Colostomy
A practical guide to stoma care
Back in 1976 when I had my colostomy, I was a young mum with 4 children, so I was understandably very upset at the prospect of the operation and worried that I would not be a ‘normal’ mum and wife. There were no booklets to read then, and very little choice of appliances.

It was thanks to the invaluable help and encouragement of the hospital colostomy visitor, who was also married with two sons, that I was able to see for myself that perhaps it was possible to live a normal life. I made a good recovery and became determined that one day I would try to give other people that same encouragement I had in those very early days.

It was 2 years before I became involved with the Colostomy Welfare Group (as it was then) and I now work as National Services Co-ordinator at our headquarters in Reading. I feel privileged to have been part of the continued development and expansion of the Group over the years.

The British Colostomy Association came into being on 1st January 1989, succeeding the Colostomy Welfare Group which was founded over 25 years age by Frances Goodall CBE, SRN. Our objectives remain the same as they were over 25 years ago and our members still provide the important service of ‘visiting’ new colostomists to give them encouragement and support.

Cathy Richards
Former National Services Co-ordinator.

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.
**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 a ‘colostomy’ 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 a colostomy 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. Whatever your reactions and feelings, you will find hospital staff very understanding and supportive. They have helped very many people through the same experience and back to a full, active and happy life.

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 Colostomy Association can help with advice and visits from other (happy, healthy) colostomists. The creation of a stoma is often a lifesaving operation, and for many people – there are thousands and thousands of people with colostomies – it actually improves the quality of their lives.

By the time you leave hospital you will be able to manage the pouches for your colostomy. 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**

Simplified diagram of the digestive system

1. Oesophagus
2. Small intestine (ileum)
3. Large intestine (colon)
4. Rectum
5. Anus
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 a colostomy?

Sometimes a small part of the rectum and/or colon (1) has to be removed completely or temporarily bypassed. This means that faeces can no longer leave the body via the anus in the usual way.

The surgeon therefore needs to create a new outlet for waste material to be passed and this is done by making an opening onto the abdomen at the front of the body.

A colostomy may be sited at one of several places in the colon.

Simplified diagram
A small opening is made on the outside of the abdomen (not through the main operation incision) and the end of the remaining colon (2) is brought through and attached to the surface. This is a stoma. (The words ostomy and stoma come from the Greek word meaning ‘mouth’ or ‘opening’ and a colostomy is an opening created in the colon.)

A stoma 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.

**The waste matter from a colostomy**

Food from the stomach travels round the small intestine, where nutrients are absorbed leaving just indigestible matter and water. This then travels round the part of the colon that remains and is passed out of the stoma. At first there is little control over this but often a regular pattern will emerge.

The colon has the job of absorbing water from the waste matter back into the body. The consistency of the waste material passed will therefore depend on how much colon is left – the further along the colon the stoma is situated, the more water will have been absorbed and the firmer the faeces will be.

**Other types of stoma**

**Ileostomy**

An ileostomy is a similar type of procedure to a colostomy, except that the stoma is created in the ileum (small intestine) rather than in the colon (large intestine).

Because the waste matter has not travelled round the colon, little water is absorbed from it and the faeces evacuated from an ileostomy are usually more liquid and in greater amounts than that from a colostomy. An ileostomist needs to wear a drainable stoma pouch so that the pouch may be emptied several times a day.

**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 colostomies carried out?

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

Permanent colostomy

There are many reasons why surgery may have to be carried out and a permanent colostomy created. These include obstructions or growths of some kind in the colon or rectum, accidental injury, and occasionally severe cases of inflammatory bowel diseases like Crohn’s disease.

Sometimes, patients will have had little idea that anything was seriously wrong because their condition caused only minor symptoms. The proposed surgery can therefore come as a shock, but it is very necessary before further problems develop. For others, surgery can bring welcome relief from years of bowel problems. A colostomy in itself will not stop anyone from leading a full and active life.

Temporary colostomy

Colostomies can also be created as a temporary measure, to allow part of the intestine to rest and heal. Rejoining of the intestine then takes place at a later date.

A temporary colostomy may be created following accidental injury, or as part of the treatment for severe diverticular disease, where small pockets of faeces become trapped in the bowel and cause inflammation, pain and bleeding, or for some other reason where the gut needs to be bypassed for a while.

