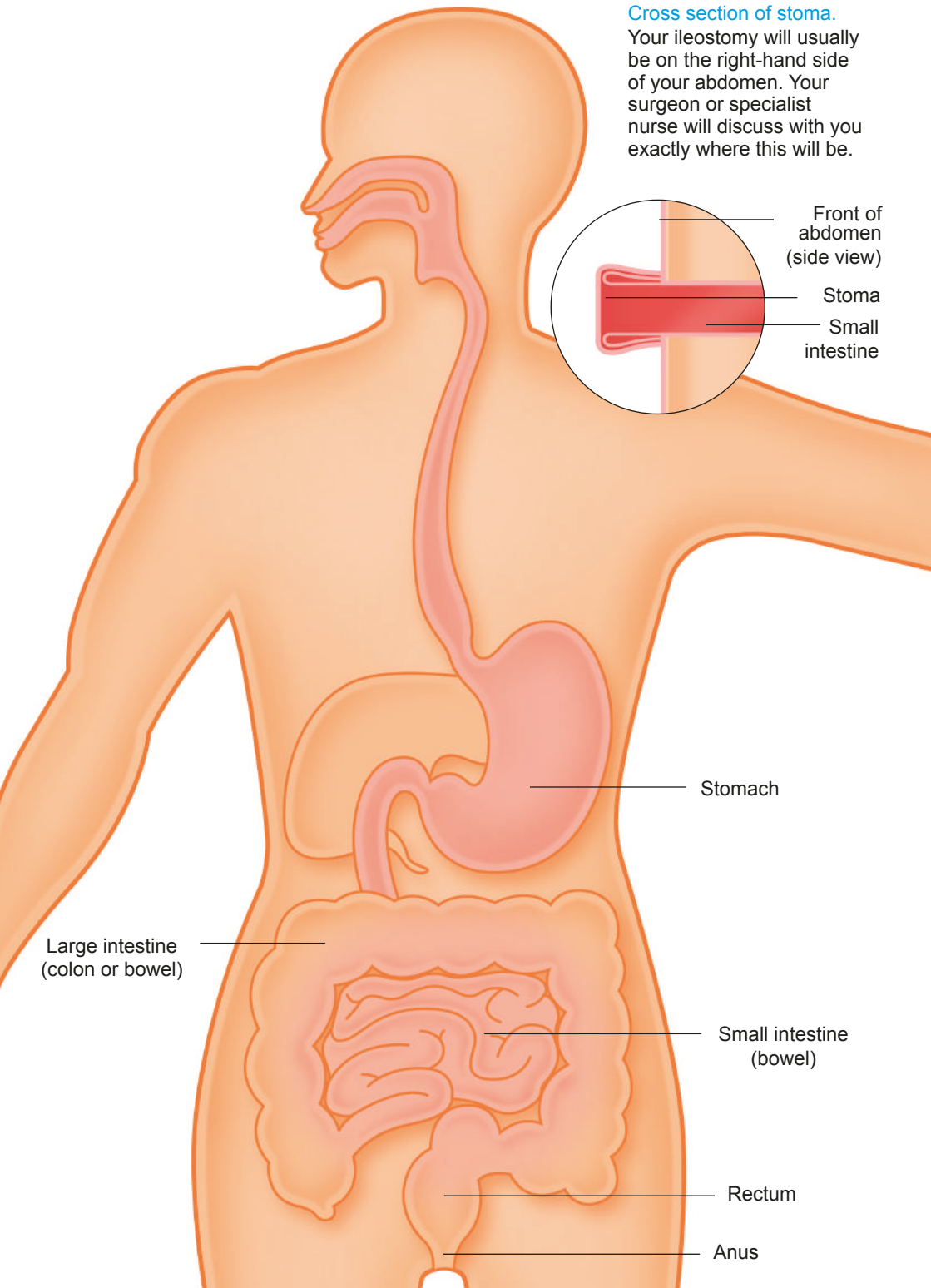
Your ileostomy will usually be on the right-hand side of your abdomen. It looks a bit like the inside of your mouth and is soft to touch. Its normal colour is pinkish-red, it should be moist, and it may stand out by a few centimetres. Your surgeon or specialist nurse will explain whether this will be an end or a loop ileostomy, as shown in the diagram below, and will also explain the differences.

