Summer 2010 | Issue 18



Dedicated to Colostomates their Families and their Carers

inside...an Ostomate's travelogue downunder



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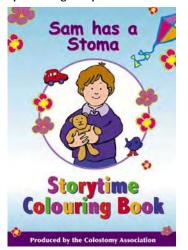
www.coloplast.co.uk



welcome to summer

## Did you know...

The **Colostomy Association** have redesigned their popular childrens colouring book which will be available soon - kind thanks go to Pelican Healthcare for sponsoring the production of...



Sam has a stoma a colouring book aimed at younger children who have a stoma or who may need help to understand that a family member now has a stoma.

#### The Colostomy Association has

over 70 contact volunteers up and down the country. All have experience of living with a stoma and many can offer more specific advice due to their own personal experiences e.g. irrigation, keeping fit, travelling abroad. If you would like to chat to someone then please call or email head office and we will put you in contact with someone.

The **Colostomy Association** can be found on Facebook - the online social utility connecting people with friends and others who work, study and live around them. The site is growing and now has a membership of 337. Discussion topics are many and varied. Joining Facebook is simple visit: www.facebook.com



Macmillan Cancer Support offers a benefits advice service. If you are affected by cancer and have money worries call 0808 808 00 for a chat or visit: www.macmillan.org.uk/ financialsupport for advice.



I simply can't believe that it's the time for strawberries and cream, summer sunshine hopefully and yes! Wimbledon again. This summer we also have the added attraction of the Football World Cup, which I'm sure many of you will enjoy. I must say that I'm not a great follower of the beautiful game but when it comes to supporting England I'm right there! Let's hope they do a little better this time!

Again the editorial team have had some fantastic contributions from YOU for this issue and I have taken the liberty of picking out a few great reads, which I am certain you will enjoy. Moira Hammond ostomate and CA volunteer writes about travelling downunder, Susan Fifer shares her thoughts on becoming a colostomate and Claire Loaiza writes about a new support group in the North East of England.

If you are new to reading Tidings I would like to welcome you aboard and hope that you find the magazine informative, helpful and supportive.

YOUR stories, letters and contributions are so valuable and supportive to all who read Tidings and I know from conversations with stoma care nurses that they give Tidings regularly to their patients.

Here is an offer of help - to those of you who are contemplating writing or have a story to tell and feel you need a little guidance or would like to be interviewed, please pick up the phone, write or send an email to CA, my contact details can be obtained from Head office. It's good to talk and I have to some of you but I would like to encourage more of you to share your thoughts, ideas, and experiences with other readers. Tidings magazine is a platform for YOU to have your say so let's hear from you! Our regular feature Open Door covers the launch of a new initiative – High Impact Actions for Stoma Care Nursing. We are delighted to welcome the author of the feature Dame Catherine Elcoat DBE. Dame Catherine explains the concept behind the initiative and demonstrates how Clinical Nursing Specialists have a key role to play in constantly improving the quality of patients' experience.

Mr John Lengyel - Consultant Surgeon University Hospitals of North Staffordshire NHS Trust Stoke-on-Trent writes about Laparoscopic Bowel Surgery.

NEW to Tidings magazine – is a series of articles examining problematic stomas written by Melanie Jerome and Amanda Gunning stoma care nurse specialists Chelsea and Westminster Hospital NHS Foundation Trust. In this issue they examine dips, and creases. I know from my own experience caring for my mum in her eighties and her stoma (which became my stoma due to her reluctance to accept her body's change and function which I fully understood) what difficulties some ostomates face living with their stoma - simple changes can make all the difference to a person's well being and quality of life. Information and awareness can and often does lead to a problem being identified and a positive outcome being sought and delivered.

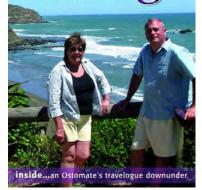
The Colostomy Association provides a FREE telephone helpline 0800 328 4257. The line is manned 24 hours a day by office staff and trained volunteers who are themselves ostomates just like you. If you have a problem do get in touch we are here to help!

On behalf of the team I hope you enjoy this issue and welcome your feedback - without it Tidings cannot truly reflect YOUR interests, ideas and concerns.

