

Living With A Colostomy

Jason Dale



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Living With A Colostomy

The Ostomyland.com Lifestyle Guide
By Jason Dale

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The Boring but Essential Bit:

(Disclaimer and Reader Advisement)

If you are ever concerned about your health or stoma or bowels your first stop should always be your own Doctor, Surgeon or Stoma Nurse (ET Nurse).

I am not a Doctor, and therefore have no medical qualifications. The contents of this book are based purely on my hospital diaries, and my experience of living with a colostomy. Therefore, if you read this book then you do so on the understanding that you must verify the advice/information with your own medical team before acting on anything herein, and take their advice over mine if they disagree.

The History Bit:

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Author becomes Multi-millionaire: In his dreams...

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Author's Note

This guide was originally written specifically for the younger Colostomist-to-be, especially those in their late teens and early twenties, their partners and/or their immediate family.

While I was waiting for my Colostomy I bought, and borrowed, a couple of books on the subject to try and ease my mind, and while these books were still a wealth of information they didn't really tell me what I was wanting to hear as an adult in my early twenties. The books were all about twenty years old, way out of date and written by the older generation for the older generation. They mainly concentrated on the appliances and diet side of things rather than routine and what to expect before, during, and after the event.

Over the years that I have been running my colostomy website I have come to realise you don't have to be a young adult to still find this book of interest. Colostomists' problems are universal regardless of age, only our priorities are different once we get older.

This book aims to be a complete guide to help ease any worries there may be towards having a Colostomy, and to be an invaluable source of reference for all Colostomates in the years to come whether you are twenty or eighty. It has also been completely updated in May 2010 to take account of the changes with ostomy care over the last 12 years or so.



Fuzzbutt Says:

Hi, I'm Fuzzbutt - Ostomyland's furry mascot! I'll be popping up within these pages with some of my own top tips on caring for your ostomy, as well as some useful tidbits of info about Ostomyland! I also have my own section on the Ostomyland website where I post more top tips and feature my favourite member blogs. Check it out at:

<http://www.ostomyland.com/fuzzbutt>

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What is a Colostomy?

So, you've been to see your surgeon. He's told you the bad news that you need to have an artificial outlet for stool, a Stoma, created in your abdomen; in other words, a Colostomy.

But what exactly is a Colostomy? How do they do it and will it be permanent? These are all questions that your Surgeon should have answered for you already but it never hurts to recap.

The origin of the word Colostomy is Greek. It is derived from two words, "Colon" and "Stoma". The Colon is the large intestine and the Stoma is the name given to the artificial outlet that is formed to replace the anus.

By giving you a Colostomy the Surgeon is diverting any waste matter you produce away from the rectum area, through the abdomen where the end of the bowel is stitched in place, usually on the left hand side of the abdomen just below the belt line. This way the whole digestive system works as normal whilst bypassing any inflamed or damaged problem areas in the bowel.

Before the operation you'll have had complete control over the passing of any waste matter. You'll have felt full when you needed to go and will have been able to hold it until you got to a toilet.

With a Colostomy things are different. You have no muscle control over a Stoma whatsoever and this is why it is necessary to wear an "appliance" (bag) over the stoma to collect all waste. There are literally hundreds of different bags and systems on the market these days all tailored to suit different people's needs and life styles. Your Stoma nurse will make the initial choice for you and then after that you are free to experiment.

Just because you are having a Colostomy it doesn't necessarily mean you will be wearing a bag for life. These days it is getting more and more common for Surgeons to perform temporary Colostomies.

So what is the difference between "temporary" and "permanent"? The difference is the removal of the sphincter muscles, anus and the rectum itself. If this is removed then the colostomy will be permanent, there is no way to reverse the operation (although in

the future who knows, we are already seeing surgeons experimenting with pig transplants into Humans so maybe one day people can have bowel transplants from pigs!)

With a temporary Colostomy the sphincter muscle, anus and rectum is not removed, and the stump end of the rectum is simply sewn up to prevent any leakage into the body's system and left inside.

As said previously this is becoming more and more common and these days a Surgeon is reluctant to remove a person's bowel if they are under the age of 45, unless it is cancer.

If the bowel is still in the body you will notice that at times it is still working. It may have been disconnected from the rest of the digestive system but this does not stop it from producing a mucous which will need to be passed into the toilet about once a fortnight.

There are some disagreements about how long a bowel can be left unused before reversal is no longer a possibility. The longer it is left the harder it is to reverse successfully. Over time the bowel begins to go on strike and the longer it is left the harder it is to kick start back into action. If this was the case you could be left incontinent and the Stoma might have to be returned.

However, my own Stoma Nurse has told me a story of how a three day old baby had a Colostomy and eighteen years later the operation was reversed and she hasn't looked back since. With that knowledge one can't help but feel that one day we can all have our stomas reversed.

I suppose that another reason for the hospitals being keen on temporary Colostomies rather than permanent ones is because that with a temporary Colostomy the turn around in the patient is quicker. This is especially so if the procedure is laparoscopic (i.e. a keyhole surgery operation, such as a "Hartmann's Procedure" Colostomy).

I was lucky as my operation was performed in a teaching hospital with all the latest equipment and methods. This meant I was one of the first in my area to have my temporary Colostomy performed by keyhole surgery.

Keyhole surgery is undoubtedly the future of this operation. To have a Colostomy - temporary or otherwise - performed by open surgery means you are looking at a two-week stay in hospital and six month recovery period. All because of the large incision they need to make.

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Keyhole surgery takes less time, and because the Surgeon need only make two tiny incisions (one for the instruments and one for the air hose) you'll merely spend on average four days in hospital, if that. You'd be out next day if it weren't for the fact that you need guidance with the appliances and stoma care for the first few days.

Because of the lack of cuts you heal much more quickly and can be back to normal in a matter of weeks, although your Stoma Nurse or Surgeon would probably recommend a space of up to three months or so before exerting yourself. During this time care needs to be taken so the stoma can heal quickly to its full strength.

The stoma itself is fairly unobtrusive. It is oval in shape and looks similar to the inside of your bottom lip, a nice pinkish colour. As I mentioned earlier there is no muscular control over the stoma, and there is also no nerve supply so you can gently touch it if you want and you will not hurt yourself.

Immediately after the operation the Stoma will be extremely swollen and bloody. This is perfectly normal. The swelling is the bowel's natural defence mechanism coming into effect. You have to remember that the bowel has been manhandled and moved from its comfy resting position! Over the course of the first few weeks the Stoma will shrink and the stitches that are visible will dissolve away to leave a clean, healthy (and much smaller) stoma.

So that is the operation itself but what do *you* have to do before during and after?

The Stoma Nurse

Once you've been told of your up and coming Colostomy it is a good idea to ask your Surgeon or GP to arrange a meeting with the local Stoma Nurse. This is a highly trained Nurse with many years nursing experience that deals specifically with Stomas and the relating conditions. He or she will be well aware of any anxieties you or your family may have towards the operation and it is prudent to have a long chat with them to help ease any fears.

The Stoma Nurse will probably arrange to meet you at your home, this way you feel more comfortable around your own surroundings.

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The Nurse will then be your guide through the Colostomy for as long as you need their services after the operation and they are always there in case of any problems that might arise after the event.

It is a good idea to have your family/partner with you at all of the meetings if at all possible. That way you have their recollection to call upon, as you will almost certainly forget some of the things she tells you, and it is nice to have that reassurance.

In the pre-operation visits the Nurse might take the opportunity to test you for skin sensitivity. This is a simple case of sticking small samples of a variety of bag adhesives onto your skin, most probably your back. They will be left in place over a few days then removed and any red rashes or skin sensitivities to certain brands will be noted.

These days most bag adhesives are very hypoallergenic and sensitivity is rare. However even if you are allergic to certain brands (as I am) there are products such as Second Skin Wipes, which prevent the adhesive from touching the skin, yet don't compromise bag security. They are fairly simple alcohol based wipes that you rub onto your skin before sticking the bag into place. This creates a thin layer, like a second skin. The Bag then sticks to the second skin and peels off easily when removed leaving your skin free of allergy.

During these pre-operation visits you will probably see your first few bags and get a rough idea of what they look and feel like. You'll be made aware of all the different styles - drainable or closed, one-piece or two-piece, large bags or small bags - the possibilities are unlimited.

Without a doubt the most important part of these early meetings will be establishing the location of the Stoma. This is quite a task at times, as you are needed to think ahead to the future and what you expect you'll need from your stoma. This is difficult as, at that stage, you are still unnerved by the whole idea of a Colostomy. You need to consider the trousers or skirts you wear for example. Where does the waistband generally lie? The last thing you need is your waistband constantly rubbing against the stoma.

Then there comes future doubts over sex, you could do without the stoma getting in the way of that!

The Stoma Nurse will get you to lie down, sit down, crouch, maybe even stand on your head (only joking!) to try and find the best possible position for your Stoma. If you disagree with the

positioning express your opinion as that will not be the only place it can go. Areas around old scars, natural creases, skin conditions, the hipbone and your belly button are best avoided. The chances of finding a location that you are perfectly happy with all your life, through all your different clothes is minimal, so in the end it is best to make an agreed compromise.

As a general guideline a Colostomy Stoma is best placed on the left hand side of your abdomen below the belt line avoiding all irregularities. But most importantly it needs to be accessible. You need to be able to see the Stoma clearly for when you come to clean it after the operation and in the future.

If after talking to the Stoma Nurse you are still concerned about life with a Colostomy it could be possible for you to talk to someone from your local support group, or if there isn't one near you try phoning the Colostomy Association (CA) help line if you live in the UK, or by visiting the United Ostomy Association of America (UOAA) website for USA groups, or The International Ostomy Association (IOA) which contains details of all Ostomy Associations.

CA (UK): <http://www.colostomyassociation.org.uk>

UOAA (USA): <http://www.uoaa.org>

IOA (Worldwide): <http://www.ostomyinternational.org>

UOAC inc. (Canada): <http://www.ostomycanada.ca/>

ACSA (Australia): <http://www.australianstoma.org.au/>



Fuzzbutt Says:

For links to patient support associations in other countries, please check out our message board's "links" section (NB: free registration required to view our message board).

<http://www.ostomyland.com/msgbrdlinks>

These support groups are generally run by Colostomists on a voluntary basis and are very useful. It is comforting to talk out your fears with someone who has already been down that road.

If you organise a meeting with your local group member then you'll find that just the fact that they are sitting there is a comfort as it shows that there is a life after a stoma, however distant it may

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seem at the time. And I'll make you one guarantee... if you'd not been told you'd never have guessed they had a stoma, so why should anyone think you have? The only people who'll know you have a Stoma will be the ones you tell! Honest.

What does a Stoma Look Like?

This is an Ileostomy stoma. It protrudes like this so that the liquid stool does not burn the skin. The stoma is located on the right hand side of the tummy.

Picture: <http://ostomyland.com/mainsite/images/bl3883.jpg>

This is a colostomy stoma. Note how it is flusher with the skin, and located on the left hand side of the tummy.

Picture: <http://ostomyland.com/mainsite/images/bl3885.jpg>

This is a close up of a colostomy stoma. It may look sore and red but this is normal and there is no discomfort from a stoma. My own stoma smaller, less red and does not protrude so much. So it goes to show that no two stomas are the same.

Picture: <http://ostomyland.com/mainsite/images/pg13.jpg>

Sadly, I have not been able to include the pictures themselves in this guide, as I do not own the Copyright to them, and the permission I've been given to integrate them in these pages only included the website version of the guide. The complete website version of this section can be viewed at:

http://ostomyland.com/mainsite/?page_id=7

However, the pictures that are included on that page are very much the stereotypical / textbook stoma, not only in shape and form, but also in size. So they can give you a very good indication of just what a stoma should look like and are well worth checking out if you can.

At The Hospital

The big day has finally arrived and you present yourself at the hospital ready for everything they can throw at you.

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For most of the younger Colostomists this will be your first major operation, and hopefully your last! So what can you expect to happen during your stay in hospital?

What follows is a rough day-by-day guide to life on the ward when you're having a Colostomy. Obviously not all hospitals or wards have the same routine or procedures and this is a rough guide only, so don't think you're dying if you get a few extra Doctors coming to see you!



Fuzzbutt Says:

Why not keep your own diary or blog about your experiences with an Ostomy. They are a great way to get your feelings into the open, and over time you'll be able to review your posts and see just how far you've come since those early days! Ostomyland offers all message board members free blogs, so why not have a go at writing your own!

<http://www.ostomyland.com/blogs>

Day One

Before you arrive at the hospital it is a good idea to have a few "entertainment" items with you, as life on a ward is one long boring wait.

It's a good idea to save up a few favourite magazines. Try not to read the current issues of your favourites then take them with you on the day. A good book is always recommended although there may well be a hospital library round during your stay (but you can guarantee you've never heard of the books and there are pages missing!). At times like this it is best to steer clear of medical novels like Robin Cook's "Coma"!

An I-Pod or MP3 player is essential to all younger patients, especially when accompanied with a few of your favourite songs. And a Nintendo DS or PSP can be a big help too once you start to feel a bit better post-op and want to relieve the boredom. Do remember though, Mobile Phones are usually banned in most hospitals as their signals can interfere with critical medical equipment, so please switch yours off whilst in the hospital if you take one with you.

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The food in hospital is renowned the world over as being more likely to kill you than help your recovery! Having said that though, I never found the food too bad in the hospitals I've stayed in. But it never hurts to smuggle in a few packets of crisps (potato chips), biscuits, sweets and a bottle of your favourite diluted drink. One word of warning though, fizzy drinks should be avoided. They cause wind (gas) and this could cause you some serious discomfort if you get wind cramp in your bowels while they are so sensitive from being handled during the operation.

Apart from these, there really are only the regular essentials you need take with you for your stay in hospital; Items such as pajamas, dressing gown, slippers, towel, soap, toothbrush, comb, pen (to fill out your menu card!) and most importantly, a lucky cuddly toy; from my experience nurses on the ward love to see them.

You'll be asked to arrive the afternoon before the operation day, or the morning of the operation itself, depending on whether your operation is planned for an AM or PM time slot. The rest of this Hospital guide shall be written as if you are admitted the afternoon before the operation day, as this is what happened to me, and this section is heavily based on my hospital diary.

Once on the ward you'll be shown to your bed. As soon as you sit on the bed and hear the backbreaking crunch you'll want to go home, but be brave!

After a few minutes your Named Staff Nurse will appear. This nurse is responsible for you while you are in hospital. Although you will see many nurses during your stay, you are officially his or her patient, and they are responsible for booking you in and out, and checking that all your paper work is in order. If there is one thing you will learn in your stay at the hospital it is that the Modern Day nurse spends almost as long filling out paper work as she does looking after patient care.

First things first: The nurse will take the starter readings of your blood pressure, pulse and temperature (word of warning, try to avoid this for up to an hour after a cup of tea or hot drink, otherwise you'll end up with a really high temperature reading and have nurses panicking all over the ward!). The nurse will then ask you a few questions, including your name, address, next of kin, any known allergies and simple things like that. She'll probably also ask you if you know why you are there - as if you could ever forget! But

it is a legitimate question for the elderly patients.

Once she's completed the paper work, you'll have a patient wristband attached to your wrist, and one maybe even attached to your ankle as well, depending on hospital procedure. This simply tells them your name, Consultant's name, hospital number and the ward you are placed. If you've mentioned any known allergies you'll have an extra red plastic wristband attached which clearly states these.

Finally the nurse will place a sign on your bed headboard that says, "fasting" or "Nil By Mouth" and that is the worst bit of the pre-op period. Because of the anesthetic you are not allowed any food or drink before the operation and you have to sit and watch everyone else tucking into his or her meals. The other patients may be moaning about the food resembling cardboard fritters, but the longer you do without food the more appetizing it looks!

