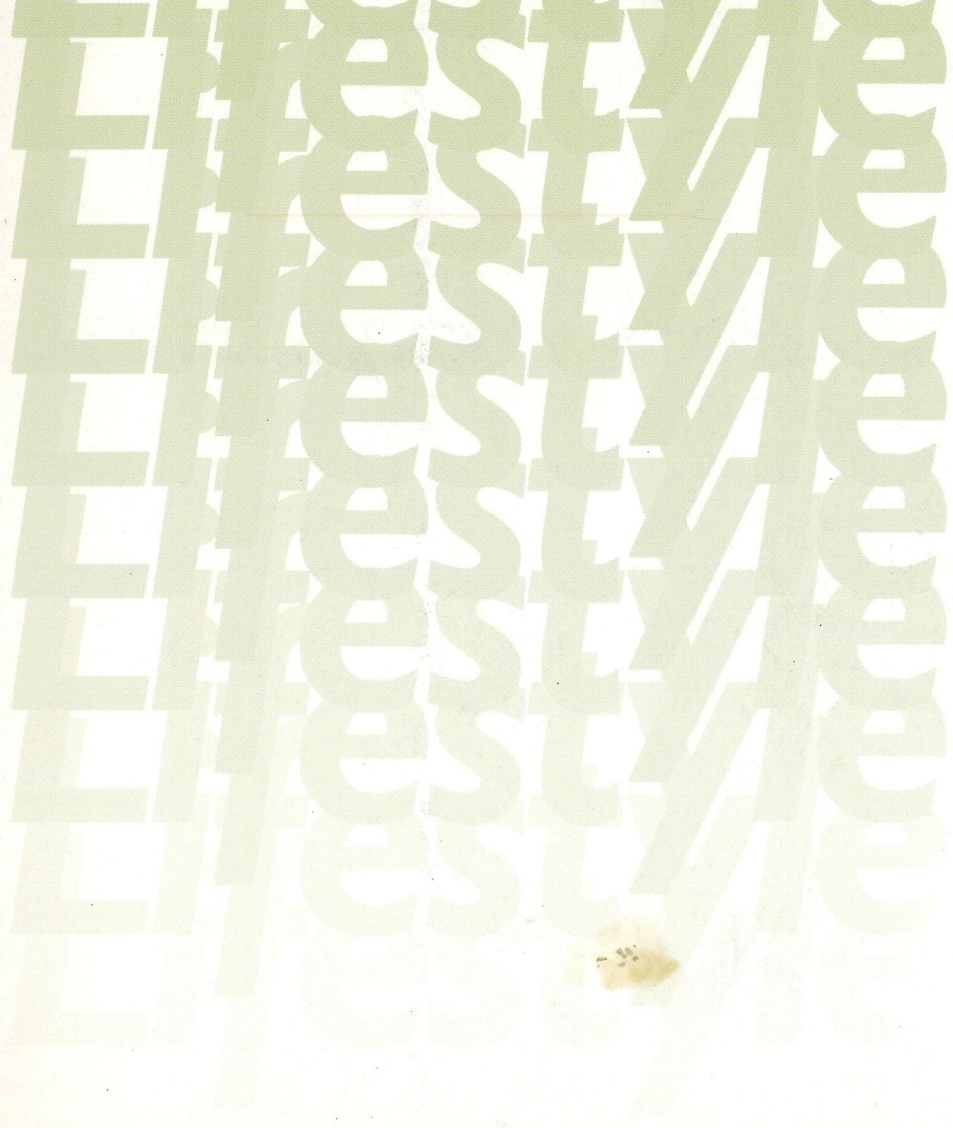


# Lifestyle

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# Welcome to Lifestyle

This booklet has been especially written for those of you who are about to have an ileostomy operation, or are already on the road to recovery. As the name suggests, it is about your 'Lifestyle' and getting the most out of life following your operation.

In easy steps, we take you through all of the different aspects of your ileostomy, from explaining what is actually involved in the operation and your stay in hospital, through to the appliances you will be using afterwards. Looking ahead to when you go home, we have spoken to other ileostomists about their lifestyles and hope to encourage you, through this booklet, to make the most of your new way of life.

