SecuriCare®

Ileostomy

A practical guide to stoma care

Putting you first

Foreword

Having ileostomy surgery can be a life-changing experience. For some, it is relief from a debilitating illness and for others a temporary measure to heal and prepare for further treatments. Although major surgery of this nature with a change of bodily function may disrupt a person's lifestyle, the advances in surgical techniques, specialist nursing care and the developments in ostomy equipment over the years help ease the journey to recovery.

Recovery can also be enhanced by the support available from ***ia***, whose main aim is to help those with an ileostomy or internal pouch return to a fully active and normal life as soon as possible after surgery. Established in 1956 as the Ileostomy Association by a group of people with ileostomies and some members of the medical profession, ***ia*** now has 54 member organisations throughout the UK and Ireland. These local groups, which are managed by volunteers, most of whom have an ileostomy or internal pouch, provide contact and meeting points. With a unique non-medical perspective based on personal experience, ***ia*** can offer practical help and encouragement pre- and post-surgery.

Literature such as this booklet also plays an important role, providing a reference point for information on all aspects of life with an ileostomy.

Anne Demick
National Secretary
ia (the ileostomy and internal pouch Support Group)

Contact details for ***ia*** can be found on page 27.

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Introduction

It is a worrying time when you learn that you need to undergo major surgery. It can be particularly traumatic when you learn that as a result of that surgery your bodily functions will not be the same – that you will have an 'ileostomy' and will not be able to pass motions in the normal way but will wear a 'pouch' on your abdomen.

You may not have heard of an ileostomy or a stoma before or have only a vague idea what one is. You may feel horrified and upset, or temporarily numb at the news. You may, on the other hand, feel relief that something is being done to relieve what may have been years of debilitating symptoms. Whatever your reactions and feelings, you will find hospital staff very understanding and supportive. They have helped a great many people through the same experience.

Very experienced nurses who specialise in stoma care will be there to care for you and help you with information, practical assistance, advice and reassurance about what having a stoma involves. A support organisation like the Ileostomy and Internal Pouch Support Group (***ia***) can help with advice and visits from other (happy, healthy) ileostomists. The creation of a stoma can not only be a life saving operation, but for many people (and there are thousands and thousands of people with ileostomies) it actually greatly improves the quality of their lives.

By the time you leave hospital you will be able to manage the pouches for your ileostomy. You will in your own way learn to cope and to come to terms with the change in your body and with your stoma. Caring support is also readily available within the community, so you won't feel alone. Soon, your stoma seems less important, and becomes just an everyday part of your life.

This booklet is intended to 'fill in' on some of the information you may have been unable to take in at the time of your surgery, to give you background information and practical advice about the day-to-day care of a stoma and to answer some of the queries that are bound to arise. It will also act as a reference source of other relevant organisations and of advice available.

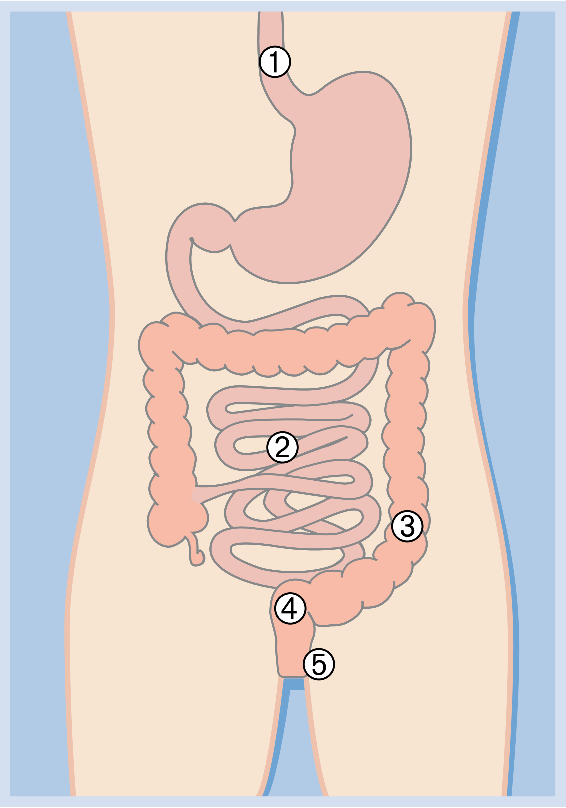
How the digestive system normally works

Digestion begins in the mouth where the food is chewed. Swallowed food passes down the oesophagus ① into the stomach.