It is usually referred to as a stoma and that's what we'll call it from now on. At first the stoma will be swollen and will take a couple of months to reduce in size.



Cross section of stoma.

Your ileostomy will usually be on the right-hand side of your abdomen. Your surgeon or specialist nurse will discuss with you exactly where this will be.



Front of
abdomen
(side view)

Stoma

Small
intestine

Stomach

Large intestine
(colon or bowel)

Small intestine
(bowel)

Rectum

Anus

Will I always have the stoma?

Whether your ileostomy is permanent or temporary will depend on why you need your operation. Your surgeon will tell you which it is. If your surgeon plans to join your bowel back together again, you will need another operation at a later date.

This means you will need to learn how to manage your stoma and you will go home wearing a stoma bag. You will need to discuss all the facts with your surgeon and specialist nurse.

Where will my stoma be?

The stoma is usually on the right-hand side of your abdomen. It also needs to be on a part of your abdomen that isn't lost in folds of skin when you sit down or stand up.

Before your operation, the specialist nurse will usually mark where the stoma should be as a guide to the surgeon. It will be in a position where you can see it so that you can change your stoma bags easily. However, it may not always be possible to put the stoma in the exact position your nurse has marked. If you need a stoma in an emergency, it may

not be possible to decide upon a position beforehand.

How do I care for my ileostomy?

You will need to wear a stoma bag to collect your bowel motion. The stoma bag sticks to your abdomen and is designed to be emptied frequently. There are a wide variety of stoma bags to choose from, and your specialist nurse will discuss which is best for you. Your specialist nurse will explain how to look after your stoma and how to change your bag.

Most stoma bags are about the same size as this page and all are designed to be worn under your normal clothes. Many have air filters to allow the wind to escape from the bag gradually and also to absorb any smells. Most stoma bags are also covered with soft material to make them comfortable to wear. You can leave your stoma bag on or take it off when you bath or shower - it's up to you. Water cannot get into the bag or the stoma.

If your rectum has not been removed you may still feel like you need to go to the toilet. Sit on the toilet and if you pass blood, mucus, wind or bowel motion, deal with it in the usual way.



Will it smell?

Yes, but only when you are emptying or changing your bag. Remember that everyone produces smells when they go to the toilet. There should not be a smell at any other time because the bags are odour-proof.

Leaving hospital

When you leave hospital, your specialist nurse should give you some of the stoma bags of your choice. You will need to get a prescription for more stoma bags and your specialist nurse will be able to give you advice on this. Your GP will give you a prescription which you can then give to your specialist supplier or local chemist who will supply your stoma bags.

You can choose where you get your bags from and which make of stoma bag you use. You need to feel as comfortable as possible when you're wearing the bags, so choose the ones that suit you best.

Prescription charges

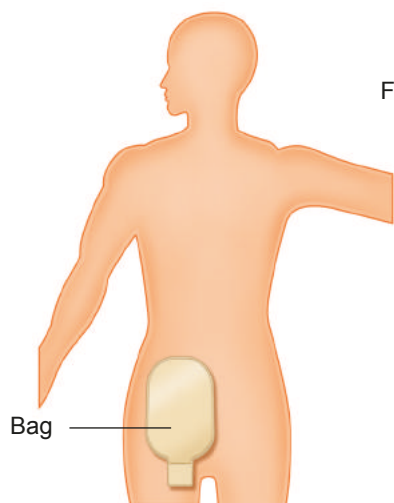
If you live in England, are under the age of 60 and will need a permanent stoma you will need to apply for a prescription exemption

certificate by obtaining form FP92A from your GP surgery. Once you have this certificate you will be entitled to receive your prescription free of charge.