Once this has all been completed the Nurse will ask the Houseman - this is the Ward Doctor - to come and have a chat with you. This will be the first of many visits by a whole variety of Doctors up and down the scale of authority. So now is a good time to start getting used to answering the same questions over and over.

The doctors' questions relate more to your medical condition, and so on. This is in contrast to the Nurses' questions, which tend to revolve around whether you have stairs in your house or not!

You'll be asked to give brief details of your condition, to describe any pains you may have, past illnesses and once again you'll be asked if you know what you've gone into hospital for. The Houseman will be frantically writing everything you say down in the famous doctor's scribble that will be totally illegible to you if you ever got to see it!

Then the doctor will want to examine you. He or she will check your pulse, listen to your heart whilst getting you to breath in and out, having you lying down, sitting up, coughing, moving your eyes and various other little tests. It all seems fairly pointless but it is important that everyone is satisfied that you are fit enough to undergo surgery and that the anesthetic will cause you no problems.

Finally, once all that is over the Houseman will want to take a sample of your blood. This is so that the operating theatre has plenty of your blood type ready and waiting for the operation.

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While in the mood for needles the Doctor may well take the opportunity to insert a Cannula (you may also hear the nurses calling it a Venflan) into the back of your hand. This is a long plastic, needle-like tube that sits in your vein during the majority of your stay in hospital and is usually taped to the back of your hand. If you have problematic veins then you may find the nurse will insert it in your arm, or side of the wrist, or the bend of your elbow.

All you'll see of the Cannula is the capped off plastic nozzle that rests on you hand. Its main purpose is to act as the entrance of the initial surgery anesthetic, for any drips that may be necessary during your stay, and for the post operative antibiotics. This one needle saves you a whole host of other needle pricks, as all the syringes will fit into the nozzle.

At some point before the operation you will be requested to sign a form of consent, unless you are under the age of sixteen then the responsibility falls on your parent(s) or legal guardian(s). Before asked to sign you will be made aware of what the operation entails, how they plan to do it and any risks that there may be. You should have already have been told all of this information by the surgeon himself anyway when you first saw him and he told you that you needed the Colostomy, so there should be no shocks in what the Houseman has to say.

This piece of paper work is vital. Once you've signed it you have given permission for the surgeon to operate. Without the signature the surgeon cannot even examine you let alone operate.

Your Stoma Nurse may pop in to see you, just to check everything is okay and that you are still happy with the positioning with the Stoma site since the last time you talked to him or her. If s/he doesn't visit you before the operation, and you have a question or two that you desperately need to ask them then ask the Ward Nurse to beep/page them for you, and they should come and see you.

And that is pretty much your first day. Although you'll have been sitting on a bed for the majority of the day you'll undoubtedly feel tired and drained. You'll look forward to a good nights sleep, and you'll hardly be disturbed by the nightlife on the ward. Just before the lights go out the nurse will call around to take your blood pressure, pulse and temperature again.

Day Two

You'll be awake between six and seven am by the morning shift nurses enthusiastically throwing open the curtains, I'm willing to bet the Nurses relish that bit! Despite your pleas for a lie in you'll be encouraged to get out of bed to get a wash and brush up before the breakfast trolley is wheeled around - not that you can eat though because you'll still be fasting in preparation for the operation.

While the breakfast is being served the nurse will take your blood pressure, pulse and temperature readings again. She'll also bring you a surgical gown and notify you of the time you are expected to go down to theatre. You need only put the gown on one hour or so before you go down to theatre, as the operating lists rarely run to time.

The nurse may well also give you a rather fashionable pair of white surgical stockings to wear. You can put these on just before you go down to theatre too but will need to wear them all the time until you are well enough to be up, about and walking around freely without spending too much time lying down. You'll think she has given you a pair far too small for you as they grip your legs like a vice and take a few minutes to get used too. They are meant to be that tight as they are designed to help the blood flow around the legs. Because you are going to be spending quite a bit of time lying down during your stay, the circulation in your legs can be affected. These are simple yet effective at keeping things moving freely and preventing clots.

In some hospitals they have disposed of the stockings completely and replaced them with a tiny daily injection usually given in the upper thigh or tummy region. Some hospitals even use both the jabs and the stockings! Oh joy.

Sometime after that your surgeon, or his senior registrar, and the rest of his surgical team will pay what is most probably their first visit to you since your arrival at hospital. You can expect to see them everyday at roughly the same time on their ward rounds.

Because they have to see all their patients throughout all the hospital it will be only the quickest of flying visits. No sooner have they arrived than they are gone, but it makes a refreshing change from the previous visits from the Houseman the day before.

The Houseman will also be with the surgical team on their visit to let them know how you've been over night. He won't have a lot to say

to them before the operation but once you've returned he'll have more to work with.

This will be the last time you'll see the team before the operation and it is the best time to iron out any final worries or ask any last questions you may have about the procedure. The team may be in a hurry but one member of the team will be only too happy to reassure you about anything and answer your questions, in fact he'll be pleased that you're taking an interest.

The anesthetist may or may not be the next professional to pay you a visit. It is very much up to the individual anesthetist whether they pop by or not. Most of the information they need about anesthetic allergies and your weight have already been asked by the Houseman the day before and is readily available from the notes. However quite a few anesthetists like to introduce themselves to the patient on the ward before they are taken to theatre so that the patient recognizes their face once they are taken into the anesthetic room before surgery. It also gives them a chance to double-check the answers you gave the day before.

If you have any worries about anesthetic this is a good time to air them. If you are like me you'll be extremely nervous about the whole going to sleep business and waking up during the operation. The anesthetist will explain the whole procedure to you and how it is practically impossible for you to be aware of any part of the operation. I found his words a real comfort.

If there is no sign of your anesthetist presenting himself before the operation and you want to speak to him for reassurance or some other reason ask the Nurse if he is coming. If he isn't planning on it, request it. The Nurse will gladly arrange for him to be 'bleeped' and get him to come and see you if he has the time.

Regardless of whether or not you were visited by your Stoma Nurse the day before you can guarantee you'll see her on the day. She'll bring with her your starter pack and spend sometime going through each item with you. The items in it vary very much to the needs of the individual patient but some items remain constant. Inside the box there will be a small box of drainable two-piece pouches and a set of flanges. I won't go into explaining these just yet as the appliances deserve a full chapter to themselves and you'll find that later on. The Nurse will guide you to begin with. As well as the pouches and flanges you'll find a packet of lint-free medical wipes for cleaning the stoma and a packet of perfumed disposal bags that all used appliances and wipes go into once soiled.

For the first few weeks all your bags will be clear rather than the standard opaque, they will also be huge compared to some of the bags you may have seen before admission – my friends and I often refer to these as the “elephant bag” because of the sheer size of its flange.

The early pouches need to be made of clear plastic so that any nurses that visit you, either on the ward or once you arrive home, can look at the stoma and the consistency of any waste without having to remove the appliance. This in turn allows your stoma more time to heal and to get a bit of strength around the wounds.

As you can imagine constantly removing the adhesive seals that are placed around the stoma would weaken the healing process.

The next time you see your stoma nurse will be when you are actually getting ready to remove your first ever bag.

I found the prospect of the initial sight of the Stoma more worrying than the operation itself because I had not seen a picture of one before so had no idea what to expect. I only knew only what the Stoma Nurse and Support Group Members had told me to expect.

If like me you are worried about your first look at the Stoma then try to leave that moment until the Stoma Nurse is with you. She will then be able to reassure you that what you are seeing is in fact normal and that everything looks nice and healthy.

At some point between all these official visits the nurse will have to come and administer your bowel prep. This is best thought of as a high power laxative and can be given in the form of a Sodium Phosphate enema, or in the form of a large powdered drink. Depending on the severity of the operation it is also possible that the bowel prep will start on Day One, or the day before you arrive at the hospital, just to be absolutely sure everything is clean as a whistle and empty inside. In my case I had my operation in the early afternoon and had the pleasure of two enemas - one early in the morning, and the next one a few hours later.

The effects are truly outstanding. It is pure dynamite for the bowels. The nurse will administer the full enema and you'll be instructed to hold it for as long as possible before expelling it into the toilet. If you can hold it for ten minutes you've done really well. The laxative scene in Jim Carrey's "Dumb and Dumber" has nothing on this! It also helps if you can avoid watching comedy programmes on the television at this time...

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If at all possible try to have your relatives or friends visit you to keep you company up to the operation. That way your mind is occupied and less likely to dwell on any nerves that may be lingering.

When it is your turn the theatre porter will bring the trolley to your bed. A nurse from your ward will come with you to the theatre but before you go there are a few more questions, and she will check the name band on your arm to be absolutely sure you are the right person. Once done you'll be covered in a blanket and wheeled down to theatre. The nurse will stay with you until you are taken into the anesthetic room, and maybe even until you are unconscious. Once you leave theatre and are taken to the recovery room she'll be told and will be there for when you wake up so that you see a friendly familiar face.

You will not be wheeled straight into the theatre and placed on the operating table. You'll be taken to the Anesthetic Room where the Anesthetist you spoke to earlier will hook you up to a whole array of equipment, which looks complicated but basically it reads your heart rate and blood pressure and displays it on a little screen.

Your nametag will be checked one more time before a syringe full of anesthetic will be injected into your arm via the cannula. You'll be asked to count backwards from Ten to One. You won't make the ten count before you drift off to a deep sleep with the nurse holding your hand.

When you wake up you'll be in the recovery room. Around you will be the friendly nurse from your ward and a couple of the surgery team. The nurse will quietly reassure and tell you that everything went fine and that it is all over. Meanwhile the surgery team will ask you if you are in any pain or discomfort and where it is. If you are you'll be given a shot of morphine or its equivalent if you are allergic to it, and within a few minutes any discomfort will just fade away.

You will not be moved from the recovery room until you are 'stable'. In other words in no pain and are well on the way to being fully awake. Once that happens you'll be wheeled back to your hospital bed where your family will probably be waiting for you. However you'll still be quite groggy and just drift off to sleep. The healing process has begun.

The ward nurses will come to have a look at your stoma every two hours or so to check everything is okay. You'll probably still be groggy but remember that you do not have to look at it with them unless you want to. Just turn your head and look elsewhere. If you are curious to know ask the nurse how she thinks it looks.

Post-operative antibiotics will be administered intravenously for the first twelve hours to make sure no infection forms in any of your new wounds. However most of this will go on without your knowledge because you'll still be groggy from the operation. Sleep is always the best healer.

Day Three

The convalescence path you take depends upon whether your surgery was performed by laparoscopic keyhole technique or the more traditional open surgery method. The length of time and recovery routines for these two methods are so vastly different that it is worth while discussing each recovery period separately over the course of the next few pages.

KEY-HOLE:

When you are awake you can start to fully comprehend what is going on around you. Probably the first thing you'll notice is a tube attached to your cannula with a saline solution drip attached. This is to prevent dehydration because, after all, you haven't eaten or drunk anything for 24 hours or longer by now.

When the breakfast trolley arrives you'll be offered a drink. It is doubtful you'll be allowed to eat anything until the surgical team has been around and given you the go ahead. It will be the most delicious cup of tea you've ever tasted!

The nurse will come around as she does twice every day to take your blood pressure readings and temperature. She'll also look at the stoma to check how it is progressing. It is also possible that she'll insist you get out of bed and sit in your bedside chair at some point during the day, but this depends on the go ahead of the surgeon. It is highly unlikely he will say no.

When the surgical team arrive they will examine your stoma through the bag, and ask the Houseman if you had a restful night. They will most probably instruct the Nurse to remove the drip and tell you that you can eat small amounts of light food (such as mashed potatoes or soup) today and progress to proper food tomorrow. Of course the team could be so impressed with your

progress that they tell you to eat normally straight away, which is always an excellent sign.

Your next visitor will be the Stoma Nurse. It is unlikely that he or she will want to fiddle with the stoma today but just simply have a peek under the bag. Now is a good time to have your first look at the stoma if you wish. The nurse will unclip the bag from the flange to get a proper look.

You'll probably notice that there is quite a bit of blood in the bag - don't panic. This is perfectly normal. With the bag clear you'll notice how the stoma is swollen looking, a dark red colour and covered in blood. The nurse will likely tell you that everything is fine, then replace the bag, and leave you to get some rest. Tomorrow you'll remove the entire appliance and clean the stoma for the very first time.

After that the day is pretty much yours to do with as you please. You'll probably sleep most of the time but if you are in your bed too long during the day the nurse will frown at you, and help you into your chair. Any trips to the toilet will probably be in a wheelchair unless you feel brave enough to slowly walk with – or without - assistance to the toilet.

You'll have something to eat and think it's the best food in the world. As you get better you'll feel more like complaining about it like everyone else!

OPEN SURGERY:

When you come around properly you will be aware of the number of tubes leading from your body. This is quite a frightening moment if you do not know what they are for but in reality they are there for simple little things.

Firstly there will be a Saline drip tube attached to your arm to prevent dehydration, which will be attached to your cannula. You'll not be allowed to eat for quite a few days and allowed only small amounts of clear fluid until you've been built up to full fluids. This drip simply stops you dehydrating.

Secondly there will be a drain leading from the wound itself, with a small bottle on the end to catch any blood.

There could well also be a very fine tube placed up your nose and down into the stomach, this is to help prevent you from vomiting.

Finally, there may or may not be a catheter attached. And I am sure you do not need me to tell you where that tube will be attached. You will most likely be unable to leave your bed for a few days so you will be given a bedpan or bottle if no catheter is in place. However, having the catheter fitted before the end of surgery is quite common, and certainly less distressing for the patient as they are asleep.

Even with keyhole surgery you can experience Urine Retention. It is a natural reaction in some people for your bladder muscles to clench up during an anesthetic. Should this happen the catheter cures the problem and next day you'll be able to freely pass water.

The usual daily routine will carry on around you while you rest. The surgical team will call around on their rounds to say how everything went and ask the Houseman how your night was. The ward nurses will take your blood pressure, pulse and temperature again. This will happen twice a day, every day that you are in hospital.

The Stoma Nurse will pop around too. You will not feel much like visitors and they will not mind at all if you doze off. The nurse will have a look at the Stoma and check your wound. Your abdomen will be quite bruised and a strange yellow colour. This is not one large big bruise but the remains of the iodine the surgeon spreads over any wound site before he actually cuts. It will all wash off easily and there will be localized bruising left around the main wound, which you'll notice has been neatly stitched up and topped off with a few staples.

The nurse will not remove any appliances for the first day to give everything a chance to settle down, besides you'll feel sore and not in the mood for a bag change.

You'll be able to see the stoma through the bag. It will be swollen, large and bloody. The nurse will assure you this is perfectly normal and the stoma will shrink as time goes by.

You'll be pretty much left to your own devices today. The nurses will keep popping by every two hours to check on the stoma, and will always be near if you need any pain relief. On the whole though, you will sleep through the daily ward life.

Tomorrow, the work starts.

Day Four

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KEYHOLE:

You'll be able to walk much more freely today. You may be slow and take your time, but you are getting there. This new independence will make a vast difference to your outlook on the whole situation. Just going to the toilet without the need of a wheel chair or a nurse to hold onto you is just wonderful.

The breakfast trolley rolls around and you will feast on the cereal of your choice and maybe even some toast all washed down with a hot cup of tea. Lovely. Lets face it, even the hospital cooks cant mess up a box of cereal and a slice of toast can they! But then again...

If everything is okay the surgeon may well say that as far as he is concerned you may go home. However do not get too excited too quickly. The final say on whether you can go home or not will rest with the Stoma Nurse, and seeing how you've never changed a bag she'll keep you in until she is satisfied you can handle the stoma routine successfully with no guidance.

