

Coffee Mornings 2013

7th January	Monday	BBraun	Seminar Room 1	Level 6
22nd January	Tuesday	Independence Products	Seminar Room 8	Level 6
6th February	Wednesday	Oakmed	Seminar Room 3	Level 6
21st February	Thursday	Fittleworth	Post Grad Room	Level 5
8th March	Friday	Coloplast	Seminar Room 8	Level 6
18th March	Monday	Salts	Post Grad Room	Level 5
2nd April	Tuesday	OstoMart	Post Grad Room	Level 5
17th April	Wednesday	Dansac	Seminar Room 1	Level 6
2nd May	Thursday	Marlen	Post Grad Room	Level 5
17th May	Friday	Hollister	Seminar Room 1	Level 6
28th May	Tuesday	ConVatec	IFU Room	Level 9
11th June	Tuesday	CliniMed	Post Grad Room	Level 5
26th June	Wednesday	Oakmed	Post Grad Room	Level 5
11th July	Thursday	Suportx	Post Grad Room	Level 5
26th July	Friday	Fittleworth	Post Grad Room	Level 5
9th September	Monday	Coloplast	Post Grad Room	Level 5
24th September	Tuesday	ConVatec	Seminar Room 1	Level 6
9th October	Wednesday	Pelican	Out Patients	Level 3
24th October	Thursday	Dansac	IFU Room	Level 9
1st November	Friday	Hollister	Seminar Room 1	Level 6
11th November	Monday	CliniMed	Post Grad Room	Level 5
26th November	Tuesday	OstoMart/Salts	Post Grad Room	Level 5
11th December	Wednesday	Xmas Party	Post Grad Room	Level 5

Volume 8
Issue 3



STOMA SUPPORT GROUP WORKING WITH ST. MARK'S AND NORTHWICK PARK HOSPITAL
Incorporated with St. Mark's Hospital Foundation Charity Registration No. 1140930

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Merry Christmas Everyone

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National Association Crohn's & Colitis

Tel: 01727 830 038

Ostomy Lifestyle Helpline

Tel: 0800 731 4264

Stomawise

Tel: 01978 355 626

Urostomy Association

Tel: 0845 241 2159



Want to join the Support Group?

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

Name _____

Address _____

Postcode _____

Telephone _____

Annual membership subscription £5.00. Cheques payable to "St. Mark's Hospital Foundation"
Diane Owen, 170 Malvern Avenue, Harrow, Middlesex, HA2 9HD

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. Anyone acting upon them does so at their own risk. We recommend that you consult your stoma nurse or doctor before changing your procedures.

Fifty Sheds of Grey

The novel "Fifty Shades Of Grey" has seduced women - and baffled blokes. Now a spoof, 'Fifty Sheds Of Grey' offers a treat for the men. The book has author Colin Grey recounting his love encounters at the bottom of the garden. Here are some extracts...

We tried various positions - round the back, on the side, up against a wall... but in the end we came to the conclusion the bottom of the garden was the only place for a good shed.

She stood before me, trembling in my shed.
"I'm yours for the night," she gasped, "You can do whatever you want with me." So I took her to McDonalds.

She knelt before me on the shed floor and tugged gently at first, then harder until finally it came. I moaned with pleasure. Now for the other boot.

Ever since she read THAT book, I've had to buy all kinds of ropes, chains and shackles. She still manages to get into the shed, though.

"Put on this rubber suit and mask," I instructed, calmly. "Mmmm, kinky!" she purred.
"Yes," I said, "You can't be too careful with all that asbestos in the shed roof."

"I'm a very naughty girl," she said, biting her lip. "I need to be punished."
So I invited my mum to stay for the weekend.

"Harder!" she cried, gripping the shed workbench tightly. "Harder!"
"Okay," I said. "What's the gross national product of Nicaragua?"

I lay back exhausted, gazing happily out of the shed window.
Despite my concerns about my inexperience, my rhubarb had come up a treat.

"Are you sure you can take the pain?" she demanded, brandishing stilettos.
"I think so," I gulped. "Here we go, then," she said, and showed me the receipt.