The surgeon will advise if the colostomy is just a temporary measure and the surgical procedure will differ somewhat. Day-to-day care of the stoma, however, remains the same.

In hospital

Before surgery

Members of the medical team will help to prepare you and advise you about your coming operation and answer queries. The procedure involved will be carefully explained to you and the doctor will tell you whether your colostomy is going to be a permanent one 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 also very helpful to meet another person who has experienced living with a colostomy and this can be arranged, usually through the British Colostomy Association.

Where will the stoma be?

A colostomy is often sited on the left side of the abdomen but it depends chiefly in which part of the colon the colostomy has been created. 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.

You should also make sure you can see where the stoma will be, to make appliance changes easier.

Before the operation you will probably have your bowels emptied and a washout given – medical staff will advise.
After surgery

When you first come round you will find there are various tubes attached to you and you may feel some weakness or discomfort. This is quite normal after any operation. All the tubes and drains will gradually be removed during the following days, you will feel stronger 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 colostomy 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 or be removed. The stoma will become smaller and neater. (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.)

Leaving hospital

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

In hospital

You are likely to be in hospital for somewhere between one and three 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. Your stoma care nurse will also fit you with a more discreet type of pouch, after discussing with you what types of pouch are available.
At home

When you return home

You will receive visits from your stoma care nurse and/or community nurse. The stoma care nurse can be contacted by phone, and many hospitals hold regular stoma clinics. The Colostomy Association and other support groups are very helpful and supportive.

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 colostomies are permanent. Apply for exemption on the special P11 form given to you in hospital or available from your doctor, Post Office or local Department of Health office. The form should be signed by your hospital doctor or G.P.

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.

Stoma care pouches

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

To help you when choosing a pouch that is right for you CliniMed have produced a simple guide – available via the Careline 0800 585125.

Colostomy pouches

The waste passed out from a colostomy is usually fairly firm so a ‘closed’ or non-drainable stoma pouch is used. The pouch is removed and replaced with a new one once or twice a day or as required.

The consistency of waste matter passed out of a stoma does vary, however, according to the position of the colostomy in the colon. If the waste is very liquid (and therefore in greater quantities), some colostomists wear drainable stoma pouches clamped shut at the bottom. The pouch can be unclamped and emptied as often as necessary during the day.

Whether you wear a closed or a drainable pouch, you will find there are basically two types of stoma pouches, one-piece and two-piece.

One-piece pouches

These simple pouches are very popular and easy to manage. They are fixed around the stoma by means of a self-adhesive wafer and/or adhesive tape collar. When changing a pouch for a fresh one, the whole pouch is gently removed and a new one applied in its place.

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. All of the Welland pouches, for example, are affixed with HyperFlex. HyperFlex is extremely conformable to your body shape, and therefore very secure. This helps to avoid soreness around the stoma.

If you would like information about the wide range of stoma care pouches and accessories please contact the Careline on Freephone 0800 585125
Stoma care pouches

There is also a choice in the size of pouches available with some manufacturers offering standard, shorter length and mini sized pouches.

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).

Wind and odour

Wind is an individual matter and can be a problem for some. It is usually most affected by what foods are eaten and when. Any wind produced has to escape, however, so many pouches have a built-in filter. This allows wind to be evacuated (thereby avoiding ‘ballooning’ of the pouch) and helps to absorb any odour from it.

If you are conscious of odour when changing your pouch, deodorant sprays such as LiMone are available on prescription.

Odour generally should not be a problem with modern pouches which have odour-proof film.

One piece pouch with flushable liner

A recent advance in pouch technology was the development of a closed one-piece pouch FreeStyle™ Flushable featuring a detachable, toilet-disposable inner liner. This liner can be easily removed and conveniently flushed away.

Two-piece pouches

These have a flange (or baseplate) that fits round the stoma, 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.

Aperture sizes

The size of a stoma varies in diameter and stoma pouches are available with different sized apertures or holes. Most manufacturers supply a measuring device. 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 pouches with cutting guides printed on. Alternatively if you use a delivery service then they can cut them for you.
Stoma care pouches

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.

Other accessories

The importance of cleaning carefully and gently, and of taking care of the skin around the stoma, cannot be emphasised too much. If the skin becomes sore, it can be difficult to get it to heal and to get a good fit with the stoma pouch.

Barrier preparations which help protect the skin are available on prescription. These include handy disposable wipes that when wiped around the area, will dry to form an invisible skin.