Email: editor@colostomyassociation.org.uk

PS. Why not send a hint or tip, letter or article to the editorial team for consideration in the next issue of Tidings!





## **EDITORIAL TEAM**

**F**ditor Jane Wood

**Associate Editor Rosemary Brierley** 

**Executive Trustee Colostomate & Helpline** Volunteer Sue Hatton

Trustee **Colostomate & Helpline** Volunteer Jackie Dudley

**Office Administrator** Gill Herbert

**Office Administrator** Jo McKenzie

**Colostomate & Helpline** Volunteer **Georgina Williams** 

**Colostomate &** Volunteer **Bob Buckley** 

**Stoma Care Nurse Advisor** Amanda Gunning RGN, CNS

Kind thanks to all who have contributed to this issue of Tidings.

Front cover picture courtesy of Moira Hammond pictured on

holiday with her son Michael.

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responses to our spring article

PATHWAYS TO A COLOSTOMY



Diverticular Disease written in partnership with Christine Hyde **RGN CNS** with two reader's experiences

Tidings is YOUR Magazine...

#### **Editorial Submissions:**

We welcome your contributions to Tidings - if you have a story, article or letter that you would like featured in the magazine we would like to hear from YOU!

If you have an idea for an article and would like to discuss this with the Editor or would like help writing your

Tidings Magazine: The views expressed by the contributors are not necessarily those of the Colostomy Association. Great care has been taken to ensure accuracy, but the Colostomy Association cannot accept responsibility for errors or omissions.

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recommendation of these products and services by the Colostomy Association.

## **READERS STORY** An Ostomates Travelogue downunder



by Moira Hammond **CA Volunteer** 

YOUNG OSTOMATES Breakaway Weekend 2010



A buzz of activity and excitment...

#### **OSTOMY COMMUNITY** Ostomyland Website 36 Celebrates Anniversary



story please get in touch. Tidings is also interested in commissioning articles please contact the Editor.

We will always do our best to include your contributions in the next issue of Tidings or will hold them back for a future issue. When submitting your information don't forget to supply your name, address, phone number and e-mail address if you have one.

Please include any relevant photos or illustrations as these HEALTH **NEW SERIES** Stoma Care Management



Problematic Stomas... Dips and



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HEALTH 42 **ASPECTS OF MEDICAL CARE** Laparoscopic **Bowel Surgery** 



## HEALTH Dear Nurse



your letters and queries

really help to bring YOUR magazine to life! You can send these as prints or digital images.

Supply of digital images: When supplying digital images for inclusion in Tidings please try to observe some or all of the following criteria;

 Images should be in RGB mode

 Images should not be less than 2480 pixels x 1772 pixels at 300 pixels per inch



SUPPORT GROUPS in your region support groups strengthen and empower people

## Don't delay... **Donate** Online today!

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Visit the CA website and simply click on the donate panel on the home page.

## JustGiving<sup>-</sup>

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(equal to 21cm x 15cm). • File sizes not less than 10Mbytes uncompressed

- Images compressed in JPEG format.
- For scanned images please set at 300 ppi in RGB mode and scan original @100%.

Feedback...We are always trying to improve your Magazine and welcome your feedback. Enjoy this edition of Tidings we look forward to bringing you the next edition ...



## About... the Colostomy Association

The Association represents the interests of colostomates and other ostomates. We provide support, reassurance and practical information to anyone who has or is about to have a Colostomy.

The Colostomy Association is a charitable company limited by guarantee (Registered Charity No: 1113471).