"Hurt me!" she begged, raising her skirt as she bent over my workbench.
"Very well," I replied. "You've got fat ankles and no dress sense."

"Are you sure you want this?" I asked. "When I'm done, you won't be able to sit down for weeks." She nodded. "Okay," I said, putting the three-piece suite on eBay.

"Punish me!" she cried. "Make me suffer like only a real man can!"
"Very well," I replied, leaving the toilet seat up.

"Pleasure and pain can be experienced simultaneously," she said, gently massaging my back as we listened to her Lady Gaga CD



Q & A

Common Concerns

Q: I have been told that my stoma has retracted. What does that mean?

A: When the stoma is drawn or pulled back behind skin level. It can be either partial or complete. If it is problematic you may need to use a convex product or a seal to prevent leakage, sore skin and maintain confidence. You will need to visit your local stoma nurse for advice.



Q: I have a loop stoma. What does that mean?

A: A loop stoma consists of two ends: proximal and distal. The proximal end is the functioning end and the distal is the non-functioning end.



Q: I would like to take up sporting activities again, can you please advise me on how I can protect my stoma

A: OstoMart do a sports shield that is worn over the top of the stoma bag. Ensure that the shield is covering your stoma. This product is available on prescription



Do you have problems measuring your Stoma?

- Using a measuring guide, find the most suitable size of your Stoma
- This should be about 2-3mm bigger than your Stoma
- Measure a new Stoma at least once a week for up to 8 weeks after surgery



Introducing your new Chairman

Martin Morris



Hi all,

This is my opportunity to introduce myself to those of you who don't know who I am? I am Marty!

Over the next twelve months, I want to encourage more social activity amongst us members, but like many of you, I also don't want to keep talking about Stoma's or Illnesses or "How terrible I feel". No, instead I want to look at the POSITIVE side of life, what we CAN do, how we DO fit-in to ordinary life. (I know I have achieved far more in the last sixteen years, since having a Stoma, then I would ever have dreamed of prior to my operation! So if I can, you can too!).

But all this can't be done by one person, no, we all have to get involved, not full time, and not to the detriment of our other interests etc, but gone are the days where we can sit back and let others arrange everything for us, now is the time for all of us to act. We all have the opportunity to shape I.O.S.S.G. into an organisation which suits us all, where we can all benefit and fulfil each and every idea we all have.

I can be contacted by:

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By post: c/o Janice Ferrari
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Level 5, Watford Road
Harrow, HA1 3UJ

By phone: 07815 918 055

So with your support and encouragement we will all lead I.O.S.S.G. into a new era with a different slant on the words "Self-Help". Let's help each other to help ourselves.

I would like to see the idea of I.O.S.S.G. – as a self-help group – be rolled out nationwide, so as every hospital and every community in the UK will have a self-help Ostomy Group, with so many 'temporary' ostomy operations being performed, where new and existing Ostomists can go and talk with comfort, not feeling awkward or ashamed to ask questions of a personal nature. To be able to share experiences and receive understanding and support from people who have experienced their problems.

Marty

Why Me?

A story of TPN, a Fistula, a Transplant and a Stoma

By Jan Barnett

Continued from previous issue of Inside Out.

One of the biggest challenges was eating and drinking because of the regime I had to follow when I had my fistula, I was not meant to drink a lot (no more than 1ltr per day because it dehydrated me more than I already was) and I was used to eating without obstruction or pain (the 1st time in probably 14 years). Whereas with my new bowel and stoma I was told to drink around 3 litres per day and eat as much as possible which I found difficult due to the lack of appetite (hospital food and being dehydrated) and not being used to drinking (the fact that I had to drink Dioralyte, which is a powder used to replace lost electrolytes in the body and in my opinion tastes horrible) didn't help!

So my mum brought in food from home (200 mile round trip) or made some in the on-site hostel (provided very generously by Addenbrookes Hospital for patients or relatives of long stay patients) where she was staying, in order to get my appetite up as well as providing moral support. Because I was not eating a lot, I was put on a Nasal Gastric feed, which is a very uncomfortable and intrusive process and one of the best reasons to eat!! So on Boxing Day 2009 I found my appetite and started eating. With my legs slowly healing I started to get a little bit more mobile and started walking (after a few failed attempts) and that's when I knew I was getting better.