Many people have found that it is their families and close friends who offer most comfort and support during and after surgery. We hope that they will also benefit from reading this - they are, after all, very much part of your lifestyle.

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# What is an ileostomy?

An ileostomy is formed by using part of the small intestine to create an artificial opening in the abdominal wall. The waste matter from the small intestine will now pass through this opening instead of continuing through the large intestine (or colon) to the rectum as it did before your surgery. Most or all of your colon will have been removed, and in some cases, your rectum also. The diagrams on page 14 show what is usually removed during surgery - although the precise amount may vary.

Despite being called your "large intestine", the colon is not vital to you. All the goodness has been taken from digested food before reaching it. Its function is to absorb water and salt from food residue, so life can continue just as well without all or part of it.

The opening that is made through your abdomen is called a "stoma". Immediately after your operation the stoma will be red and swollen which is quite normal after surgery. It soon shrinks in size. Like the inside of your mouth, a stoma will always appear red and moist because it has a healthy blood supply. It has no nerves so should never give any pain. Occasionally a stoma may bleed slightly but this is generally nothing to worry about.



It is over your stoma that your appliance or bag will be fitted to collect your body's waste. Straight after your operation your body waste will be quite liquid as little water has been absorbed, but as time goes by, your small intestine will be able to absorb a small amount of the water, making the waste slightly thicker.

Your waste will contain digestive juices. These are a normal part of digestion and help break down food. They would normally be destroyed in the colon, but as you no longer have one, they will be present in your body waste and can cause skin irritation if appliances are not used and fitted properly.

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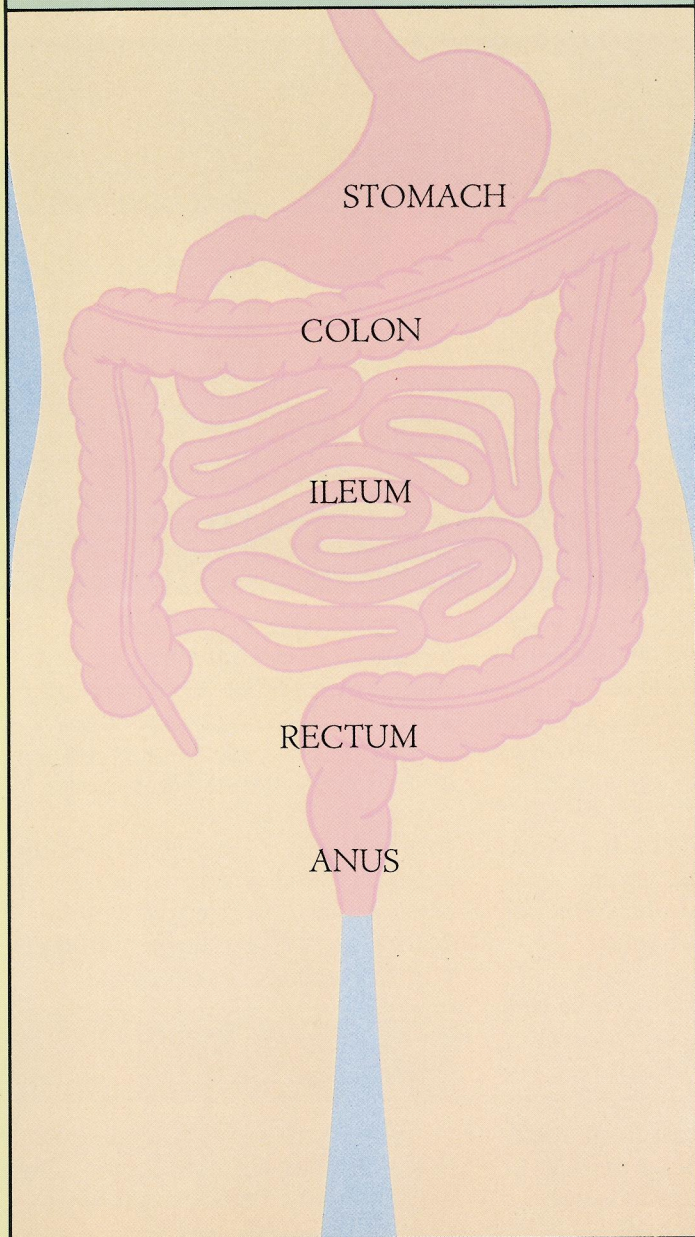
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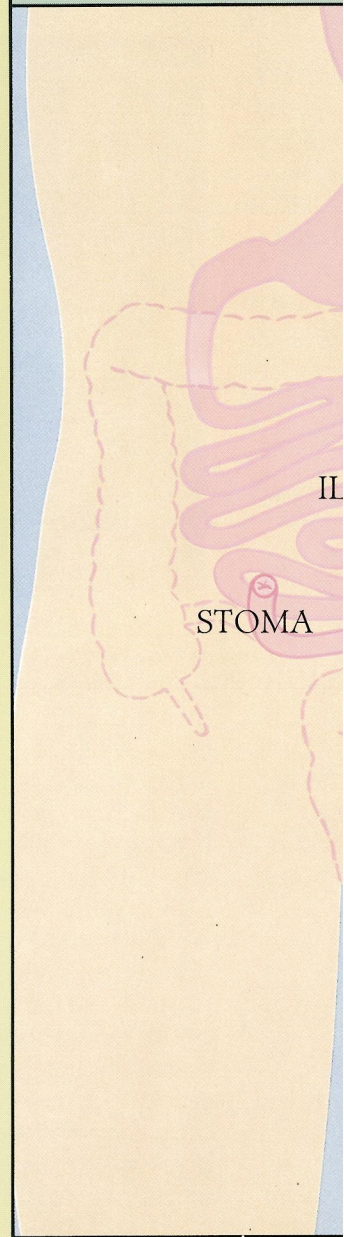
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# Lifestyle

