

SecuriCare



Ileostomy

A practical guide to stoma care



Foreword

Stoma care in the U.K. has changed considerably since 1945 when Dr Lionel Hardy, a senior physician in Birmingham who was specially interested in ulcerative colitis, brought back from America a few samples of rubber pouches and some tubes of adhesive.

Dr. Hardy asked Mr. Bryan Brooke (later Professor) to carry out ileostomy operations on some of his patients in a way which would allow the new pouch to be used, and stoma pouches began to be manufactured in Birmingham.

Since then surgical techniques have been further developed and ileostomy equipment which would have been beyond the dreams of those who had their ileostomies in the 1950s is now freely available.

The aim of **ia** is to help people who have an ileostomy operation to return to a fully active and normal life as soon as possible. We and they are able to achieve this thanks to Lionel Hardy and Bryan Brooke, to all the physicians and surgeons who have followed their lead, to stoma care nurses, and to companies like CliniMed, who not only supply high quality stoma care products for ileostomists but also provide excellent literature such as this booklet.

Bruce Mckenzie,

Former National Secretary.

ia – the Ileostomy and Internal Pouch Support Group.

SecuriCare is one of the UK's leading stoma care companies and it is part of a British Healthcare group. We run a specialist home delivery service for stoma goods and also provide stoma care nursing in hospitals and in the community. If you would like any further support or guidance please call our Careline on **0800 585 125**.

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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.

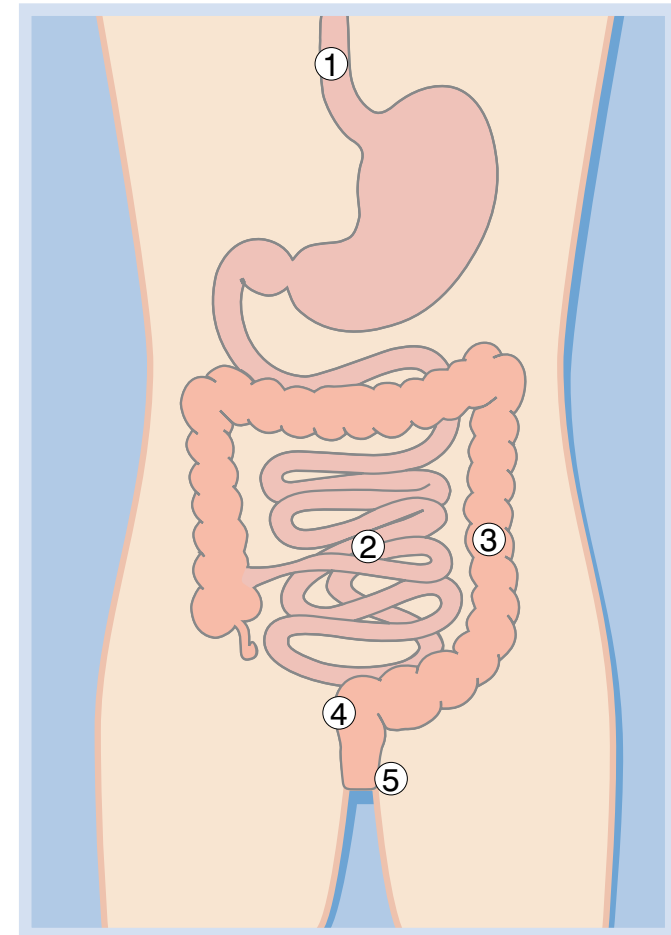
Very experienced nurses who specialise in stoma care will be there to care for you and help you with information, practical assistance, advice and reassurance about what having a stoma involves. A support organisation like the Ileostomy and Internal Pouch Support Group (**ia**) can help with advice and 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 you will get back to normal 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

Simplified diagram of the digestive system



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

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).

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.