So my appetite came back and I was learning to help with putting dressings on my leg, to put on my Stoma bag which took a little while (a few weeks-a month to get almost right due to where it is and how thin I was.) and learning to walk again. Once I could make it on to the ground floor of the hospital and into the restaurant I was set and started going down for breakfast on a regular basis. Whilst down there I watched the patients, relatives and staff and when you see what other patients had to deal with and to see a child hooked up to so many machines that they probably weighed more than they did, just made me think how lucky I am, as well as reminding me of how I was in a similar looking position at 8 years old and that I made it through that, just as I am this.

Well after 3 months, 2/3 operations and a lot of learning, pain, determination and superb care from the incredible Nurses, Doctors, Surgeons and all the other people involved, I finally escaped...sorry, got discharged to go home and that's where the real recovering started again...

I had to get used to taking the medication on my own as well as get it all ready (my medication consists of 50-60 tablets per day) as well as supplements and Dioralyte, (yes I still have to drink that, but luckily I found out that I can mix it with sugar free squash so it tastes much better, so much so that I can't stop drinking it). And then there's the Stoma equipment which I'm sure you know all about.



Me enjoying a sneaky Guinness in a London pub in 2009

A day in my life as a person with a Fistula and on TPN:

By Jan Barnett

Between 7 and 10 am:

Get up and take down my TPN when it's finished, which took around 30+ minutes or put up another bag of fluids (mostly Saline to keep me better hydrated as drinking anything would only dehydrate me more) this would run over 4 hours and sometimes even longer.

On rare occasions I would be 'hooked up' to fluids for 23 hours and spending 1 hour taking down and putting up my TPN and Saline. Once the TPN was taken down, I was a 'free man' and went to have a wash and then came breakfast (which went from getting up, till almost going to bed). Now for someone with no intestines, I sure ate a lot because for the first time in my life, I could just eat without discomfort or pain and being a 'retired' chef, I was cooking none stop. But sadly I was not getting any nourishment from it.

Between 11 and 12 Noon:

If I could tear me myself away from the food and TV and have the energy, I would maybe go for a walk to take some photos or take the bus somewhere, and just try to sit as comfortably as my body would allow and not for too long or travel too far.

I was restricted by my energy and the Fistula bag because if the bag leaked I couldn't change it till I got home, so I would always have my phone with me to call mum or someone to come and get me.

2pm:

I would be back home by now exhausted if I had gone out. If I had stayed in I'd either be sitting in my massage chair as I could not sit on a sofa or normal arm chair because of discomfort and the size and stiffness of the bag.

Rest of day was either spent watching TV or chatting with friends on Facebook. Now Facebook can be either a real blessing in that it allows you to keep in touch with friends all around the world, so you never feel alone, or it can be an absolute curse because you'd be on it all day. Also you can see how everyone is living their lives, doing the things you wish you could do or being in places you wish you could go to if only you were not in the situation you were in. Don't get me wrong, I'm always happy that my friends have happy and successful lives and relationships, it's just that I wished I could be in the same situation.

4pm:

Take 4 litres of TPN out of fridge and lay it flat on the dressings trolley to get up to room temperature.

7pm:

Grab a quick shower, try to stop eating, put my TPN up and then it's time for changing my Fistula bag (which could take anything from 2 to 4+ hours depending on how badly the skin was burned from leaks).

I manage to surf the net, chat on MSN and Facebook as well as watch a movie and all while suctioning my wound (could be why it took so long!). Who says men can't multi-task?! Beat that ladies!

Between 10 and 11pm:

Time to go to sleep, just night drainage bag and I'm ready.

As with my Stoma bag, I need to get up a couple of times in the night to use the toilet, bound to happen when you have 4 to 4½ litres pumped into you over night.

A day in my life as a Small Bowel Transplant recipient with a Stoma

By Jan Barnett

8 am: Take my morning medications, then shower, change my Stoma bag and then breakfast which 9 times out of 10 is porridge with sugar and supplements of protein and glucose for a little more energy.