On today's visit the Stoma Nurse will give you your first opportunity to look at the stoma properly when she removes the bag for the first time and shows you how to clean your new stoma. The nurse will take this opportunity to give it a good examination and check for any signs of infection. There shouldn't be any because of the postoperative antibiotics you were given yesterday.

The cleaning usually takes only a few minutes but the nurse will be going through each step very slowly so it may take 30 – 60 minutes today. After explaining each step she will be allowing you to have a go yourself.

The stoma will look so red and sore that the mere thought of touching it with a wet cloth will send cold shivers down your spine, but remember there is no nerve supply to it so therefore it will be a totally painless experience.

Once the stoma is cleaned, you'll be able to see the stitches around the stoma that hold it in place. These will dissolve away in time. They can take up to three weeks. If they are still in place after this length of time then the Stoma Nurse will remove them, as they can start to be detrimental to the healing process if left for longer than this.

The nurse will cut your new appliance for you and show you all the techniques for fitting it securely in place. The whole process could

take up to an hour, but at the end of it I'm willing to bet that you're thinking the stoma isn't quite as bad as you had envisaged and that maybe this isn't going to be too bad after all.

Once the nurse has gone there will be nothing else planned for the rest of the day. You'll look forward to your family and friends visiting you, and they'll be able to see the difference in you from the day before.

Lunch arrives, then there's an afternoon tea break, and soon after that it's teatime. The food will be welcome, although you might not be all that hungry as you may have been delving into the supplies in your bedside cabinet all day.

You should be allowed to have a shower or bath today. You will feel more or less human again after this, but remember that if the bag you are wearing has a filter to cover it with a sticky filter stop or the pouch will slowly fill with water.

OPEN SURGERY:

The day will begin with a bed bath, and you'll be amazed how different you feel after that. It may be a bit sore but worth the effort.

The surgical team arrives again to examine you and is gone before you can blink. Soon after the Stoma Nurse arrives.

Today is the big day. The appliance you've worn since theatre will be removed and the stoma cleaned. This will be your first up-close-and-personal look at it. If you've avoided the inevitable up until now, then it is time to be brave. The nurse will be there to reassure you. Remember you'll have to clean the Stoma regularly when you leave hospital so you will have to look at it sometime.

Today is pretty much the same as for a keyhole patient, however you will not be allowed to walk about.

The nurse will most probably insist on getting you out of the bed today, and get you to sit in your comfy chair for as long as possible. Although the chair is only next to your bed you'll have felt like you've run two marathons back to back by the time you return to your bed. You'll still be weary and sleep most of the time in the chair.

You should be starting to survive the day without any serious

amount of painkillers, but if you do need them go ahead and ask.

Day Five

KEYHOLE:

Today you should be extremely hopeful about being allowed to return home. As long as your Stoma Nurse is happy you can change your appliance confidently (regardless of the length of time, so don't think you'll be kept in because you are not the Speedy Gonzales of Colostomists!) you'll be allowed home. Remember the surgeon effectively discharged you on day three; such is the wonders of the keyhole technique.

When the Stoma Nurse arrives she will ask you to change your appliance. As I said you will not be fast because, after all, this is your first full solo flight as it were. The nurse will not expect you to remember every single detail in order and will prompt you along the way. As you get more and more practice you'll be able to get a complete clean and change down to ten minutes.

The nurse will probably have a rough idea on whether she is willing to discharge you or not today based on the confidence you showed yesterday when you took your first few tentative steps at cleaning a stoma.

Hearing the news that you can go home will be wonderful. You'll want to phone your relatives and dance around the ward telling everyone else. While you'll be able to phone home you will not feel much like dancing as you'll still be sore and stiff!

You'll patiently wait for your ride home - you'll not be allowed off the ward unless you are getting taken home. Public transport after surgery is a major no-no. This will be one of the questions you'll be asked by the nurse when you first arrive on the ward on day one - how you plan to get home.

OPEN SURGERY:

On their early morning rounds the surgical team will probably request the removal of most – if not all – of the tubes around you, providing everything is okay and you have managed to successfully get out of bed. This may even have been requested the day before but it depends very much on your own hard work. You'll be pleased to see the back of the neo-nasal tube that you've had since day two. The drain will probably be left in for a few more days to make sure there are no more dribbles of blood coming from the main wound.

You should now have been allowed to start eating proper food, and this will just as big a step towards your convalescence as the bed bath did the day before.

Providing the doctor is happy you should be allowed to venture to the bathroom and have a bath, but not until the Stoma Nurse has been for her daily visit, as you might miss her otherwise. Remember to cover the filter on your appliance before you get in the water otherwise it'll fill with water.

When she does arrive she'll take very much a back seat. It will be up to you to clean and change the appliance yourself. She will be there to guide you if you should falter, you will not be expected to have learned it all overnight.

From here on your days on the ward will start to become very predictable and you'll find you're getting fewer and fewer doctors and nurses coming to see you as the days go by.

Day Six

OPEN SURGERY:

Losing all the various tubes and being allowed the freedom of the ward makes a difference to your recovery. At the time you'll not feel like doing much more than sitting and watching the ward life, maybe even reading, but it is nice to know you can get up when you wish and go to the toilet.

The Stoma Nurse starts to spend less and less time with you as you get quicker at the change and more confident at dealing with the Stoma. By now the stoma should have passed its first motion.

You will also most likely start to see a new white-coat coming to your bedside each day. This is the physiotherapist. His or her job is to help get your body recovered and moving again as quickly and as safely as possible from the large entry wound in your abdomen, so that your breathing doesn't become too shallow, and so that you become more self-reliant as time goes by. It is also likely that he or she will leave exercises behind for you to follow, such as deep breathing or sitting up and standing up exercises.

Day Seven

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OPEN SURGERY:

You are well on the way to recovery, and getting ever nearer to the magical discharge day. The surgical team will authorize the removal of the last tubes, if any remain.

As each day passes you'll be getting more and more confident with the stoma. The Stoma Nurse will probably come to see you daily, but only as a matter of routine and not because it is essential. As far as she is concerned you can probably go home when the surgeons are happy.

You start to realise that the food isn't quite as nice as you first thought.



Fuzzbutt Says:

Have you visit our Ostomy Wiki yet? It's an online encyclopedia that's edited by Ostomyland admins, and by you - our readers and members. It's a continual work in progress and already has nearly 250 pages/definitions in it and you too can write pages for it! Why not have a read at:

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Discharge

The average length of stay after open bowel surgery is between ten and fourteen days. As you can imagine it is very much up to your own healing speed, there are no set rules for this. Usually your stitches are removed before you go home, however if they are not the district nurses will call to your home and remove them.

The average length of stay after Keyhole bowel surgery is up to five days. Again this could be more or less, depending on how you progress. In my case the surgeon was happy for me to return home the day after the operation, but he was aware that the Stoma Nurse would say otherwise.

You'll be given the okay for discharge so long as you can walk around freely without too much trouble, you are eating as per normal, that the stoma is working, and most importantly, that you are not suffering any pain or discomfort from the stoma and surgery wounds.

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When you are discharged you'll be given numerous items from the staff.

1. Your prescription. It is most likely that you'll be given a bottle of painkillers in case of any discomfort. As soon as you "over-do-it" your wounds will tell you. These will probably be paracetamol (a.k.a. Tylenol) and either Voltorol or Diclofenac (these two are in fact the same thing, the only difference is the brand name). They are anti-inflammatory painkillers and designed to kill pain from wounds that are moving etc. so are therefore ideal for post-op pain relief.
2. A letter for your doctor. This is just a copy of the discharge form that you may or may not have been asked to sign. It depends on the bureaucracy of the individual hospital. Give this to your doctor as soon as possible when you get out. It is often a good idea to arrange an appointment to see your doctor as soon as humanly possible after the discharge, as the Doctor will want to know how things progressed and it is an ideal opportunity for you to get a top up prescription of appliances and other necessities.
3. An Outpatient's appointment. One will be made for you by the ward nurse usually for between four to six weeks after your discharge. By that time you will be feeling so much better that you'll be wishing you had the operation earlier! Over the course of those weeks to the appointment you may well have a list of questions that you'd like to ask, such as "Is this normal?" and so on.

If it is necessary the hospital will arrange for you to be visited by the District Nurse upon your arrival at home. If you are a keyhole patient this will be essential, as you'll be observed while you clean and dress the stoma for maybe two weeks. (Open Surgery patients have had this already catered for by the daily ward rounds of the Stoma Nurse.)

By far the most important item given to you at discharge is your discharge pack from the Stoma Nurse.

Inside you'll find enough appliances and supplies to last about two weeks after you leave hospital. You'll also be given a supply card, which lists all the items you are currently using and their appropriate prescription order number. You need to get a top up prescription from your GP immediately.

You could also be given a whole host of literature to read. If you live in the UK then the most important booklet will be your prescription exemption form. Now you are a Colostomist you qualify for free prescriptions whilst you have a Stoma.

Other leaflets which are likely to be included for you will be details of the Colostomy Association, or your National colostomy association wherever you live in the world, along with information on any local support groups in your area.

Appliance manufacturers may well ask the Stoma Nurse to give you literature on their products too.

Finally you could be given a supply of cleaning wipes and disposal bags for used appliances, or some other handy freebies courtesy of the Ostomy Manufacturers and Supplies Home Delivery Companies, such as Dansac, Salts, Coloplast, Convatec or Hollister etc and they will make sure their details are in the pack.

The Stoma Routine

This section concentrates on the everyday routine of living with a Stoma - principally the cleaning of it, and coping with any problems that may arise.

Cleaning

Initially you can expect to be quite slow at changing your appliances and cleaning the surrounding area. But as with most things in life the more you practise it the faster you'll get.

It is helpful if you pick a time to be in the bathroom where you can be undisturbed for the duration of the change. The last thing you need is to have a knock on the door and a faint "I need the toilet, hurry up will you, I'm bursting!" coming your way when you've got your jeans around your ankles and are cleaning your stoma. So check no one needs the bathroom before you 'freshen up' and try to get into a routine that works well for you.

Of course, you do not necessarily have to change everything in the bathroom, you could use your bedroom if you wished and it made you more comfortable. Just take a small bowl of tepid water with you before you commence. I would however recommend the bathroom as it is a completely private place and has easy access to

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warm water and a toilet in case of emergency.

Before you start you need to get yourself a small container in which you can keep all your supplies and a few pouches. An ice cream container is ideal, or if you use a home delivery service you'll soon have a travel bag coming your way that is specifically designed for the job. The suggested contents for your wash kit can be found below.

Once you are safely locked away in the bathroom it is a good idea to prepare everything before you even consider removing the appliance, as you can guarantee that Sod's Law states that the stoma will work while you are at your most vulnerable! Lay everything out so that you can easily reach them, on top of the toilet cistern or on a windowsill is ideal.

To start with you need to cut out your stoma shape onto the flange or bag. Cut this so that it fits snugly around the stoma. Your Stoma Nurse will show you how. Try to make sure it is neither too tight a fit nor too large a hole. If too tight the stoma may be damaged, if too large then you may risk a skin irritation on the exposed skin or even leakage due to pancaking and other such mishaps.

Take your bag and add any odour control liquids, or powders, that you may need. These are not always necessary and you may be happy to manage without them.

With your flange or pouch cut to size you are now ready to remove your current appliance. Carefully peel away the adhesive from the skin working off any bits that may be resisting.

Wet a cleaning wipe with warm water and clean the skin around the stoma. No soap should be necessary but you can use a non-perfumed soap if you wish (don't use perfumed as it may affect the stoma). Carefully wipe the stoma so it is totally clean. Try not to rub it too hard, as the stoma will begin to bleed. It is very fragile. If it does begin to bleed despite taking care and attention do not worry, it will stop almost as quickly as it has started.

Pat the skin and the stoma dry with some of your remaining dry cleaning wipes. Avoid lint/fluffy towels or cotton wool to do this. Towels may carry germs that could infect any areas of the stoma that are bleeding, especially freshly formed stomas where the wound has yet to heal properly. Cotton wool is too fluffy and will leave bits sticking to the Stoma.

If you need to shave the area around the stoma to remove any body

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hair from the abdomen now is the time to do it. Be careful not to catch the stoma with the blade. Any hair on the stoma edge is best removed with rounded end scissors, or if you are feeling brave you could just pluck them out - ouch.

Next, apply the second skin wipe if you are using one, or any barrier creams and stoma pastes that you may be using. The creams help protect your skin, while the Stoma Paste fills in any natural grooves that may affect the adhesion to the skin.

Now you are ready to fit your clean appliance. Carefully bring the bottom edge of the hole in the adhesive flange in line with the underneath of your stoma, use the mirror if necessary (as you get more practice the mirror will become redundant). Gently press into place starting at the bottom and working up being careful to avoid any wrinkles in the flange or bag adhesive.

If you are using a one-piece system that is everything complete. If you are using a drainable bag don't forget to check that you've closed the pouch clip securely. I have heard stories of people leaving the house in a hurry and having once arrived at work they have realized they have not placed the clip on the drainable bag. So checking the clip may seem obvious but it can be easily forgotten if you are in a hurry.

If using a two-piece system you now need to clip the bag itself on to the adhesive flange. Again, work the appliance onto the flange carefully from bottom to top. Once it is on check that it is firmly in place by giving the bag a gentle tug; if it isn't you'll soon know, as it will slip off easily.

To dispose of the soiled bag simply place it along with all used wipes in a disposal bag or wrap in a few layers of newspaper, and discard in the bin outside.

You may empty the bag into the toilet if you wish before doing this but it is messy and best avoided. To do this simply cut the bottom off the closed bags or unclip the drainable one, and hold the stoma hole near the toilet's main water flow in the bowl and flush through.

Do not, under any circumstances, attempt to flush pouches, flanges or wipes down the toilet unless the manufacturer states the appliance is flushable. Being plastic and solid they will soon block up the drainage system.

A soiled pouch is classed the same as a dirty nappy (diaper) as far

as clinical waste goes. So, if you find it necessary to change in a public toilet, it is perfectly acceptable for you to place any wrapped up soiled appliance in a public waste bin.

Suggested Bathroom Wash Kit Contents

- **A good pair of surgical quality scissors**
Preferably with rounded edges.
- **A Razor**
Not necessary if there is no hair growth on your tummy.
- **A pen**
To draw the stoma template onto your new bag or flange.
- **A small mirror**
To check positioning of appliance on underside of Stoma.
- **A Supply of disposal bags.**
Newspaper is a good substitute.
- **Lint-free cleaning wipes**
- **A fresh pouch and flange**
- **All your pastes and creams**
If used.
- **A bag clip**
If using drainable pouches.
- **A clothes peg**
To help keep your rolled up sweater and shirt out of the way while you clean yourself up.

For your home-based waste it is a good idea to ask your GP if the local council operates a 'yellow bag' scheme. This is a clinical waste collection service that comes once a week to your home to remove all your waste and incinerate usually free of charge. Not all councils operate this for domestic purposes, but most do. However some Councils and Local Authorities may try to charge you a small fee for the service.

Once you are finished with your change, make sure you wash your hands, return all items to your container or travel bag and re-stock

it if supplies are getting low. Try to keep the container in a cool place like a cupboard or bedroom drawer.

Emergency Changes

When you are eventually back on your feet and feeling fit again, your desire to go out and about will return. If you intend to leave the house for the day it is best to take a small pocket-sized travel bag (this could be a specially designed one that repels heat or could be something as simple as a bum-bag!). The suggested contents for this can be found in the box-out below.

