

# A practical guide to **stoma care**



#### Foreword

The content of this brochure was originally developed in the UK by SecuriCare Itd who are specialist stoma care and continence nurses, providing patient care in hospitals, the community and via their friendly home delivery and support service for ordering medical supplies.

Not all products mentioned in this brochure will be available in all markets, please check with your supplier.

The information presented in this brochure is for general use only and is not intended for people living with any medical conditions who are seeking personal medical advice; it is not a substitute for the advice of your doctor. If you have any questions or concerns about individual health matters or the management of your condition, please consult your doctor or stoma care specialist.



#### Contents

Introduction		4			
How the digestive system normally works What is an ileostomy? Why are Ileostomies carried out? Before your operation		5 6 8 9			
			In hospital	After your operation	10
			At home	When you return home	12
				How to obtain stoma care supplies	12
Stoma pouches	One piece pouches	13			
	Two piece pouches	14			
	Aperture sizes	15			
Protecting your skin	Stoma care accessories	16			
Changing a stoma pouch		17			
Back to normal	Food	19			
	Drink	20			
	Travelling	20			
	Sex life	21			
	Contraception	21			
	Pregnancy	21			
Problems that may arise with a stoma		22			
Your questions answered		23			



#### 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.

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. Soon, your stoma seems less important, and becomes just an everyday part of your life.

# How the digestive system normally works

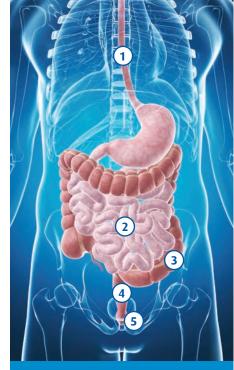
Digestion begins in the mouth where the food is chewed. Swallowed food passes down the oesophagus ① into the stomach.

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 semisolid form.

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



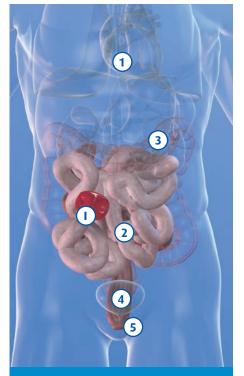
- 1 Oesophagus
- 2 Small intestine (ileum)
- 3 Large intestine (colon)
- 4 Rectum
- 5 Anus



## What is an ileostomy?

There are three types of stoma procedures: colostomy, ileostomy 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
- **I lleostomy**

# What is an 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!

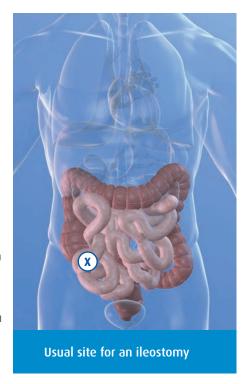
An ileostomy will not in itself stop anyone from leading a full and active life.

## Before your operation

Members of the medical team will help to prepare you and advise you about your coming operation and answer 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 write down any queries you have as you think of them, so that 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. There may be local patient associations your nurse can put you in contact with.



#### 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.

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.



# In hospital

#### After your operation

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 drink and eat

Your stoma will begin to be active within a few days. You will be encouraged to help with looking after your ileostomy



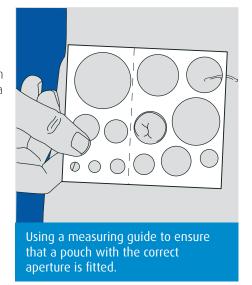
as soon as possible. At first the stoma will be swollen, surrounded by stitches, and the pouches used at this stage are transparent. The swelling will soon begin to go down, however, and the stitches disappear by themselves or will be removed. The stoma will become smaller and neater. (The stoma will continue to become smaller even after you are allowed home and you will need to check that your pouches are still a good fit.)

# In hospital

You may 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 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.

#### **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 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.

This information is based on the UK market, your doctor will be able to advise more specifically on the procedure in your country.



#### At home

#### 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. There are many support groups which are very helpful and supportive.



# Stoma pouches

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 flange. 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.



# Stoma pouches

The type of self-adhesive flange 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® hydrocolloid. Hyperflex® hydrocolloid is extremely conformable to your body shape, and therefore very secure.

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.

#### **Two-piece pouches**

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

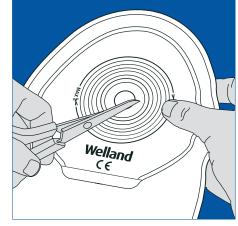
The flange is left in position and a new pouch is fixed to it when required. The flange is usually changed once or twice a week. The advantage of a two-piece pouch is that the pouch can be replaced numerous times without disturbing the skin around the stoma.



# Stoma pouches

#### **Aperture sizes**

The size of a stoma varies in diameter and stoma pouches are available with different sized apertures or holes. Welland pouches come with a measuring card as part of the box lid. 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 card as a basis, or using the pouches printed cutting guides. 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.





# Protecting your skin

#### 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 get it to heal and to get a good fit with the stoma pouch.

Various barrier preparations which help protect the skin are available in many markets. 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 layer.







# 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.



#### 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.

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





## Changing a stoma pouch

#### 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.

#### Changing a stoma pouch

If necessary, check the size of your stoma, using a measuring card. If your pouch needs adjusting, cut a hole to the required size using a pair of pouch cutting scissors.

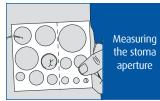
A skin barrier may be used if required before fitting a new pouch or flange around the stoma.

#### 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 flange. Allow a few minutes for the flange to mould to the skin

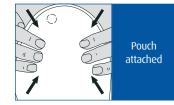












Do not attempt to burn pouches as the plastic gives off toxic fumes when burnt.

#### Back to normal

#### **Food**

Once you have recovered from your operation and are getting back to normal, 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



Certain foods have a tendency to produce more flatulence (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.





#### 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 flatulence.

#### **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.

Pack a good supply of stoma pouches and accessories in your hand luggage in case your suitcases go astray.



#### Back to normal

#### 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.

#### **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 doctor

#### **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.





# Problems that may arise with a stoma

#### 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 your 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, or doctor.

## 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 – carry on swimming, dancing, playing games, gardening or whatever you enjoy doing most. Patterned one-piece costumes disguise any slight bulges for women, while men 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!

#### 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 to help with this), 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.

#### 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 doctor, if necessary, that you have a stoma – some tablets can go through and come out unchanged at the other end!







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