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Ileostomy & Internal Pouch Support Group
0800 018 4724

NACC
01727 830 038

Urostomy Association
0845 2412 159

The Colostomy Association
0800 587 6744

CUI Wear
Underwear + Swimwear for ostomists
0800 279 2050 Quote Ref IOU256



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

Name

Address

Postcode Telephone



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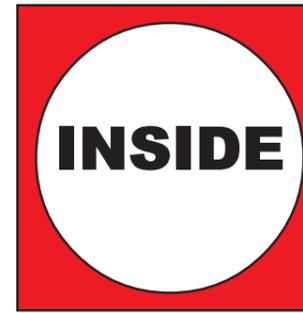
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**Summer 2007
NEWSLETTER
Volume 3 Issue 5**

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, I have been hearing from a number of you who have not been too well just lately. Many of you have had your stoma for a while and yes I have been one of those who have been through the mill. We all go through periods in our life when our bodies seem to drain us for one reason or another. We take our medication, as requested. Sometimes it hits the nail on the head, other times we feel like guinea pigs. It seems no one is quite sure what the problem is. I have, through the years learnt to listen to my body, you know when things are about to happen, you have had the warning signs before. It could be an ache above your kidneys or feeling drained. Go straight to your GP and ask to be checked over. Remember, you know your body better than anyone else and drink plenty of fluids especially now that the warmer weather is upon us.

Now, Sarah Varma, one of our stoma care nurses, who most of you know, is participating in the British 10Km London Run on the 1st July 2007. Monies raised from this event will be donated to the Inside Out Group to help us to be able to continue to provide support to those who need it. You can make a donation either through her web site www.justgiving.com/sarahvarma or by sending it to Miss Zoe Huntingford, c/o St Marks Hospital Foundation, Level 5, St Marks & Northwickpark Hospital, Watford Road, Harrow, Middlesex HA1 3UJ. We are all behind you and willing you on. Many Thanks!

This year Cancer Research UK Relay for Life Harrow will be held at the Bannister Sports Centre on the weekend of 8/9 September. Last year was an inspirational and uplifting experience and we are hoping to make this year even better. If any of you would be interested in getting involved with the event then please email Gill Moss, relayforlifeharrow@london.com or tel: 07976 33 9898 to let her know you are going to be there on the day or if you can be of help on the day.

Finally, **Remember, Remember the 2nd of June. Open/Information Day.**

Kind regards to you all
Bob
Chairman, Inside Out

Dear 'Inside Outers'

It's that time again when I'm expected to produce some apt and meaningful words to you all.

Mostly, I leave this to our respected and indomitable chairman.

I am sure the weather that we are experiencing at this moment in time must help those of you who are feeling under the weather for one reason or another. Sunshine is as good as any tonic! Hopefully, when this newsletter comes out, we will be experiencing similar weather.

Bob has reminded you of our 'Open Day' on the 2 June 2007 at St. Mark's Hospital, in the Himsworth Hall (6th floor), 10.15am to 4.00pm. Use St. Mark's car park, pay the minimum charge, and then use the door in the corner. The lift, on the left, will take you to the 6th floor and the Himsworth Hall. Once you have arrived ask for a ticket that will enable you to park all day at no extra charge. This of course means that you will now have to make your way back down to the car park to display this ticket before you come back up for your cup of tea/coffee!

Membership fees. Our membership fee is only £5.00. This does not cover the cost of our Open Day and the postage for your newsletters. It would really be a great help if you would let me have your membership before June 2nd. It would even be 'greater' if you would set up a direct debit, forms from me at the reception desk.

If all members had paid their membership then Sarah Varma (our Stoma nurse) would not have to run in the 10Km London Run to boost our finances, though I'm sure that she enjoys all the hard work involved in getting fit! Have you sponsored her? Any cheques sent for this and/or membership should be made payable to 'St. Mark's Foundation (Inside Out)'

I will be with you on the 2nd June but I'm not sure what state I'll be in, because the day before I return from taking part in a sponsored walk for St. Luke's Hospice in the Wicklow Way, south-east Ireland. I aim to walk 50miles in 5 days – maybe not a lot for some of you but it will have taken me a lot of time and effort to get fit enough to complete this walk.

Looking forward to meeting you on the 2nd June. I know distance is a problem for some of you but for those nearer it is really worth making the effort, ask anyone who has attended in the past.

Keep well

**Diane Owen -
Secretary/Treasurer**



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.

Thursday 7th June

Monday 18th June

Tuesday 3rd July

Wednesday 18th July

Monday 3rd September

Tuesday 18th September

Wednesday 3rd October

There are no meetings in August due to holidays



Editor's Page

I'd like to start my extract by wishing Joan and Henry our brilliant and recent editors better health this year, sentiments which I know are echoed by you all. Their contributions to the Newsletters have been fantastic and I hope fervently that I can in some way replicate their skills and insight.

