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The Colostomy Association
0800 587 6744

CUI Wear
Underwear + Swimwear for ostomists
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Want to join the support group?

If you have a colostomy, ileostomy or a urostomy and you would like more information, please complete the form below and send it to:
Sarah Varma c/o Stoma Care Department, St. Mark's & Northwick Park Hospital, Watford Road, Harrow, Middlesex, HA1 3UJ

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Spring 2007
NEWSLETTER

INSIDE

OUT

VOLUME 3
ISSUE 4

STOMA SUPPORT GROUP WORKING WITH ST. MARKS AND NORTHWICK PARK HOSPITAL
Incorporated with St. Mark's Hospital Foundation Charity Registration No. 1088119



Bob's Hello

Dear Friends

Happy New Year to you all and let's hope that it is! It's amazing how time seems to move so fast these days or is it me and my senior moments?

It is said that this is meant to be a time for reflection. Maybe, but I for one feel it is time to look forward, as what has happened is over, finished and it is time to plan for the future. I appreciate for the new stoma patients this may seem daunting as you have not long had your stoma and you are tired, your body has been attacked by surgeons, the nurses have pushed you to get out of bed, to walk etc. the stoma nurse has been and instructed you on how to manage your stoma and you do not necessarily love it, as it is uncontrollable and you are not sure if you can get back to living. You remember how your life used to be before your stoma surfaced on the top of your abdomen, before your very eyes!

Believe me, from past experience, and from everyone we have helped through the support group, there is light at the end of the tunnel. Slowly at first, you learn how living with it, (although some of you have given your stoma a name), is actually giving you a better quality of life. You will find that it does not have to control your everyday movements, that the things you did before the illness that caused you to have a stoma, you can start to do again, like your past hobbies or getting back into work or even just living and enjoying your life with your family and friends.



I would like to take this opportunity to say a very big thank you to Joan Greenwood and her husband Henry for editing our newsletter for the last five years. They have both given a lot of their time and provided us with a very comprehensive insight and covered many varied subjects which have been relevant to us as stoma patients. They both feel it is time to give someone else the chance of editing the newsletter for our group. In doing so, I would like to welcome Carolyn Derecki, who has in the past served on the committee and is one of our be-frienders, Carolyn has said that she would give it a try. I'm pretty sure that Carolyn will do a magnificent job and with Joan's guidance, hopefully will decide to make it a permanent post.

This year at the AGM on the 2nd of June, we have Peter MacDonald, who will bring us up to date with what is happening in the cancer field. Sharon Fillingham will be talking about urology issues. The third speaker will be myself and I will be talking about the fifty eight years that I have lived with my stoma and what changes I have seen during this time. Plus our suppliers will be there with their stands and, of course we will hold our AGM meeting as usual. I look forward to seeing as many of you as possible, In the mean time, our coffee mornings will continue and you are more than welcome to come along and have a good old chin-wag.

Kind regards to you all
Bob
Chairman, Inside Out



Dear Fellow 'Inside Outers'

It's that time again - for me to try and find some words of wisdom to impart to you! I do have problems thinking of what to say. Forgive me if I just ramble.

It doesn't seem possible that Christmas 2006 has passed, all the decorations are down, the house looks bare and there is no excuse not to dust now that all the cards have gone. 2007 has arrived in all its glory! I hope that the New Year brings you all health, wealth and happiness – especially the healthy part. We've all been through 'the mill' at some time or other, for various reasons. Those of you who have been through 'the mill' recently perhaps are not feeling as positive as those of us who are old hands at being 'ostomists'. Believe me, 99% of us live a normal life, doing all the things that we used to do and certainly a life with a much better quality to it than before the 'op'!

Our 'Open Day' is well worth entering into your diaries – June 2nd 2007 - same place – the Himsworth Hall (level 6), St. Mark's Hospital. Come and meet other ostomists, the manufacturers and listen to the speakers – all there to be a help to you.

We also supply some refreshments. It is all free! We do ask that if you haven't paid your annual fee of £5.00 then this would be the time to do so. Don't forget if you have any questions, for our Question Time, that you would like answered please let me know by letter, fax or email. We'll do our best to answer them for you or at least, if we know ahead of the meeting, will find out the answer. Remember other people might be interested in your question too.

There should be another 'Inside Out' before June 2nd. but in case there isn't this is the time to put the date into your diaries and try to keep it free. The time goes past so quickly it is worth realising that we will be in summer by then. I think this as I look out of the window to the wind blowing in the trees and the rain pouring down. Still, with our weather it could be the same in June! Hope not!

I look forward to seeing you all in June, some for the first time. Please do try and come along – it is a very informative, interesting, friendly day.