## How to get to in touch...

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- By post: Colostomy Association
- 2 London Court, East Street, Reading RG1 4QL
- By telephone: •
  - General Enquires: 0118 939 1537
  - Stoma care queries only: Helpline: 0800 328 4257
  - By E-mail:
  - cass@colostomyassociation.org.uk
  - Find us on Facebook:



#### How to become a member of the Colostomy Association...

Simply visit our website and register at: www.colostomyassociation.org.uk or contact General Enguires: 0118 939 1537 for more information



## How to contact the Editor

#### Write to:

- **Colostomy Association** 2 London Court
- East Street Reading Berkshire RG1 4QL

#### or e-mail:

- cass@colostomyassociation.org.uk
- or e-mail the editor direct: editor@colostomyassociation.org.uk
- **Advertising Enquiries**
- For advertising enquiries and media pack
- Tel: 0118 983 6226
- TIDINGS SUMMER 2010 5

Creases CHATBACK **Readers**'

your letters

## Letter from the CA office...

## Dear All.

We have had a tremendous response to our request for voluntary donations from the Spring edition of Tidings. We have received over £10,000 in donations and on behalf of the Charity I would like to thank all who donated for your continued support and to all who help us continue to make a difference!

It's hard to believe that I have been with the CA for over a year. It has been a very interesting period and I have met some great people.

The office continues to be very busy, I have introduced changes within the office to ensure its smooth running and instigated a review of our accounting system and procedures with the help of Cheryl Manning. This has taken some time to achieve but I am sure will pay dividends for the future.

The new volunteers training manual is in its final stages and is being piloted by a few volunteers to gauge feedback before rolling it out to all. Staff in the office have worked very hard answering your queries, collating and sending out information, and dealing with Open days. The team has handled several mail outs for Open days resulting in approximately 30,000 individual pieces of mail being sent. I hope you have taken the opportunity to attend an Open Day they are very worthwhile.

You may remember from the last issue of Tidings we were in the process of changing our Tidings print and mailing supplier. This process is now complete and Superior based in Melksham have won the contract.

The CA Database has also been reviewed and cleansed which will mean costsaving efficiencies with regard to the mailing of Tidings. I would also like to thank the volunteers who come into the office on a regular basis for their ongoing support Colin Allum, Heather Nicolls, Jackie Dudley, Margaret Simister and Monty Taylor.

This brings me on to mention our own Open Day which will take place on Saturday16th October at the Heritage Motor Centre near Gaydon in Warwickshire, we will use this event to celebrate our 5th Anniversary. You can read more about the event opposite.

You will I am sure be pleased to learn that we have new Ostomates joining us on a regular basis which is great news!

Regards,

**Richard Bray General Manager** 



Richard pictured with staff at Superior passing Tidings on press

## CA Open Day... at the Heritage Motor Centre in Warwickshire...



## A Date for your diary...

Date: 16th October 2010 Time: 10:00am - 3:00pm

Venue: Heritage Motor Centre Gaydon, Warwickshire

The Heritage Motor Centre is home to the world's largest collection of historic British cars.

Those attending this Open Day will have FREE access to the Museum and its catering area. The Association's Open Day will be housed in the Conference Centre, which is within the Museum and has excellent facilities.

Those attending this Open Day will gain increased knowledge about their stoma via workshops and talks on the day. We will be inviting stoma care professionals from the local and regional hospitals to get involved and join us on the day. Also, patient associations will be invited to come along and local support groups will be most welcome.

Stoma care industry representatives will be in attendance to answer product queries and exhibit the latest stoma care products and accessories.

For more information contact: **Richard Bray General Manager** Tel: 0118 9391537

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## Diary... Medicine and Me by Vanessa Denvir - CA Volunteer

In the comfortable surroundings of this 200 year old institute approximately thirty people gathered together. They were a mix of ostomates and medical professionals. Some had taken the effort to travel from as far as Switzerland!

The fact that it was an intimate group made it much easier for the audience to discuss issues with the speakers. Irrigation was discussed by the audience and the medical professional's response was that perhaps it was up to them to raise awareness about Irrigation, especially considering it was widely encouraged in America.

Also mentioned was the change in NHS regulations regarding stoma care products (as has already happened in Scotland) as was getting replacement supplies in an emergency, especially taking into account the recent travel delays caused by volcanic ash.

Another topic was confidence, whether it was with swimming, altering ones clothing style or rebuilding self-confidence after surgery.

Having had surgery five years ago and being an active campaigner for greater awareness for those living with a colostomy. I felt grateful for the opportunity to speak out about my own personal experience. Everyday since my surgery has been life changing in so many ways. However, I have remained positive and my experience had led me to realise forgotten ambitions.

