

INSIDE OUT

Welcome to issue 5 of the Inside Out newsletter. We begin with a message from the chair of the group - Bob

Dear friends

Our charity line-dance night went very well, so well that we have been asked to do more. We raised, between us, £500, which will be divided between the Marksman appeal and Cancer Link.

My heartfelt thanks and gratitude go out to the unsung heroes who helped put the event together and to our sponsors:

Salts, Dansac, Respond plus, Clinimed, ConvaTec, 3M, Kingsbury Travel and Marksman.

A very big thank you goes out to Leslie and her gang of sundancers who, with their patience and skill, made us all into perfect line dancers.

Especially Mary (wheelchair bound), who achieved her personal ambition to line dance, Mary toe tapped, hand clapped and turned with everyone, her eyes and face said it all!

Well done everyone and thank you all!

Bob

(Chairperson)

Diary Dates

Coffee mornings 2000

Mon 30th October 10am to 12pm
Tues 21st November 10am to 12pm
volunteers welcome

Next Year's meetings

AGM	Tues 16th January 2001
Quiz night	Tues 6th March 2001
Charity Night	Tues 5th June 2001
TBA	Tues 11th Sept 2001
TBA	Tues 4th Dec 2001



Loud Tie Day

This year's loud tie day takes place on Friday 3rd November. The aim is to raise awareness of the symptoms of bowel cancer as well as funds to help beat this disease. Clare Bossom would love to hear from anyone willing to volunteer some time to rattle collection boxes in St Mark's (wearing the obligatory loud tie of course). Please call her on 0208 235 4110 if you can spare some time.

In Memory

Ian Brooker, our secretary, passed away in July at Mount Vernon hospital. Our thoughts go out to his family.

Useful Contacts

Chairman of Inside Out Group

Bob Azevedo-Gilbert, 256 Merlins Court,
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020 8426 5203

Editor of Newsletter

Susan Tuck 13 Osborne Road, Redhill, Surrey
RH1 2HX (all submissions welcome)

Ileostomy & internal pouch support group

01724 720150

Urostomy association

01245 224294

NACC

01727 830 038

British Colostomy Association

0800 328 4257



THE ZEN OF PERFECT POUCH APPLICATION

by Karen Daniels

So rare does a pouch change come when there are no difficulties or hazards happening.

One day it occurred, some 9 months in after my ileostomy. The bedroom prepared, no struggling in the cold small bathroom/toilet. With mind calm, the pouch was slowly and meticulously set out in regular order and all neatly aligned. There were those little extras, like a mirror to check beneath my stoma in case the skin was damaged or I missed cleaning up well; scissors to shape the pouch hole to a perfect size fit, special powder, liquid soap, the pouch deodorant, disinfectant, bowl with warm water, wipes, custom shaped thick see through plastic sheeting (from the local garden centre) across my knees as I sat in a comfortable chair, positioned "just so" and portable fan heater carefully adjusted, together with two sources of electric light and the blind drawn down.

Now to work, scissors wiped in disinfectant, bag for used pouch positioned carefully, no spills today, or droppings on the floor! No messy cutting of the pouch hole, or forgetting the pouch deodorant until after you put the pouch on. Then the careful removal, stress free from a sudden urge of volcanic output from my stoma (a clean up that as usual was meticulously carried out), then the positioned wipe - successful in forestalling those many after clean-up spills. Dare I say Savlon cream applied to a red skin patch - excess removed, powder smoothly appliedmmm, THINGS ARE REALLY WORKING WELL TODAY!

And now for the pouch application A moment of meditative calm, before carefully positioning the pouch, and having gauged to "nth degree" the best position to avoid leaks from those dips and bumps in the skin surface that invite them - skin stretched "just so", the pouch is applied. Oh! It fits so well - the outer portion very firmly and smoothly stuck down today.

I WAS STRUCK WITH AMAZEMENT OF THE PERFECTION/SUCHNESS OF IT ALL I sat back and collected the clip to secure the pouch exit. Where was the end of the pouch??... ALARM... Oh! don't say it has no exit! One of those manufacturing aberrations.

Then I realised that the
POUCH WAS ON UPSIDE DOWN!!!

OSTOMY HUMOUR

Ostomies can give us reason to laugh at times as these stories from the US demonstrate...

I had a temporary ileostomy put in and was told I would have it for a few months. My reversal surgery was December 17, and my surgeon told me it was an early Christmas present from her and the staff. The morning of my surgery, still bandaged clear around my abdomen, I decided since I was the "present" I should look like one. I took the Christmas gift tags that said 'no peeking' and 'do not open until Christmas' and attached them to my bag and dressing. When I woke up in recovery my surgeon had drawn Santa Claus on my dressing and a little present where my stoma had been. What a great Christmas present!

I have had an ileostomy for about three years. Recently, my wife and I went to a restaurant for lunch, but had to wait for a table to be available. While we were waiting, I suddenly felt my stoma producing A LOT of output. This continued for some time, until I became nervous that something was seriously wrong. I was about to say something to my wife about leaving, when I finally realised that the sensation I was having was caused by the beeper vibrating that had been supplied by the restaurant. I had clipped the beeper on my belt near my stoma and the restaurant was trying to signal me that our table was ready!

Letters to the editor

HAVE EQUIPMENT, WILL TRAVEL!