The stomach acts like a liquidiser, churning the food in digestive juices until it is reasonably liquid and passing it into the ileum ② or small intestine.

The food passes along the small intestine (the walls of the stomach and intestines contain muscles that expand and contract to produce a wave like movement that urges the food onwards – this is called peristalsis).

Simplified diagram of the digestive system



① Oesophagus
② Small intestine (ileum)
③ Large intestine (colon)
④ Rectum
⑤ Anus

During its journey through the small intestine most of the nutrients in the food are absorbed into the body, leaving a fairly liquid mixture of indigestible matter and water.

The large intestine, or colon ③, has the job of taking water back into the body, leaving the indigestible or waste matter (faeces) in a semi-solid form.

At the end of the colon, waste material is stored in the rectum ④, before being expelled through the anus ⑤ .

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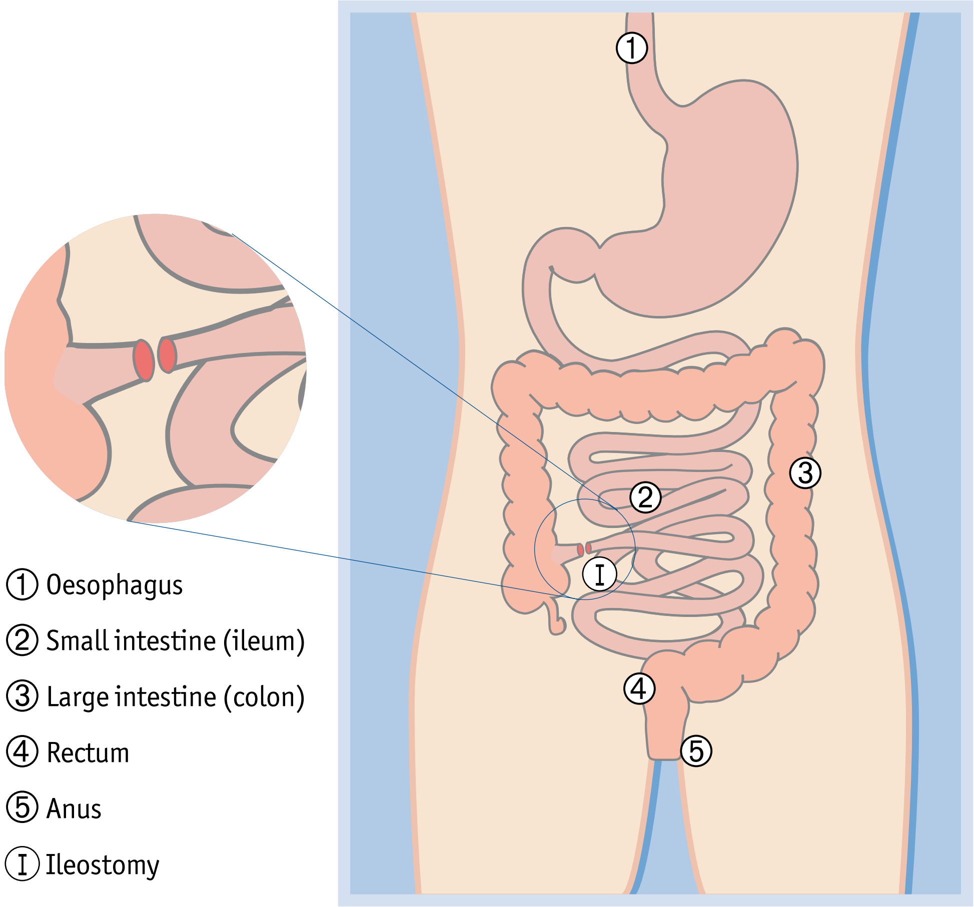
There are three types of stoma procedures: ileostomy, colostomy and urostomy.

An ileostomy usually involves removing, or temporarily bypassing the colon ③ and sometimes the rectum ④. Faeces cannot then be passed via the anus in the usual way.