I hope the event gave others inspiration and motivation to live life positively after surgery and that in future, other ostomates will take the opportunity to attend such an interesting and informative symposium.

#### Sue Hatton supports new ostomy group in Torbay 'name to be decided' - This was an initiative by

**decided'** - This was an initiative by Donna Ashbrook, supported by her stoma nurse Neita Matthews from Torbay Hospital and sponsored by Kim Hill of Hollister. It was a very happy initial meeting. Most members had their Tidings and loved the magazine. Any one interested in joining this monthly meeting and getting details of the next venue can call Donna Ashbrook on 01626 854 862.

## Feedback... Open Day at Buckfast Abbey... by Rosemary Brierley - Trustee and CA Volunteer

More than 130 ostomates along with relatives and friends attended the Salts Healthcare Open Day in the tranquil grounds of Buckfast Abbey in Devon.

The day's proceedings began with the history of Salts Healthcare. This familyrun business has been around for 300 years and spans ten generations. Next came presentations about the latest range of stoma appliances produced by Salts.

A local colorectal nurse specialist gave an insight into how stoma care has changed since the introduction of the Enhanced Recovery Pathway – from more information and improved preparation before surgery to getting patients up and about much sooner after the operation and involving them in the care of their stoma at a much earlier stage. A dietitian was also on hand to answer ostomate's foodrelated questions.

The ostomy associations were each allocated a seminar room where they held interactive sessions. These small informal groups gave ostomates the opportunity to participate and ask questions.

The Colostomy Association's topic was irrigation - a stoma care nurse gave a very clear explanation of what it is and demonstrated the equipment required. The Ileostomy Association had invited a surgeon to talk about "the view from the other side of the table" - an amusing and informative look back at the first attempts to create a stoma in the eighteenth century and forward to future trends in colorectal surgery. Ostomy Lifestyle concentrated on the different types of stoma and why they are formed. For the twenty urostomists present, the Urostomy Association held a successful question and answer session.

A very interesting and enjoyable day.

## Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group Freephone: 0800 0184 724 www.iasupport.org
- UA Urostomy Association Tel: 01889 563191 www.urostomyassociation.org.uk
- IOA International Ostomy Association www.ostomyinternational.org
- Gay Ostomates
   Email: brian@gayostomates.org
   www.gayostomates.org
- Stomadata & Stomafr www.stomadata.com www.stoma.fr
- Macmillan Cancer Support Freephone: CancerLine: 0808 808 2020 YouthLine: 0808 808 0800 www.macmillan.org.uk
- Cancerbackup Freephone: 0808 800 1234 www.cancerbackup.org.uk Macmillan Cancer Support and Cancerbackup have merged all telephone numbers and websites remain the same at the present time.
- National Association for Colitis and Crohn's disease Tel: 0845 130 2233 www.nacc.org.uk
- The Gut Trust (Irritable bowel syndrome) Tel: 0114 272 3253 www.theguttrust.org
  Bladder and Bowel Foundation (B&BF) Formerly Incontact and Continence Foundation General enquiries: 01536 533255 Web: www.bladderandbowelfoundation.org
- Bowel Cancer UK Tel: 020 7381 9711 Email: admin@bowelcanceruk.org.uk Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK Tel: 08450 719300 (Lo Call rate) Web: www.beatingbowelcancer.org

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SecuriCare

## Launch of **High Impact Actions for Stoma Care Nursing** at the Royal College of Nursing...

written by Professor Dame Catherine Elcoat DBE



## The High Impact Actions are an exciting development for stoma care nursing which will help to further enhance patients' experience

In May 2010 Richard Bray - General Manager of the Colostomy Association and Jane Wood, Editor of Tidings Magazine were delighted to be invited to the launch of High Impact Actions for Stoma Care Nursing. The launch was held at the Royal College of Nursing in London, and hosted by Coloplast Ltd. The High Impact Actions are an exciting development for stoma care nursing, which will help to further enhance patients' experience whilst saving costs for the NHS, at this time of economic difficulty. The event was attended by Stoma Care Nurses, representatives from Patient Organisations, Nurse Managers, journalists and representatives of Coloplast Ltd. In September 2009, the Chief Nursing Officer for England, Dame Christine Beasley DBE, launched eight High Impact Actions for Nursing and Midwifery. When Stoma Care Nurses became aware of these High Impact Actions, they immediately recognised the contribution they could make to this important work.