Suggested Pocket-Bag Contents

- **Scissors**
- **A replacement pouch**
Preferably already cut to your current size if one piece
- **A disposal bag and a few wipes.**
- **The all important clothes peg**
- **A small packet of wet wipes**
(in case you are stuck in a cubical with no water)
- **A second skin wipe**
(if used)
- **The Radar disabled toilet key.**

If you are just nipping into town and back or intend on being out of the house for only an hour you can check your appliance before leaving the house and leave this kit at home. As you gain confidence around your stoma, you'll learn the limits of how long you can leave a bag on, how full it can be before problems arise with smell etc. However even if you are still only strolling to the post office or going out with the dog it is a good idea to tuck a spare pouch in your pocket before leaving. Once you've settled on your particular brand you can easily pop a spare appliance inside a pocket of all your coats so that you know that even if you've left everything at home

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you are not totally stuck.

The major ostomy manufacturers usually have a FREE “No Waiting” card on offer for customers who contact their help lines. This is a card that can come in very handy at times. If you are in a busy shopping centre and for sake of argument your appliance does give up the ghost and starts to come off you can go into any large store produce the card and ask to use their staff toilet facilities. The staff would probably have to check with the Manager/ess beforehand but they will be unlikely to say no. This is true of the big chain stores; however small family run stores may be more apprehensive to do so. Thankfully, I've yet to be placed in this situation but it is nice to know that you have that protection.

If you suffer from Colitis or Crohns disease in the UK and have joined the NACC you may already have one of these no waiting cards. Wherever you get one from, it is advisable you get one and carry it with you at all times either in your purse, wallet or coat pocket.

Now that you are a Colostomist you qualify for RADAR's disabled toilet 'National Key Scheme'. At the time of publication you could get your own key that opens the door to every disabled toilet in the British Isles for £3.50. For a further £10.00 you could also obtain a copy of the book, which lists all the sites. The RADAR scheme is exclusive to the UK however other similar schemes may operate in other countries. Please contact your local support groups or colostomy association for details.

Because the disabled toilet doors remain locked there is less chance of the facilities being vandalized beyond use or recognition, as is the case with a lot of public conveniences these days.

Inside you'll find a toilet - no great surprise there - as well as a washbasin with hot and cold water supplies. It will also be brightly lit and roomy which is a nice plus as a lot of cubicles in standard toilets are cramped.

There may be a clinical waste yellow bag in there too, but if not you can always place your carefully wrapped disposal bag in a street bin.



Fuzzbutt Says:

Why not visit our message board and ask our members about their cleaning routines? Or read existing posts about stoma care?

<http://www.ostomyland.com/ostomyboard>

Quick Ref. Guide to Cleaning Your Stoma

1. Prepare new appliance and flange before removal of soiled appliance.
2. Remove/Peel-away the soiled pouch and flange.
3. Clean skin around stoma; followed by stoma itself using wipes and warm water then pat dry with wipes.
4. Shave area if necessary and wipe with damp cloth once finished.
5. Apply skin lotions, cream and pastes if necessary.
6. Carefully stick on new appliances, be sure the fit is wrinkle free, checking clip if necessary.
7. Wrap soiled appliances in disposal bag or newspaper.
8. Wash hands.

Prescriptions

Please Note: The following is relevant only to the United Kingdom. Patients in other countries should contact their own Hospital/Stoma Nurse for correct information regarding prescription services.

All the appliances and accessories mentioned in these pages are available on prescription.

When you are discharged from hospital the Stoma Nurse will give you a list of the items you are currently using and their appropriate order numbers. These numbers are very useful, as even if nothing else were written on the prescription list your supplier would know

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exactly which items are required.

Once you have your prescription there are a number of ways you can get it dispensed.

Firstly there is your normal everyday chemist/pharmacist. They will not have the bags in stock and it will be necessary for them to order them especially for you. This can take up to a week.

Or you may want to try a specialist home delivery service. These are companies that supply only Ostomy products and their warehouses stock every single item that is currently available on prescription, and deliver to your door free of charge regardless of whether you order one box or thirty boxes.

There are loads of different companies to send your prescription to, all offering the same services. They all offer a free cut-to-fit service (so long as you supply the stoma template), free disposal bags and wipes. Some companies can be stingy with the wipes. If you need more than the amount they usually supply don't be afraid to write this on your prescription. If they want your order they'll send you more wipes! Finally they all offer free delivery, freepost envelopes to send your prescriptions in (although lately it is becoming more common for the delivery companies to obtain the prescription for you on your behalf which makes things much quicker for you) and most importantly a free phone number in case of emergency.

If you have any problems with your stoma and are unable to contact your Stoma Nurse you can call one of these companies with your customer number and ask to speak to the in-house Stoma Nurse, for expert advice. Not all of them have a qualified nurse on their staff, however the larger Ostomy Companies (Coloplast, Convatec etc) usually do have one that you can seek advice from.

You'll also find that the home delivery companies will be prepared to bend the rules for you. For example if you ran out of bags or flanges and had been unable to get your prescription from the doctor in time, you can phone the companies with your requirements and they will forward the items to you, all you need do is get the prescription for the items they have sent you, back to them, as quickly as possible – or let them obtain the prescription for you on your behalf.

If you went to your local chemist/pharmacist and asked for an advanced order it is unlikely they would be able to accommodate you.

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With time you'll find one delivery company you like and will settle with. Until then these companies will clamber to dispense your prescription for you. It is obviously a big business and they bribe you to try their service by offering free travel bags, scissors, phone cards or skin lotions with first orders. By the end of it you could have a cupboard full of travel bags and complementary items. Some companies also offer extra little incentives that no one else does like offering to make a donation to your local patient association with every prescription they receive or to other ostomy-or-bowel-related charities.

You can still take your prescription to your local chemist but you will generally find it easier and more convenient to send it to a Home Delivery Service. The Chemist does not cut flanges, or supply free wipes and disposal bags. These would have to be purchased separately.

Once you settle on a certain product you'll be able to order up to three months supply in advance on your prescription. Believe me, three months supply is a big box full, and it would be awkward carrying it back from the chemist. The home delivery services deliver to the door and take the hard work out of the task for you, usually with a next day service, although some can take a couple of days. The parcels are usually delivered by courier and may, therefore, require a signature at delivery.

Regardless of who dispenses your prescription, you should start thinking about placing a new order once you have enough supplies left for a two to three weeks period. This way, even in the event of the lengthiest delay possible you should still have more than enough supplies to see you through to delivery.

Once you've had the Colostomy operation you'll find you are most likely exempt from prescriptions for the duration of the time you have the Stoma.

To apply for the exemption certificate you need to fill in form "P11" which is available from your local Health Authority, although the Stoma Nurse might have tucked one in the discharge pack you were given when you left hospital.

When you read the form you'll see that it says the exemption is only for people who have permanent Colostomies. If you have a temporary Colostomy don't panic, as you might still be able to claim. If there is no reversal intended in the near future then your GP will hopefully have no hesitation in signing the declaration for

you, after all you could have this Colostomy for years, if not life, and it would be unfair to say that it is temporary. But this is all down to the individual GP and not guaranteed.

Before you send off your prescription to the home delivery service, or take it to be dispensed at your local chemist, it is vital that you fill in the declaration on the back, otherwise you'll be charged full whack for the products and that would be one hefty bill especially when you consider that at the moment a tube of Stoma Paste costs around £10 to buy, and the average pouch is £1-2, and flanges £2-3 each! A full 3-month supply of appliances and accessories would soon add up, and that's why these companies are so keen to get your order. They will more than likely encourage you to try their service with goodies and will be more than willing to supply you extra wipes if you asked for them.

If you cannot get your GP to sign the P11, then you need to think about getting a Pre-Paid "Season-ticket" which gives you unlimited prescriptions for a three-month period for a set-fee (Around £60 the last time I checked).

Problems with Diet

'Problems? What problems?' The first mention of the word "problems" to a Colostomist-to-be may be worrying, but there is no need to worry. By "problems" I mean the common run of the mill conditions that affect everyone more regularly than we wish to admit to regardless of whether we have a Stoma or not. I refer to these as 'The Big Three': Wind, diarrhea and constipation.

The Big Three

1. Wind/Gas:

As a general rule all the foods that caused you to suffer The Big Three before your Colostomy will still cause them in you after the Colostomy.

Wind is embarrassing at the best of times but whereas before you had muscular control over its discharge, now you do not. Your stoma has no muscular control whatsoever and despite your best efforts you will not be able to delicately deliver the wind quietly so

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no one notices. You'll feel it coming just like before but will be powerless to stop it.

For the first few days after the operation you'll be amazed at the quantity of wind you'll pass. Because your bag will most likely be drainable it will probably have no integral filter so it will be trapped in the appliance until you open the clip and let it escape. I woke up the day after the operation, my bag was near bursting point and I was frankly amazed that I wasn't floating across the ceiling, and out the window where a good gust would have blown me across the Atlantic faster than Richard Branson's latest trans-Atlantic record bid!

Because of this lack of control and the inevitable embarrassment it will first cause it is best to try and quash the wind at the source.

Certain food causes wind - we've all heard the after effect of baked beans and peas for example. But there are other foods that can be rather windy too like chocolate or beer. It is best to experiment to find out any effects. If a certain food, like beans, does affect you it is best to eat that food in moderation. Don't feel you have to avoid it, just eat smaller amounts.

It is also helpful to eat slowly, making sure to chew food well with a closed mouth so that no air is gulped down with the food. Try to avoid fizzy drinks while eating and for about an hour after the meal. These are a major contributor to flatulence.

Check out the Food Effects Chart (page 43) for a list of 50 or so common foods and drinks and their effects on a colostomy.

2. Diarrhea:

Spices, onions, fruits, greens, chocolate (especially dark) and beer are all foods that can bring on a bout of diarrhea if consumed in sufficient quantities.

This problem may not necessarily be caused by diet though. Anxiety and emotional stress can often have a softening effect on your motion. To try and combat it, spend a little time on a low fibre diet, but not too long.

Once you've had a Colostomy your motion is automatically softer than before as it no longer passes through the rectum. The main function of the rectum is to absorb liquid from the stool to firm it up.

As a guide a Colostomist's motion will have a consistency similar to that of mushy peas out of a tin. However it may be softer or firmer than that depending on how much of your Colon has been by-passed in the operation. Your Surgeon will be able to advise you on this.

If you are suffering from a prolonged bout of diarrhea it is best to switch to a drainable bag if possible, and the largest size you can get. This will help keep the stoma free of the stool.

If diarrhea persists consult your GP to have it checked out, but do not take any shop bought remedies without his or her prior approval. Also, be sure to drink plenty of water to get the liquids back into your body to help prevent dehydration.

3. Constipation:

Celery, sweet corn, coconut and nuts all help to make stools firm. Eggs and boiled rice help the motion set like concrete.

If you are suffering from constipation try a little gentle exercise. Walking helps to get the bowels moving and with luck it will work the stool out of the system.

Failing that, increasing your intake of fruit, or fresh fruit juice, will help to grease the wheels.

Make sure you chew your food properly too, as unchewed food can help firm things up. If you were an Ileostomist you'd be at risk of blocking the stoma if you didn't - that shows how important it is.

Diet Guidelines

Reading this you'll probably be wondering what you can eat! No chocolate, sprouts, peas, cauliflower, baked beans, spices, alcohol! How can you live like that?

In all fairness I was warned about diet before I had the operation and although I was far from a healthy eater I found the food I was eating was perfectly fine for my Stoma. As far as I was concerned all this about diet was utter cobblers. The only thing that affected me badly was sweet corn. But, which foods affect you depends very much on your current diet and your own digestive system.

Until you have healed fully from your operation it is wise to stick to the post-operative diet to help your healing. After that time, feel

free to experiment as you wish with foods.

It takes anywhere from 16 to 22 hours for food to reach the stoma from being swallowed in the average human being. So, it is a good idea to introduce new foods one at a time and monitor the effects the following day. If you think one particular food has affected you do not rule it out immediately. Give it up to three goes. If you are then certain it was affecting you try eating small amounts.

Your new dietary restraints are a matter of trial and error. We all have to go through this and hopefully at the end of it you'll have to boycott hardly any foods at all.

Whether foods upset your routine or not it is worthwhile trying to make sure you eat regularly at meal times, eating three meals a day.

You will not be able to stop your stoma working by stopping eating and in the long run you will upset the stoma from working to a regular time pattern, just like your bowels did before the operation.

Post-Op Diet

Once you arrive home you'll undoubtedly feel hungry and dying for some proper food after the 'food' the hospitals have served up. Well, we may mock the food in hospitals for the quality but as far as dietary requirements go they are spot on, and designed to help your recovery.

Even if you are not hungry at meal times it is important that you at least try to eat something. You need many more calories than before the operation to help the healing process, and to build up your strength. Remember you've had a major operation.

Glucose drinks are very helpful in helping you to build up your strength. Try adding glucose to milk or fruit juice (use about 20g of glucose per 400ml of liquid).

You do not have to eat full meals either. Ask your family to make the meal for you or if you are at home alone frozen or fresh ready meals from the supermarket are a Godsend, especially considering they are simply heated up. Even in your weakened state you'll be able to put a slab of frozen lasagna in the microwave.

Regardless of what you eat remember the golden rules: Always chew your food properly, avoid fizzy drinks at meal times and make

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sure your calorie intake is high.

During the first fortnight of your new Stoma it is best to eat a low fiber diet.

Once you've recovered from your Colostomy be adventurous but at the same time observant. Try to follow your normal diet routine and observe which foods upset your stoma routine, which foods increased the smell in the bag and so on.

As I said earlier, at the end of the day what effects you and what doesn't will be down to your individual digestive system. The items I've mentioned here are only guidelines. Experiment and enjoy!



Fuzzbutt Says:

If you can, try to always introduce new foods into your diet one at a time. This way, if you get any undesired digestive effects, such as excessive gas, or constipation, you can be sure which food was the culprit!

Food & Drinks Effects Chart

After you have had a stoma operation you may find certain foods affect you in ways they didn't before. This can be embarrassing at times and it helps if you know which food can do what to your system. This table is designed to help you find problems foods, and either avoid them or moderate your intake to see if they do indeed affect your system.

Key:

F = May cause flatus

O = May cause odour

L = May cause loose stool

C = Requires chewing well

D = May discolour urine

Col = Colostomy patients

Ileo = Ileostomy patients

Uro = Urostomy patients

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Food & Drink	Col	Ileo	Ur
Apples		L	
Apricots		L	
Artichokes	F		
Asparagus	F		O
Bananas	F	F	
Beans (all types)	FLO	FLO	
Beef		C	
Beer	F	F	
Beetroot			D
Broccoli	O	FO	
Brussels Sprouts	F		
Bean Sprouts	L		
Cabbage	F	LF	
Cauliflower	FO	FO	
Cereals		L	
Cheese		O	
Celery		L	
Chocolate	L	L	
Coconut		CL	
Coleslaw		C	
Cucumber	F	OF	
Curry	LF	LF	
Eggs		OF	
Figs	L	L	
Fish		O	O
Fizzy drinks	F	F	
Gooseberries		L	

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Grapes		LC	
Kiwi Fruit		L	
Lamb		C	
Lettuce		L	
Mango		L	
Mushrooms	F	F	
Nuts (all types)	C	C	
Oil based salad dressing	L	L	
Oranges		L	
Onions	OF	OLF	
Parsnips	O	O	
Peas		L	
Pears	L	L	
Pineapple		LC	
Plums		L	
Popcorn		L	
Porridge		L	
Potatoes		C	
Prunes	L	L	
Radishes	F	F	
Raspberries		LC	
Rhubarb	L	L	
Spinach	LF	L	
Spring Greens		O	
Strawberries		L	
Sweetcorn	L	LF	
Tomatoes		L	
Turnip	O	O	

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About the Pouches

When you mention the word "Colostomy" to someone the first thing that immediately comes to mind is bags. As I've already mentioned there are dozens, if not hundreds, of different appliances available to Colostomists now.