Best wishes to you all
Diane Owen - Secretary/Treasurer

Piano Recital

Valerie Goldsborough's Piano Recital in aid of St Mark's Foundation and St Luke's Hospice on October 28th was a great success, playing with her usual finesse and aplomb we were treated to 14 pieces, many of them our old and trusted favourites. Valerie had a surprise for us at the end, inviting Mr Peter McDonald on to the platform to entertain us by singing and playing the violin. At the end he announced that he would play the Skye Boat Song and we the audience were instructed to sing it, fortunately we had been given a sheet on which were the words. There was one other little gem of a recitation and numerous people requested a copy of the words, so here they are

The Surgeon stood before the
Heavenly Gate
His face was lined and old
He stood before the Man of fate
For admission to the fold

"What have you done,
St Peter said
To gain admission here?"
"I have worked for the National Health Service
For many and many a year!"

The Pearly Gate swung open wide
As St Peter touched the bell
"Come in and take a harp, my dear
You've had your share of hell!"

There was also some interest in Peter's fiddle which turned out to be English, made in East Anglia near Norwich in 1880. Henry Greenwood who was a professional violinist remarked that it had a nice bright tone and that Peter had a good facility which I understood to mean that he handled it rather well.

J.G



Inside Out Coffee Mornings

In the Out Patients Department of St. Mark's, Level 3
10.00am to 12 noon

We are there to enable you to seek advice about your stomas, or if you just want a good old chin-wag and a cup of tea or coffee, then you are more than welcome.

Tuesday 6th March

Tuesday 8th May

Wednesday 21st March

Wednesday 23rd May

Thursday 5th April

Thursday 7th June

Monday 23rd April

Monday 18th June

Attention! Important! Please Read:

Whilst every care has been taken to ensure that the information in this publication is accurate and complete, the contents of this newsletter are provided for general information only and should not be relied upon for any specific purpose. Inside Out Stoma Group accepts no responsibility for the accuracy or statements made, members act upon them entirely at their own risk. We recommend that you consult your stoma nurse or doctor before changing your procedures.

I am very sad to announce the death of Ellen Buckingham who died in the early hours of 16th December 2006 at the age of 87.

Her son-in-law, David, told me that Ellen, though not always able to make the Inside Out coffee mornings, did find the group a source of great help, and enjoyed reading the Newsletters.

Ellen also found the time to talk and share problems with others and will be greatly missed by all who knew her. Our condolences go to her family.

C.D

Our new Insideout Newsletter Editor is Carolyn Derecki. Married with three grown up children and three grandsons she returned to work as a librarian at Manor Farm Library, Ruislip. A little later she attained a BA(Hons) in English Literature and Sociology and so began lecturing in Higher/Adult Education, which she will still be doing albeit less than in the past.



Having introduced Carolyn to you it grieves me to have to tell you that owing to poor health Henry and I have to resign from the Editorship of the Inside Out Newsletter. I have found it to be a really lovely pastime but Henry hasn't participated for at least two years. We couldn't be more pleased about our successor Carolyn Derecki. Actually, Carolyn has agreed to take over the next two seasons, that is spring and summer but my sincere hope and belief is that she will take it on permanently. If you have any stories or articles that you want written about any subject of interest to the members I'm sure that Carolyn would be so pleased to hear from you.

She knows that I will be as helpful to her as I can. I am sure that you will all welcome her and join me in wishing her well.



Ileoanal Pouches - an update

Miss Sue Clark MD FRCS(Gen Surg)

Many of you will have heard of or even had an ileoanal pouch, an operation pioneered by Professor John Nicholls at St Mark's. I am honoured to have taken over his post on 1st March 2006 on his retirement.

I am not new to St Mark's, having started my two years of research at City Road, and moved with the hospital to Northwick Park in 1995. I came back for my final year of specialist training in 2002, and spent some time at Mount Sinai Hospital in Toronto, the main pouch centre in Canada, before starting my previous consultant job at the Royal London in 2003.

Since the first operations in the late 1970s, over 1500 pouches have been constructed at St Mark's, one of the biggest series in the world.

Careful follow-up of this large group of patients has given us valuable experience of the problems that can arise, as well as accurate information about what pouch patients can expect in the long term. I hope that this article will provide an update on the subject.



What is an ileoanal pouch?