At a national symposium, sponsored by Coloplast Ltd., in December 2009, the High Impact Actions were discussed and there was overwhelming support from a large number of delegates to identify the ways in which Stoma Care Nurses could work together, to support the implementation of these High Impact Actions and develop a small number of additional actions specific to the specialty of Stoma Care Nursing. A steering group of experienced, Stoma Care Nurses was established, led by



Back row from left to right - Sue Frost, Julie Morrisroe, Tracey Virgin-Elliston, Dr Terri Porrett. Front row from left to right - Jill Dean, Yvette Perston, Elaine Swan, Allison Sharpe, Maddie White, Amanda Smith, Carol Katté and Professor Dame Catherine Elcoat DBE

Professor, Dame Catherine Elcoat DBE, herself a former Stoma Care Nurse. This initiative was supported by Coloplast Ltd. as part of their ongoing commitment to support Stoma Care Nurses in the valuable role they undertake.

The steering group determined how the initiative would be taken forward to build on the national work that is already in place. The steering Group decided that there were two streams to this work

• to determine how Clinical Nurse Specialists in stoma care can support and contribute to the implementation of eight nationally identified High Impact Actions

• to determine what if any High Impact Actions could be identified relating specifically to the specialty of stoma care nursing

The process followed was the same as that used to identify eight High Impact Actions for Nursing and Midwifery. All Stoma Care Nurses across the United Kingdom were invited to contribute ideas and suggestions relating to the work, with a particular emphasis on improving the quality of patients' experience and reducing costs.

The proportion of Stoma Care Nurses that responded exceeded the national response in the previous identification exercise.

The ideas and suggestions which were generated were considered by the Steering Group and a priority list was identified. A review of relevant clinical research was then undertaken to identify evidence to support the interventions. An initial, high level, economic analysis was undertaken to provide an insight into the possible cost savings resulting from these actions. More detailed work is now planned to determine more robustly the potential impact Stoma Care Nurses across the NHS can make.

The launch on May 27th was an important step in the continued development of Stoma Care Nursing. Stoma Care Nurses have seized the opportunity to lead the way, again, in demonstrating how Clinical Nurse Specialists, as nursing practitioners and leaders, are cost effective and have a key role in improving the quality of patients' experience.

The High Impact Actions for Stoma Care Nursing document has been endorsed by The Chief Nursing Officer for England, The Chief Executive and General Secretary of the Royal College of Nursing, The World Council of Enterostomal Therapists, Association of Coloproctology Great Britain and Ireland and the Patient Associations.

The document sets out the Stoma Care Nursing contribution to the eight High Impact Actions for Nursing and Midwifery, together with a small number of additional actions relevant to the specialty of stoma care nursing. The document also includes some illustrative examples of best practice which highlight the important contribution made by Stoma Care Nurses and provides supporting evidence. At the back of the document there is an example of a typical colorectal patient's clinical pathway, which demonstrate the vital contribution which Stoma Care Nurses make to patient care and experience, identifies the key areas in which

Stoma Care Nurses support their Trust to meet waiting time standards, appropriate NICE Guidance, together with the promises made in the NHS Constitution.

With the support of Coloplast Ltd, it is planned to consolidate this important work, the next phase will look to demonstrate cost savings which result from the high quality specialist services provided by Stoma Care Nurses. In November 2010 this further work will be presented at a National Symposium hosted by Coloplast Ltd., to demonstrate the work of this important document.



## **Editors Comment**

If you would like to learn more about High Impact Actions for Stoma Care copies of the document are available for download from the Coloplast website visit:www.coloplast.co.uk

## Ten Weeks Later...

"I've got a friend who's had one for thirty years. She goes dancing, swimming, hang-gliding' pot-holing..." Does this sound familiar to everyone else who reads this magazine? Why do I keep feeling irritated by something that is obviously only said to reassure me?