Although the first few bags you wear will be monsters as far as size goes you will soon be able to pick and choose to your own requirements, and there are numerous different sizes available for different occasions.

With continuing research today's pouches are close to miraculous compared to twenty-five years ago. These days the bags are rustle free, can be opaque or clear, and most closed pouches are now fitted with integral filters which not only let out any passed wind but help retain any smell that may be around.

The adhesives used now are far more hypoallergenic and skin friendly. As little as twenty-five years ago most adhesives were made from rubber, a product that was about as hypoallergenic as hot tar. Constant application, and removal, could lead to skin ulcers and quite nasty rashes. When these occurred patients were admitted into hospital to have the area treated, this was necessary as no appliance was to be worn at the time for many days.

There are two main pouch systems available for you to try, and all bags revolve around this: One-piece or two-piece? That is the question.

A one-piece bag has the adhesive built onto the back of the product. To use you simply cut the base to size and stick around the Stoma. Once the bag is full you have to peel away the bag, clean around the stoma and apply a fresh appliance. Over the course of the day you could end up changing bags three times. There are two ways over this hassle.

Firstly you could try a drainable bag. This sticks on the same way but because you are able to unclip the end and drain the contents the bag itself can stay in place for up to five days, although most glues are tested to seven days. This sounds ideal but you will be unable to clean the Stoma until the bag is removed.

Secondly you could try a two-piece system. In this case, a plastic

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clip replaces the adhesive on the bag - this in turn clips onto a flange (a base plate). The flange sticks to the skin, again for up to five to seven days, and used appliances simply clip on and off.

Because the bag is no longer stuck to the skin, the chances of rashes or sores, from constant removal of bags is reduced to one removal every few days. The other main advantage of this over the drainable one piece bag is that you have access to the Stoma to clean it regularly, and being able to give it a wipe at every change of appliance cuts down on the amount of cleaning necessary when you do eventually remove the flange. Think of it as a saucepan after you've heated up a tin of baked beans. If you wash the pan straight away it is easy to clean, if you leave it on the draining board for days on end the task becomes much more laborious!

As your stoma starts to shrink after the operation, you'll be cutting less and less out of the bases. After about six months your Stoma will be at its constant size and shape. Once this happens you'll be able to send a template of your stoma size to your bag supplier and they will cut all the flanges for you (this applies to flanges only, they will not do this for one piece systems).

Immediately after your operation your Stoma will be quite erratic. It can work a number of times each day at different times each day. In the early days it will be impossible for you to anticipate the time when the bowels will work. This is simply because the bowel has been handled and the routine upset. As the stoma heals you'll notice that it starts to work at a certain part of the day. This may take months, or a few weeks, it is up to your own system. Once the routine is back in place you'll be able to gain extra confidence by using various size bags during the day.

In my case the Stoma usually starts to work just before I get up in the morning and is finished by ten o'clock. When I go to bed I put on a standard size bag and forget about it until lunchtime next day. By that time the bowels have emptied so there is no need for me to wear a huge monstrosity of a bag. I slip on a small sports pouch, which is about a third of the size. I find it gives me more confidence to go out as they are so small you might as well not be wearing one, however there is room in it should there be any last dribbles during the day. As time goes by you'll develop your own routine.

Most companies products are similar to each other although there can be big differences in the sizes of some bags. Unfortunately you cannot mix and match bags and flanges from different companies. They all have different fittings and only their bags will fit. That is a

bit of a shame really as you may like a certain flange but find the bags themselves to be no good for your needs. At the end of the day you'll find a brand to settle with and will probably use them all the time.

Just because you have a Colostomy though do not be lead to believe that you will always have to wear a bag. Even if you have had a permanent stoma you could well get away without using a bag.

There are two ways to do this. In either case discuss it thoroughly with your Stoma Nurse before you attempt it.

Firstly, you could irrigate. This is a lengthy process that can take up to an hour every two to three days. Basically it is like a self-administered enema that flushes the bowel totally clean. Once this is done you need only cap the stoma off to prevent any damage and forget about it for the next few days. This can be useful if you are traveling long distances or going away for the weekend and don't want to be bothered with the routine of appliance changing and stoma cleaning in unfamiliar circumstances. The Stoma Nurse will probably ask you to check with your surgeon before starting this, to be sure that your condition does not prohibit this.

Secondly, there are stoma plugs, however these are becoming less and less popular and may even cease production in the near future.

These are very similar to a tampon when in use and looks like one, only smaller and with a plastic cap at the base. It is a very simple idea really. After the bowel has worked its main motion of the day out you remove the bag and insert a plug into the stoma. This will then expand to block the stoma and prevent any further stool from being passed. This plug can be worn for up to eight hours and is ideal for people who wish to go to work or school and not have to worry about having to change their bag during the day.

It is a two-piece system and once the base flange is applied the plug is carefully slid into the stoma and clipped into place on the flange. Once inserted the plug may at some point feel like it is dropping out but it isn't. A word of warning though, once the plug is inserted and clipped into place do not try to prying the cap off to see if the plug has expanded, this will dislodge the plug and it will not block as successfully.

The plugs are available in two different lengths: 35mm and 45mm. The size that is best for you is determined by your height and weight, your Stoma Nurse will have the chart and a demonstration

kit to explain how everything works.

As with Irrigation it is necessary to check with your Surgeon that you can use this system before you try it. If you suffered from an inflammatory bowel condition then this system is not recommended.

With the developments that have been made towards colostomy appliances no one will be aware that you are wearing one. All today's equipment is very discreet. If you are worried about the bag security then you will be able to order either a belt, corset or panty-girdle which you wear over your pouch, so that in the highly unlikely event the bag does lose its grip on your skin it will not fall onto the floor in sight of everyone. These are available on prescription too and your Stoma Nurse will gladly give you the details. Wearing one of these items will give you that little extra bit of self-confidence, should you find you need it.



Fuzzbutt Says:

The Ostomyland website includes sections on the major Ostomy Manufacturers. Each featured company has their own page which they had editorial control over at creation and so most of the pages feature their most popular, and latest, products on the market.

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Leakage and other Skin Problems

Even with today's advances in stoma care products all ostomists will admit that leakages happen occasionally. They're a huge source of irritation; not only to the ostomist's pride, but more importantly to their skin.

If leakage is constant your skin will get burnt away with all the motion forcing it's way past the adhesive and sticking to the skin.

The aim of this section is to ask a series of questions, so that with vigilance and care you can stop most skin and stoma problems before they happen. It is better in the long run to quash the cause

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of the skin irritation at source rather than rely on barrier creams or splurging on layer after layer of stoma paste to prevent leakage.

What follows is a list of questions that you should ask yourself whenever you experience a leak or have sore, problematic skin under the flange. Advice given here is not necessarily what will work for you, but is intended as a guide. As always if you are in any doubt whatsoever over your stoma or skin you should seek medical advice.

Leakage

When does the leakage occur?

If the answer is 'any time', or when you are bending or stretching and finding yourself creasing the flange or making its security questionable you may benefit from wearing a small security belt. The major ostomy manufacturers all produce a stoma belt and/or cap. Wear the cap over the pouch, and secure it in place with the belt.

Has the nature of the stoma output changed?

Diarrhoea can create major problems by seeping underneath a weak flange or pouch, then forcing its way out of the side and down your belly. Try to work out which foods cause this effect in you, and avoid them or eat in moderation. However once you know which foods do what you can eat whatever you want so long as you are prepared for it.

Are you using any lotions or creams on the skin around the stoma?

These creams can do more harm than good. You should make sure that any creams or lotions you apply to the skin are especially for ostomy requirements (so that they do not stop adhesion to the skin), also make sure that the cream has all been absorbed by the skin. Your skin must be clean and 100% dry before you stick the flange on otherwise the security of the flange will be compromised and you'll have leakage.

Has the stool "pancaked" around the stoma rather than collecting in the pouch?

This is caused by there being no air in the bag, or the stool being too sticky. A handy tip here is to screw up a couple of pieces of toilet tissue and put this in the bottom of the pouch; this helps to prevent pancaking but isn't a guaranteed cure. I personally feel this is one area where we are let down by the ostomy manufacturers.

Have you gained or lost weight recently?

Both instances can cause the layout of a stoma to change by creating creases in the skin where the less flexible adhesives struggle to stick. Whenever possible try sucking your belly in before slapping on the flange. We all like to think we've got a flat tummy but in an ostomist's case very few can claim they have a leak-proof/flat tummy. Sucking your tummy in before applying the flange helps prevent it creasing when you sit down. I personally had major problems with this when I went back to work with sitting down all day. In the end all I needed to do was suck my beer gut in. :o)



Fuzzbutt Says:

To help your pouches adhesive flange to stick better, gently warm the sticky side with a low heat hairdryer for approx. 30 seconds. This helps the flange become more mouldable to your body contours, and also seems to help make the glue stickier.

Sore Skin

This is the most common problem ostomist's face, and more often than not it is caused by leakage.

Are you removing the pouch/flange an excessive number of times?

Any more than three times in 24 hours is asking for trouble. Try to avoid it if you can.

Does the soreness match the shape of the tracking on the back of the flange?

This is a positive sign of leakage as opposed to an adhesive allergy, which would cover the entire flange footprint on your skin. (See next question)

Does the soreness match the shape of the flange backing?

If yes, you are allergic to the adhesive on the flange, try another

make or manufacturer's products. Seek the advice of your Stoma Care Nurse, as he/she will be able to advise which products are similar or different.

Is the affected area around the edge of the stoma?

A badly fitting flange causes this. Try getting your stoma nurse to create a paper template for you, which you can use when you cut future flanges. Weight gain or loss can also affect the size of a stoma.

Bleeding from the stoma?

In most cases caused by the flange fitting too tightly, or you are cleaning the stoma too vigorously. You need to wipe the stoma gently because you need only look at the stoma and it'll start bleeding due to it having a rich blood source to its surface. If you find you have a bag full of blood, which has come from inside the body and not from the stoma's surface then you should seek medical advice immediately.

Are you currently undergoing a course of chemo- or radiotherapy?

These treatments make the stoma very fragile. If bleeding should occur apply gentle pressure on the stoma, using a lint-free wipe.

Prolapse

This is not a skin complaint but can be a cause of leakage. A prolapsed stoma looks hideous and you'll know if you have one by the look of the stoma, and the amount of pain you'll be enduring. Look for a change of colour in the stoma, with it getting a grey or darkish tinge to it. If you are unlucky enough to experience this you should seek immediate medical attention. Surgery may not be needed but I should think that in most cases it is, and it is only a minor job.

Colostomy Irrigation

Colostomy Irrigation is a major part of thousands of ostomists' routines. Not all ostomists can irrigate though, so you need to check with your Doctor or Stoma Nurse first to check that it is OK for you to irrigate.

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So, what is Irrigation? Is it a good alternative to the pouch? And, can you give it a try?

Everyone has heard of the infamous Colonic Irrigation, indeed it was reported that Princess Diana was a very big fan of the procedure and it's supposed health benefits.

In a Colostomist's terms, Irrigation involves inserting a cone-shaped pipe end into the stoma, the pipe in turn is attached to a large bag of warm water usually suspended above head height, and this warm water floods into the colon, and over the space of the next 30 – 60 minutes on average the water is distributed, absorbed a little, and the stool finally floods out into a specially large funnel shaped pouch.

The main advantage of colostomy irrigation is that the procedure usually clears the bowels out totally, and it can be up to 3 days or so before you will need to irrigate again, or start to pass stool into a pouch the regular way. During these three days, you do not need wear the full size pouch, most people get away with a very small sports cap that has just the slightest capacity in case of any stool that does manage to work its way out earlier than expected.

The knowledge of the fact that its XX number of days before the stool flows again (the number of days being dependant upon your own digestive system and bowel speed) helps give people new found confidence in their ability to live life to the full post-op. This is especially true if the patient is trying it because they are having major problems with pouch security, and the resultant leaks and smells. For other patients, it doesn't give them more confidence; it's just a lot more convenient way of dealing with their stoma.

As I mentioned earlier though, not every Colostomist can irrigate, so you need to consult with your Surgeon, GP or Stoma Nurse to find out if this option is open to you, or not.

Here's a rough list of guidelines to see if irrigation is maybe an option for you. Please note though, every case is different, so you MUST STILL ask your medical team's opinion before starting to Irrigate.

1. You need to be a Colostomist (Ileostomists cannot irrigate due to the liquid-like output).
2. You should have a reasonably mushy stool consistency (i.e. not liquid like an Ileostomy output, and not rock hard lumps).

3. Generally people who have their colostomy formed due to an ulcerative condition are best off avoiding irrigation. However your Stoma Nurse can tell you for certain if this is the case for you if you have had, say, U.C. or C.D.

I myself cannot irrigate so I have no experience of it, and know very little about it as far as practical tips and experience-based advice goes. However, a regular visitor to the website volunteered to write an irrigation article for the guide section of the website. Sadly I have not been able to contact Robert to see if it is OK for me to publish his article in this printed version of the guide, so it's only available to read online.



Fuzzbutt Says:

For more information about irrigation read:

Irrigation: A viable alternative, and personal story.

Written by Robert Picken

http://www.ostomyland.com/mainsite/?page_id=34

Doug's Irrigation Video

<http://www.ostomyland.com/dougsirrivid>

Sports and Swimming

Regardless of whether you were actively enjoying sports before your operation or not, you need not let your stoma deter you from taking up a new sport or picking up where you left off with your favourite.

At first the mere thought of returning to sport will seem an impossible goal. But as with most of the Colostomists hurdles these disappear with time, as it is more commonly an emotional problem rather than a physical one that is holding you back. If you were a keen footballer or hockey player before your operation there is nothing stopping you from returning to the field once you are fully healed and feel fit enough.

Before your operation you most probably felt quite debilitated and

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suffered from a severe lack of energy and enthusiasm. After the operation most Colostomists feel as fit as the day they were born and gain a new desire to experience more from life.

One of the most common concerns for the sporting Colostomist is the strength of the Stoma. How much exertion can it take before it gets damaged? The truth is that surgical wounds are usually well healed within ten days of the operation itself, a further two months after that and all scar tissue will be at its strongest peak.

Most people have different recovery times, so it is up to you to decide when you are fit enough to take up sport. Ask your Stoma Nurse to examine your wounds to check they are fully healed before attempting anything too exerting.

Remember that you have had a major operation and initially you'll not be at your fittest. Slowly build up your strength and stamina before you plan on your next marathon!

As to restrictions on sport, there is not really that many. In fact there are none, but if you are wise you will steer clear of some.

While there is no medical reason to stop you taking up Karate, Kickboxing or rough contact sports like Rugby it is best to avoid them. I deem this as tempting fate and would hate to have to endure another operation to repair the stoma because I fancied myself as the next Bruce Lee or got tackled too roughly. However, if you really want to take these sports up, seek your GPs advice first, and wear a hard plastic stoma cap to prevent injury to the stoma itself.

Weight lifting too is another area to be wary of. Again don't let it stop you, try and be careful and find your limits as a prolapsed stoma or hernia would mean further surgery.

If participating in sports there are a few guidelines to stick to which will help your confidence out on the field or on the court.

Try to wear a pouch belt or girdle during the game. This will keep the bag in place at all times, even if the adhesive does start to come away from the skin. This way, you know the bag will not dropping off onto the floor to embarrass you.

An Ileostomist friend of mine told me once that he was playing football for the first time after the operation and presumed that his appliance would be secure enough. Well, he sweated and the

adhesive became loose and just as he scored a goal the bag dropped off onto the floor. He said he didn't know which one to pick up first, the ball or the bag!