① Oesophagus
② Small intestine (ileum)
③ Large intestine (colon)
④ Rectum
⑤ Anus
Ⓘ Ileostomy

To allow waste matter (faeces) to leave the body, the surgeon makes a small opening on the outside of the patient's abdomen and brings through the end of the small intestine (ileum) ②. This is a stoma and because it is a stoma created using the ileum, it is called an ileostomy.

(The words ostomy and stoma come from the Greek word meaning 'mouth' or 'opening').

An ileostomy looks like a small spout, deep pink in colour similar to the inside of the mouth. Although it looks raw, it has no feeling. Waste matter (faeces) comes out of the stoma and is collected in a special stoma pouch attached around it.

Mucous fistula

Sometimes, if the rectum has not been removed but is left in place, the cut end of that may also be brought to the surface to make a small opening called a mucous fistula. This usually needs little attention.

Consistency of the waste matter

Food from the stomach travels round the small intestine, where the nutrients the body needs are absorbed leaving just indigestible matter and water. This then leaves the body through the stoma. Because the waste matter has not travelled through the colon, much of the water in it will not have been absorbed. The waste material passed will therefore be runny and passed frequently. There is no control over this and a stoma pouch is usually worn at all times.

Why are ileostomies carried out?

Like any other major surgery an ileostomy is not undertaken lightly and doctors will only recommend it where absolutely necessary.

Although there are other causes, the main conditions that may give rise to the need for an ileostomy are covered by the general term ‘inflammatory bowel disease.’ This includes Ulcerative Colitis and Crohn’s disease.

Inflammatory bowel disease varies tremendously in its degree of severity and can cause a variety of symptoms. Having inflammatory bowel disease does not necessarily mean that an ileostomy will have to be carried out. Only in the more serious cases, where adults or children have suffered from severe, debilitating symptoms for some time or where emergency surgery becomes necessary, will an ileostomy be considered.

Ileostomies are sometimes created just as a temporary measure, to allow the remaining intestine a chance to rest and heal, and ‘reconnection’ takes place at a later date. A temporary ileostomy may be necessary in conjunction with the removal of a tumour or with the construction of an internal pouch. Your surgeon will advise if the ileostomy is just a temporary measure.

Whatever the reason for a stoma being created, many patients find that having an ileostomy, and thereby losing a badly diseased bowel, leads to a dramatic improvement in the quality of their lives and, for some, particular freedom in not having to plan their lives around the immediate availability of a toilet!

An ileostomy will not in itself stop anyone from leading a full and active life.

Before your operation

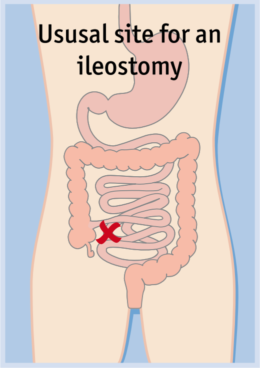
Members of the medical team will help to prepare you and advise you about the coming operation and answer your queries. The procedure will be carefully explained to you, and the doctor will tell you whether your ileostomy is going to be a permanent one, or if it is being created as a temporary measure.

It is quite likely that you will not be able to take in all the information at first. It may help to jot down any queries you have as you think of them, so that when you see the doctor you can remember what to ask.

In many hospitals specially trained stoma care nurses will be available to help you and your family. These nurses will be closely involved in your care and will make sure you have continued support in the hospital and at home. It may be helpful to meet another person who has experienced living with an ileostomy and this can be arranged, usually through the Ileostomy and Internal Pouch Support Group (***ia***).

Where will the stoma be?

An ileostomy is usually sited on the right side of the abdomen but sometimes if previous operations have been performed, leaving scars, the stoma is put on the left. Usually a mark is made on your abdomen before the operation. You can become involved in this planning by indicating what might suit you best, by sitting and standing and discussing what clothes you like to wear, and where the waistbands are likely to come.



Before you come into hospital for your operation, you may be given a chance to try wearing a pouch and to practice changing it at home. This can help you to become confident more quickly at looking after your stoma after your operation. This is called ‘fast track care’ and it can also shorten your stay in hospital after your operation.

You should also make sure you can see where the stoma will be, to make appliance changes more easy. Before the operation you may have your bowels emptied and a washout given – medical staff will advise.

