

Winter 2019 Issue 6



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



in the Making!



Around the end of October beginning of November 1999, I myself had just been going through a very rough time I had just about recovered from having urgent surgery where they had taken 18 centimetres of gangrene from my intestines due to a twisted gut. (I had had a colostomy since I was 3 months old and much later I had to have a urostomy due to perforations in the base of the bladder.) My surgeons, yes two, because at the time of the operation I had two stomas, one was Mr Christopher Ogden, urologist and the other was Mr John Northover, gastrologist. Between them they worked a miracle and saved my life. This operation just added to my self-pity, for a few years I had been very down on myself. The urostomy was supposed to be temporary.



Well you can imagine my anger after I found I had a hernia. You know what it is like when you are told 'well its temporary' and you automatically put your life on hold. You say to yourself 'its ok' I do not have to deal with this now as it is going to go away. Wrong. It's like I am having a bad hair



day, or I am having a bad dream and I will wake up soon and it would all be over. It is not just a British thing; it is the same the world over. We go around with that stiff upper lip approach to life and harden ourselves create a shell that cannot be penetrated by anyone even our close family. Why, because we do not want to be seen hurting inside especially men. We are head of the family, or we think we are; we know really it's the ladies of the household that keep things together.



Where this is going, you may ask. Well I was approached by Claire Bossom, the Community Stoma Care Nurse, if I would consider starting up a support group and to think about it while she spoke with her boss Celia Myers on whether or not it was feasible.

I, on the other hand, had to do some thinking. What could I bring to the table, what was a support group supposed to do, could I see myself being of much help to others especially as I was not able to get myself up and running. Clare was sure but Celia had doubts at first. We had long discussions. The first thing we decided on was that it would cover all forms of stomas: urostomy, colostomy and ileostomy as well as pouches

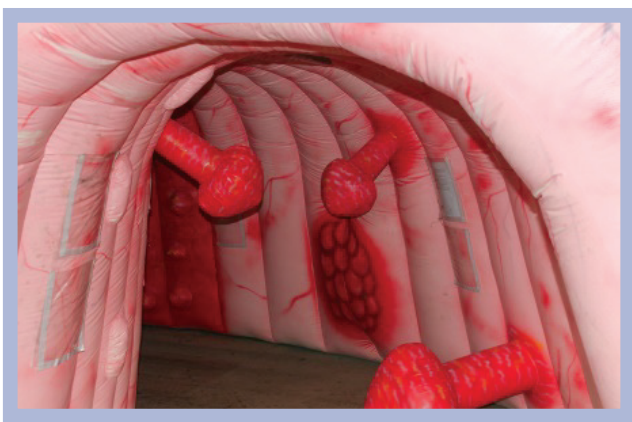
(and anything else that may come along in the future). This was agreed and I went to work with inviting people with stomas to come for a coffee and chat, I then put the invitations into envelopes and handed them to Clare.

Due to the data protection laws I was not able to know who they were sending them out too. So now we sat and waited to see if we had any bites to our invitations. Meanwhile I was asked if I would chat with Barry. We both had two stomas and because we had one on either side of our bodies I said at least we can stand up straight. That cracked the ice. We were in a special club as not many ostomists had two stomas to brag about.

Talking to Barry brought back memories of when even at the age of eight years of age I was being asked when I was in hospital to talk to new patients about what it was like having a stoma and what difference it was going to make. I can remember one old gentleman who had been through both wars and had only one eye was asking me about whether he could ever eat his lovely tomatoes he grew. In those days you were told that eating anything other than bland food and nothing with seeds etc.. Well I was eating everything even then, so I said that it is a matter of trial and error. If you loved



something so much you should try a little at a time and allow your body to reengaged itself to what you used to eat by eating small portions, building up the tolerance level. It is as true today as it was back then, especially those who love spicy food or fruit. Those of you who have just had a stoma do carry on eating what you had before. Yes, it may go through you like a dose of salts at first but persevere, as why deprive yourselves of something you enjoyed eating before, life is too short!