Ten weeks ago, I woke up in intensive care after an emergency operation to correct a laparoscopic colectomy for colon cancer. The join had not held but had leaked into the abdominal cavity. Apart from the immediate effects on the system of two major operations in seven days, the other unexpected result was a colostomy, something for which I ought to have been prepared, but for which I wasn't.

The possibility of a leakage for the first operation is apparently as low as 5%. Since I'm always complaining about media stories which misunderstand or misrepresent risk, I should have thought more about it but, as it wasn't the original intended outcome, I didn't.

I've had to do a lot of thinking about it since then. I've had help and support from the stoma nurses at my local hospital and throughout everything I've felt loved and cherished by friends and family. But it's still a very personal experience. Despite always being generally very upbeat about most things in my life, what I really want to know is how the dancer/swimmer/hang-glider/potholer felt after six weeks, ten weeks or four months – not thirty years.

I know how it feels to me; magazines like Tidings and associated websites help but it's hard to know whether the problems I have – physical, emotional and 'equipment-related' are down to my inexperience, my ineptitude, my attitude or are just part of the learning process. After all, I was a teacher and keep telling students that these things take time. It's somehow different, isn't it, when it's so "up close and personal"?

So I thought I would draw up a list of things I have discovered which are helping me come to terms with my changed body. It might just help others who are perhaps six or ten or fifteen weeks in to this process

## Susan's List:

**One** - There are lots of bags available; work with your stoma nurse to find what suits you. I have an inverted stoma and so use a convex flange. I don't know how common it is for the stoma to be inverted but decided that I couldn't be alone in this since they wouldn't have just developed a product with a market of one.

Two - I have decided that a drainable bag is a better solution for me, even though my stoma output is probably more suited to a closed bag. Apart from the problems of having to change the bag frequently (I have skin which is prone to irritation), I wanted to be able to go deal with the situation of less than perfect circumstances for a full bag change when I was out of the house. My partner, a retired mechanical engineer, suggested that I could use the drainable bag more easily by having an empty washing up bottle filled with water which I could add to the bag through the drainage end just before emptying, thus making it easier to send the contents into the toilet bowl. This works well at home and I have found a small lotion bottle in Superdrug that I can put in my "going out supplies bag" which I can fill up with water whenever I get to my destination.

**Three** - The anti-sickness drugs you are given in chemo-therapy can give you constipation (though chemo itself can give you diarrhoea – so we are in for a delicate balancing act over the next few months!) Constipation with a small inverted stoma is no joke. It probably isn't funny either with a normal stoma. My stoma nurse said that a couple of glasses of Tropicana orange juice (the one with the bits) works well for a lot of people. I'm all for the natural approach and certainly don't want laxatives if I can possibly help it.

Four - Pancaking and ballooning sound like things from a children's party. This readership will know that these are the bane of the ostomist's life. The most helpful tip for me was that a small piece of tissue in the bag can help prevent the vacuum effect which is often the cause of pancaking. Finding out about the filter covers is helpful too – though I haven't yet got the balance right at night and often wake up with what feels like a mini gas canister stuck to my left side. Removing the filter cover helps at this point.

Five - Do reconnaissance at places you are likely to visit frequently and check out the facilities. I now have a Radar key to use with disabled toilets. I am going up to central London soon and will check out the facilities in major stores, museums and art galleries.

So, that's what I've learned so far. It helps to talk about it, particularly to people who have been in a similar situation. As you all know, the most difficult thing is the steep learning curve, at a time when you are just recovering from surgery and facing further treatment. This is not something that you can put off like learning Spanish or taking up hanggliding. Anyway, I never wanted to go pot-holing, with or without a colostomy!

#### **Susan Fifer**

We will be including another article from Susan in a future issue of Tidings, when she will tell us how she feels..."Ten Months Later".

# this Work might hurt!



## Appeel is no sting – even on sore skin

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# Update on new stoma care products and services

Tidings is always interested to learn about new stoma care products and services...from manufacturers and suppliers. Colostomates... if you have found a stoma care product or service beneficial to 'Living with a colostomy' please let Tidings know...your findings could make all the difference to other colostomates.