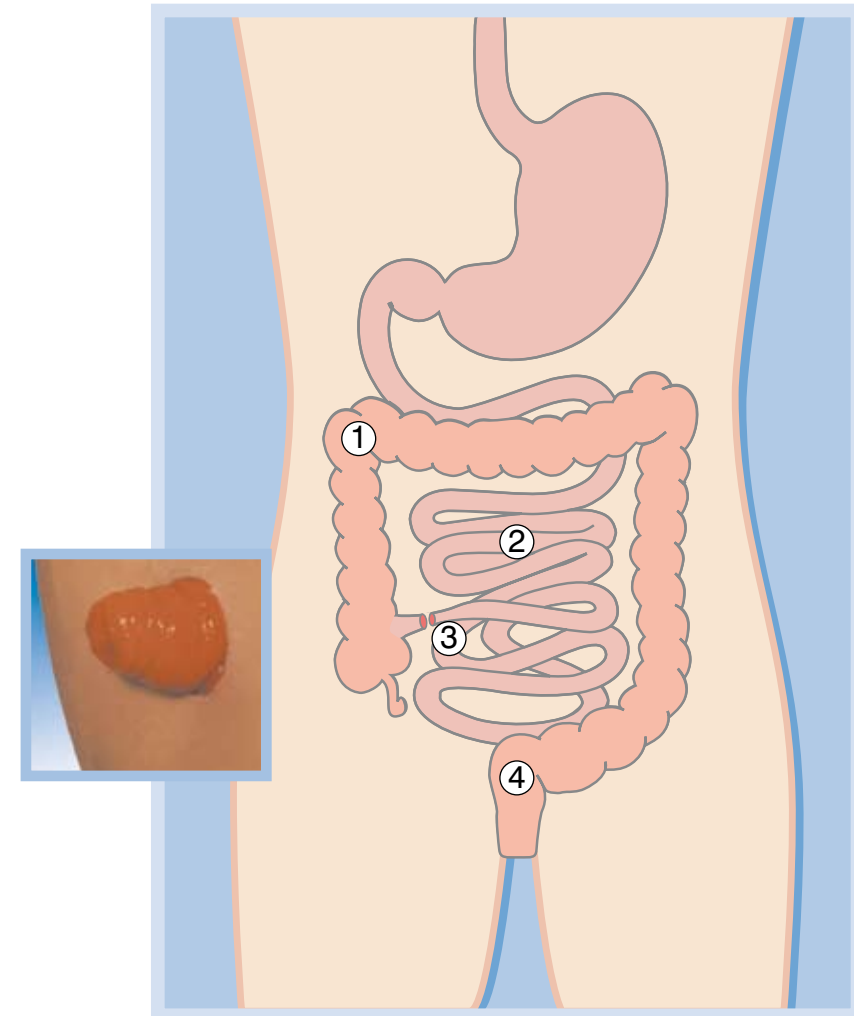
At the end of the colon, waste material is stored in the rectum (4) before being expelled through the anus (5).



What is an ileostomy?

An ileostomy usually involves removing the colon (1) and sometimes the rectum (4). Obviously, motions cannot then be passed in the usual way.

Simplified diagram



- | | |
|---------------------------|-------------|
| ① Large intestine (colon) | ③ Ileostomy |
| ② Small intestine (ileum) | ④ Rectum |

What is a 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 and attaches to the surface the end of the remaining small intestine or ileum (3). 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.

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. 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. You can contact your stoma care nurse for further advice on this procedure.

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. Day to day care of the stoma, however, remains the same.

Other types of stoma

Colostomy

A similar type of procedure to an ileostomy is a colostomy. Here the opening is made into the colon (large intestine), rather than the ileum (small intestine). Because part of the colon remains and does its job of absorbing water from the gut contents, the faeces evacuated from a colostomy are often more solid than from an ileostomy (dependent on how far along the colon the stoma is created). A colostomist will usually pass (semi-solid) motions only once or twice a day and uses a different type of non-drainable, or 'closed', stoma pouch which is changed completely once or twice a day.

The average age of people with colostomies tends to be older than those with ileostomies.

