

What I've learned about bowel surgery

Important Note: 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 have no medical qualifications. The contents of this book are based purely on my hospital memories, and my experience of living with an Ileostomy and J-Pouch. Therefore, if you read this article/posting/document then you do so on the understanding that you must verify any advice/information, found within it, with your own medical team before acting on anything herein, and take their advice over mine if they disagree. I will not be held liable for any injury occurred as a result of reading, and acting on, this guide. See also - further legal disclaimer at the end of the document.

Table of Contents (use <Ctrl>+click to jump to page)

Three of the more common reasons for Bowel Surgery	2
Options for Surgery	3
Ileostomy & J-pouch Surgery	4
Stage 1	4
Removal of the colon and formation of an end or Terminal Ileostomy.	4
Preparing for surgery	4
What happens after I leave the ward?	5
Post-Op - waking up in the recovery area	5
Getting to know your new stoma	5
Getting mobile after the op.....	6
Post operative depression - the blues.	6
When do you go home?	6
Internet support groups - a shoulder to lean on.....	7
There are various links available at:.....	7
Stage 2 of the 3 stage procedure	7
Creation of the J-pouch - formation of a loop Ileostomy.	7
J-Pouch - explanation of how it's made	7
Creation of the temporary loop Ileostomy	8
How is it done - graphic representation of overall process	8
Preparation and recovery	9
Output from the anus during the dormant period	9
How can I prepare for the takedown?.....	9
Final procedure	9
Takedown of the loop Ileostomy and reconnection of the pouch.....	9
What can I expect from my new J-pouch?	10
Colostomy and other Ostomy Surgery.....	10
Outlook and hope for the future	11
Legal Disclaimer.....	11

This document is based on an e-mail I sent, in response to a request for information on bowel disease, which was posted on the UK Ostomy site of Yahoo Clubs in early 2004

All names have been changed to protect the privacy of the members.

A legal disclaimer has been added at the end of the text of the article itself, which quite clearly states that: *I am not a doctor and do not claim to have any specialist medical training or knowledge other than my own surgery and hearsay from other Ostomists.*

E-mail to "Joanne"

Hi "Joanne",

I read your request for information in the notice board on the UK Ostomy site and I have tried to lay out a reasonably full response to your query - I hope it's not too long and boring but I wanted to try and cover the more common questions asked.

I reprint your original request e-mail for reference:

I have suffered from bowel disorders for over two years now; I have now been told that I should have my bowel removed. HELP!! This to me sounds like a big, painful operation, can anyone advise me on what it entails and what will happen to me.

My reply to the query

The first thing I should explain is that I am not a doctor and that any information I give you is **based on personal experience** and the result of being in **contact with other Ostomists and j-pouch people** over the last 4 years or so. The most important thing about this situation is that *everybody's condition is personal to them and so no two situations are absolutely identical*. I say this because you don't give any details of the reasons for your bowel re-section (removal).

[Return to index page](#)

Three of the more common reasons for Bowel Surgery

- *My own condition was caused by a disease called Ulcerative Colitis which is more common than people think and leads to the large bowel (or colon) becoming inflamed, losing its lining, and really severe cases, perforating and leaking into the surrounding tissues. It can be treated with steroids and anti-inflammatory drugs but when these fail, the only remaining solution is to remove the offending colon (Total Colectomy) and either temporarily, or permanently, re-site the exit from the Small Intestine onto the outside of the abdomen and into what is called a "stoma" or artificial opening. (More of this below)*
- Another common cause of bowel operations is Crohn's disease. The symptoms in Crohn's are very similar to those in UC - diarrhoea, bleeding and frequency of motions. The main difference with Crohn's disease (as I understand it) is that the disease is not limited to the Colon but can appear anywhere in the gastro-intestinal tract from as high as the oesophagus down to the rectum although it is most commonly found in the bowel. Again the treatment is by removing or re-sectioning the affected piece of bowel - when

all other treatment has been exhausted - and then diverting the output to a stoma. As I understand it (and I can only repeat what I've heard here because I do not have Crohn's) the stoma in a Crohn's case can be temporary in nature and the two parts of the bowel may be reconnected after time. The biggest problem with the disease is that even when you have removed the bad bit of bowel, the disease can come back and start up somewhere else which is why J-pouch (see "options for surgery" below) is not always recommended in Crohn's cases.