Before an ileostomy



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is easy to face. You will find though that any questions or anxieties can be discussed with your medical team. They will have been responsible for many hundreds of others recovering from their operation and will have helped them to return to a normal life. You are likely to have walked past many ileostomists in the street and not realised. Your ileostomy will become part of your lifestyle.

An ileostomy may be necessary for a variety of reasons. You may have ulcerative colitis, which is an inflammation of the large intestine resulting from ulcers forming in its lining. An ileostomy will be performed if the condition cannot be controlled with drugs. Alternatively, your medical team may diagnose that you have Crohn's Disease which can occur anywhere in the alimentary canal and which can cause severe pain and diarrhoea.

In some cases, an ileostomy operation is performed for cancer of the large bowel (or colon) or other injuries to the colon as a result of accidents.

Even after your Surgeon has explained why you will have to have an ileostomy, your Stoma Care Nurse will see you as often as requested to answer any questions you may have, or just make clear what you may not have understood. Try to seek as much advice as possible from your Stoma Care Nurse - she is there to help.

### *How long will it take to recover?*

This is a question on every ostomist's lips before and after their operation, but there is no easy answer. Each patient's recovery period varies depending on the extent of surgery. There is no firm rule saying how long you will be in hospital - don't be alarmed if you are in for at least two or three weeks - make the most of the help around you before going home again. If you have queries about your recovery, ask your medical team.

Many Ileostomists, due to the nature of their illness, will have been severely ill before their operation. As a result, considerable weight and strength will have been lost making you weak and unfit for surgery. Your

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# Appliances

*Find the one that's best for you*

One of the main concerns of having an ileostomy is the realisation that you will have to wear a 'bag' for the rest of your life. It is almost impossible to believe that it will ever feel part of you and that people won't notice it beneath your clothes. It doesn't take long though to master the knack of changing your bag and feeling confident about wearing it.

Immediately after surgery, the Nurses will care for your stoma, making sure the skin is clean, and will fit and drain the bags for you. As soon as you are ready, your Stoma Care Nurse will talk with you about the different bags that are available and help you start using and changing them yourself. This discussion may include your partner so they feel involved and can offer help at home if you ever need it.

Ileostomy systems and appliances have been used for many, many years and have changed and adapted to allow for what you want. They are more secure, reliable and discreet than they have ever been before to give you peace of mind.