You will not be entitled to free prescriptions if you have a temporary stoma and live in England. If you think you will have to pay for four or more prescriptions in three months, or 15 or more items in 12 months, you may find it cheaper to buy a prescription prepayment certificate (PPC). If you have been told that your stoma may be temporary, please discuss this with your surgeon or specialist nurse and your GP.

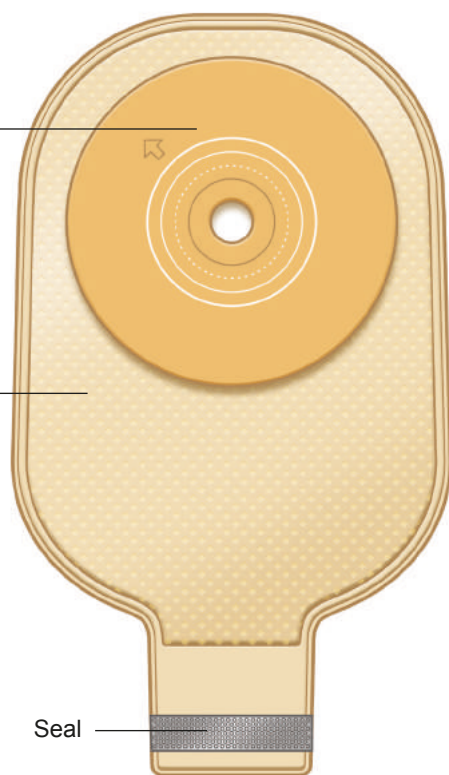
Prescriptions in Scotland, Wales and Northern Ireland are free of charge. Different schemes operate in Ireland and your current circumstances may determine which one applies to you. Your GP or specialist nurse will be able to provide you with further information.

IA's booklet: 'Going Home - for all round support for an ileostomy' provides additional information and is available on joining IA.



Flange

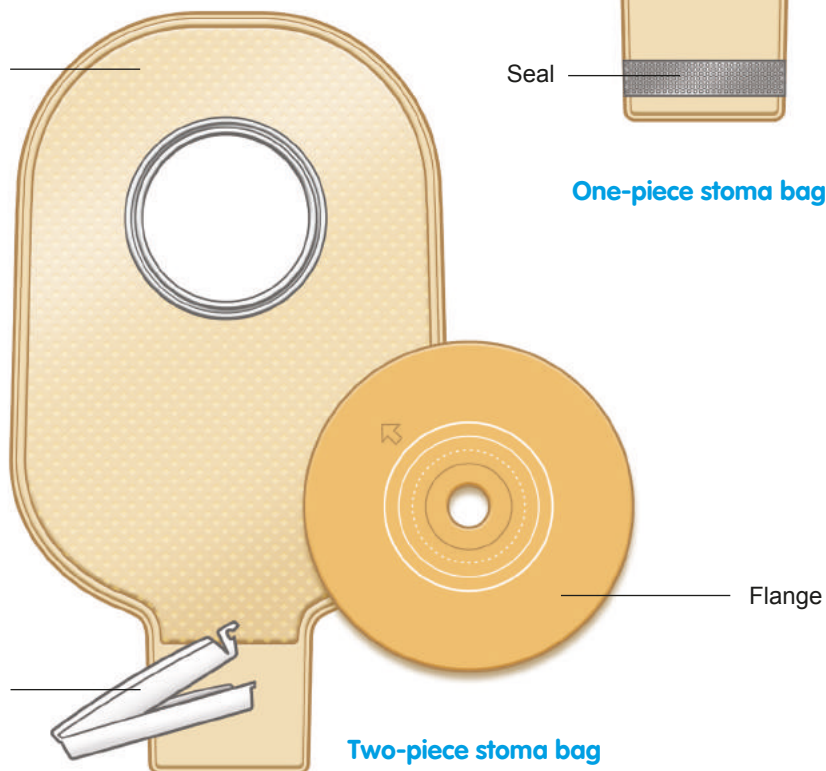
Bag



One-piece stoma bag

Bag

Clip



Two-piece stoma bag

Dealing with your used stoma bags

Empty the contents of your stoma bag down the toilet, seal the used stoma bag, put it in a plastic bag and put it in your household dustbin. Don't flush the bag down the toilet.