11 am: Time for my Immune suppressants only 2 tablets

1pm: Lunch time mostly consisting of pasta or potato if at home time for my lunch meds, 10 tablets

3pm: Another 2 tablets

6pm: Dinner time 16 tablets. This is the time I really eat, especially if I've been out since lunch. I pretty much keep eating till I go to bed. I know what you might be thinking, 'not the best thing to do before going to bed', but I'm always very hungry around this time.

Between 10 and 11pm: Time to go to sleep, just night drainage bag and I'm ready.

Between 11 and 12 pm: 13 tablets and then off to bed after a shower. If I'm lucky, I only need to get up once in the night. Then 8am rolls around and another day starts. Depending on how I feel and how much energy I have, I go out during the day, to visit friends, shopping or just drive somewhere for lunch or look around and of course go to the 'Inside Out' coffee mornings. I have to think about what I need to do every day and plan how to get the best out of every week, so I try to plan days of rest between appointments or going out as my body tires quite quickly. But I'm a stubborn little so and so and always try to push myself as much as possible,

Most of my time is spent going to medical appointments either local (Surrey), St Mark's or even Cambridge. They range from blood tests to an Ileoscopy to make sure there are no signs of organ rejection, right up to psychotherapy sessions and many things in between.

In December 2010 I bought my first pet in 20 years... a Bearded Dragon called Hannibal (the Cannibal) named after a character from a book and film. Now considering I am immune suppressed, a reptile may not have been the best choice, but I haven't had an infection from him yet. Considering he can't speak, (in fact he doesn't make a sound), Hannibal makes a great pet and companion because he's the perfect size to hold, and contrary to belief he's got a soft warm side to him, as well as making me smile. I've always had a certain liking for reptiles and think they get a really bad reputation because of the lack of understanding and representation in books and stories. But if you get to know and understand them, they're just as much fun as other pets. I love my little guy and prefer him over other animals. How can you not like that little face???



I couldn't finish this little snippet of my life's story without thanking everyone in the NHS who has looked after me and has helped in my operations, care and recovery. In particular Dr Simon Gabe who is a phenomenal man and Dr, Dr Steve Middleton, his team and Andrew Butler at Addenbrookes Hospital, Sarah, Abigail and Hilary in the Stoma Department at St Peter's Hospital, Chertsey, you'll always be my 3 angels). All the nurses who do such an amazing and difficult job looking after all of us and make us as comfortable as possible; they are all true angels in uniforms!

Thank you once again to my Donor's family and friends for making a very difficult decision and honouring his/hers. Hope he/she had a long and happy life. And a very big thank you goes out to my family and friends, who have put up with me through thick and thin and for their support through not only the last 3 1/2 years but also my whole life. I love you all! (Even though I don't say it enough). And last but by no way least, Bob for encouraging me to write this and of course you dear reader for reading it! If you have any questions or would like to know more about transplants or would like any advice, please don't hesitate in contacting me at: the_underdog1978@hotmail.com

In the last 3 years I've been on a roller coaster with highs and lows. I've managed to finally do my driving licence and even passed 1st time (I almost said "Are you mad" to the driving examiner) which has helped me a great deal. I sadly also have lows such as the side effects of the medication. But I now have a Stoma and I'm very happy and grateful for it because I have more freedom to get out and do things, I can still remember my 1st bag change in a bar in Kingston (something impossible to do with a fistula bag). I can change a bag in 4 minutes instead of 4 hours now. I now can get nutrients from my food instead of a 4 litre bag of TPN (it took me a long time to realise this, unbelievable! When I came out of hospital after my 1st 3 operations in 2008 I started taking photos nearly every day when I could, mostly of the things I saw or did, just nature and the world around me and I thought to myself how lucky I am to be able to walk, see the sun rise and set, hear my music and taste food (and Guinness).