Eleven years ago when I received my ileostomy (permanent - out of choice) I don't remember anyone coming to see me while I was recovering and chatting to me about what I could or should eat with an ileostomy. Probably, they did and I was too drowsy to pay attention, however, for me that meant that when I returned home I carried on with the diet that I had enjoyed prior to the wretched UC. Quite simply, a very varied diet with lots of fruit, salads, vegetables, meat and fish and cereals, not forgetting some delicious wine and champagne. It also helps in that my hobby is cooking so I have every incentive to eat what I have taken time and energy to prepare. I realise now that I am one of the lucky ones in this respect and maybe I should not tempt fate, but I can honestly say that my stoma appears to cope with everything I ask it to deal with.

Sadly, I am well aware that for some of you that isn't the case. Particularly, I learn that fruit can cause quite severe watery output. We are told that apples can aid this by bulking up the system and so I thought that since this would seem to be positive I would share with you the following recipe that I regularly enjoy.

Jablka po Królewsku Apples in Royal Mood

Serves 6

This recipe is the work of Karol Zych who 30 years ago was the head chef at Cracow's restaurant, Staropolska. It can be an exotic sweet dish but it makes use of basic inexpensive fruits.



6 dessert apples
250 ml (1/2 pt) water
200 g (8 oz) sugar
Juice of one large lemon
6 thick slices of peeled orange

Decoration - Any different fruit such as kiwi, peaches, apricots or pineapple

Peel and core the apples. Poach gently until tender in sugar syrup made from water and sugar with lemon juice added. Keep pan covered.

Transfer cooked apples with syrup to dish. Cover and chill.

Before serving as a dessert, place slices of oranges on small plates and put apples on top. Fill apples with ice cream, crème fraiche or whipped cream and decorate with other fruit. Pass syrup separately.

I often enjoy this for breakfast when instead of cream I fill the centre of the apple with fresh yoghurt. Contrary to popular belief, Polish food is *not* heavy, can often be a joy to behold and a palatable pleasure. It is a little ornate, even flamboyant perhaps, but it is always good, always pure and, most important, always edible. Also, dear readers this is quick and simple to make – enjoy!

Your News - Your Views

We do receive letters at the Inside Out Group from people who for many reasons wish to share their experiences both good and not so good. It is always lovely to hear from you and we will always do our very best to print your news and comments. The doctors' and surgeons' articles have of late been very full and informative, which is just what we want, that does mean however, that there may not always be space for all the things we would like to include, so patience is the byword.

In this issue I am very happy to include a letter which will certainly inspire us all.

Mrs Sheila Baker wrote to St Mark's Hospital. They passed her letter on to the Inside Out Newsletter. We thought that more recent patients would find it very interesting and comforting. Those of us who have been St Mark's patients from years ago endorse her sentiments.

"I am writing to St Mark's as I was a patient of yours many, many years ago when the hospital was in the City Road, London, and have for so many reasons to be grateful for the care I had there, and thought it would help other people in your care now."

"I had ulcerative colitis in its severest form and had an ileostomy performed in March 1956 at the Memorial Hospital, Woolwich, by St Mark's surgeon, HE Lockhart-Mummery, and afterwards made permanent at the City Road site in 1958, also by the same surgeon."

"It might help another person to know that at nearly 70 I have had a very full and happy life, a 50 year marriage, two beautiful children and am a grandmother to five. My husband and I have travelled the world, and my own working life except when my children were small was 15 years as a swimming and coaching instructor, and 20 years as a carer of young people with learning difficulties. I competed at swimming, running and shooting until I was 58 years old!!!!"

"An ostomy is not the end of life, I am proof of that, and as I approach my 50th 'anniversary' with an ostomy, I just thought I would let St Mark's know!"



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 entirely at their own risk. We recommend that you consult your stoma nurse or doctor before changing your procedures.

Dietary Advice for those with Ileostomy / Colostomy

Holidays are upon us and for some of you it will be the first time you have been away from home with a stoma. It is only natural to feel a little apprehensive, but remember that all the benefits a holiday entails such as fresh air, sunshine (hopefully) and different foods far outweigh any anxious thoughts. When you return home you will feel less stressed, healthy and so pleased with yourself that you have found the confidence to venture away from home after surgery.



As an aide-memoire the following dietary advice for those of us with ileostomies/colostomies is invaluable.

Trial and error is the order of the day. Certain foods which may cause problems initially may be tolerated at a later date. Do not be

afraid to re-test foods. Be adventurous!

It is important to eat as varied a diet as possible in order to maintain health, being too restrictive with what you eat may lead to nutritional deficiencies and almost certainly to boredom.

For the first two weeks...

You may be advised to follow a low fibre diet i.e. Avoid or eat in moderation fruit, vegetables and wholegrain products.

After the initial two weeks...

It is very important that you follow a normal diet.