I have today received the latest issue of "Inside out" with interesting content as usual. I would just like to say and let your readers know how irrigation has certainly much improved my lifestyle. Giving greater confidence to do all the things that at times are a no no, for colostomists - such as swimming, walking on the beach with your shirt off etc. I have been using the new Coloplast Con Seal plug since the early part of the year and this with irrigation completely obliterated wind. Every 48 hours I irrigate, that day, using a plug which usually remains in place for up to 12 hours, giving a great new freedom and confidence. I would certainly recommend this to other colostomists. Clare gave me training and great support and a bit of a laugh while this is going on - so why not give it a try!!!

Changing direction slightly, we have recently returned from holiday in the Italian lakes. A wonderful location, the best holiday we have had in many years. Irrigation works just fine and all the necessary equipment can be found locally (see photo)!!



Thanks Clare, for encouraging me to try irrigation, it does take time but it is well worth the effort.

My appreciation to you and your colleagues, keep up the good work.

Derek Cutler

THANK GOD FOR AN ILEOSTOMY!

I made it at last! My long awaited trip to America. I had waited over ten years for this holiday. Why? Up till last summer I had been suffering with ulcerative colitis. Unfortunately, this turned to cancer and I had to have an ileostomy. Poor me, I thought. But every cloud has a silver lining and the ileostomy cloud has one.

I walked around San Francisco, Sacramento, Lake Tahoe, Yosemite National Park and many other places that I visited in America with "calm composure". Why "calm composure? Because for the first time in over 30 years I did not need to walk around spending all my time worrying about where the next public toilet was and would I make it in time.

I really enjoyed my holiday, for many reasons but mainly because of having an ileostomy released me from the pressure of worrying about where the next rest room was and it allowed me to thoroughly enjoy myself.

Thank God, and Mr Windsor, for my ileostomy.

Diane Owen

OSTOMIES ARE FOR ALL AGES

by Susan Tuck

Contrary to popular myth and the image portrayed by the leaflets from Ostomy manufacturers people of all ages have ostomies. I was first given a temporary" one at 28 which soon became permanent following other complications. I readily admit the idea horrified me and I did think "but I'm too young". I, like many people, thought of ostomies as something I would not have to worry about until I was much older, not so. I soon discovered just how many people of all ages have ostomies.

Why such a hang up about age? Why should it matter what age I get an ostomy? Precisely because of all the

literature and the popular impression of ostomies. I have even had friends say to me (usually prior to thinking about it) "Isn't that what you get when you are old"? Once I started to get literature from ostomy manufacturers and organisations this view was heightened for me. All the images were of happy smiling people showing how the ostomy had not affected their lives but all over a certain age. I joined forces with one of the other young ostomates I met on the internet to harangue the manufacturers and have recently noticed some of them having much more positive images showing people of all ages in their literature. I don't mean to offend anyone with my annoyance at the images used not showing people of all ages but it does have a huge impact when you realise people of the same age etc have the same problem. You feel less alone and less unusual.

The other problem I had with getting an ostomy at 28 was the thought of so many years with an ostomy terrified me, and on bad days still does. How many operations might I need to deal with any ostomy problems? Can I have children? Would it affect me lifting any children I did have? Would it affect my career? All real fears. However in the last 6 months I have come to realise just how little it need change your life. I still have a healthy social life (in all areas!), still drink and eat what I like. The only difference is my colostomy likes to act like my Mother after I have had a heavy night drinking by teaching me a rather messy lesson (if you get my drift)!

I have found huge comfort from the internet and have made some great friends including one girl who is the same age, has exactly the same medical history- the only difference between us was our names and that she lives in America. Both of us readily admit we have found the opportunity to moan to one another when needs be very helpful. The weeks following my operation were full of emails flying around the world checking on wound breakdown etc.,etc etc.

The downside has been some ignorance and at least one comment about "bag ladies". Imagine how much worse children could be to a younger ostomate!. We need to keep promoting more positive images of ostomates of all ages.

On a more personal note, the main reason I have been able to cope with my ostomy (and don't get me wrong I have had very bad days about it all and would not tell anyone it is all peachy) has been the love and support from the stoma care nurses and counsellor but especially my husband and family. My husband and I both spent 6 months saying the ostomy was fine "as long as it is not permanent" then we had to revise our opinions pretty quick. At the risk of sounding sentimental it is the days when I'm looking miserably at my scarred body, with bag attached, in the mirror that he puts his arms around me and tells me he loves me.

*That makes up for all the operations,
tears and distress.*

NEXT MEETING

Tues 5th December at 7pm

"Future of stoma care and irrigation"

by Mr Robin Philips, consultant surgeon
Medawar Room, level 6, St Marks



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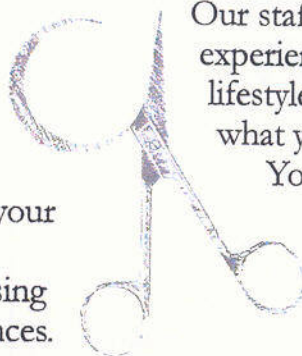
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**Want to join
the support group?**

If you have a colostomy, ileostomy or a urostomy and you would like more information, please complete the form below and send it to:

Clare Bossom c/o Stoma Care Department, St. Mark's & Northwick Park Hospital, Watford Road, Harrow, Middlesex, HA1 3UJ



Name _____

Address _____

Postcode _____

Telephone _____