Getting back to talking and thinking over what Clare and Celia wanted me to do. It felt like it was the right thing to do. I suggested to Barry that he joined me to start this group off; he should come along to the first of the meetings and we would see what happens from there. Our first meeting took place in the treatment room of the Stoma Care Department on the 3rd floor of St Mark's. We had two people come along at the first try and even then it was a little cramped but we managed. We talked about problems people were having and because I had had a stoma for a long time I passed on my experiences of how I managed the problem, suggesting how they might try it at home to see how it went and if it resolved

the problem. At the next meeting we had a couple more people turn up, so now we were gathering momentum, but we could not go on meeting in the treatment room as there was very little room to move. Barry and I approached Clare and Celia to see if there was somewhere else we could meet up. They made some enquires and asked us if we would mind meeting in the evening. Barry and I thought why not try and see what happens. We moved up to the Medawar on the 6th floor, this was luxury we had so much space: tables, chairs and a counter where we could make tea and coffee. We were growing quite fast; talking about stomas but we moved on to other items: gardening, dancing, getting on with life.

During those first meetings I was introduced to one of our company reps who came from Convatec, their offices were in Ickenham. I was invited along to meet up with the help desk people who answered the phones. While I was there I noticed that they were renewing some of their computers. Being cheeky I asked what they were going to do with the old ones and could we have one of their old ones. Well you know the saying if you don't ask you don't get. You could have knocked me down with a feather when they agreed. I went back a couple of days later to pick one up. I didn't know how to use it



but we could learn, not knowing where was I going to put it or how to use it? So yes please and thank you and I left with a big smile on my face.



It so happened that the government was having a drive on getting the older generation up to speed on using computers. Barry and I signed up and after 10 weeks we were top of the class and walked away with our certificates. Now, we had the skills to create mayhem! We were able to word process and do data bases and even send an email, but to whom.

As they say 'from little acorns do big oak trees grow'. Our evening meetings began to swell; our reputation of helping others to come to terms with having a stoma was gaining momentum. This one particular evening we decided we needed to have a name for our group. A few names came up "Bags Aloud", "Bottoms Up" etc. then someone said why not "Inside Out" and everyone thought this was great. That's what we started to call ourselves.

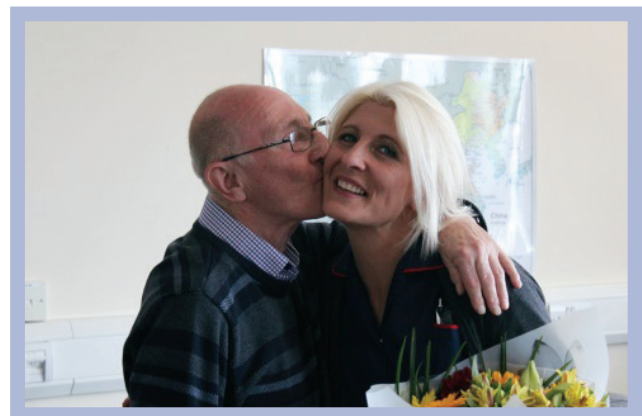
Now with all our training in computers Barry and I thought we needed to create a newsletter about what our group gets up

to. We put it around the hospital to see if we can get a few more people to join us. By this time I was able to ask Coloplast if they could donate a printer so that we could at least print out our newsletter. Our first attempt was black and white; it talked about an event that was put on by Celia and Clare, Happy Clappy Day, a fashion show. Respond Plus provided the clothes for us to wear and show that having a stoma was not preventing people from wearing fashionable clothing.

Councillor Bob Currie, the Mayor of Harrow, came. He went away with one of the biggest smiles on his face and always talked about that day whenever I met him. Why? As both Barry and I did a striptease in front of everyone to the music of the stripper. Not completely, we did stop at our speedos and let the bags do the talking.

Sue took on the role of editor for the newsletter from then on as she had more experience with computers and putting things together. The company she worked for did graphic design and allowed her to print off the newsletter at work, which now had grown to 2 A4 sides.

In March 2000 a representative from Convatec mentioned that if we approached



Fittleworths, one of the supply companies, they may produce our newsletter for us and print it off for free. Now who could refuse an offer like that, I could not. So, I phoned them and asked. And, behold, they have from that day on continued to print off our newsletter in colour, still free of charge, to which I thank them dearly. Through them we have been able to bring important information to those who are unable to attend our coffee mornings. We have become so technically minded now that you can get our newsletter by email or on paper (for those like me who prefer a paper version).



In those early days, we started to invite speakers to come along to our coffee mornings to talk to us about things that could, or possibly in the future may, influence our quality of life. I remember one meeting inviting a stoma care nurse from a different hospital. Tracy was and still is a specialist nurse who also deals with sexual matters. I invited her to talk to us. There we were sitting around a table, after I introduced her Tracy said that she was going to talk about sex. If you could have seen the member's faces, it was a picture. This is not a subject matter that is not spoken about openly; what we were trying to get across was just because

we have stomas it does not mean everything stops, even if you are not of youthful age.