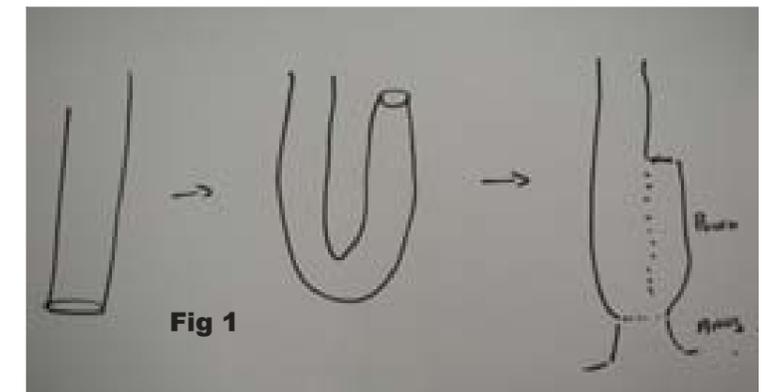
A pouch is made from small bowel to create a reservoir. This can be used to hold urine, or be situated inside a continent ileostomy (Kock pouch), in which case it is emptied several times a day by passing a catheter through the specially designed ileostomy into the pouch. These are both uncommon types of pouch, so I will not mention them any further. Most pouches are joined on to the anus, so that the faeces are held in the pouch and then evacuated via the anus in the usual way.

How is a pouch made?

Basically pouches are made by opening lengths of small bowel to produce 'strips', and then joining these 'strips' together to form a bag (Fig 1). In the early days a number of different designs of pouch were tried, all made from different numbers of 'strips' joined together in different ways (Fig 2). The commonest of these were S, W and J pouches. Almost all pouches made nowadays are J pouches. W pouches are a little bit bigger, so may hold more faeces, requiring less frequent visits to the toilet, but sometimes they do not empty efficiently, and more bowel is needed to make them.

The 'strips' of bowel used to make the pouch were originally sewn together by hand, but usually special staplers are used now. The staples are made of a titanium alloy, so they do not rust, and do not set off airport metal detectors or cause problems with MRI scanners! They can be seen on X-rays though. The pouch can be joined to the anus (anastomosis) either by hand stitching or using a special circular stapler. Hand stitching is difficult, and the anus is stretched and can be damaged when it is done. Stapling is more straightforward, but sometimes it is necessary to make the join very low down in the anus, where it has to be hand-sewn.

Usually after a pouch has been made a temporary loop ileostomy is formed upstream of it to allow all the various joins to heal before the pouch is used. Usually the pouch is tested to check for leaks after 6-12 weeks, before the ileostomy is closed. This is done using a pouchogram: the pouch is filled with X-ray dye passed in through a catheter placed into the pouch through the anus, then several X-rays are taken over a few minutes.



Who needs a pouch?

Before the pouch operation, patients who needed to have their entire large bowel (colon and rectum) removed were inevitably left with a permanent end ileostomy. The introduction of the pouch allowed the small bowel to be joined to the anus with acceptable functional results. Virtually all patients with pouches have one of two conditions:

- 1 ulcerative colitis (UC)
- 2 familial adenomatous polyposis (FAP)

No patient 'has' to have a pouch for medical reasons. The 'treatment' part of the surgery is the removal of diseased bowel. The creation of a pouch is a way to join the bowel up again and avoid a permanent ileostomy. Some people who have the colon and rectum removed (proctocolectomy) prefer to have an ileostomy, and not run the risk of poor function or future complications associated with pouch surgery.

Ulcerative colitis

This is an inflammation of the bowel. The underlying cause is not understood. Increasingly it can be successfully treated with drugs, but in about a quarter of patients surgery is necessary. In most cases this involves removing the entire colon and rectum. If surgery is done as an emergency the colon is removed, but the rectum is left inside, because removing it in a very sick patient can be dangerous. It is better to wait until the person is better, then go back a few months later, remove the rectum and create a pouch. In people who are less unwell, it is possible to remove all of the large bowel and form a pouch at a single operation.

There is another inflammatory bowel disease called Crohn's disease, which can behave very like UC in some patients. Pouches frequently develop serious complications in Crohn's disease, so we are always very careful to make as sure as is possible that we are dealing with UC rather than Crohn's by checking biopsy results and the pathology of the colon if that was removed at an emergency operation. Even then it can sometimes be very difficult to be certain that the diagnosis is not Crohn's disease.

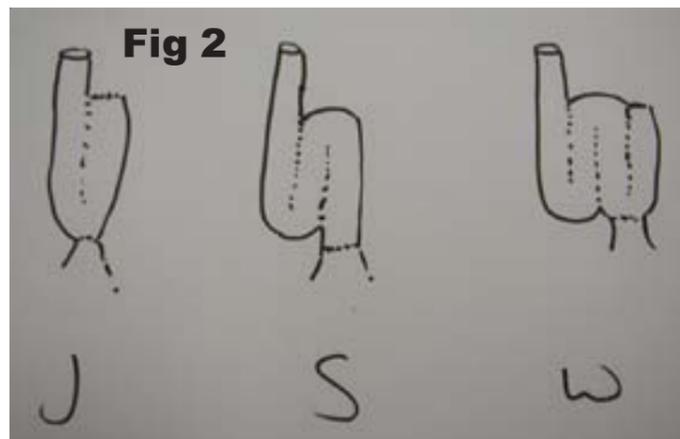
Familial adenomatous polyposis

This is an inherited condition in which people develop many hundreds of pre-cancerous polyps in the bowel when they are teenagers. These then turn into cancer in the thirties and forties. The only way of preventing this process is to remove the affected large bowel. In some people with FAP (but not all) this means removing the colon and rectum. The only way to avoid a permanent ileostomy is to have a pouch.