Other accessories available include support belts for extra security and deodorant sprays. For free samples of these products please call our Careline on 0800 585125.

Irrigation

There is an alternative to wearing a stoma pouch that some colostomists prefer and this is called irrigation. This involves washing out the bowel every 24 or 48 hours to remove faeces. However, only certain stomas are suitable for irrigation, so this method must be discussed with the doctor. Even if suitable, proper training by the stoma care nurse must be given first. Irrigation kits are available from some stoma care manufacturers.

For more information see CliniMed’s Colostomy Irrigation booklet.

Changing a stoma pouch

A colostomy pouch may be changed as often as necessary, usually after a motion has been passed. With a one-piece pouch, the whole pouch is replaced. If a two-piece appliance is used, the pouch is changed for a new one as often as required and the baseplate (flange) is usually replaced once or twice a week.

(If you use drainable pouches, the pouches may be emptied when necessary and the routine below followed when a pouch change is required. Make sure when applying a new drainable pouch that the bottom of it is securely fastened).

Changing pouches

When you are changing the pouch for a new one, make sure you have everything you need immediately to hand.

Gently and slowly supporting the skin with one hand, ease off the pouch. An adhesive remover can help to remove the flange.

The used pouch can be emptied (cut off the bottom of the pouch to do this), rinsed out under the flush of the lavatory pan and placed with any tissues etc into a plastic disposal bag – or wrapped in newspaper and put in an ordinary plastic bag.

NEVER FLUSH USED POUCHES DOWN THE TOILET UNLESS THEY ARE SPECIFICALLY DESIGNED WITH FLUSHABLE PARTS. DO NOT ATTEMPT TO BURN POUCHES AS THE PLASTIC GIVES OFF TOXIC FUMES WHEN BURNT.

Cleaning the stoma area

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

A skin barrier may be used if required before the application of a fresh pouch.
Once you have recovered from your surgery and are getting back to normal, having a colostomy needn’t restrict you in any way. You can do what you like, wear what you like, go back to work and generally live your usual life. Other people will not be aware, unless you tell them, that you have a colostomy.

**Settling down**

Do not be surprised if your stoma is active frequently in the early days. It will soon settle down to a fairly regular routine. This is helped by you eating sensibly and regularly.

**Food**

There is no need to be on a special diet or be restricted in any way just because you have a colostomy – enjoy your food as before.

As everyone knows, however, some foods can cause digestive problems, whether you have a stoma or not. If you want a curry, have one – but be prepared to use extra pouches the next day! Trial and error will show if there are any foods that particularly upset you, e.g. giving you excess wind, diarrhoea or constipation.

Some foods have a tendency to produce more wind or odour (e.g. beans, onions, cabbage) and some people prefer to avoid these foods in excess.

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.

Don’t forget that, like anyone else’s, your insides can just as easily be put out of routine by emotional upsets etc!

You are your own best judge of what you can 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**

Alcohol in moderation will not harm you, although large quantities of beer or lager may give you wind.

**Travelling**

A colostomy will not prevent you from taking trips in the U.K. or abroad by land, sea or air.

Carry a travel kit, packed in a small pouch or toilet bag, containing: clean stoma pouches, tissues, barrier wipes if used, scissors, deodorant spray if required and plastic disposal bags (plus diarrhoea medication as advised by your doctor just in case). You can then empty or change your pouch wherever there is access to a toilet and handbasin. SecuriCare provide you with a free travel pack when you place your first order.

If you are travelling by air, pack a good supply of stoma pouches and accessories in your hand luggage in case your suitcases go astray. We provide you with a travel certificate in foreign languages explaining about colostomies. Check your travel insurance to make sure it does not preclude any pre-existing conditions or have any age limits.
Sex life
After such major surgery it is bound to take you some time to get back to normal. Don’t be in too much of a hurry about love-making, take your time.

You may feel shy at first because of the change in your body and because of the stoma pouch. Pouch covers can help, or ladies can treat themselves to some appealing underwear or nightwear (perhaps lacy cami-knickers or silk pyjamas) that can be worn during love-making.

In some cases, after the operation, there may be some local nerve damage or scar tissue that causes difficulties. Problems often resolve themselves with time and understanding. Even if some difficulties do eventually remain, there are many different ways of enjoying pleasurable sexual contact.

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 an organisation like Relate National Marriage Guidance or S.P.O.D. (addresses in the back of this booklet).