Storing your stoma bags

Make sure you store your stoma bags in a cool, dry place away from direct heat or sunlight.

Types of bag

There are two main types of bag:

- The one-piece system sticks straight on to your skin.
- The two-piece system has a separate base plate (a flange) which sticks to your skin, and a bag attaches to this. You can change the bag without removing the flange.

What can I eat and drink?

You should try to eat regular, well-balanced meals. This can include all your favourite foods.

Remember to chew your food properly to help your digestive system. You may find that certain food produces more wind from your stoma than others. If this bothers you, simply cut down on this food and you will soon find a balance that is right for you.

It is important that you drink plenty of fluids, especially water. Alcohol is fine in moderation, but beer and lager can produce wind and cause the bowel motion from the stoma to become more liquid.

If you feel you are underweight or overweight, please discuss this with your specialist nurse.





Are there any things I should and shouldn't do?

The important thing is to be guided by your body.

- Do give yourself time to get over your operation.
- Do take plenty of rest and let your body recover.
- Do try to take short walks to begin with and remember you have to be able to get home again.
- Don't lift anything heavier than a kettle for about eight to 12 weeks following your stoma surgery and, even then, don't overdo it (this can vary depending on your operation).
- Don't do abdominal exercises for about eight to 12 weeks following your surgery, for example, sit-ups.
- Don't drive until at least six weeks after your surgery and you feel confident to do so. (You should also check with your motor insurer as policy conditions can vary.)

Will my stoma change my life?

In some ways it will. You've just had an operation. Your body has been altered and it may take a while to get used to how you now look.

However, that's as far as it should go and, with some adjustment, the rest of your life does not need to change. Talking to someone else who has an ileostomy might be helpful, and your specialist nurse can arrange this for you.

See IA's Visiting Service on page 18.

Can I go back to work?

Yes, but you will need time and rest so listen to your body. Everyone is different when it comes to how long it will take to get back to work and this depends on the type of work you do and the operation you have had. You should discuss this with your specialist nurse, surgeon or GP.



Can I go on holiday?

Of course you can. A stoma doesn't stop you from travelling, but do give yourself time. Start with a short trip and see how it goes. If in doubt, ask for advice. IA produces some useful information on travelling and your specialist nurse should be able to give you some advice.

Remember, when you are travelling abroad you will need insurance cover for any medical conditions you have. (Insurance companies call these 'pre-existing conditions'.) Above all, just get on with life and enjoy your holiday.



Hobbies and sports

Keeping fit and having interests is good for everyone and having a stoma shouldn't prevent you from doing most things. If you prefer, small stoma bags are available to use when you are swimming or playing sport. Your specialist nurse can give you details.

What about my sex life?

After your surgery, you can continue with a normal loving relationship.

Sometimes it may not be possible to continue in the same way as before your operation. Men may find it difficult to get or maintain an erection. Women may experience discomfort during sex. Trying a different position may help.

Your partner will be welcome to join in the discussions you have with your surgeon or specialist nurse if you would like them to.

Do speak to your specialist nurse. They will be used to discussing this subject with patients and their partners.

Pregnancy and contraception

Before your operation it is important for men and women to consider fertility issues, particularly if other treatments are part of your medical plan.

We recommend that you discuss this with your specialist nurse or GP. Oral contraceptives may not be fully effective, so you may need to consider another type of contraception. Many women have had normal successful pregnancies after an ileostomy.