Wear a cotton pouch cover (these and the belts and girdles are all available on prescription) to help prevent any chaffing of the skin. If your flange or pouch fits too tightly around the stoma and you do a lot of running there is a chance that the stoma will swell a little and look rather angry for a while. This usually vanishes after a while. If it doesn't, ask the Stoma Nurse to check it for you.

'But can I still go swimming?' I hear you ask. Once again, there is nothing to stop you from going for a swim other than your own self-confidence. It is understandable that this is one of the scariest sports for the new Colostomist. After all it involves getting changed in communal changing areas, some of which do not even have cubicles for privacy. Your bag will be on display to the rest of the world! Arghh.... "Will the bag stay on, or will it peel away and float past me on my next length? Will people be able to see through the trucks and be staring at the appliance?" Those were some of my concerns about returning to the pool.

If you find yourself in a swimming pool after a Colostomy you've broken probably the second biggest psychological hurdle facing any Colostomist. The only one that is a bigger worry to the Colostomist is the sexual/physical intimacy thing.

Lets take the fears one by one: Firstly, the possibility of the bag or flange dropping off in the water. Most modern adhesives are designed to stay on in water, in fact the water strengthens the adhesives to make sure the bag is super secure during a swim. You could dive in the water off the highest diving board and your bag will stay in place - your shorts might come down but the bag won't!

If you do not believe me try getting into your bath at home with the appliance on. Watch it carefully for a few minutes and you'll see that it is secure in the water as it is out, if not more so. Once out of the bath try to peel the bag away... you'll find it very difficult indeed to part the bag from your skin.

If you are worried about people seeing your appliance through your wet swimming costume, experiment at home in the bath. Climb in with your regular costume on. It is best to wear swimming shorts if you can, as these are better at hiding the pouch. Once in the bath you'll find that you'll hardly be able to notice any difference, and if you can it's most probably because you are looking, the people at

the pool will not be looking in fact I was told that they'll probably not even notice the colour of your costume!

If you are in a communal changing area and you are shy about your appliance try wearing a long tee-shirt for as long as possible. If you are still worried towels work wonders. Wrap one around your waist and away you go getting changed.

You could always get changed at home and arrive in a track suit, then all you need to do is remove the track suit have a swim, get a general dry with the costume on, put the track suit back on and return home. Some people do this anyway regardless of whether they have a stoma or not. It may be cheating but don't let any worries about getting changed stop you.

There are a number of specialist swimwear manufacturer now that supply flattering swimwear for male and female Colostomists. If you find your appliance is still too much on view with your average everyday costume, give these people a try.

Special pouches are available for the Colostomist to wear whilst swimming. These are small with little or no capacity so it is best if wearing one of these to time your swim after your main bowel movement of the day.

If using an everyday pouch, you can always roll the end up a little bit and tape this to your skin, that way the bag becomes less obtrusive.

Either way, a closed bag is recommended, and if this has a filter remember to cover it with one of the special filter covers supplied in the box.

Any fears you have about taking up a certain sport, or which appliance to wear for swimming, can be discussed with your Stoma Nurse.

To recap, as long as your Doctor and Surgeon gives the go ahead you can enjoy any sport you wish to try. But do remember to check with them first that there are no reasons specific to your case that you cannot take your particular choice up.

Travel

Once you have fully healed from your operation you can look forward to doing everything with your family that you used to do before. And that means holidays! Be it home or abroad there is no reason why your stoma should prevent you from going away and having the time of your life.

While you are at home convalescing from your operation and trying your best to adjust to the Stoma routine you'll not feel much like traveling, and may even be thinking you'll never be able to face it again.

As you get better these feelings will disappear and you'll look forward to your holidays as much as everyone else. All you need to make sure of is that you are well prepared for everything by planning well ahead.

If you are traveling within the UK you will be relatively at ease and familiar with the surroundings and services available to Colostomists. It may be worth considering a short UK break before you set your sights on further away, more exotic climates (or short same-nation break if you don't live in the UK). This way your confidence has been built up and you know you can travel anywhere!

Before setting off

If you are traveling abroad make a visit to your Doctor to check that you are fit enough. The GP will suggest any inoculations that may be necessary if you are traveling to exotic countries.

Before you go to see your GP telephone the your national Colostomy Association and ask for a Travel Certificate. This is a certificate printed in many languages that explains that you are carrying medical supplies and that you must have them with you at all times. Taking this to your GP and getting it signed and stamped by him or her will help speed your journey through the Customs departments in any Country.

If you are taking medication with you either prescribed or otherwise it is a good idea to get a letter from your doctor explaining what they are for.

When you plan your stay away, pay special attention to the length of time you'll be away from home, work out the number of bags you usually need, then double it. This is the amount you should carry with you. It is always better to carry much more than you need than gamble on just taking enough. One bout of diarrhea and you could be well and truly scuppered and left searching a foreign country for a bag supplier.

Have a word with your Stoma Nurse before traveling. Most pouch manufacturers have agents abroad. Ask for the name and contact address of your firm in the Country you are traveling to. That way if there are any supply problems you can contact them.

It is a good idea to carry all your supplies in a picnic cool bag, the soft canvas kind, not the solid ones. This way everything is kept together and you'll have no problem carrying it on to the plane as hand luggage. Do not let it out of your sight. At airports your luggage can sometimes go on holiday too... without you!

When booking your holiday ask the representatives to thoroughly check through the travel insurance for you. Be certain that the cover does not exclude pre-existing conditions; this is what a stoma is termed as for the basis of travel insurance. It is essential to have medical insurance that covers all costs before leaving home. If you were abroad and had a medical problem without the insurance you could be facing a very hefty bill. Your Travel Agent will recommend the appropriate cover for you.

Traveling

Before you set off check you have everything, and make sure you have your pocket travel kit with your quick change items in so you can be certain that even if the worst comes to the worst you have at least three changes up your sleeve.

Since 9/11 Airport security has become far more stringent on all flights, but especially International flights. Sharp implements, like scissors etc, cannot be carried onto planes in your hand luggage anymore. Therefore it is a good idea to pre-cut any flanges that you take with you before you go to the airport. Then, should you need to change the flange on the plane, you have one to hand already pre-cut and the lack of scissors on the plane will not be an issue for you.

When you arrive at the airport check-in desk make sure you arrive early so that you are near the front of the queue. This way you can request an aisle seat near the toilet, and you don't have to clamber

over other passengers to get to the toilet. You may be able to book these seats in advance with your Travel Agent - it depends on the airline.

Once on the plane and in the air you can expect your bag to balloon a little with wind/gas. This is due to the change in cabin pressure so do not think you've eaten something you shouldn't have. Provided there is a filter on your bag this shouldn't be a major problem. To try and ease the situation you can watch your diet for a few days before your flight, being wary of any foods you know make you flatulent. Try to avoid our old friend, the fizzy soda drink, before and during the flight.

Once on the ground your Stoma may be erratic for a few days but it will soon settle down again into its usual pattern.

If you are traveling by road try to plan the journey breaks around places that have adequate toilet facilities. Most roadside cafes, restaurants, service stations and hotels have public-access toilet facilities. Do not be afraid to ask if you need to use them, and remember you should hopefully have the 'No Waiting' card if it is needed.

Once Abroad

If you can afford it, try to make sure you stay at a hotel or apartment complex that offers en-suite facilities. You do not want to be queuing at the end of the hall with the rest of the floor's residents waiting to go while someone inside has settled down with a cigarette and a copy of Tolstoy's War and Peace!

Be wary of the water supply in some countries. If you have any reason to doubt it whatsoever, use bottled water instead, even when cleaning your teeth. It is fairly cheap and could save you a lot of upset tummies. It would probably also be a good idea to avoid eating any side salads or full salads in these countries too as it will most likely have NOT been washed in bottled water.

Staying on the water theme, when you order drinks at the bar in these exotic countries try to avoid ice cubes too. Were they made with bottled water, or below standard tap water? That is the question.

Of course though this is a holiday and the last thing I want to sound like is a killjoy. Enjoy yourself; just make sure you travel with lots of diarrhea tablets for the family just in case.

It may even be advisable to clean your stoma using this bottled water if the local supply is that unreliable. If you have a bath or shower make sure an appliance covers your Stoma. Most pouches and flanges these days are impervious to water so you can soak away in confidence.

Don't be afraid to go sunbathing while you are abroad either. If you like spending lots of time in the sun on the beach it is best to cover your pouch with a cotton cover. These are available on prescription and help stop your skin sweating under the plastic of the bag. It also helps prevent any sweat rashes that could develop.

Instead of a bikini or trunks wear a pair of swimming shorts. You can still wear your bikini top (or not if it's a topless beach), as the shorts will more than adequately cover the average Colostomy Pouch from view.

If you want to go swimming you can swap your regular pouch for the stoma cap or mini size and swap back once out of the water. If you have only the large size bags, or can't be bothered to change the pouch, you can roll the bottom up and tape it to your skin or leave it dangling – its all about making yourself comfortable, and only you know what will achieve that for you.

Traveling Summary

1. Carry enough supplies with you in your hand luggage.
2. Plan your journey and arrange convenient seating if at all possible.
3. Be certain you have sufficient travel insurance.
4. Avoid local water, used bottled instead.
5. Always carry your pocket travel kit with you, whether it's for day excursion or for an hour on the beach.
6. Obtain an E111 if necessary.
7. Most importantly, enjoy yourself!

Medical Treatment

What do you do if the worst happens and you fall ill abroad or have problems with your stoma?

Your local travel representative will be able to advise you on reputable medical facilities and where to find them.

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If you are a UK citizen and are traveling within the EU you qualify for free emergency treatment, or treatment at a vastly reduced cost providing you have a completed EHIC (European Health Insurance Card) which can be applied for by completing the *A1* application form which is available from most main Post Offices and your local Social Security Office. Apply for this form at least six weeks before you travel. It not only covers costs it helps to explain what to do in an emergency.

For Non-EEC Countries you can still get free or reduced health care providing the Country offers a reciprocal health agreement. Ask your travel agent for details, so you are 100% sure before you go.

For all other countries including the USA and Canada you must have adequate health insurance to meet the costs of health care.

A medical alert bracelet or necklace, which notifies the medics of your condition in case of an emergency is also a wise purchase before setting off. The medic alert foundation will be able to help you with that.

Returning to Work/School

Please note: *Always check with your local Job Centre for the most up-to-date information on the schemes or benefits that may be available to you.*

Another common question a Colostomist may ask is whether or not they will be able to return to their usual work after the operation. In general the answer is yes, however as with sports it is wise to exercise a small amount of caution. Heavy lifting and a job involving a lot of manual work is best avoided, and it may be necessary for you to switch to a lighter job.

Before you consider returning to work you need to receive the go ahead from your Doctor and Surgeon. If you are at all worried about your ability to work have a word with your Stoma Nurse as well as these people. With their combined advice you'll be to make an informed decision.

Once you feel you can change your pouches in the work environment without too much trouble, can feel comfortable about traveling to and from work and that you have enough energy to face

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a full day (a bad one at that so you can face the worst with confidence) you are ready to seek permission to return. Remember, there is a cavernous difference between pottering around at home in your slippers for a day, and being able to function at full capacity in the stress filled work environment.

If you think this may be a bit of an uphill struggle to honestly expect yourself to return to the deep end, why not try a little volunteer work at your local hospital. This way you get back into the rhythm of work and being needed at a certain place at a certain time. In other words it returns you gently to the work routine. This also has the added benefit of making you feel like you are doing some good for the hospital that has saved your life.

If you are claiming Sick Pay or Income Support from the Social Security people on the basis you are too sick to work you need to check with them first that your money will not be affected. Provided you get a letter written by your GP stating that the work is of a therapeutic value there should be no problems with this, but you should always get confirmation of this from them first.

When you do return to work remember to always take your emergency change pocket kit with you, as it is likely that you'll have to change or drain your bag at least once during the day. If at all possible make up a separate pocket kit that you can leave in either your desk drawer or locker. This way even if you do forget it you have this to fall back on.

Just like when you are playing a sport you want to be sure that your bag is secure whilst you are at work. You could wear a girdle or support belt around the pouch if you are worried about the possibility of the appliance working loose. Hopefully by the time you have returned to work you'll have complete faith in the everyday use of your appliance and feel safe that the adhesives can do their job without too much help.

Returning to work would be far less daunting a task if you knew your employer was sympathetic towards you if there were any problems. The last thing you need is to be stuck on a machine line waiting for your break so you can change your appliance.

If you are using your operation as an opportunity to obtain different work, or are looking for your first ever job (you've just left school for example) then it is advisable for you to go to your local Job Centre and ask to speak to a Disability Employment Officer.

This may seem a bit ominous but this officer will help you to find employers that will be sympathetic and will not tie you to your desk come hell or high water. These days there are lots of incentives that are offered to employers for taking on a "disabled" person and you'll qualify for these equal opportunities.

For example, employers that are dubious about your Stoma getting in the way of the job will be offered a six-week trial to take you on. You'll be given full pay rate, and the Government will pay in the region of £45 per week of your wage to the employer. It is then up to you to prove you can do the job and that your Stoma does not get in the way of your working life - a fact you already know but your employer may be reluctant to believe. Financial benefits are a wonderful thing! (This is a UK only Scheme; so if you live elsewhere in the world, please check with your own local employment office to see if similar schemes are in operation in your area, and amounts quoted above are believed correct at time of writing.)

You could also be able to walk into the interview with a possible grant for the employer to upgrade their facilities to disabled standard. Check with the officer to find out what you can offer the employers.

The DEO will also be able to arrange any retraining that may be necessary.

As previously said a "Disability Officer" does sound ominous but it is worth mentioning that up until the abolishment of the UK Disability Register in December 1996 you would have been able to sign on the disability list. This can help you get a job, as most large employers operate an equal opportunities charter and if they do this then 10% of their workforce must be disabled or a minority covered by the charter (again, believed correct at time of writing). This would make you an attractive prospect to a future employer because you will not consider yourself even remotely disabled.

Although this list is now abolished you still have the chance to fill their 10% and that, combined with grants, makes you an employee to fight for!

Of course if you under-perform you can still expect the same treatment as someone without a Stoma, but if your Colostomy gets in the way the employer will have to be more sympathetic.

When you come to apply for a new job it is usually inevitable that the application form will request details about your medical history –

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although I believe that in some countries this is considered discrimination in itself, and I only wish this were the case here in the UK, but sadly it isn't.

This medical history section of the form used to send shivers down my spine! Heck, it'd be a twenty-page essay by the time I'd finished – and that was the condensed history!

Whatever you do, do not lie about your medical history. If you got the job, and were later found out to have lied on the application form, this could lead to dismissal. Also, if it was a particularly unforgiving employer, it could lead to prosecution.

The best policy is to be concise, yet complete. Give the name of your illness and the approximate dates that this happened. Then follow this with the date of your Colostomy and any previous operations that may have been performed for this condition.

In most cases the Colostomy is the operation that cures the illness, if this is so make sure you write something like "illness cured by Colostomy." This way there is no shadow of doubt that your illness will not flare up again within a few months, and this removes any worry the employer may have. It could also be beneficial to state that you are back to full fitness after the operation.

The subject will certainly be brought up at the interview, and this is the tricky bit. Whatever happens, do not drone on for hours about how ill you were, blah, blah, blah, trying to drum up sympathy. The employer will be bored to tears by it. Simply say it was a serious condition and that the Colostomy was a life saving operation but finish on a positive point by saying you are back to full health and it's the best you've felt in years. Let the employers ask the questions about it if they want to know more, and no matter what happens always try to drag the topic back to a good point to conclude. Employers will then hopefully admire your positive attitude and if you've got the interview on the recommendation of the Disability Employment Officer it doesn't hurt to say something like you do not consider yourself disabled as the operation gave you life, it hasn't taken anything away.