### Bullen Healthcare & Pharmore Plus Bullen Healthcare has teamed up with Pharmore Plus to provide Ostomates with a full prescription home delivery service.



BULLEN This unique service means that along with the HEALTHCARE discrete delivery of any make or manufacture of ostomy appliances we can now deliver all of your pharmore and drug and medication requirements. This personalised service will work in the same way for the medication as for the appliances. Your named representative will

call you monthly to run through what you need, we will then collect the prescription from your GP on your behalf and deliver all the items directly to your door in one box on a mutually agreed date.

To learn more...about this fantastic new service please complete and return the Freepost insert included in Tidings or call one of our customer service operatives on Freephone 0800 888 501.

There's now a lot more to Bullen Healthcare's home delivery service...Pharmore!

independence products - the new name in innovative healthcare accessories, has launched a new range of five stoma care accessory products that are available on prescription.



Adhesive Remover Wipes - The wipes are made with a superior quality soft non-woven material and provide fast and effective removal of sticky residue. They're available in

convenient and discreet individually wrapped sachets. Product code is ARW1 and there are 30 wipes per box.

Adhesive Remover Spray - The spray has all the same residue removing properties as the wipes. It's available in a handy 59ml aerosol that features a unique twist-open/closed top that removes the need for a separate cap. The product code is RS1.

Barrier wipes - A new superior quality soft non-woven wipe with a special non-sting formula that creates a barrier film layer on the skin. It's supplied in individually wrapped sachets for convenience. The product code is BW1 and there are 30 wipes per box.

Odour eliminator - Unlike other sprays that simply mask the odour with fragrance, this unique odour eliminator encapsulates bad smells and neutralises them on contact. It's available in a handy 59ml pump spray. The product code is PR310.

Absorbent Strips - These wafer-like super-absorbent strips quickly convert fluid into a gel and reduce odour and staining. Add two to three strips to an ostomy bag to aid fast and clean waste solidification and disposal, as each strip absorbs approximately 30ml. The product code is P100AS.

All products are available on prescription from your usual supplier. For further information or samples to try, please visit www.independenceproducts.co.uk, email us at enquiries@independenceproducts.co.uk or call us on 01773 536814.



## Lift Plus No-Sting Adhesive Remover

Lift Plus Spray and wipes are recommended by Stoma Care Nurses and widely used to clean residue from peristomal skin and to ensure pain free removal of pouches and flanges. Following on from user feedback Opus Healthcare have introduced improvements to the spray mechanism that result in a more consistent spray that is easier to direct. Lift Plus wipes and spray are available on prescription and can be obtained from your usual supplier. Free samples are available by visiting www.opus-healthcare.co.uk or calling free of charge: 0800 458 7605.

Pelican Healthcare is delighted to

announce that we are now the sole distributor of the popular  ${\bf Eakin\ Cohesive}\, {\rm (B)}$  range in the UK (formerly distributed by Salts Healthcare). For over 30 years Eakin Cohesive<sup>®</sup> has helped improve the quality of life for ostomists.

Eakin Cohesive® Seals are specially designed to hug the base of the stoma to help prevent output from your stoma from coming into contact with the skin. Eakin Cohesive® Seals are completely mouldable to ensure a perfect fit every time and prevent leakage by forming a waterproof barrier around the stoma. Clinical studies have confirmed that Eakin Cohesive® offers the most absorbent Seal available.

Eakin Cohesive® Seals have a proven record of healing sore and irritated skin, and are quick and simple to use.

Eakin Cohesive® Paste can be used independently or in combination with Eakin Cohesive Seals® for the ultimate in skin protection. Eakin Cohesive® Paste does not contain alcohol, and therefore will not sting when placed on sore skin.

Eakin Cohesive® products are available on prescription now - to request your complimentary sample please see our advert within this brochure, call the **Freephone Sample Request Helpline on** 0800 052 7471 or e-mail contactus@pelicanhealthcare.co.uk

Hollister are pleased to advise that our new Moderma Flex Closed pouch with QuietWear material is now available on prescription.