*How do ileostomy bags work?*

As an ileostomist you have two choices of appliance types. A one piece appliance, where the protective skin barrier and the bag is integral and attaches straight on to the skin, or a two piece system that enables you to clip bags securely onto a separate protective skin barrier around the stoma.

One piece bags have a wide choice of integral seals and adhesive skin barriers. Most come with a range of pre-cut stoma sizes so there is no cutting involved in getting them to fit snugly around the stoma.



As already mentioned, the two piece systems have a separate skin barrier that requires cutting to size with scissors to fit around the stoma. It is on to this that bags with plastic 'gaskets' are clipped.

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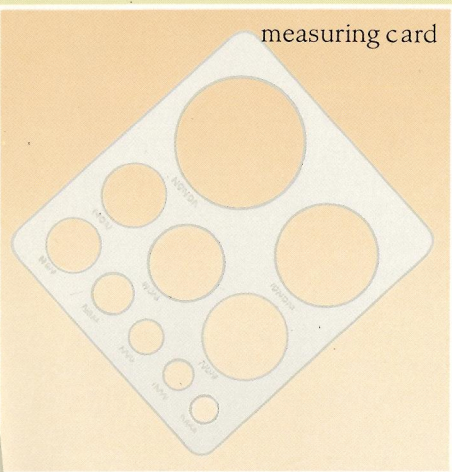
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Some are fitted with a flatus filter that allows flatus (or “wind”) to escape from the bag through a small deodorising pad.

### Getting the perfect fit

Stoma sizes can vary, and they can also shrink gradually in the months after surgery. It is therefore important to check occasionally the size of your stoma against the measuring cards included with your appliances. These cards tell you what size appliance you should be ordering to achieve a perfect fit.

An ill-fitting appliance can cause many problems. Apart from feeling uncomfortable, it may leak or promote skin irritation. If you are having problems with your appliance, speak to your Stoma Care Nurse.



### Extra security and comfort

Both one and two piece systems can be fitted with a belt which is attached to belt tabs. Many people prefer the extra security of knowing their bag is very definitely part of them.

Some people like to have covers over their bags — cotton against the skin can often be more comfortable and it obscures the view of the bag's contents. Belts, tabs and covers are easily obtainable on prescription.

### Emptying your bag

To empty the bag you can either sit on or beside the toilet. Put some toilet paper in the bowl before emptying as this helps stop the contents from splashing. Lift the end of the bag slightly to avoid any spilling while it is being opened and direct the contents of the bag into the bowl. The bottom of the bag should then be wiped with a tissue and the bag reclosed.

After a while you will feel confident enough to deal with most situations and will not find it difficult to drain your bag when you are away from home. It is a good idea always to empty the bag before it becomes too full.

### Dispo

Flush down the toilet and rinse the wrapper in a plastic bucket or dustbin. Do not flush the lava.

Some people use a collection bag. Your Doctor or Chemist can advise.

### Caring

It is a good idea to keep your skin as clean as possible to avoid irritation. Some people can cause a few points of irritation.

- Before applying the stoma, wash the skin with soap and water around the stoma thoroughly.
- Carefully clean the stoma and the skin around it as the adhesive is removed.
- Do not use disinfectant on the stoma or the skin around it.

# Enjoy your food and drink

You still have a healthy and efficient digestive system and you should be able to enjoy a normal diet. It is important not to skip meals and to chew food thoroughly.

As your digestive system settles down and your remaining intestine takes over some of the water-absorbing function that the removed section used to perform, you will be able to try different foods and build up to eating normally. Do drink a lot of fluids, especially after the operation. Alcohol is fine, but in moderation.

There are no real restrictions on what you eat after the initial post-operation period, so try anything you want to. It will help if you add new foods to your diet one at a time, then you will be able to identify any that upset your digestive system. In hot weather you may need to drink more fluids and add extra salt to your food.

Some people may have problems digesting certain foods such as dried fruit, coconut, peanuts and celery, so when you eat these, remember to chew thoroughly to help with digestion. If something doesn't agree with you, try it at least three times before you decide you cannot tolerate it. Remember too



that other factors, like emotional pressure or travel, may upset you just as they may have done before your operation.