We then and still are run on a shoestring. It is not for the purpose Inside Out in making money that our group was formed; it is because we are there to support those who need our support at the time when they need it. There is always someone who has already experienced what you are going through and if there is not, we then go out and find the answer for you, so that you may continue to have that quality of life that you are entitled to.

We asked members if they could afford the sum of five pounds a year towards the group's expenditures and we still charge the same today. We manage to get by, by asking our fantastic manufacturers if they could help us by providing x y z and if it is possible they come up trumps. We hold open information days where we charge our manufacturers one hundred pounds to put up a stall and this helps to pay for the food and drinks we provide on the day and keeps us going for the rest of the year (or two). We keep our expenses down because of our committee and volunteers do not take any money for what they do, to keep the group going. Our website is sponsored by CL Support; I have known Alex and Harvey for many years and



have kept me technically out of trouble. With their guidance we were able to put in free Wi-Fi into St. Mark's wards so that patients could phone or email family and friends, or they could stream down films or music.



We have come a long way from our humble beginnings to what we are today and have over the twenty years helped many people one way or another. I am very proud to have been a part of it, it helped me as well as it helped you. I got through my crisis moment as I was involved in helping others through theirs.

Over the years I have noticed that there is a lack of psychological support for stoma patients, Nine times out of ten it is missed that a patient and their family need deeper help to get through their crisis. Because it takes so long to get an appointment with a psychologist after you have left hospital, this is where our group is the next best thing to sliced bread. As we encourage you to venture out, talk with others in an environment that is comfortable and meet up with others in the same situation. You can see and hear about other products. Sometimes you get to hear a speaker on subjects that matter to you or that have been worrying you. Surgeons come and explain the procedures they have

performed and what has changed, from open surgery to laparoscopic to robotic, temporary stomas and internal pouches.

We have come a long way in medical terms since my day 71 years ago when I had my colostomy. There were no appliances for children, no stoma care nurses and no support groups; this has all changed for the good, plus now there is no stigma to having a stoma. You are the same person as you were before you had your operation.

As for me, I have deemed it an honour and a privilege to have been your chairman and then your president, I have enjoyed every second of it. It is now time for me to step away and let others take the reign to continue ensuring the support is there for others. I will be more involved with the politics and fighting for ostomists where ever I can. I have been invited to join a few committees where I feel I can make a difference and be a voice for all ostomists so that they can have a better quality of life. That does not mean I will not drop into one of the coffee mornings to see how everything is going. I have passed everything that I have gathered through the time on to Diane. I am sure Barry, with the rest of the committee, will endeavour to keep Inside Out Stoma Support Group going for another twenty years.



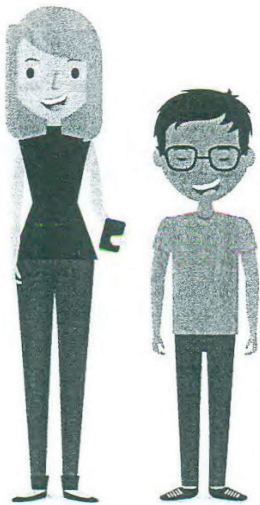


Putting **patients**
at the **HEART**
of everything we do

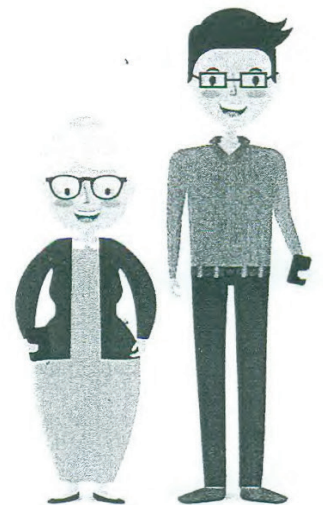


London North West
University Healthcare
NHS Trust

NHS WiFi Zone



For visitors and patients:
Look for 'NHS Wi-Fi'
on your device and
register for free



#letsgetdigITal

digITal services
Digitise
Enable
Share
Inform
Transform

Framed

An old gentleman, whose name was Anil, thought his eyesight was deteriorating, so he decided to go to see an optometrist and have them tested.