Contraception
Whilst it is unlikely that having a stoma will affect fertility, it would be advisable to discuss this matter with your stoma care nurse or GP.

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

Back to normal

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 – can result in some obstruction, with consequent flatulence and discomfort. Extra fluids, fruit, or more fibre in the diet may help. Constipation sometimes occurs as a side effect of medication such as certain types of painkillers. If the problem is severe or happens frequently talk to your stoma care nurse.

5. Diarrhoea – drink plenty of fluids to replace those 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. Drainable pouches can be useful while you have diarrhoea, to save changing pouches too often. Frequent or severe diarrhoea (or persistent vomiting) – seek medical advice.

6. Skin soreness – make sure the aperture on the pouch is the right size. Ensure absolute cleanliness of the surrounding skin at each change of pouch (but treat skin gently). The use of special protective products, e.g. peristomal wipes may help. Never remove the pouch too quickly and change it only when necessary. Occasionally there may be an allergy to skin creams, adhesives or foods. Consult your doctor or stoma care nurse.
Problems that may arise

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. Consult your stoma care nurse.

8. Flatulence or gas – can be a problem with a colostomy. It is often aggravated by certain foods. Many colostomists discover that by juggling their diets they can manage the problem better. Some find that taking fennel tablets or eating yogurt can help. Experiment to see which foods cause it, e.g. cabbage, beans, fizzy drinks, nuts.

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

10. Slow healing – after major surgery on the rectum. It is quite common for scars and wounds in this area to continue to weep for quite some time. This is quite normal, but if it happens to you and you are worried about it, have a word with your nurse.

11. 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 of causes you discomfort tell your stoma nurse or doctor.

12. Phantom rectum – If you have a permanent colostomy and your rectum (back passage) has been completely removed, it may feel strongly to you as though you need to open your bowels in the old way, even though you cannot any longer pass motions through the anus. This feeling may last for several months after the operation, but speak to your doctor or stoma nurse if you are concerned about it.

Your questions answered

Will people be able to tell I have a colostomy?
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 a colostomy?

When should I change my pouch?
Usually when a motion has been passed. Many colostomists find that their bodies settle into a routine, passing faeces at fairly regular intervals, e.g. first thing in the morning or last thing at night.

What about sports?
No problem – carry on swimming, dancing, playing games, gardening or whatever you enjoy most. Patterned one-piece costumes are probably most suitable for female swimmers, while males will probably need to wear fairly high-waisted boxer type shorts. Baggy T-shirts are great cover-ups on the beach or at any time.

Whom should I tell?
It’s entirely up to you and who to tell is a very personal decision.

Will odour be a problem?
Just as with normal bowel motions, there will obviously be some odour while you are changing the pouch (deodorant sprays are available on prescription), but if you are aware of odour at any other time, check the appliance and if necessary consult the stoma care nurse. The food you eat can affect odour produced.
Your questions answered

Baths and showers?
Yes, either with the pouch in place or, at times of inactivity of your stoma, without a pouch on. Water will not go into your bowel even in the bath.

Can I take medicines?
Yes, but remind your GP that you have a stoma – some tablets can go through and come out unchanged at the other end! Some drugs may alter the bowel output, i.e. constipate or loosen stool.

Will my life insurance be affected?
All insurance companies you deal with should be notified about your colostomy.

Associations and support groups

Colostomy Association
Celia Waters – General Manager
15 Station Road, Reading
Berkshire, RG1 1LG
Telephone: 0118 9391537
Freephone: 0800 3284257
E-mail: sue@bcass.org.uk

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CancerBACUP
3 Bath Place, Rivington Street
London, EC2 3JR
Telephone: 020 7696 9003
Cancer Information Service
Freephone: 0808 800 1234

National Association for Colitis and Crohn’s Disease
4 Beaumont House, Sutton Road
St Albans, Herts, AL1 5HH
Telephone: 0845 130 2233

Relate National Marriage Guidance
Harbert Gray College
Little Church Street, Rugby
CV21 3AP
Telephone: 01788 573241

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

Bowel Cancer UK
(Information on Bowel Cancer)
7 Rickett Street
London, SW6 1RU
Telephone: 020 7381 9711

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
- National Advisory Service to Parents of Children with a Stoma
- RADAR
- Relate National Marriage Guidance
- Urostomy Association