When at the interview it would be wise to highlight the fact that you do wear an appliance; that at times things can go wrong and you'll need immediate access to a toilet in an emergency.

If the employer should have any doubts over your health or suitability to the job because of the Stoma you can suggest they

talk to your Surgeon, GP or Stoma Nurse. Check with them all before offering this and I'm sure they'll be only too pleased to give their professional opinion on your behalf.

By following these suggested guidelines you have been totally honest with the employer and both of you know what to expect. Don't forget though that it is impossible for me to write a step by step guide to the perfect job interview as a lot of it is spontaneous and different every time. Therefore, a large proportion of the interviews success goes down to your own personality, and ability to deal with the unexpected – just like all job interviewees have to do.

If the worst did happen and you felt you had been refused a job because of your stoma, or worse still you were terminated because of it, talk to you Stoma Nurse and the British Colostomy Association (or your national association if you live outside the UK). They will give you advice on what to do to find out if you genuinely were discriminated against.

However, it must be said that it is highly unlikely that you will have been, or will be, and that that course of action will ever be necessary.

If you are returning to School after your operation all of the above information about job seeking and interviews will not be relevant to you just at the moment, but one day it will.

Until then there are one or two things that you can do to make your school life easier. The most important of these will be arranging a little meeting between yourself, your parents and the Head Teacher or Principal of the school/college.

Just as a prospective employer needs to be aware of their employee's need for good toilet facilities in an emergency, so too does your Principal or Headteacher.

Most school toilets are similar to public conveniences with a number of cubicles (sometimes totally vandalized with rude words spray painted on the walls) with the sink and water supply well away from them. This is completely useless to a Colostomist who has a change of appliance to deal with.

Seeing as you ideally need a toilet and wash basin together, and more importantly privacy, ask the Principal if it is possible for you to use the Staff Toilets in an emergency. From my experience these are not vandalized and are ideal as they usually are a single toilet

with a wash basin next to it and a lock on the door because there are far less teachers than pupils that the facilities need to accommodate. These are usually located just off the main Staff Rest Area and this is why you need the Head's permission first. When I was at School if you were caught in the Staff Room you got an immediate detention! (Honestly, you'd think that they thought we were we going to steal the end-of-year exam papers or something... again.)

Secondly, you may want the head to inform the PE teacher not to push you too hard or to insist you join in the contact team sports. If you are at all nervous about communal changing areas and other kids seeing your appliance (lets face it, kids can be cruel when they want to be!), whether changing or showering, then you should be allowed to change and shower in the PE Teacher's changing area which like the toilets is always separate from the students' changing facilities and usually far more private.

Whether at school, or at work, your teachers and/or employers will always treat the information about your Colostomy with the strictest confidence. It will be up to you, and you alone, to decide whether you tell the other pupils in your class, or your other workmates, that you have a Colostomy.

Relationships

Your operation may successfully cure your physical problems, but it is fair to say you will not find the emotional side of things easy at first.

This is a troublesome area for just about every Colostomist. After all, we all worry about how we'll be accepted by our loved ones - present or future.

Your local support group members, or Online Ostomy-based Message Board and Chat Room friends, will be an invaluable support to you during the early stages of your Colostomy. Hearing that what you are going through is not unique, that others have overcome the emotional hurdles and that you can do it too, will be a big help.

But without a doubt your biggest shoulder to cry on will be your immediate family or your partner. They are going through this operation with you, and will be just as worried as you ever will be.

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For the younger Colostomist your parents or guardians are your best allies.

Try to talk about any problems you have with them, they may not be able to answer the questions for you but just talking the problems through will take a load off your mind.

Strong emotional worries may well lead to tears, don't bottle them up. Let them flow freely, and afterwards, you will more than likely feel better for it.

If you are older than that and have a partner already, discuss the problems with them, or if single, with your best friend, the one with whom you would trust your life and you know will keep a secret and listen to your worries. Chances are you already have one friend singled out whom you have shared the problems with your health problems with so far and know you can trust - a friend that you would more than likely do the same for.

Don't rely on just anyone, as chances are they will not understand how delicate the situation is and blab it to the world.

If you live with your parents or live with your partner try to have someone from your household present when you are being taught how to change an appliance. This gives you the advantage of their support and at the same time they are learning how to change an appliance so should you be unable to manage for a period of time, say you break your hand or a few fingers, someone can give you some help to manage.

Other people will be concerned for your well being too as they will know you are going for an operation. For example work colleagues, neighbors and everyday friends. You do not have to tell them that you are having a Colostomy; it is up to you how much you fill them in on the news.

When you meet new friends who are unaware of your previous health problems there is no need for you to tell them that you have a Colostomy, and they will be totally unaware of the fact. If you do eventually decide to tell them they will most probably be totally amazed, as they never would have guessed.

But what about personal relationships? Well, there is no doubt that the new Colostomists worries about this are far less if they are already married or in a serious relationship at the time. Your partner will be there with you will be more sympathetic and caring towards

you than a total stranger as they knew you before the Stoma and before you were poorly.

If you are single at the time of the operation then you have another possible psychological hurdle to climb over. The time will eventually come when you have to explain to your new love that you have a Stoma and need to wear a surgical appliance at all times. The issue cannot be dodged forever, and will more than likely be forced by a marriage proposal or leading up to a sexual relationship.

This is a decision that you have to make yourself. No matter what advice is given in books there is a time and place for everything and only your own judgment can decide when is the best time to tell your partner. However as a rough guide don't tell straight away (it's not the best chat up line in the world by any means "Hello, my name's Jason and I wear a Colostomy bag!") and don't leave it until the last minute. Your partner could be offended that you felt you couldn't trust them enough to tell them sooner when in reality you were shy about it. So don't whisper it as a sweet nothing during a heavy petting session, it'd be a pretty major turn off.

I think the best time is somewhere shortly after you've been on numerous dates (say on the third or fourth date), and definitely before the relationship goes sexual. Like I said the timing is individual and best left to your own judgment but this way your partner can see that you lead a perfectly normal life with it, that it doesn't stop you from having fun and at least allows him or her to accept the fact that when you are naked in bed together you will have the appliance on and it will be visible.

My biggest fear at this point was fear of rejection. I was hardly the most self-confident person on the face of the planet and was genuinely convinced that I would be rejected by the love of my life once I told her of the Stoma and the bag. Being single and unattached at the time I felt my social life would be extinct.

I told my nurse about this and she said that rejection was a possibility but when you think about it if the person is not willing to accept you as you are because you are not quite perfect then they are not worth bothering with in the first place and you are better off without them. This is perfectly true but we also agreed that this didn't necessarily mean rejection wouldn't be a possibility, and that it wouldn't hurt.

Sex / Intimacy with an Ostomy

WARNING: Reader Discretion Advised

The following chapter contains material of a sexual nature and openly discusses sexual terminology and actions.

When you are fully healed from your Colostomy operation there is no reason why you cannot enjoy a full and happy sexual relationship with your partner.

When you first see your Stoma you may well imagine that you'd never be able to face sex again but the apprehension will fade away, especially when you get in the right circumstances!

Once you remove all your clothes there is no hiding the appliance. If you are involved in a genuine loving relationship your partner, and you, will soon be oblivious to the existence of the appliance.

Like I said facing a relationship is easier on the Colostomist's nerves if the partnership is already well established, especially if you're married. If this is the case your partner will most probably be with you while the surgeon explains the procedure, and if you have any questions about sexual function then discuss them with him. Of course, your Stoma Nurse will also be able to offer invaluable advice (as always) as this is a common area of worry and they will be used to frank discussions.

Recovery from a major operation takes time and you'll not be fit enough to make love for quite a while. As a rough guide you need to be able to successfully walk about a mile without too much pain or too many problems before you can consider yourself fit enough for intercourse.

If you find you are lacking in confidence try leading up to this with a session of heavy petting and foreplay. This may not be everyone's idea of fun, but the intimacy and tenderness involved helps break down any barriers that may exist, one thing leads to another and before you know it...

There is a chance that a Colostomy appliance can get in the way of things a little and there are a few tips that can help you.

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Firstly make sure you are wearing a fresh appliance that is empty. If your bowels are empty and there is little chance of them working during the act then you can maybe wear the smallest pouch which is more like a small cap for the stoma, which will be less obtrusive. If using a large appliance try folding the end up and taping it to the skin.

A cotton cover is essential really, not only does it hide the appliance and looks more friendly, but it also prevents the plastic of the bag from chaffing your partner's skin whilst you are sweating during intercourse.

The biggest problem for the male Colostomist is impotence. This is the inability to achieve erection and thus ejaculation. The nerves that control these functions (called the parasympathetic nerves) are located around the area of the rectum. In a worst-case scenario, damage to these nerves may occur during the operation. If this happens erection may be difficult or impossible to achieve.

Your surgeon should make you aware of these dangers before surgery and will no doubt reassure you that the chances of this happening are very rare. I was warned of this by my surgeon and was concerned. It is only natural, so I contacted the British Colostomy Association. They told me that they are yet to be made aware of any sexual function related nerve damage relating to an Ulcerative disease based proctectomy, which is the main reason younger people have a Colostomy.

However, if the operation is necessary because of bowel cancer there is a possibility of damage but again the chances are so small it's hardly worth mentioning.

If you think you have suffered a little bit of nerve damage please do not despair, it can take up to two years for permanent damage to be diagnosed as it can take around that length of time at most for everything to settle down in the perineum area. It may simply be a glitch in the system, a sort of post-operative stress, or that your body is taking its time in recovering from the operation.

Even if you were the unluckiest person in the world and you suffered total impotency from a colitis operation there is hope. New surgical techniques are constantly being developed to help the impotent male. Then, lets not forget Viagra! :-)

If your colostomy is temporary, and the rectum, sphincter muscles and anus are left in place and untouched, then the odds of any

surgical based nerve damage to your sexual function reduce significantly. So, an already small chance of damage becomes an almost microscopic risk.

For the Female Colostomist there are different difficulties which may become apparent during intercourse.

The main problems revolve around the removal of the rectum. If you are not having a permanent colostomy (i.e. your rectum, anus and sphincter muscles removed) these will not be relevant to you.

Firstly the wounds caused by the removal of the rectum (called the perenial wound) will be the slowest to heal and this can lead to pain if intercourse is attempted too soon.

Pain can also be experienced because of a slight shift in the uterus. This is a rare occurrence though, as is the chance of vaginal dryness.

Just as with the male's risk of impotency, there is a possibility of nerve damage for the female. In this case a loss of feeling will be experienced in the clitoris. This need not be total, and may be a slight loss of sensitivity but again it is so rare it's hardly worth mentioning, but your Surgeon is obliged to tell you of all that can go wrong in the absolute worst-case scenario. Its all part of the surgeon-client consent form business.

If intercourse is painful due to the effects of the perenial wound, reconstructive surgery can be undertaken to rid you of this problem. Until then, or if you don't want further surgery try to find the most comfortable position, you may well end up having to boycott the missionary position (the most common position). Be creative. Buy the Karma Sutra if necessary but don't endure pain because you are embarrassed to experiment. Your partner will understand, be supportive, and only too keen to make sure you are comfortable - after all he wants you to enjoy it too!

If you are homosexual, male or female, there is no reason why the stoma should be detrimental to your sex life. However if you are a gay male and have your rectum removed you will no longer be able to be receptive of gay sex. However your ability for erection and ejaculation should not be a problem.

If you are concerned about the removal of your rectum because of your sexuality discuss this with your Surgeon and Stoma Nurse.

Whatever happens you must not, under any circumstances, use the stoma for sexual entrance and activity – be it penis or toy-based penetration. This is extremely dangerous and will certainly lead to further emergency surgery. I know, it sounds horrific, and how anyone could consider doing that to their partner/loved one I do not know, but over the seven years I've been running the colostomy website I've had THREE emails asking about this subject, and had it posted about on the old message board which is now archived.

I appreciate all this sounds daunting, but I am certain with a bit of love and care and attention you will soon be back into the swing of things. Think of it as losing your virginity for the second time. You had pretty much all the same worries then that you have now... "Will s/he like me?" ... "Will I be able to perform?" ... "Will it hurt me?" ... "What if I cant do it right?" and so on. And as with the first time you lost your virginity, once you get into the swing of things, the thoughts and nagging doubts in your mind will no doubt vanish into the bed sheets and never been seen again. And if they don't, do not despair! That is what the local support groups and website messages boards and chat rooms are for – to give you support, encouragement and constructive experience-based advice to help you over the more difficult hurdles.



Fuzzbutt Says:

Ostomyland has a forum dedicated to Sexual Intimacy Problems on it's message board. You can visit it at:

<http://www.ostomyland.com/fuzzbutt>

(Free member registration required to access the message board.)

Pregnancy

Having a Colostomy will not affect your ability to become pregnant. However if you wish to start a family or become pregnant again you do need to consult with your GP first. If the GP has any doubts (which is unlikely) then you may be referred back to the Surgeon to be sure and then to a gynaecologist.

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As a Colostomist you should not experience any difficulties during pregnancy arising from your Stoma - unlike an Ileostomist who runs a greater risk of her Stoma blocking up due to pressure exerting on the intestine. The pressure of straining during the delivery can, in rare cases, make the stoma prolapse which would most likely require surgery to fix it. However as with the sexual function nerve damage risk at the time of surgery, the chances of a stoma prolapsing during childbirth is very slim.

During pregnancy it is likely that your Stoma will change shape a little bit. If this happens you need to be sure your appliance still fits properly. Ask your Stoma Nurse to check this for you and be prepared to change to a different brand of appliance if necessary.

The delivery should be no more complicated than for a woman without a Stoma, however removal of the rectum may lead the specialist to discuss the possibility of a Caesarean Section delivery.

Whichever way the baby is delivered you'll need to change the appliance as soon as possible afterwards as the stoma will swell due to the pressure and strain exerted during delivery.

When you and your husband are busy preparing the emergency labour kit (the bag of goodies most mums-to-be leave by the front door!), make sure you pack sufficient stoma supplies for your stay. With luck you'll deliver the baby in the same hospital you had your Colostomy and in which your Stoma Nurse is based, this way you can be visited regularly by the Nurse to have the stoma checked, just like you did when you had the Colostomy.

Temporary Colostomy Reversal

With the marked increase that we are seeing in the keyhole surgery technique to form Colostomy stomas we are seeing more and more temporary Colostomies being made. Likewise if you have a bowel cancer operation you could end up with a temporary colostomy instead of a permanent one thanks to the advances made in cancer treatment and surgical procedures, regardless of if your operation was performed via Keyhole or not.

So, let's say you've had a temporary colostomy for a while and it's due to be reversed next week. What can you expect?

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The main "problem" with a reversal is a possible lack of bowel control for the first few days after the reversal. I say "problem" in inverted commas because really it is only a slight inconvenience. The main rule to bear in mind with this "problem" is that the longer the rectum is disconnected and unused, the harder it is for the rectum to get back into some semblance of control and rhythm.

In a way, when the colon/large intestine is disconnected from the rectum, the rectum effectively goes on strike - has a holiday - goes into retirement... whatever you'd like to call it. And, the longer it is left in this state of rest the longer it takes for the rectum to get back to its old habits. This sounds bad but we are talking a matter of maybe one day's incontinence. After that it may be couple weeks until you get back into your regular motions and rhythm - but at least you do have the control over it to prevent accidents.

Surgically speaking, most keyhole-formed colostomies are reversed via the same method. It is the surgical equivalent of an appendectomy. You will most likely be in hospital for one or two nights depending on your Surgeon's action-plans for such operations.