What can go wrong?

Any operation carries risks, such as thrombosis (clots) in the veins of the legs, chest infections or wound infections, etc. In the longer term anyone who has had extensive abdominal surgery will have adhesions (scarring which sticks loops of bowel together), which can cause episodes of obstruction (blockage). In most cases this settles down of its own accord, but sometimes surgery is needed to unkink the bowel.

The pelvic surgery required to remove the rectum can be difficult and involves operating close to the urethras (tubes which drain urine from the kidneys into the bladder) and the nerves which allow erection and ejaculation in men. The risk of damaging these is small (1-5% risk of impotence) and is really a risk of removing the rectum, rather than of pouch surgery itself. The most serious problem is leakage from one of the seams (usually between the pouch and the anus). An ileostomy protects from the worst effects of leakage, but an abscess can form outside the pouch. Sometimes this can be successfully drained and the hole in the seam can heal. This does not always happen though, and chronic inflammation can result in a scarred pouch which will never work well.



Sometimes the join between the pouch and the anus narrows down (a stricture or stenosis) so that the pouch cannot empty properly. This may require stretching under anaesthetic, and then regular use of dilators to keep the anastomosis open.

About 30% of people with pouches for UC develop inflammation of the pouch (pouchitis) at some time. We do not understand why this happens, but in most cases it can be easily treated with a course of antibiotics and does not return. A few people have troublesome recurrent pouchitis.

Pouches made for FAP can develop polyps, so we follow this group of patients up very carefully and remove any large or worrying polyps.

Research done over the last five years has shown that women who have had pouch surgery may have difficulty getting pregnant. This is likely to be due to adhesions forming around the Fallopian tubes, and is actually probably a result of removal of the rectum rather than pouch formation. We are now trying to avoid the pouch procedure in young women, postponing it until they have completed their families if at all possible. If a woman with a pouch is having trouble getting pregnant we suggest IVF treatment.

Long-term results

On average someone with an ileoanal pouch will need to go to the toilet five times per day and once at night. There may be some mucus leakage. As this is an average, some people will empty their pouches less often than this, and others will go more frequently. Codeine or loperamide can help to slow things down. Over many years function seems to improve a little.

Some people have more difficult problems with continence, due to a combination of anal muscle weakness or damage, the loose faeces which are normal with a pouch and advancing age. Occasionally, an ileostomy is needed in these cases.

Overall about 90% of pouches are a success, and 10% fail, usually because of leakage and infection or severe pouchitis. In some cases a new pouch can be made, but the failure rate of 'redo' pouches is considerably higher than those done for the first time.

What have we learnt?

So what has changed in the thirty or so years since pouches were first performed? Virtually all pouches formed now are stapled J pouches, with either stapled or hand-sewn pouch-anal anastomosis. We can give people a good idea of what to expect in the short, medium and long term, and have developed ways of diagnosing and treating most pouch-related complications.

Recent work has shown that pouch surgery has a major effect on fertility, so we can now warn women about this, and try to avoid this type of surgery in young women who may wish to have a family. Careful follow-up of patients with FAP has shown that they can develop polyps in their pouches, and need very careful follow-up.

The future

The team at St Mark's has developed a database which includes details of all pouches formed at the hospital. This is crucial in monitoring long-term results. We also have research groups looking at the following areas:

- 1 fertility in women, to try to understand why this surgery affects fertility, and what the results of fertility treatments are in women who have had pouch surgery.
- 2 the cause and treatment of recurrent pouchitis
- 3 polyp formation in pouches in FAP – why polyps develop in the pouches and how to prevent them

We are enormously grateful to the patients who take part in these studies, as without them we cannot improve the surgery and other treatments which we offer.

In terms of technical progress, one of the most experienced laparoscopic (key-hole) surgeons in the country, Robin Kennedy, has recently moved to St Mark's. He is developing the 'key-hole pouch' operation. Several small cuts are needed to insert the key-hole instruments, and an incision is still needed to remove the diseased bowel, but this is far smaller than the wound needed for traditional surgery. This approach will not be suitable for all patients, but may benefit many in the near future.