If you get a watery output for more than 24 hours, consult your Casualty Doctor or Stoma Care Nurse. Alternatively, if your ileostomy hasn't worked at all for 6 – 8 hours, consult your Doctor immediately. Don't take medicines for either of these situations without seeking advice.

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# Travel and Holidays

Some of life's most enjoyable times are spent on holiday. Despite this, when you are in hospital having had your ileostomy, it may be difficult to imagine how you will ever face the upheaval of a journey again — even short business trips.

Your travelling shouldn't have to stop just because you have become an ileostomist. Once you have got used to the changes imposed by your operation, there is very little stopping you from travelling anywhere in the world. Ostomists have cycled across mountain ranges and walked through deserts. A few years ago, two ostomists cycled throughout Europe for a month. The holiday was such a great success that they repeated the journey the following summer.

It is quite understandable that the first break or business trip after your operation could be quite daunting. In your mind there develops an endless list of potential disaster areas. Will there be clean and private bathrooms?



What effect will strange food have on your system? Where will you be able to get proper medical help if you need it? Even the thought of not sleeping in your own bedroom, where everything is familiar, can be a worry.

To help overcome this, the following series of tips will make your preparation for your holidays and journeys a lot easier and should avoid any problems whilst you are away.

### Think ahead

- Pack your supplies when you are changing your appliance — it will remind you of everything you need so nothing is left behind.
- Take an over-generous supply of bags — it will give you peace of mind as much as anything else, but will also avoid supply problems if you are away over a longer period than expected and have a delay in replenishing your stock.
- Packing a variety of different sized bags will offer you flexibility in choice depending upon what you are doing. Maybe there is a long journey to face which will require a larger bag, or perhaps you are planning a lot of physical activity or swimming when a smaller sports bag will be useful.

- Baggage handling is never totally reliable — luggage has been known to end up in a different continent to its supposed destination. To avoid the possibility of losing your supplies, take them as hand luggage so they do not leave your side.
- If you have to carry any drugs through customs and baggage control, it is advisable to obtain a note from your Doctor saying exactly what they are. It will help prevent embarrassing questions and unnecessary delay.
- Don't use tap or running water when abroad. For drinking, cleaning teeth or other purposes, bottled water is safer. Avoid ice cubes except when from a totally reliable source. Do drink *plenty* of extra fluids in hot climates.
- Be wary of food — especially spicy snacks — from street stalls and markets. Wash and peel fruit carefully and buy it uncut. In the Far East and elsewhere, avoid having too many spicy meals. If you do get a tummy bug, *seek medical advice*, you may dehydrate quickly.

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# Ileostomy Careline

Stoma Care Nurses regularly hear the same questions being asked by ostomists. There are obviously common areas of concern amongst you all, so we asked a selection of Stoma Care Nurses around the country for their answers to the most frequently asked questions.

**Q** I was surprised at the colour of my stoma, will it always be so red?

**A** Don't worry, it is quite normal. Your stoma is part part of your intestine and rather like the inside of your mouth, it will remain moist and red.

**Q** I have had a happy and active sexual relationship with my partner. I am very worried that our relationship will be affected when I have had my ileostomy.

**A** I imagine that you have shared everything with your partner, so why should this be any different? Your Stoma Care Nurse will be able to explain to both of you why the

operation is necessary, how the appliances will be used and how you will be affected, both initially and in the long term.

Of course a sexual relationship would not be advisable in the first weeks after your operation because you will feel tender after surgery. There is no reason why things won't get back to normal and you can both continue your relationship as soon as you feel ready. Meanwhile, there are other ways of showing affection!

Some people have found that it is nicer to wear a cotton cover over their appliance while making love, but it depends on each couple's preferences. It is advisable to empty the bag before going to bed.

If it is a problem, however, that you are worried about, please talk to your Stoma Care Nurse, Surgeon or General Practitioner — they are used to helping with what is quite a natural concern.

**Q** Will we be able to have children?

**A** Many couples, with one or both having an ileostomy, have had children. It is advisable, however, to discuss this fully with your doctor before the operation.

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**Q** When I have had my ileostomy I am convinced that there will be odours from it that I will not be able to cover up.