Urostomy

A different type of stoma, the urostomy is nothing to do with the digestive system, but is an opening made to divert urine from the body.



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.

Symptoms

Inflammatory bowel disease varies tremendously in its degree of severity and can cause a variety of symptoms. These include (amongst others) diarrhoea, abdominal cramps or discomfort, weight loss and blood in the motions. Suffering from these symptoms does not necessarily mean inflammatory bowel disease and, similarly, having inflammatory bowel disease does not necessarily mean that an ileostomy will have to be carried out – symptoms can be mild or sporadic and even the more severe ones can often be controlled by medicine. Only in the more serious cases, where adults or children have suffered from severe, debilitating symptoms for some time; where physical problems dictate; or where emergency surgery becomes necessary will an ileostomy be considered.

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 WC!

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

In hospital

Before surgery

Members of the medical team will help to prepare you and advise you about the coming operation and answer your queries. The procedure involved will be carefully explained to you, and the doctor will tell you whether your ileostomy is going to be a permanent one (and whether there is any chance of a reversal in the future) or if it is being created as a temporary measure and when you can expect further surgery.

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 senior staff called 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 is often 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 help the staff 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.

In hospital

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

After surgery

When you come round after surgery you will have a number of drips, tubes, catheters etc. attached to you and you will feel some discomfort and weakness. All the tubes and drains will gradually be removed during the following days and you will start to take fluids and light foods. Your stoma will begin to be active within a few days.

You may not want to look at your ileostomy at first – do not worry, the nurses will manage it for you. The stoma will be swollen, surrounded by stitches, and the pouches used at this stage are large, transparent and slightly cumbersome. The swelling will soon begin to go down, however, and the stitches disappear by themselves.



In hospital

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 1 and 3 weeks. 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 and how to care for your stoma generally. The stoma care nurse will also fit you with a more discreet type of pouch.

When you leave hospital you will be given an appointment for your first check-up and your family doctor will be notified. You will be given enough supplies of pouches etc. to keep you going for the time being. A list of the items you need will be given to you.

When you return home you will receive visits from your stoma care nurse and/or community nurse. The stoma care nurse can also be contacted by phone, and many hospitals hold regular stoma clinics. The **ia** is very helpful and supportive (address at the back of this booklet).



At home

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 prescription charges if their ileostomies are permanent. Apply for exemption on the special P11 form which will either be given to you in hospital or is available from your doctor.

How to obtain stoma care supplies

Your doctor writes you a prescription. You can then have your prescription dispensed by 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 manufacturer 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 please contact the Careline on

Freephone 0800 585125

Stoma pouches

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 1/2 to 1 pint). A drainable pouch clamped shut at the bottom is therefore used so that the pouch can be unclamped and emptied 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 unclipped at the bottom and emptied when necessary. When changing a pouch for a fresh one, the whole pouch is gently removed and a new one applied in its place.



Some drainable pouches offer the choice of having a filter. The existence of a filter helps wind to escape easily thus preventing ballooning under clothes.

Stoma pouches

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 stays 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.



Stoma pouches

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 which are available with cutting guides printed on.

In the months after surgery the stoma size usually reduces slightly while it is settling down. 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.



Stoma pouches

Other 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 get it 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.

Free disposal bags (to put used stoma pouches in), belts and deodorants are also among the many stoma care accessories available.



Changing a stoma pouch

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.

Changing the appliance

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.

The used pouch can be rinsed out and placed with any tissues etc. into one of the handy sealable plastic disposal bags supplied by some manufacturers or wrapped in newspaper and put in an ordinary plastic pouch. Some ileostomists keep a pedal bin with a polythene liner in the bathroom to put their used pouches in.

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.

A skin barrier may be used if required before carefully smoothing on a new pouch or baseplate around the stoma. Make sure the new pouch is closed at the bottom.

NEVER FLUSH USED POUCHES DOWN THE TOILET AND DO NOT ATTEMPT TO BURN POUCHES AS THE PLASTIC GIVES OFF TOXIC FUMES WHEN BURNT.