- A third major cause of bowel surgery (and there are many other less common causes of which I am more or less ignorant) is Cancer of the bowel. I know very little about this except that it is treated in much the same way as the above two diseases, usually after chemotherapy has been tried, and the recovery and prognosis depends very much on the exact type of Cancer involved. If this is the condition from which you are suffering the best option is to speak to your surgical consultant for more information or to post another query on the club notice board for people who have the same condition.

[Return to index page](#)

Options for Surgery

Your own surgeon should advise you on what's best for your particular condition but I'll try to explain the most common procedures. Another consideration is the sex of the patient and a good person to speak to here would be one of the specially trained "stomacare nurses" who operate as advisors and carers within the NHS.

I'll start by taking you through the operation that I have personally been through - again without knowledge of your exact condition it's hard to predict what you'll be having done.

If you have UC (and sometimes also with Crohn's) the usual thing is to remove the Colon and replace it with an artificial rectum made from the last few feet of your small intestine which is then reconnected to the anus and restores the semblance of a natural opening. This is called a J-pouch or W-pouch.

The operation is performed either as a 1, 2 or 3 stage operation *although as far as I can* tell the 1 stage is not usually carried out in this country and it seems to be an American phenomenon. I had the 3 stage operation and I'll explain that in detail here. In the 2 stage operation parts 1 and 2 are combined into one procedure and performed together. This usually depends on the fitness of the patient and the original cause and is decided by the surgeons at the time of the initial surgery.

[Return to index page](#)

Ileostomy & J-pouch Surgery

Stage 1

Removal of the colon and formation of an end or Terminal Ileostomy.

As I understand it, this is a relatively straightforward operation taking 30 - 40 minutes under general anaesthetic (GA for short). The abdomen is opened (depending on your surgeon it will be done either vertically or horizontally. I have heard that sometimes, in females, they try to use a horizontal opening to disguise the scar in the natural folds of the skin afterwards - my wife had this for a hysterectomy and you can hardly see the scar today. The large bowel is then stapled at both ends and then removed. I didn't even have to stop eating until 8 hours before the surgery and I had **no bowel prep** (enema or laxative given to clean you out before surgery) because my surgeon said it wasn't necessary.

Some surgeons do like to clean you out first and one method that I have personal experience with is to have a drug called Picolax, which you drink in two lots 24 hours before surgery. It tastes lemony and is reasonably pleasant. Unfortunately it has the same result as turning on a tap and you spend 4 of the next 24 hours on the loo but it does clean you out.

Another method for cleaning out is to use a large dose of a liquid preparation like Movicol, which is not absorbed by the bowel and more or less washes you out by sheer liquid pressure.

Whether you will end up with a permanent or a temporary stoma is irrelevant at this stage because, whatever the surgeon decides to do, you will have some kind of Ileostomy for a minimum of around 6 to 8 weeks and usually longer than this .

The Ileostomy is the opening which empties the bowel content into a bag **securely fastened** to the skin on the lower abdomen.

[Return to index page](#)

Preparing for surgery

In the UK, before the op, you should be visited by a stoma nurse who will show you the appliances available and help you understand how to fit the bags and may also mark you up with a marker pen on the spot where the new opening will be. This is done to try to make it so that clothing will not interfere with the Stoma (opening) too much.

You may be offered a sleeping pill the evening before your op and at some time you will be required to shave the area of the incision and the stoma. This depends on how much and where they are going to cut. About an hour or two before surgery You will be given a pre-med; this is usually something like Valium™ (Diazepam) or Temazepam or some such to help relax you. At this point you then get in to one of these delightful "theatre gowns" which you go into arms first like a short nightgown that ties at the back. As I recall these are usually open at the back and tend to freeze your butt off. You may also be given a little cardboard sick bowl and a little elasticised cap to put on your head. [Return to index page](#)

What happens after I leave the ward?