**A** Between bag changes and draining there should be no reason for odours. Make sure that your bag fits properly, the seal is secure and appliances are changed regularly and you shouldn't have any difficulties.

**Q** Despite being careful about my diet I still find wind an embarrassing problem.

**A** There are a few simple rules which we advise you to follow when eating, especially if you are experiencing wind problems. Don't drink during meals — have any liquids you want afterwards. Always chew well and carefully and finally, don't talk during your meal or gulp air.

Obviously this isn't always possible, especially if you are eating dinner with friends, but try to eat calmly and slowly and chew every mouthful for as long as possible.

You can get appliances that are especially fitted with 'flatus filters'. A small hole in the top of the bag allows air to escape through a filter and will absorb any odour very effectively.

**Q** How much will it cost me to keep buying my appliances, or do I qualify for a discount?

**A** All people with a permanent ileostomy can obtain their supplies free. Your Doctor or Stoma Care Nurse will give you a prescription exemption form to be signed by your GP, or you can obtain one from your local Post Office. Once your pharmacist understands your special needs, he will be able to supply you promptly, but you should give him a few day's notice.

**Q** Can I still bathe, shower or swim?

**A** Certainly you can. Your appliance will be quite secure in water.

Obviously it is a wise precaution to drain your appliance before going swimming so that it will be nice and flat under your swimming costume.

There are firms who specialise in designing swimwear, for people with stomas. Your Stoma Care Nurse or the Patient Associations can advise you. (See page 19 for contact names and addresses.)

**Q** I take great care in looking after my skin round my stoma but sometimes it becomes sore and irritated.

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# Extra Support

Most of our large hospitals have a Stoma Care Department and Stoma Care Nurses responsible for the care of ostomists. Throughout your stay in hospital and after returning home, it will always be possible to see and speak to your own Stoma Care Nurse. Your Nurse will also meet and get to know your family so every one understands what is happening and where help and advice can be found if necessary. Every effort is made by hospitals to ensure that patients have the

same Stoma Care Nurse throughout their treatment so strong relationships are built up and it is easier to discuss any problems that may be on your mind.

Families can also play an important role steering patients back to full recovery, so it helps if they have regular contact with the medical team. Your natural reaction may be to keep things private, but great strength can be gained from a partner being involved as early as possible.

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# Leading Your Life to the F

“Don't worry dear, you're not the first to have had this operation”. How many times has someone said that to you and it made you feel no better about having your ileostomy?

It can be a lonely feeling when, in your own mind, you are trying to work out exactly how you feel about your operation. Someone who has recovered from their ileostomy surgery, however, could help you come to terms with it and answer questions that you may feel are trivial, but are in the back of your mind.

The opening sentence of this section may offer little comfort at first, but it is true that there are many ileostomists who have coped with their operations and now lead healthy and full lives.

John and Clive both have ileostomies and live in London with unbounding enthusiasm for life.

Clive had his operation when he was a teenager and his immediate concerns related to his social life. His worry was that having an ileostomy would stop him playing sports altogether and that he would lose confidence to approach attractive girls.

In fact, Clive found the operation helped him to become more outgoing and confident in himself. Having coped with a

series of operations and a change in lifestyle, Clive found he had the determination and sense of humour to make the most of life.

Now, almost 10 years after his ileostomy operation, Clive works as a Stockbroker in the City of London. Recognised as a highly stressful and demanding job, Clive has not let his ileostomy stand in his way.

Working long hours, however, doesn't leave a lot of free time to devote to sport and socialising, but Clive manages to keep fit by playing competitive table tennis and squash during the weekends and swims whenever he can find the time.

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# Lifestyle

determined to make the best of it. The result was that during the six months spent recuperating at home, John had the best time of his life!

During his illness, John's wife was expecting their first baby and gave birth to a baby girl just after John returned home. John was left to look after her while his wife went back to work. Having a baby to look after made his own operation pale into insignificance, keeping his ileostomy in perspective with life in general.

Having an ileostomy, although difficult to come to terms with at first, does not mean life comes to a grinding halt. In fact so many ileostomists have found their lives have improved tremendously since their operations.