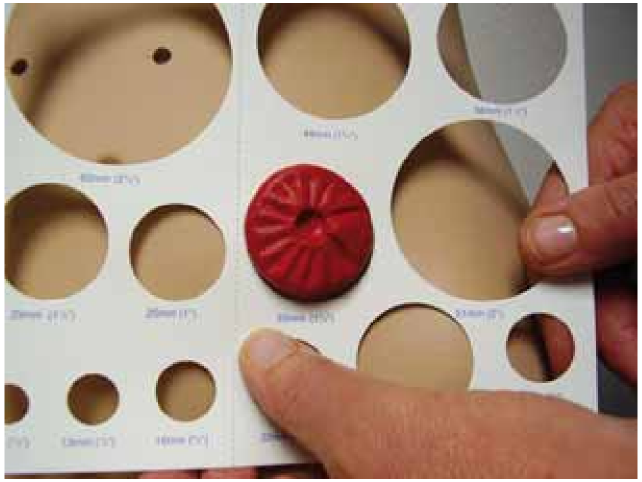
After your operation

When you come round after surgery you will find various tubes attached to you and will feel some discomfort and weakness. This is quite normal after any major surgery. All the tubes and drains will gradually be removed during the following days and you will start to drink and eat. Your stoma will begin to work soon after the operation, possibly with a large amount of waste matter.

You will be encouraged to help with looking after your ileostomy as soon as possible. At first the stoma will be swollen, surrounded by stitches, and the pouches used at this stage are transparent and may be cumbersome. The swelling will soon begin to go down, however, and the stitches disappear by themselves, or will be removed.

The stoma will become smaller and less obtrusive. (The stoma will continue to become smaller even after you are allowed home and you will need to check that your pouches are still a good fit.)

You are likely to be in hospital for somewhere between five to ten days. The stoma care nurse will teach you how to change pouches, how to measure the stoma to see that the aperture of the stoma pouch is correct *(see pic)* and how to care for your stoma generally. The stoma care nurse will also fit you with a more discreet type of pouch.



Using a measuring guide to ensure that a pouch with the correct aperture is fitted.

Leaving hospital

When you leave hospital you will be given details of how to contact your stoma care nurse for information or advice. You will also be given an appointment for your first check-up and your family doctor will be notified of your return home. You will be given enough supplies of pouches to keep you going for the time being, plus a list of the items you use so that you can ask your doctor for a prescription.

Blue disposal bags and wipes are supplied free to patients ordering supplies through the SecuriCare Home Delivery Service. For information call free on 0800 585125.

When you return home

Support is available from your stoma care nurse and/or community nurse. The stoma care nurse can be contacted by phone, and many hold regular stoma clinics. The ***ia*** is very helpful and supportive (address at the back of this booklet).

Ask your doctor to give you a prescription for the stoma care items you need. You are exempt from charges if you are over 60. People of any age are exempt from charges if their ileostomy is permanent. Apply for exemption on the special FP92A form given to you in hospital or available from your doctor or local Department of Health office*. The form should be signed by your hospital doctor or GP.

How to obtain stoma care supplies

Your doctor writes you a prescription. You can then go to your local retail chemist in the normal way. They may need a little time to obtain the items you need, so do not wait until supplies are too low.

Supplies may also be obtained direct from the manufacturers of the pouches you use, and also from general ostomy suppliers. You will need to send your prescription to these organisations. Manufacturers are also very helpful if you need emergency supplies.

If you would like information about the wide range of stoma care pouches and accessories plus information about the SecuriCare Home Delivery Service, please contact the Careline on

Freephone

0800 585125

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* Applies to England only.

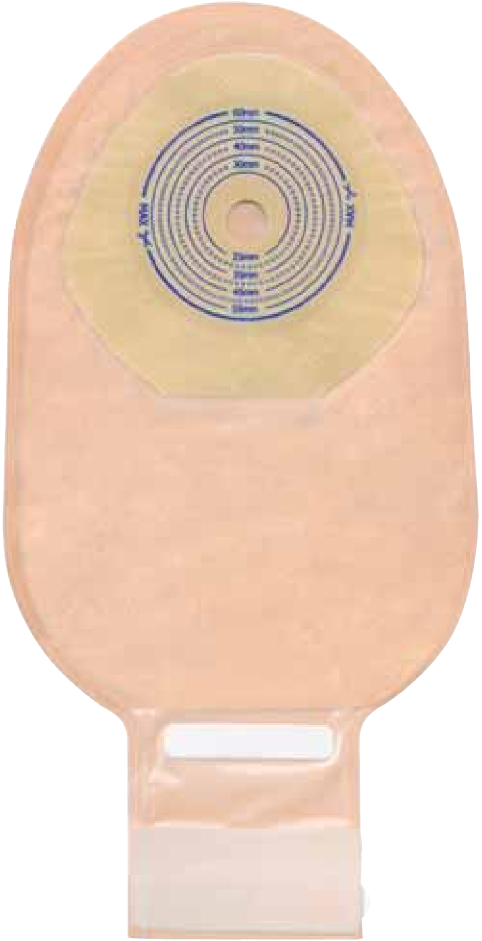
Your stoma care nurse will be able to show you a selection of pouches and accessories available.