At the appropriate time you will be wheeled down to theatre where the anaesthetic will be given. Not all hospitals use the same method of anaesthesia and I can't comment on the method which I didn't have. When you've arrived at the hospital they will have put various lines into your veins for use both at surgery and afterwards - at this point one of these will be used to administer the initial "knock out shot" and they will usually talk you through it. I've had this done 3 times now and it's the best part of the whole thing for me - you see the plunger on the syringe going down and the guy is talking to you and then it just gets all warm and then you wake up and it's all done. In my case the anaesthesia after the operation was via an epidural which is drip fed through a needle in the back.

[Return to index page](#)

Post-Op - waking up in the recovery area

When you wake up it will be in the recovery room and things may seem strange, you will probably be mildly disorientated at this point and may feel tied down a bit. This is due to the fact that most of your muscles are still "sleepy" and also you may have various tubes draining from the wound site, the bladder and or the new stoma. You will also have lines going into you at this point and in most cases, at least where our surgeon works, you will have a central line going in to the neck.

You may well be attached to an epidural drip and other liquids through the central line. At first the tubes and cables and attachments may be a little overpowering but they are all there to help you recover and deal with any pain. Morphine will probably be your best friend for the next few days and, if it's controlled properly, you should not suffer undue pain. I would be lying if I say there will be absolutely no pain - for instance when they get you up for your first shower or when the physiotherapist tries to teach you how to breathe properly it will probably hurt. The important thing to remember is that with a good anaesthetic regime you learn to manage the pain. Some hospitals - ours is one of them - have introduced "analgesia sisters", who's only job in the hospital is pain management. The reason for this, I was told, is that the less pain the patient suffers, the faster they will heal so it's in everybody's best interests to keep you comfy.

[Return to index page](#)

Getting to know your new stoma

There are different types of stoma appliance and you may have a removable or a drainable bag to start with. The usual thing is to have a clear plastic bag to start with, which allows the surgeons to inspect the stoma without disturbing it. It looks pretty gross to start with but you get used to it.

Don't worry about the colour of the output which is a dark green liquid usually to start with - this is just bile as you haven't eaten anything and are on liquids only for 24 - 72 hours after the op. Eventually, over a few days, it should settle down and become a **porridge-like liquid** which will vary in consistency depending on your diet. Because the small bowel does not contain the same type of bacteria as the large bowel, it will

smell rather different from colostomy or normal faecal output. This is normal. (see [section on Colostomy below](#))

It's probably a good idea to examine the stoma and some people have even been known name it. It will seem very strange to you at first as this is part of your body that you would normally never see. As the stoma is made from your ileum (small bowel) and is still part of that structure, it will continue to show signs of peristalsis (contractions of the bowel that push the contents through) and may appear slightly larger or smaller at times as a result.

When you first change the bag you will be assisted by the Stoma care nurses (if they operate in your hospital) and they will teach you how to take care of the appliance and how to look after the stoma, which needs to be protect from bangs and bumps.

[Return to index page](#)

Getting mobile after the op

Getting up and about after the op is different for every individual. I was one of these people who, as soon as they had "forced me to stand up shakily and wobbly at the side of the bed" and got rid of the epidural tube in my back (about 36 hours post-op) was raring to go. It was at this point that they fitted me with a morphine pump - it's a little pump which administers morphine at a given rate into your arm. If you have increased pain, you can press a button and it gives you more - up to a limit. With this pump on and dragging a drip stand behind me, I actually walked the length of the ward 48 hours after my op. The nurses said I was a bit crazy but I have heard quite a few stories of others doing this type of thing. I have had conversations with others about this and it seems that the sooner you get back on your feet, the faster you will heal - provided that you don't push yourself too hard, which could make things worse!

[Return to index page](#)

Post operative depression - the blues.

It is not unusual to become a bit depressed and mentally drained about 4 - 6 days post op, although the time varies with each individual. Don't feel you are alone if this happens to you; the nurses are very aware of it and should be specially supportive at this time. You have, after all, just had part of you removed and it is perfectly acceptable to miss it. The good news is that there are many others who have gone before you in this and would agree that **you will feel better** as the time passes and the wound heals up.

[Return to index page](#)

When do you go home?

Everybody is different so it can be anywhere from 8 to 18 days on average, depending on how you are healing, where you are living in relation to medical care and what the policy of the individual hospital happens to be. Each area will be different on this point but, in the UK, you should be visited by the stoma care people who saw you at the hospital. In our area they continue to visit you for a while but if you are in a city they may ask you to come in to a clinic, until you are fully confident in your care of the stoma. You may also be visited by the local district nurse

depending on what region of the country you live in. A post op surgical appointment should have been arranged for you before you are discharged or shortly afterwards. This is where your surgeon will check everything over and review the next stage of your treatment.