Back to normal

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, spare closure clip, tissues, 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 provide you with a free travel pack when you place your first order.

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



Back to normal

When travelling to a hot country bear in mind that ileostomists need more fluids than most 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.

Food

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

As everyone knows, however, some foods 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.

Any blockage caused by food (e.g. sweetcorn, nuts, fruit or vegetable skins, coconut) is usually only temporary but it will cause severe colic pains and these foods are best avoided.

Some foods have a tendency to produce more wind (e.g. beans and onions) and some people prefer to avoid these foods when they are eating out.

Hot 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.



Back to normal

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.

Sex life

It's likely to be the last thing on your mind at first. After convalescing from the operation, however, you will feel much fitter and healthier than before and may 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. Bag covers can help, or best of all treat yourself to some appealing underwear or nightwear (a lacy 'teddy'? cami-knickers? silk pyjamas or boxer shorts?) that you can wear, if you like, 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.

Back to normal

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

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 medical adviser.



Pregnancy

Many women with ileostomies have had successful pregnancies, reporting no more difficulty than that of seeing over their bumps to change their stoma pouches! If you want to try for a baby, discuss the matter with your doctor or stoma care nurse.

Problems that may arise

1. **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.
2. **Bleeding from inside the stoma** – not normal. This or any change in stoma size should be reported to your doctor.
3. **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.
4. **Constipation** – you cannot be constipated with an ileostomy but if the waste matter in your pouch seems too thick, drink extra fluids.
5. **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. Severe diarrhoea (or persistent vomiting) – seek medical attention. If your ileostomy output is persistently watery, or if you need to empty your pouch very frequently, ask your stoma nurse for advice.
6. **Skin soreness** – check aperture size of pouch is correct. Change 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.
7. **'Accidents'** – shouldn't happen! Check to make sure the pouch is applied properly and/or 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. Don't put up with these problems – speak to your stoma nurse.

Problems that may arise

8. **Flatulence or gas** – 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.
9. **No faeces** going through into the pouch, associated with severe pains – seek medical advice.
10. **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.

Your questions answered

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 insurance 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.

Associations and support groups

ia – the Ileostomy and Internal Pouch Support Group

Anne Demick – National Secretary
Peveerill House
1-5 Mill Road, Ballyclare
Co. Antrim BT39 9DR
Freephone: 0800 0184724

CancerBACUP

3 Bath Place, Rivington Street
London EC2 3JR
Freephone: 0808 8001234

National Association for Colitis and Crohn's Disease

4 Beaumont House
Sutton Road, St Albans
Hertfordshire AL1 5HH
Telephone: 0845 130 2233

Royal Association for Disability and Rehabilitation (RADAR)

12 City Forum
250 City Road, London EC1V 8AF
Telephone: 020 7250 3222

Colostomy Association

Celia Waters – General Manager
15 Station Road, Reading
Berkshire RG1 1LG
Freephone: 0800 3284257

Macmillan Cancer Relief

89 Albert Embankment
London SE1 7UQ
Freephone: 0808 8082020

Urostomy Association

Mrs Hazel Pixley – National Secretary
18 Foxglove Avenue
Uttoxeter, Staffordshire ST14 8UN
Telephone: 0870 7707931

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

Harbert Gray College
Little Church Street, Rugby CV21 3AP
Telephone: 01788 573241

Websites

www.bcass.org.uk

www.cancerbacup.org.uk

www.clinimed.co.uk

www.bowelcanceruk.org.uk

www.the-ia.org.uk

www.macmillan.org.uk

www.nacc.org.uk

www.naspcs.co.uk

www.radar.org.uk

www.relate.org.uk

www.uagbi.org

– Colostomy Association

– CancerBACUP

– CliniMed Ltd

– Bowel Cancer UK

– **ia** – the Ileostomy and Internal Pouch Support Group

– Macmillan Cancer Relief

– National Association for Colitis and Crohn's Disease

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– Urostomy Association

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