I'd like to just take a few minutes to thank a very special person and that's my Donor without whom I would not be alive today. I don't know who my donor was nor have I yet written to thank their family and friends, not sure why I haven't written yet, partially because I've been concentrating on getting better, I'm scared to open up old wounds for their family and friends, I don't really know why, but I know this, it's NOT because I'm not grateful, because I am eternally grateful for them deciding to do the most selfless act anyone can ever do, which was to give life after their death and by doing so live on with in me. I made a promise to never smoke again nor drink like I used to, when you're given a second chance at life you should respect it. My family and friends are also very grateful to my Donor, their family and friends because they have their son, brother, grandson and maybe one day father and grandfather back. I hope I too can be a Donor one day, as I would like to donate my eyes so the someone else see many more sunsets through my eyes after I am gone.

Becoming a Donor is one of the best decisions anyone can make and telling their family and friends is another, because if they don't know of your wishes they may not give the Doctors permission! 1 Donor has the potential of saving up to 7+ people's lives and change so many more for the better. So please sign up to a Donor card, tell your family and friends and give others the greatest gift. The Gift of LIFE!

You can join the NHS Organ Donor Register by:

Filling in a form online: <http://www.organdonation.nhs.uk>

Calling the NHS Donor Line: 0300 123 23 23

(Lines are open 24 hours a day all year round. Calls are charged at your contracted rate for local calls)

By texting: SAVE to 84118

You can also join when you are:

Registering for a driving licence

Applying for a Boots Advantage card

Registering at a GP surgery

Registering for a European Health Insurance card (EHIC)

Sign Up, Speak Up and Save Lives!

Currently in the UK, 3 people die every day waiting for a transplant. Let's change that statistic to 0. I would like to take this opportunity to give some advice to anyone faced with needing a transplant and that is to ask as many questions as possible beforehand, write them down and do plenty of research. Find out about the possible side effects of the medication, ask how many tablets you may need to take, ask how often you might need to go to hospital for tests. Prepare yourself as best as you can. Transplants are amazing, life saving operations but they are also life changing, so prepare yourselves for them.

As you have read, earlier my transplant happened very quickly from the moment I decided to have it to the actual transplant and I'm very lucky and grateful that it did, but in hindsight I wish I would have asked so many more questions and done more research, so I could have really prepared myself for what would happen, such as the medication, the side effects, the skin grafts and the recovery. Everyone is different, every organ is different and so is every transplant, I can only tell you about my experience and about my transplant.

Whatever transplant you might need I hope it happens as soon as possible for you and that you are prepared as well as you possibly can be, both physically and psychologically. Good Luck!!

Editor's Review

OUR Open/Information Day was a great success, between 60 & 80 attended the Ostomy Lifestyle Workshop on the different types of Stomas, using their apron to demonstrate, the positions and the reasons why certain Stomas were used for specific illnesses. This was followed up by a Q & A session.



After lunch our speakers were Mr Ian Jenkins, Colorectal & Laparoscopic Consultant and Dr Yoram Inspector, Clinical Psychologist, both based at St Mark's Hospital.

Mr Ian Jenkins talk was titled "To Infinity..... and Beyond". Mr Jenkins described how things had changed throughout the year, both in surgery and also with St Mark's and its history.

Dr Yoram Inspector's talk was titled "How does it feel to have your insides out", psychological aspects of living with a Stoma. This proved to be funny and of great interest to many Stoma patients.

All those that attended had a very enjoyable day, where they met up with old friends and saw new products and were able to improve their knowledge to be able to move forward with their lives. My thanks to all who were involved in putting the event together.

Relay for Life which was held on the 7th of September at the Bannisters Sports Track, was a great success and the day was very compact with various events throughout the day and the weather was fantastic.



There were a number of stands and ours was one of them and we were next to the tunnel, I was going to say love, but we were actually next to the tunnel or piece of bowel which showed the different diseases we may suffer during a life time.

We were asked to explain things which Sarah our Community Stoma Care Nurse did a sterling job. The rest of us, Bernie, Cliff, Arthur and the two Andrew's did a fantastic backup.

Finally, I was invited to attend the World Council of Enterostomal Therapist (WCET UK), in Edinburgh, where I gave a power point presentation on the results of our survey, which you kindly participated in just over a year ago. It was very apt as the main theme was on support groups and how they will be part of the new NHS and its future.

Bob

It's beginning to look a lot like Christmas!

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✂-----

We have a range of information sheets available, please tick the relevant boxes and we will post them to you.

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