The waste passed out from an ileostomy is quite liquid and the volumes involved are around 300-700ml per day (roughly ½ to 1 pint). A drainable pouch, fastened at the bottom, is used so that the pouch can be unfastened and the contents emptied into the toilet as often as necessary during the day. There are basically two types of drainable pouches – ‘one-piece’ and ‘two-piece.’

One-piece pouches

These simple pouches are very popular. They are fixed around the stoma by means of a self-adhesive wafer. The pouch may be unfastened at the bottom and emptied when necessary. It is normally removed and replaced with a fresh one every one to three days.

Some drainable pouches have a filter which allows wind to escape. This prevents the pouch ‘ballooning’ under clothes.



The type of self-adhesive wafer and precise means of attaching the pouch vary with different types and makes, so it is worth experimenting to find one that suits you, your skin and your way of life. Welland pouches, for example, are affixed with a special thin and flexible 'skin protector' called HyperFlex® Plus. This can help to avoid soreness around the stoma.

The material the pouches are made from also varies. The most modern ones are very fine, soft and discreet, with a backing that is very comfortable next to the skin. Most manufacturers are only too happy to provide free samples for you to try (and you can also keep up with the latest developments this way).

Two-piece pouches

These pouches have a flange (or baseplate) that fits round the stoma and may stay in place for several days, with separate pouches that are attached to it.

The baseplate is left in position and a new pouch is fixed to it when required. The baseplate is usually changed once or twice a week. The advantage of a two-piece pouch is that the pouch can be replaced numerous times without disturbing the skin around the stoma.

Aperture sizes

The size of a stoma varies in diameter and stoma pouches are available with different sized apertures or holes. Most appliance manufacturers supply a measuring device to check the size. Find the correct size measuring ring which fits comfortably and snugly round the stoma, without touching it or cutting in. If the stoma is irregularly shaped, it is best to cut your own pattern to fit, using the measuring device as a basis, or using the pouches printed cutting guides. Alternatively, call the SecuriCare Careline on 0800 585 125 for assistance.

In the months after surgery the stoma size usually reduces slightly. Check carefully to ensure a good fit – many problems with leakage or skin soreness are caused by using a pouch with the wrong size aperture.

Medical adhesive remover spray and wipes

Skin barrier

Ostomy deodorant

Motion management sachets

Hydrocolloid washers

Hydrocolloid flange extenders

Stoma care accessories

The importance of cleaning carefully and gently and of taking care of the skin around the stoma to avoid soreness cannot be emphasised too much. The waste matter in the stoma pouch contains digestive juices which can harm the skin if they come into contact with it. If the skin becomes sore, it can be difficult to heal and to get a good fit with the stoma pouch.

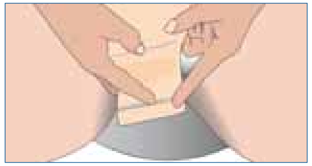
Various barrier preparations which help protect the skin are available on prescription. These include pastes, seals, powders, sprays, creams or liquids, and handy disposable wipes that can just be wiped around the area which when dry form an invisible protective skin.

Washers and flange extenders, belts, deodorants and motion management sachets are also among the many stoma care accessories available.

An ileostomy pouch is drained as often as necessary during the day. One-piece pouches are usually replaced with a new one every 2-3 days according to personal preference. The flange of a two-piece system is usually replaced once or twice a week.