[Return to index page](#)

Internet support groups - a shoulder to lean on

It is at the point where you go home that the Internet Ostomy and J-pouch support groups are very useful - at least I found that to be the case. In these web based support groups you can talk and exchange concerns with hundreds of people who have gone through similar operations to your own. They will usually try to help out with information both in the UK and all over the world. In general the treatments worldwide are similar, although the names of the drugs vary from country to country and you will soon get used to seeing different names for the same preparations.

There are various links available at:

<http://ostomyland.org/ostomyboardipb>

<http://www.iasupport.org>

<http://clubs.yahoo.com/clubs/ukostomysupport>

www.j-pouch.org

[Return to index page](#)

Stage 2 of the 3 stage procedure

Creation of the J-pouch - formation of a loop ileostomy.

This operation is sometimes combined with the first stage operation if the patient is both fit and relatively healthy and provided there is little danger of perforation. This combined operation then forms the first stage of the so called two stage procedure.

This operation continues from the end of stage one where the colon has already been removed. It lasts longer than the Colectomy operation and in my own case it took 3 and half to 4 hours. Others have taken less - some have taken longer

General preparation for stage two is more or less the same as the previous section describes.

[Return to index page](#)

J-Pouch - explanation of how it's made

The last couple of feet of the small intestine or ileum is now formed into a pouch by folding it over like a snake and then slitting and joining the adjacent sides. Imagine a

garden hose with a slit running lengthways for about a foot - fold it over in a U-bend so that the two ends of the slits are next to one another and then join them up - the result is a piece of tubing twice as thick as the original tube, which now forms a chamber. links to diagrams of the procedure.

A large part of the rectum is then removed if it has not already been taken at stage one, leaving a small rectal cuff to provide anchorage for the end of the pouch. The new j-pouch is attached by slitting the base of the U-bend and attaching it to this rectal cuff and thereby to the anal sphincter which will be used to control the flow of the output. This last point is important to understand, as the normal bowel uses the rectum as a reservoir, which in itself has a muscular component. In the new setup, the main control rests almost entirely with the sphincter muscles and any pressure used to expel faecal material comes from the abdominal muscles.

[Return to index page](#)

Creation of the temporary loop Ileostomy

In order to allow the new pouch to heal properly it is necessary to create a temporary (or loop) Ileostomy which will be in place for a minimum of 6 to 8 weeks. In my case I had the temporary for 5 months before the "takedown" or reconnection was performed. If we go back to the garden hose analogy for a moment I can explain how the loop Ileostomy works.

Taking hold of the hose at a point above the newly formed pouch we fold it over and push it through the abdominal wall onto the surface of the skin. We now have a very small loop with no more than a centimetre or so of tube sticking out of the hole in the abdomen. Instead of cutting the loop all the way through, which would sever the top and bottom half of the Ileum, it is cut half way through on its outside edge and sutured into place. This allows the contents of the bowel to drain out of the new stoma and into a collecting bag without cutting off the continuity of the bowel into the healing j-pouch within.

Because the amount of bowel in this loop is very short it is sometimes necessary to wear a special type of appliance called a "convexity" with this type Ileostomy. The convexity has a built in bulge around the opening of the bag, which pushes the surrounding skin down to allow the stoma to enter the access hole to the bag.

I would stress again that *"each case is different and you must consult with a stoma care nurse or surgeon for individual advice on this"*.

[Return to index page](#)

How is it done - graphic representation of overall process

If this all sounds a bit complicated, you may find it easier to look at diagrams of the procedures via the following links:

www.j-pouch.org/lllust.html

Or for a better diagram go to:

<http://www.j-pouch.org/illustratedpouch/index.html> You can find some via the links page at whatever support forum you reached this document.

[Return to index page](#)

Preparation and recovery

Preparation and recovery for this operation is almost identical as that of the previous stage so I won't dwell on it too much. You may find that you are required to stay in hospital longer after this operation as it is the more complicated of the two. Other than that, the support and aftercare should be the same as above but there are one or two extra things to think about after it's all over.