Corinne, the optometrist, speaks to Anil, saying, 'All right, let's check you out. You sit down here on this stool. You put your right hand over your right eye and read that chart on the wall over there.'

Anil puts his left hand over his left eye. The optometrist says, 'No, no, no. Put your right hand over your right eye.'

Poor old Anil puts both hands over both eyes. Corinne is, by now, becoming annoyed.

Anil continues to do things badly and Corinne becomes angry and says, 'All right, I'll fix you!' she mutters. She takes a paper bag out of the cupboard, cuts one hole in it, puts it over Anil's head, and demands, 'Now, read that chart!'

Anil reads it perfectly. The optometrist takes the bag off, and Anil begins to cry like a baby. Corinne then barks, 'Now, what's the matter with you?'

'Well,' sobbed Anil, 'when I first came in here, I had my heart set on wire frames.'

An Ear Full - Or Not?

Hazel went to her family physician with her crying baby. Doctor Cassidy diagnosed right away that the baby had an earache and he wrote a prescription for ear drops. In the directions he wrote, 'Put two drops in right ear every four hours', and he abbreviated "right" as an R with a circle around it.

Hazel returned to the doctor after several days and complained that the baby still had an earache, but his bottom was getting really greasy with all those drops of oil.

Dr Cassidy was amazed and looked at the bottle of ear drops and realized immediately what had gone wrong. The Pharmacist had typed the following instructions on the label: 'Put two drops in R ear every four hours.'

New Will to Live

An elderly gentleman named Morris had had considerable hearing problems for a number of years. Naturally, Morris went to his doctor and the doctor was able to have him fitted for a set of hearing aids that enabled Morris to hear perfectly.

Morris returned in a month to the doctor for his check up and was told, 'Morris, your hearing is perfect. Your family must be really pleased that you can hear again.'

Morris grinned, 'Oh, I haven't told my family yet. I just sit around and listen to the conversations. I've changed my will three times, already.'



Want to join our Support Group?

If you have a colostomy, ileostomy or urostomy and you would like more information, please complete the section below and send to: Diane Owen, Vice Chairman/Secretary, 170 Malvern Avenue, Harrow, Middlesex HA2 9HD



Name:

Address:

..... Postcode:

Telephone:

Email Address:

Newsletter:

Please confirm below how you would prefer to receive the Inside Out newsletter.

Electronically via the email address above

By post to the address above

I do not wish to receive a newsletter

Annual Membership Subscription: £5.00, please make cheques payable to: St Mark's Hospital Foundation a/c 101
Send to: Diane Owen, Vice Chairman/Secretary, 170 Malvern Avenue, Harrow, Middlesex, HA2 9HD

Useful Contacts

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Our support materials include



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advice and support for older age
Independent Age

Expert advice from a registered health expert, with a focus on tackling loneliness.
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Reconnecting with People Guide

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Loneliness Podcast Series
Reconnecting with people

In Good Company podcast

If you're feeling lonely
How to stay connected in older age

Independent Age

Independent Age Loneliness Guide



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IOSSG COFFEE MORNINGS

for 2020



DATE	VENUE	COMPANY
Jan: Monday 6 th	TBC	TBC
Jan: Tuesday 21 st	TBC	TBC
Feb: Wednesday 5 th	TBC	TBC
Feb: Thursday 20 th	TBC	TBC
Mar: Friday 6 th	TBC	TBC
Mar: Monday 23 rd	TBC	TBC
Apr: Tuesday 7 th	TBC	TBC
Apr: Wednesday 22 nd	TBC	TBC
May: Thursday 7 th	TBC	TBC
May: Friday 22 nd	TBC	TBC
Jun: Monday 8 th	TBC	TBC
Jun: Tuesday 23 rd	TBC	TBC
Holiday	Holiday	Holiday
Sep: Monday 7 th	TBC	TBC
Sep: Tuesday 22 nd	TBC	TBC
Oct: Wednesday 7 th	TBC	TBC
Oct: Thursday 22 nd	TBC	TBC
Nov: Friday 6 th	TBC	TBC
Nov: Monday 17 th	TBC	TBC
Dec: Tuesday 1 st	TBC	TBC
Dec: Wednesday 9 th	AGM	Xmas Party

Coffee Mornings for 2019

Nov: Tuesday 19 th	TBC	CliniMed
Dec: Wednesday 4 th	TBC	CUI
Dec: Tuesday 10 th	Post Grad Lev 5	AGM / Xmas Party