Draining the pouch

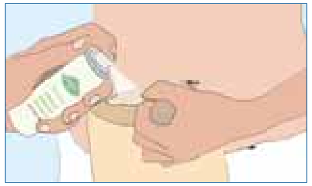
You can either sit on, kneel or stand beside the lavatory. Unfasten the bottom of the pouch and empty the contents into the lavatory. The outlet of the pouch can then be cleaned with tissues before being refastened.



Emptying the pouch

Removing the pouch

Make sure you have everything you need immediately to hand. Empty the pouch first. Then, gently and slowly, supporting the skin with one hand, ease off the pouch or flange. A medical adhesive remover can help to remove the flange.



Spraying Appeel® medical adhesive remover to ease removal of pouch

The used pouch can be rinsed out and placed, with any tissues etc. into a plastic disposal bag, or wrapped in newspaper and put in an ordinary plastic bag. Seal the disposal bag and dispose of it in the household rubbish.

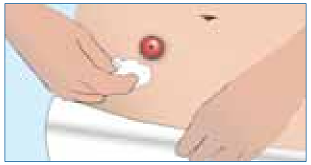
Cleaning the stoma area

Clean gently around the stoma with plain warm water (do not rub), using soft wipes or tissue. Dry the skin thoroughly by gently patting with tissue or kitchen roll – again, do not rub.

Cleaning the skin around the stoma with a soft wipe

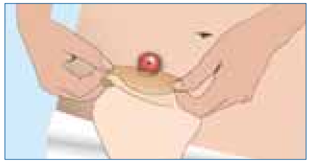
Measuring the stoma aperture

Cutting the stoma aperture to the correct size

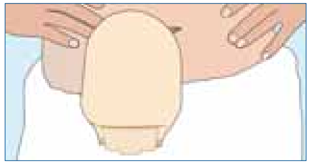


Applying skin barrier to protect the skin around the stoma

Removing the protective cover from the flange



Position hole in flange over stoma and gently smooth on to skin



Pouch attached

If necessary, check the size of your stoma, using a measuring card. If your pouch needs adjusting, cut the opening in the flange to the required size using a pair of pouch cutting scissors. Alternatively, SecuriCare can cut your pouches to the correct size from a template.

A skin barrier may be used if required before fitting a new pouch or baseplate around the stoma. Make sure the drainable outlet of the new pouch is fastened at the bottom.

Replacing the appliance

Remove the protective cover from the adhesive flange. It may help to warm the flange with your hands or even a hair dryer before removing the protective cover. This will help the flange to adhere better to the skin.

Fit pouch ensuring there are no creases in the adhesive. Allow a few minutes for the adhesive to mould to the skin.

DO NOT ATTEMPT TO BURN POUCHES AS THE PLASTIC GIVES OFF TOXIC FUMES WHEN BURNT.

Food

Once you have recovered from your operation and are eating to normal foods, you may find you have a much better appetite than before.

Some foods, however, can cause digestive problems, whether you have a stoma or not.

You do not have to eat any special foods, but keep an eye on your diet – trial and error will show if there are any foods that particularly upset you, e.g. giving you wind or causing a blockage of the stoma. Experiment and if you think a certain food has given you problems, don’t eat it for a few weeks and then try a small portion.

Some food can be difficult to digest and may cause a blockage of the stoma (e.g. sweetcorn, nuts, fruit skins or vegetable skins, coconut). This is usually only temporary but it will cause severe colic pains and these foods are best avoided.

Certain foods have a tendency to produce more wind (e.g. beans and onions) and some people prefer to avoid these foods in excess.

Spicy curries and some other foods can cause looseness or mild diarrhoea. This is not a problem unless the diarrhoea is severe (but you will have to empty the pouch more frequently!).

You are your own best judge of what you eat. In all likelihood you will be able to enjoy a wide and varied diet.

For more information see SecuriCare’s Nutritional Advice booklet.