[Return to index page](#)

Output from the anus during the dormant period

Although you are connected to a stoma bag attached to your abdomen at this point, you may also find that you get occasional "urges" to empty your bowel. This is normal. Depending on how much rectal material was left and on how your new pouch is getting on, you may find that there is a natural build up of mucus or discharge which needs to be passed. It is worth discussing this with your nurse before you leave hospital so that it doesn't come as surprise. Remember that at this stage what comes out will not be a lot and will not look like normal bowel movement at all.

[Return to index page](#)

How can I prepare for the takedown?

Just because you have a few months between operations doesn't mean you should forget about your out-of-service rear end. [Pelvic floor and sphincter control exercises](#) are an excellent way of preparing for your takedown operation. By strengthening the sphincter muscles and the pelvic muscles you are paving the way to better control of your completed functioning J-Pouch. You should take advice from your stoma nurses or other health care professionals on how to do these and more importantly - how long after the second stage operation you should wait before trying to do them.

[Return to index page](#)

Final procedure

Takedown of the loop ileostomy and reconnection of the pouch

This is the 2nd stage of the two stage procedure and the third stage in the three stage procedure.

This is usually a fairly straight-forward operation, for which the preparation is the same as the first two - except for the laxative which I believe is not given - but I'm only quoting here from my own experience. The operation takes place 6 weeks to 6 months or longer after the previous stage and in most cases takes about 30 minutes.

The surgeon will use a scope to check the pouch and then will excise the loop ileostomy from the surrounding muscle tissue reconnect the upper and lower parts and pop it back into the abdominal cavity. The abdomen is closed and hey presto - you are now a through and through person again.

[Return to index page](#)

What can I expect from my new J-pouch?

The output from the J-pouch may be difficult to control at first - remember that you are using muscles to control flow that were not meant to do so on their own in the original design. Some very lucky people do not leak; however you should not be downhearted or ashamed if you have the occasional staining or leaking at first and pads etc are usually available through your health care professionals. In almost all cases the control issues and regularity will eventually settle down. You can expect to be having an average 3 to 8 motions a day but it really depends on the individual. My surgeon told me that I should not expect miracles overnight and that the pouch would develop and stretch to optimal size over 12 to 18 months as opposed to days.

The consistency of the output will never be the same as a "normal" bowel because the colon is not there to absorb all the liquid but, the new pouch usually learns to take up a lot of the liquid and the output will firm up over the years. Or so I'm told I've only had mine a year so I'm still learning. [Return to index page](#)

Colostomy and other Ostomy Surgery

I have no direct experience with **colostomy** but the general idea is similar to the ileostomy stage one surgery above. The main difference is that where the whole of the colon is removed in the ileostomy, only part of the colon or part of the rectum may be removed in the colostomy. The end result is that you wear an appliance (bag) on the abdomen, as explained above, but it tends to be slightly lower down and because the output is from the colon as opposed to the ileum, it is more like a normal bowel movement in both consistency and smell.

Another type of ostomy is a Urostomy, where the bladder is drained artificially into a collecting bag. This is used where there is damage to the bladder itself or the tubes connecting it to the outside world. I know very little about it but help can usually be found via the support groups mentioned in the link section above. [Return to index page](#)

Outlook and hope for the future

There is one thing that seems to be consistent among all the people I've talked to in the forums, chat rooms online and in person. Assuming that the actual surgery has been successful, there has always been at least some improvement over their original condition from the shadow of the bowel disease they started with.

Remember that you are not alone with this condition

We all stick together with these conditions - the online clubs and chat rooms and, in the UK, the National Association of Crohns and Colitis (NACC) or the Ileostomy Association are all made up of **people like me and you** who have been there and done it and bought all the T-shirts.

Use the links page from the [Ostomyland](#) , [IA Support](#), [Yahoo UK Ostomists](#) or the [J-Pouch](#) organizations to take you to other relating to the diseases mentioned here.

We have *all been scared* or frightened out of our wits at times, depressed to the point of having no future at times, in pain or discomfort or just **in need of someone to talk to** - that's why these clubs were formed - feel free to ask for help whenever you need it [Return to index page](#)

Legal Disclaimer

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[Return to index page](#)