- Increase your fibre intake, try wholemeal bread (avoid those with seeds).
- Try digestive biscuits, whole-wheat/rye crackers and crisp breads, bran biscuits, try baking with wholemeal flour.
- Select a greater variety of fruit and vegetables, aim for those in season. It may be necessary in some cases to peel them.
- Avoid or be wary of seeds, pips and nuts (ileostomists only).
- Eat regularly.
- Introduce new foods one at a time so that you can identify those which may cause a problem.
- Chew the food well.
- Try to keep to your ideal weight



Fluid Intake

Be sure to drink ample fluids – at least 2 pints of liquid a day. For ileostomists, because you are losing a lot of fluids and salts make sure you drink plenty and add salt to your foods to avoid dehydration. This is especially important in hot weather.

If you think you are dehydrated drink a glass of coke and eat a packet of salted crisps (I can promise you this works quickly) or you can make the following drink.

1 litre of water
2.5gm of sodium bicarbonate
3.5 gm salt (cooking variety)
20.0gm glucose

Mix these together, add flavouring, for example, orange juice, keep in the fridge and drink throughout the day if necessary.

Problems which may arise and how to deal with them

Wind – certain types of food may cause wind: sprouts, peas, cauliflower, baked beans. So, eat slowly, chew food well with mouth closed – don't gulp air. Washing down food with a drink can sometimes cause wind – especially fizzy drinks.

Constipation – this can occasionally cause some problems and there are one or two simple remedies to try before seeking further help.

- Increase fresh fruit and/or fresh fruit juice, vegetables and fibre foods.
- Increase fluids especially when increasing fibre.
- Try, where possible, to do some gentle exercise, i.e. walking, swimming.

If this still does not solve the problem, contact your GP or Stoma Care Nurse for further advice. **DO NOT** take laxatives without first seeking advice.

Foods which may cause diarrhoea if taken in large quantities

Spicy foods, onions, pure fruit juice, prunes, rhubarb, chocolate, stewed fruit, alcohol. Follow the low fibre diet temporarily. If diarrhoea persists seek medical advice.

Foods which may cause blockage of stoma (ileostomists only)

Celery, nuts, sweet corn, coconut, seeds, stalks of cauliflower and fruit peel/skin.

Some foods which may cause an offensive odour

Baked beans, peas, onion, cabbage, egg, fish, certain cheeses, alcohol, yoghurt. Fresh parsley helps to reduce odour.

Remember – these are general guidelines only – experiment along these lines and you will soon find out which is best for you. After surgery the key words are Rest, Relax and Recover and if a holiday is a possibility then even better, you will return raring to get on with your life.

**Source: Adapted from 'Dietary Advice for those with Ileostomy/Colostomy.
With thanks to Salts Medilink**



Getting More Than Your Feet Wet

People with ostomies do go swimming – in the sea, in swimming pools, in swimsuits and in the nude (skinny dippers recommend that you tape the bottom and sides of your bag to your body to prevent it floating up like a misplaced water wing). If you haven't yet taken the plunge, then you probably have one of the two standard worries – that your appliance will show under your swimsuit, or that it will come off in the water.

My own experience is that if anything the appliance adheres even more securely to the skin when wet than when dry and I can say that I have never had a problem when swimming. However, it is perfectly natural to feel slightly nervous if it is your first time in the swimming pool or sea after your newly formed stoma.

With regard to the swimming costume – here we are very lucky in that today there are manufacturers who have beautiful ranges of swimwear and lingerie. Two that I can personally recommend are CUI Wear who Inside Out have an arrangement with and will join us with their stand at our Open Information Day on June 2 where you can peruse their delightful garments. The other manufacturer is White Rose Collection Ltd. They have a stunning collection of lingerie and swimwear which includes bikinis and tankinis. They also have a new sportswear range in cotton/lycra comprising shorts, sport trousers, vest tops and hooded tops. White Rose has a selection of indispensable accessories to make life easier particularly when travelling including travel bags, travel sprays and stoma cups.

All their underwear is higher waisted to cover your bag (or appliance as I prefer to call it), with a special full width, universal inner pouch (suits all types of stoma) to keep your appliance away from your skin, under control and stops it dropping down the leg line. This means you can choose from a wider range of styles, some of which you would not otherwise feel comfortable with. The inner pouch can help to retain any small spills should they occur and helps to reduce chafing, giving you comfort, confidence and security.

The swimwear collection has lots of new designs and fabrics with inner pouches, fully lined at the front to give a smoother outline.

Both collections include ranges for gentlemen as well as ladies.

So, look as stylish on the beach and swimming pool as you do everyday. Remember – no-one knows you have a stoma – only you – and you are beautifully in control.

CD

Details of CUI Wear on the back page of the Newsletter.

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Email: Sales@whiterosecollection.com
Website:-www.whiterosecollection.com