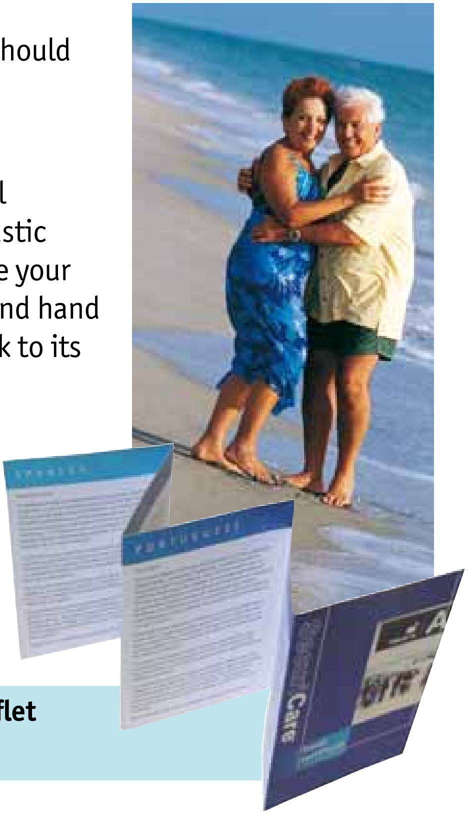
Drink

You will probably find that you are thirstier and need to drink more than you did previously. This is because you lose more fluids than you used to (your colon is no longer there to reabsorb the liquid and some of the minerals from your digestive system's waste matter). So drink plenty of fluids (and take a little more salt to replace that lost).

How about alcohol?

Alcohol in moderation will not harm you, although large quantities of beer or lager will mean that the pouch will need emptying more often and may give you wind.

Travelling



Travelling is no problem and an ileostomy should not prevent you from taking trips abroad.

Carry a travel kit, packed in a toilet bag, containing: clean pouches, tissues, medical adhesive remover, barrier wipes if used, plastic disposal bag. You can then empty or change your pouch wherever there is access to a toilet and hand basin. SecuriCare provides a free travel pack to its home delivery customers.

Pack a good supply of stoma pouches and accessories in your hand luggage in case your suitcases go astray. SecuriCare can provide you with a travel certificate in foreign languages explaining about ileostomies.

For more information or a Travel Advice leaflet please call Securicare free on 0800 585125

When travelling to a hot country bear in mind that you need more fluids and become dehydrated more easily. Take extra salt with you, together with supplies of rehydrating fluids, such as Rehidrat, and any anti-diarrhoeal preparation your doctor advises.

Sex life

It's likely to be the last thing on your mind at first. After convalescing from the operation, however, you may feel much fitter and healthier than before and find that love-making may be more satisfactory.

After such major surgery it is bound to take your body some time to get back to normal and there may be temporary nerve damage or scar tissue to contend with. So don't be in too much of a hurry, take your time. You may also feel a little shy at first because of the change in your body and because of the stoma pouch. Pouch covers can help, or you may like to treat yourself to some appealing underwear or nightwear (perhaps a lacy 'teddy', silk pyjamas or boxer shorts) that you can wear during love-making.

Some positions may be less comfortable than others (e.g. for women the traditional 'missionary' position), so take the opportunity to enjoy yourself experimenting.

If you have problems, or if you are entering into a new relationship and would like advice, specialist help and counselling on the subject is readily available. Don't wait too long, speak to your stoma care nurse or contact one of the support organisations like the ***ia*** or Relate National Marriage Guidance.

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Contraception

Having a stoma should not affect your fertility. However for women, the contraceptive pill may not be the best answer as it may be passed through the body before being fully absorbed. Discuss this with your stoma care nurse or GP.

Pregnancy

Many women with ileostomies have had successful pregnancies. If you want to try for a baby, discuss the matter with your doctor or stoma care nurse.

_ia_ – the Ileostomy and Internal Pouch Support Group

Peverill House, 1-5 Mill Road
Ballyclare, Co. Antrim
Freephone: 0800 0184724

Will people be able to tell I have an ileostomy?

The answer to that is NO – today's stoma pouches are very slim and discreet. Wear what you like and what's comfortable (see below for sportswear). Have you ever seen anyone who you thought looked as though they had an ileostomy?

What about sports?

No problem – the only sports you might prefer to avoid are the very rough physical contact ones. Patterned one-piece costumes disguise any slight bulges for female swimmers, while males might prefer fairly high-waisted boxer type shorts. Baggy T-shirts are great cover-ups at any time, but particularly over leotards for ladies' keep-fit.

Whom should I tell?

It's entirely up to you and is a very personal decision. If you've been poorly with colitis for a while, however, your friends and relatives may wonder why you are suddenly so much better!

What about odour when I empty/change my pouch?

No more than anyone else's when they go to the loo (and may even be less)!

Baths and showers?

Yes, either with the pouch in place or, at times of inactivity of your stoma, without a pouch on.