Risks and benefits

Although your doctors and nurses have recommended this operation to form an ileostomy 'in your best interest', there are always risks with any surgery.

The risks from any operation relate to:

- anaesthetics
- blood clots and
- bleeding and infection

Your doctors and specialist nurses will describe the risks from your particular operation in detail, and these risks will be included in your 'consent to operation' form.

Please discuss these risks with your doctor and specialist nurse, but remember, the risks of not having the operation may be considerably greater than the risks of having the operation.

What should I do if I have a problem?

If you have any problems or concerns, always talk to your specialist nurse or GP. The sooner they are aware of any problem, the sooner they can help sort it out.

Changes to your stoma

If you notice any changes in the shape, colour or working of your stoma, talk to your specialist nurse or GP.

Leaks and accidents

Your stoma bag may leak occasionally. However, your stoma bag should not leak regularly, and you should speak to your specialist nurse or GP if this happens.

If your stoma shrinks

Check the size of your stoma regularly because it may shrink and you may have to change the hole size on your stoma bag.

Sore skin

Your skin could become sore for many different reasons. If this happens, your specialist nurse will be able to recommend the right treatment for you.

Bleeding

Don't panic if the outside of your stoma bleeds. This is fine and shows it is working normally. If there is a lot of blood, or if the blood comes from inside your stoma, you must contact your GP.

Smells

There will be a smell only when you are emptying or changing your bag. Remember that everyone produces smells when they go to the toilet. Your stoma should not smell at any other time because the bags are odour-proof.

Abdominal pains

Some discomfort is normal after an operation. This will gradually disappear and ordinary painkillers will help. However, if you have prolonged or severe pain you may need to contact your GP.

Hernias

If you notice a small bulge around your stoma, you may have a hernia and you may need to contact your GP.

Changes in how your stoma works

This is perfectly normal for the consistency of your bowel motions to change throughout the day. It is often related to what you eat and drink.

Dehydration

If you experience symptoms such as tiredness, leg cramps, thirst, light-headedness or headaches, you could be dehydrated so you should drink more.

Blockages

If the bowel motion from your stoma has stopped for longer than is usual or your bag contains a lot of watery fluid, you could have a blockage.

You could also have a blockage if:

- the colour, amount or consistency of your bowel motion changes significantly; or
- your stoma swells in size and becomes a deeper red colour.

You should contact your doctor or specialist nurse if you feel unwell with stomach pains, nausea (feeling sick) or vomiting.



Who can I ask for advice?

There is a lot of information available nowadays, including on the Internet. It is possible though that a lot of this information may not be relevant to you. So, if you do want to know more about anything to do with your stoma, all of the following will be able to provide practical help and advice.

- Your surgeon
- Your specialist nurse
- Your GP
- Your community nurse
- Ileostomy and Internal Pouch Association.

IA's Visiting Service

Some people find it helpful to meet other people with ileostomies who are now enjoying a full and active life.

IA's visitors are people like you. They are there to listen and support and offer a unique, non-medical perspective from personal experience, which can be invaluable in your recovery from surgery and the start of your new life.

Your specialist nurse can arrange this for you or you can contact IA if you think this will help.

Joining IA

IA provides support and guidance to people living with an ileostomy or an internal pouch; their family, friends or carers. With support across the UK and Ireland, our local groups are run by people living life after surgery and have personal experience that they share and use to guide others.

IA challenges the stigma often associated with living with a bag and empowers people to return to life after surgery to enjoy the

things they like to do - things that may have been suppressed due to a period of illness.

Our quarterly journal is available to members containing articles of a medical nature and how others are living life after surgery together with the latest product information.

To join IA visit www.iasupport.org or contact us for an application form using our contact details on the back of this booklet.

We all need some space sometimes, why not use this to jot down your questions or concerns...

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Ileostomy and Internal Pouch Association is a company limited by guarantee.
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