The keyhole operation will leave you with maybe two very small scars. The location of these scars depends on your Surgeon but one under the belly button and one somewhere else on your tummy near the stoma area. This is so they can insert their implements and air-hose in to the body. (The air hose inflates the abdomen area and lights it so the Surgeon then has some room to manoeuvre whilst operating.)

Because the wounds are so small, and the operation being not too invasive, you should not feel too sore afterwards. I say "too" because it is a very small operation in comparison to your first one. However, the air that is inflated into you can make you feel very sore around the shoulders and that area until it has fully dispersed itself afterwards. In my experience of keyhole Surgery this has always been the most annoying part of the procedure because it just lingers and lingers and seems to take days to alleviate.

If your colostomy was formed via full open surgery then there is a good chance that it may well be reversed via this route too. This will be especially true if the surgeon has other work to perform in your abdomen at the time of the reversal – such as checking the rest of your intestines for further infection and disease, or to make sure any tumour has been fully removed and so on.

Regardless of how the reversal is performed the single biggest post-op “problem” is the length of time it takes the rectum to get back into its rhythm. So, all of the above information about this problem is relevant to you as well.

On the whole, most people find that even the full open surgery reversal is not as bad or as traumatic to the system as the formation was. I guess this is because the mind is more aware of what to expect, and that deep down inside of you you’re aware that you are losing the stoma at last, and that this makes it a good operation as opposed to the formation that is doubtless seen as a bad operation to have.

So, to wrap up; the reversal operation is very slight in comparison to the earlier procedures. The wounds hardly hurt if via keyhole - the air can make you ache though. The stay in hospital should be shorter regardless of the surgery technique. And most importantly, once you get home you truly are on the road to recovery and you have thoroughly earned it - so take it easy, and enjoy it. :o)

Stoma Appliances: 1900s to Today

With the advent of the 21st Century, it is fitting to end this guide book with a look at how the colostomy, ileostomy and urostomy appliances of the 20th century have evolved with the aid of the cutting edge technology of the particular era.

I was tempted to call this section the “First 100 years of the Colostomy” but there are records dating back to the pre-Christian era, which tell how abdominal stab wounds would discharge contents from a protrusion of the large intestine (Verlag V, Druik KG. Stoma Care, Medical Focus 2: Special Edition, 1989)

Realising this, it becomes apparent just how much things have advanced in the colostomy world over the last hundred years, and how before that there was little or no advancement made.

The website shows pictures which give an indication of what life as an ostomist in the early decades of the 20th Century meant. Unfortunately, I can only use the pictures online and I do not have permission to include them in this guide. You can see the pictures

<http://www.ostomyland.com>

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at:

http://ostomyland.com/mainsite/?page_id=40

With the absence of today's modern adhesives, and the designs being somewhat cumbersome to say the least, it puts our present Colostomy lives in perspective. Maybe we see things as bad at the moment, either for yourself, or indeed for me, but looking back at these pictures you can't help but feel that things are not as bad now as they were then, and could have been today.

Who do we have to thank for this improvement? The manufacturers? The surgeons? The patients? Most probably a little bit of all three.

St Mark's Hospital in London is renowned as the premier bowel hospital in the world. It is also one of the main teaching hospitals where medical students go to learn gastroenterology surgery.

The main walkway on Level three which connects the hospital to the neighbouring Northwick Park hospital has a series of historical memories of the hospital and its advancement in the medical science field since it was founded by Frederick Salmon in the 1860's. One of the pictures shows the world's first colostomy pouch, taken by a photographer of the era.

It is no exaggeration when I say it hangs from the abdomen, down to the knees, it is strapped into place by bandages, and is made from a very heavy looking rubber. It looks bizarre as if it is from the dark ages, and I suppose you could argue that the 1860's were the dark ages of the colostomy equipment and appliances compared to today's medical science.

So next time you curse your appliance and the fact you have a stoma (which we all do from time to time) try to think back to these pictures and how much worse things would be if your stoma was born twenty, thirty or forty years earlier.

Some people reading this may even remember some of the pouches featured on the website, if this is the case I hope that you can agree that the Colostomist's life is as good as it ever has been, and that with the developments that can be made over the next decade or two we could see equally radical improvements in our lifestyles thanks to the ever evolving world of medical science and appliance design. Bibliography – Coloplast Charter Magazine (UK edition)

<http://www.ostomyland.com>

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Fuzzbutt Says:

Have you visited our chat room yet? It's open 24/7 and we have a weekly ostomy support meeting at 8pm UK Time every saturday

<http://www.ostomyland.com/chat>

For Further Information

Please note: the address contacts in this section are United Kingdom details only. Unfortunately I don't have the space to list similar resources for all the major countries. If you live outside the UK please check the following Website Links section, which will have URLs for the equivalent services in your country.

The following list of addresses has been split into groups for your convenience; Important Contacts, National Toilet Scheme, Travel Advice, Swimwear Companies, Home Delivery Services and Medic Alert bracelets.

Important Contacts

Colostomy Association,

15 Station Road, Reading, Berkshire RG1 1LG

Tel: 0118 939 1537 Fax: 0118 956 9095 - Helpline: 0800 328 4257

NASPCS

(National Advisory Service for Parents of Children with a Stoma)

51 Anderson Drive, Valley View Park, Darvel, Ayrshire KA17 0DE

Tel: 01560 220024

NACC

(National Association for Colitis and Crohn's Disease) 4 Beaumont House, Sutton Road, St Albans, Herts. AL1 5HH Information Line: 0845 130 2233 - NACC-in-Contact Support Line: 0845 130 3344 - Fax: +44(0)1727 862550

<http://www.ostomyland.com>

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Relate

(Marriage Guidance) Herbert Gray College, Little Church Street,
Rugby, Warwick CV21 3AP Tel: 01788 573241

National Toilet Key Scheme

RADAR

(Royal Association For Disability and Rehabilitation)
12 City Forum, 250 City Road, London EC1V 8AF Tel: 020 7250
3222 Fax: 020 7250 0212

For Travel Advice

The World Council of Enterostomal Therapists Education Committee,

Mrs B Borwell, Stoma Therapist, Salisbury District Hospital, Odstock,
Salisbury, Wiltshire SP2 8BJ

Also phone your local **DSS office** for **T5: Health Advice For
travellers.**

Swimwear Manufacturers

Chums Limited,

Unity Grove, Knowsley Business Park, PRESCOT, L34 9AR. Tel: 0870
043 4184 (lines are open Mon - Fri 9am to 4pm)

CaSal,

Parsonage Farmhouse, Barford Lane Downton, Salisbury, Wiltshire
SP5 3PZ

Nationwide Ostomy Supplies Ltd,

North West House, 62 Oakhill Trading Estate, Worsley Road North,
Walkden, Manchester M28 3PT Tel: 0800 3167117

Salt and Son Ltd,

Saltair House, Lord Street, Nechells, Birmingham B7 4DS Tel: 0121
359 5123

Home Delivery Services

Dansac Ltd,

Freepost ANG6191 Hilston, Cambridge CB4 4BU Tel: 01223 235100
Fax: 01223 235146

Hollister Ltd,

Freepost, Wokingham, Berkshire RG40 1GZ

Salts Medilink,

Freepost BM 2652, London NW10 3BR. Tel: 0800 626388

Respond Plus,

8 The Carlton Business Centre, Station Road, Carlton, Nottingham
NG4 1BR

Homecare Ostomy Supplies,

Mantra House, South Street, Keighley, West Yorkshire BD21 1BR

BCA Direct Ltd,

Freepost NEA1938, Cramlington, NE23 6BR

All companies listed on the previous pages are tried at the reader's own risk. Whilst every care is taken the author will not be held responsible.

Medical Alert Bracelets

SOS Talisman,

Talisman Ltd., 21 Grays Corner, Ley Street, Ilford, Essex IG2 7RQ -
Tel 020 8554 5579 <http://www.medicalert.co.uk/>

Please note:

1. Where possible *all* the above addresses have been checked for accuracy at the time of writing – such as checking that the business is still trading, the address is correct and the phone number up to date. However, I cannot guarantee that all the information above is 100% correct at the time you read this. Sorry.
2. A listing in this section does not mean it is an endorsement. Services are listed purely for informational purposes only.

<http://www.ostomyland.com>

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Other Useful Websites

Organisations:

Colostomy Association (UK)

<http://www.colostomyassociation.org.uk>

British Ileostomy Association (inc. Young IA)

<http://www.the-ia.org.uk/>

International Ostomy Association

<http://www.ostomyinternational.org/>

United Ostomy Association

<http://www.uoa.org/>

List of the UOAs US based UOA Chapters/Support groups

http://www.uoa.org/chapters_states.htm

Ostomy Association of Canada Inc.

<http://www.ostomycanada.ca/>

Ostomy Manufacturers

Coloplast (Int.)

<http://www.coloplast.com/>

Coloplast (UK)

<http://www.coloplast.com/>

ConvaTec

<http://www.convatec.com/> (Choose country from there)

Dansac (Int.)

<http://www.dansac.com/>

Dansac (UK)

<http://www.dansac.co.uk>

Hollister (Int.)

<http://www.hollister.com/>

<http://www.ostomyland.com>

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Hollister (UK)

<http://www.hollister.com/uk/>

Salts (UK-based Ostomy Manufacturer)

<http://www.salts.co.uk/>

Other links:

OstomyLinks.co.uk

This is an awesome website for the Ostomate who is looking for information, communities or services online. If there's a website with anything Ostomy related on it, then its more than likely listed within the many logically sorted categories at Ostomy Links.

<http://www.ostomylinks.co.uk>

The UK Adhesions Society

Useful Adhesions info even for those who don't live in the UK.

<http://www.adhesions.org.uk/>

The International Adhesions Society

<http://www.adhesions.org/>

UK Gay Ostomates Association

<http://vzone.virgin.net/alan.edinburgh/goa.html>

Pain.com

Website that can help anybody deal with pain – be it temporary post-op pain, or chronic long lasting pain.

<http://www.pain.com>

Shaz's Ostomy Page

An Australian based Ostomy website, that has a large message board community associated with it, as well as information for all the major ostomy types.

<http://www.ostomates.org>

World Ostomy Resource

The definitive Ostomy Website list. If there's a web page that has ostomy content to it, then it will be on this list. Separated into content sections for each of searching.

<http://homepage.powerup.com.au/~takkenb/OstomySites.htm>

The White Rose Collection

UK Company that supplies underwear, swimsuits suitable for

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ostomists, as well as other products too. Delivers Worldwide.

<http://www.whiterosecollection.com/>

Yahoo Groups UK Ostomates Support

<http://health.groups.yahoo.com/group/ukostomysupport/>

Ostiwear

US-Based underwear and accessories provider

<http://www.ostiwear.com/>

Ostomy Toronto (Canada)

<http://www.ostomytoronto.com/>

LDOA

London (Ontario, Canada) and District Ostomy Association

<http://www.ldoa.net/>

Autoimmunity – The Hidden Link

A site that discusses the autoimmune links between many of today's diseases and illnesses, including some that can lead to a colostomy.

<http://www.autoimmunity.co.uk/>

IBD/Ostomy Support Board listings

<http://www.autoimmunity.co.uk/supportboards.html>

Please note:

1. All the above websites are present at the time of writing
2. Just because a website is listed in this guide does not mean that I endorse the site or its content.
3. I am not responsible for ANY website content outside of the

<http://www.ostomyland.com/.org/.co.uk> domains.

Ready For Anything

If you've read this guide from beginning to end I am hopeful that I have answered all your queries and calmed all your fears. I doubt I'll have quashed the fears as with something as big as this approaching you'll only be totally reassured when everything is over, done with and you are back to your normal life.

My initial plan when I started this guide and the website was to provide a resource that is not only useful before the operation but

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will be a good source of information after the operation, maybe even years into the future. I hope this too has been achieved.

When you do go in for your operation, whether it is in a few days or a few months, I wish you well. And I hope I have been able to prove that the main fears of a Colostomist-to-be are nearly always unnecessary yet totally understandable. You are not unique by any means.

During your stay in hospital you'll be in the good hands of professionals who have seen it all before, and surrounded by your family and friends who care about you a great deal. With their combined help you'll quickly be back on your feet, ready for anything!

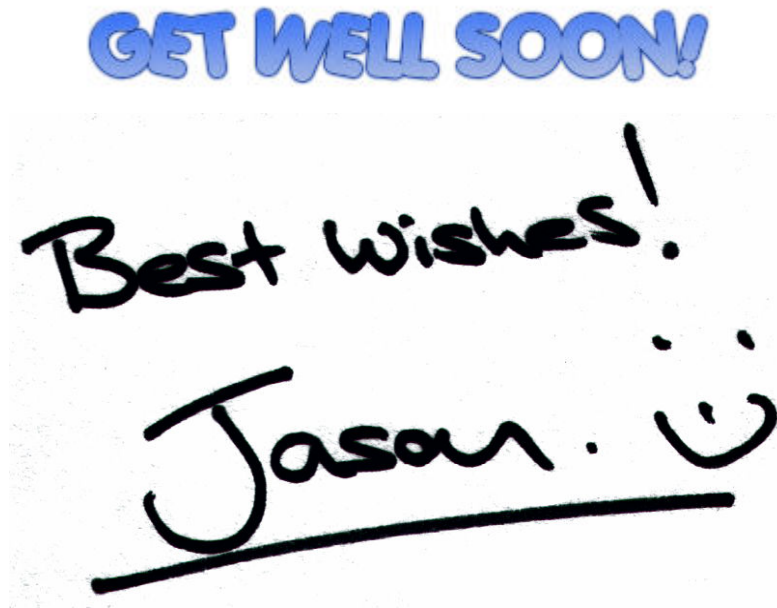
Important Note:

What you have read in this guide is advice that I have learnt myself over the past eight years of living with a colostomy. They are my thoughts and ideas, and suggestions. Just because I've experienced some of the things listed in these pages does not mean you will. No two people are the same, and at the end of the day you will find you own routines etc to follow by your own trial and error.

This book, and indeed the website itself, is here purely as a guide and is not set in stone. Please feel free to stray from these guidelines and discover you own ways, indeed you may disagree with some of the advice I've offered, but for me personally this is the way I do things.

If, at anytime, you have worries that you think need addressing, please do not hesitate to go to see your own family doctor or stoma nurse. This guide is not intended as a medical reference book, and should not be treated as such. It is purely a lifestyle *guide*. All information in this guide should be confirmed by your own medical team before being acted upon. This is for your own safety, as they have all your medical notes etc. to hand.

And so, here we are... the final paragraph of this guide. I hope you've enjoyed reading it and found it informative. I'd just like to take this opportunity to thank you for your interest in this guide, and the website, and to wish the patient - whether it is yourself, your partner, a relative or a friend - a speedy recovery and that they...



Space-filling Production-related Technobable:

This guide was updated during May 2010, on a Dell XPS M1530 laptop – a red one too – using a variety of software, including Word 2007 and AAA Logo 2009, whilst listening to the wonderful audio books of George R. R. Martin, and William Johnstone, as well as the BBC Radio 4 adaptations of the Sherlock Holmes adventures. Oh yeah, the Fridge and the Jaffa Cake tin got a hammering too. ☺

Dedicated to:

My Mum and Dad and Lucy

Thank you all for always being there for me. I don't say it often enough but I love you all and would be totally lost without you.

Special Thanks to:

The Ostomyland Message Board & Chat Room Communities.

The Ostomyland Team for all their hard work within the community

Without you there would be *NO* Ostomyland, and no book to read!

<http://www.ostomyland.com>

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My Medical Contacts / Information

Family Doctor/GP Contact Details:

Stoma Nurse / ET Nurse Name & Phone Number:

My Ostomy Appliance/Products List:

Product # | Manufacturer | Product Name

Product Suppliers / Pharmacy Contact Details:



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