Can I take medicines?

Yes, but remind your GP, if necessary, that you have a stoma – some tablets can go through and come out unchanged at the other end!

Will my life assurance be affected?

All insurance companies you deal with should be notified about your ileostomy. The ***ia*** can refer you for advice if there are any problems.

Surface bleeding from the stoma

A slight smear of blood on the wipe when cleaning the stoma is common and no cause for alarm. It can also occur if you are too vigorous in your cleaning routine or suffer a slight knock.

Bleeding from inside the stoma

This is not normal. This or any change in stoma size should be reported to your doctor.

Change in stoma colour

If the stoma suddenly changes colour, e.g. becoming dark or blueish, check to see it is not being constricted in any way and inform your doctor at once.

Constipation

You cannot be constipated with an ileostomy but if the waste matter in your pouch seems too thick, drink extra fluids.

Diarrhoea

Diarrhoea can cause dehydration. Drink plenty of fluids to replace that lost. If you think that a certain food has affected you, leave it out of your diet for a few weeks and then try again. If you have frequent or severe diarrhoea (or persistent vomiting) seek medical advice. If your ileostomy output is persistently watery, or if you need to empty your pouch very frequently, ask your stoma nurse for advice.

Skin soreness

Check the aperture size of pouch is correct. Change your appliance only when necessary, and do so slowly and carefully. Gently ensure surrounding skin is absolutely clean and dry. Barrier wipes and creams may help. Try a pouch with better skin protection. Allergies occasionally occur – consult your doctor or stoma care nurse.

Leaks

Leaks shouldn’t happen. Check to make sure the pouch is applied properly and that you are using pouches with the correct size aperture. Pouches vary in the degree of security offered, so try other types if you continue to have problems You can also use washers and flange extenders to prevent leakage. Don’t put up with these problems – speak to your stoma nurse.

Flatulence or gas

This can be caused by certain foods and can’t be controlled. Some say that eating yogurt can help. Experiment to see which foods cause it, e.g. cucumber, beans, fizzy drinks, nuts.

No faeces going through into the pouch, associated with severe pains – seek medical advice.

Discharge from the Rectum (back passage)

If your rectum was not removed, you may still pass mucus (jelly/slime) from your back passage. This is normal, but if it is frequent or causes you discomfort tell your stoma nurse or doctor. Obvious bleeding or other discharge should also be reported.

If you are concerned about any of the above symptoms, please contact your local stoma nurse.

Associations and support groups

_ia_ – the Ileostomy and Internal Pouch Support Group
National Secretary
Peverill House
1-5 Mill Road, Ballyclare
Co. Antrim BT39 9DR
Freephone: 0800 0184724

Macmillan Cancer Relief
89 Albert Embankment
London SE1 7UQ
Freephone: 0808 8080000

National Association for Colitis and Crohn's Disease
4 Beaumont House
Sutton Road, St Albans
Hertfordshire AL1 5HH
Telephone: 0845 1302233

Royal Association for Disability and Rehabilitation (RADAR)
12 City Forum, 250 City Rd
London EC1V 8AF
Telephone: 020 7250 3222

Colostomy Association
Richard Bray – General Manager
2 London Court, East St
Reading RG1 4QL
Freephone: 0800 3284257

NASPCS
(National Advisory Service to Parents of Children with a Stoma)
51 Anderson Drive, Darvel
Ayrshire KA17 0DE
Telephone: 01560 322024

Relate National Marriage Guidance
To find your nearest Relate
Telephone: 0300 100 1234

Websites

www.colostomyassociation.org.uk	Colostomy Association
www.cancerbacup.org.uk	CancerBACUP
www.clinimed.co.uk	CliniMed Ltd
www.bowelcanceruk.org.uk	Bowel Cancer UK
www.the-ia.org.uk	*ia* – the Ileostomy and Internal Pouch Support Group
www.macmillan.org.uk	Macmillan Cancer Relief
www.nacc.org.uk	National Association for Colitis and Crohn's Disease
www.naspcs.co.uk	National Advisory Service to Parents of Children with a Stoma
www.radar.org.uk	RADAR
www.relate.org.uk	Relate National Marriage Guidance
www.securicaremedical.co.uk	SecuriCare (Medical) Ltd
www.uagbi.org	Urostomy Association

Notes

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