Once fully recovered, John went back to work at Charing Cross Hospital. As a maintenance craftsman, on his return, John was concerned that the work would be too strenuous for him. Having to work shifts and carrying out heavy labour from time to time could be difficult. However, his work colleagues gave him the support he needed so that he could gradually regain his fitness. Now he simply takes a little more care when welding, lifting or squeezing through narrow gaps and he does everything he used to do before his illness — he won't accept special treatment at work from his



colleagues.

A year after his first daughter was born, his wife gave birth again — this time to twin girls. Life at home is by no means easy with 3 children, all under the age of three, but John feels his life is complete. Whether he and his

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# Choosing Your Wardrobe

You'll be delighted to know, if you haven't found out already, that as an ileostomist, there are very few restrictions on what you can wear after your operation.

Quite understandably, it is often one of the first things that springs to mind when the operation is initially explained. It seems strange that your favourite jeans will have to fit over your appliance as well, when there was perhaps little spare room before. You will be surprised how inconspicuous you can make it. Having said that, however, be

careful with especially tight clothing that the flow of body waste isn't restricted.

Shopping for clothes may take slightly longer so you can try everything on to be reassured that it looks good.

Many ostomists, men as well as women, find that they become more conscious of their appearance — not just whether or not their appliance shows, but everything from hair to shoes.

Swimwear is maybe the slight exception to the "wear what you like" rule. How brief swimming

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# On talking terms

Here are some words with which you may not be familiar; bear with us if we're repeating what you already know.

**ALIMENTARY CANAL:** The passage extending from the mouth to the anus through which food passes to be digested and absorbed.

**APPLIANCE:** There are two basic types of bags which are worn over the stoma to collect waste matter; one piece and two piece.

The one piece bag has a skin protector and adhesive square as an integral part of the bag with the stoma opening in a range of pre-cut sizes.

The two-piece appliance has a skin protector and adhesive square separate to the bag. The skin protector can be worn for a number of days with bags being clipped on and off as required.

**BIOPSY:** A piece of tissue that is removed from the body and examined to help make a diagnosis.

**COLITIS:** This occurs when the large intestine (colon) is inflamed.

**CROHN'S DISEASE:** A type of "inflammatory bowel disease" often lasting for a number of years.

**DIVERTICULOSIS:** The presence of multiple small "pouches" in the large bowel wall.

**DIVERTICULITIS:** Inflammation of one or more of these pouches.

**FAMILIAL POLYPOSIS:** An hereditary disease in which polyps develop in the large bowel (colon).

**FIBREOPTIC EXAMINATION:** Visual examination where an extremely fine flexible tube is used to look at the inside of your bowel.

**FLATUS:** Bodily gas or "wind".

**INFLAMMATORY BOWEL DISEASE:** A general word for diseases which cause the bowel to become chronically inflamed.

**INTESTINE (LARGE):** The six feet of large bowel which extends from the lower, right abdomen, up towards the ribs, across the diaphragm, descending on the left and ending at the anus.

**INTESTINE (SMALL):** It begins at the outlet of the stomach and is approximately 20 feet of coiled bowel which connects to the large intestine. It is sub-divided into the duodenum, jejunum and ileum.

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# Useful Addresses

**Hollister Limited**

Rectory Court  
12 Broad Street  
Wokingham  
Berkshire RG11 1AB  
Telephone: (0734) 775545  
Advisory Service: 0800 521377

**British Colostomy Association**

15 Station Road  
Reading  
Berkshire RG1 1LG  
Telephone: (0734) 391537

**National**

**and Croh**  
98A Lond  
St Albans  
Hertfordsh  
Telephone  
(Answerin

**Hollister Limited**

Burton Hall Park  
Sandyford Industrial Estate  
Foxrock  
Dublin 18  
Telephone: Dublin 954087

**Urostomy Association**

Buckland  
Beaumont Park  
Danbury  
Essex  
CM3 4DE  
Telephone: (0245) 224294

**National**

**Parents o**  
51 Anders  
Darvel  
Ayrshire F  
Telephone

**The Ileostomy Association of  
Great Britain and Ireland**

Amblehurst House  
PO Box 23  
Mansfield  
Nottinghamshire NG18 4TT  
Telephone: (0623) 28099

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# Acknowledgement

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