This first of a kind combination of bonded film and fabric delivers a single pouch material that will now, more than ever, address the pouch noise concerns of

Colostomates. And with its cloth-like material providing a comfortable feeling you will be able to go about your daily activities with renewed confidence and comfort. In addition, as with all Moderma Flex Closed pouches, you get all the benefits of the AF300 filter to help address pancaking and ballooning concerns.

Contact Hollister Customer Services on 0800 521 377 for more details and to request a sample.

## Varimate Resist 'eye shaped' Washers from Peak Medical

Peak Medical provide the ever popular Varimate range of products. Varimate Resist 'eye shaped' Washers are, as the name suggests, resistant to moisture and the aggressive output from faecal stomas. They are also resistant to the effects of acid urine. These stretchable, mouldable washers can be stretched to twice their original size and will remain in the desired shape. For partially retracted stomas, the washers can be folded and used as a filler to help prevent unwanted leaks and potential skin breakdown and will remain sticky even when rolled and stretched repeatedly.



Varimate Resist 'eye shaped' Washers have an 18mm

starter hole which can be stretched to 35mm and are available in packs of 10. Varimate Resist 'eye shaped' Washers are available on FP10 prescription.

If you would like to receive a sample, please call the Peak Medical helpline on Freephone 0800 6520424.

## Salts Healthcare acquires UCI Healthcare...

Salts Healthcare has acquired Oxfordshire's UCI Healthcare. A Dispensing Appliance Contractor with three Customer Care Centres, in Charlbury (Oxfordshire), Chesterfield and Newcastle upon Tyne. Salts Medilink has twelve centres and the addition of these three licenses makes the company a truly nationwide operation with more customer care centres than any other provider.

Salts Medilink, combines the expertise of specialist nurses with that of a rapid, reliable and discreet prescription delivery service of ostomy and incontinence products. No other company can offer such a comprehensive and personal service delivered by dedicated and fully-trained staff from a network of customer care centres.

Salts Medilink offers a: • 24-hour emergency freephone helpline (UK only) • All year round service (UK only) • Free cut-to-fit and personal modification service • 24-hour online ordering facility • Free pre-paid envelopes for your next order • All makes of product stocked and supplied

- Free disposable wipes and Disposapacs
- Free vanity case with your first order
- Free holiday delivery emergency service
- · Free 48-hour home delivery
- A range of accessories
- Prescription based service

For more information call 0800 626 388.

## 'Salts launches new improved Salts Seal'

Salts Healthcare has announced the launch of the 'next generation' of mouldable seals. The SecuPlast Mouldable Seal is superseding the Cohesive range, marketed for many years by Salts Healthcare. Evaluation tests and patient studies have proven the new improved 'Salts Seal' to mould very easily and stretch further for a closer fit to prevent leakages and sore skin.

#### SecuPlast Fast Facts...

With research validated by the British Skin Foundation, Research and case studies have found the following key patient friendly key findings:

- SecuPlast Mouldable Seals Are Easier To Mould
   are 30% softer and require 25-30% less energy to deform than leading competitors
- SecuPlast Mouldable Seals Are More Secure due to a higher viscosity than the leading competitor so remain firmer when wet
- SecuPlastMouldable Seals Are More Absorbant
- SecuPlast Mouldable Seals Stretch Further -10% further than other seals without breaking

SecuPlast Mouldable Seals Are Kinder To Skin - closer to the skin's natural pH level (5.8 vs 6.9)

The new and innovative Secuplast Mouldable Seal will supersede the current range of Cohesive seals and Cohesive slims in the UK with immediate effect - Cohesive Seals, Cohesive Slims, Cohesive Paste, Eakin Wound Pouches, Eakin (closed and drainable bags/Cotton bag covers), and Eakin Stoma Support Belt. The supply of the Cohesive range and other Eakin products will continue to be distributed through the Salts Medilink service in the usual DAC dispensing method for the benefit of patients.

For more information on SecuPlast Mouldable Seals please call Freephone 0800 626388 or visit www.saltsstomacare.co.uk.

We need YOU!...Fundraising is an immensely important source of income for the Colostomy Association...as we rely solely on donations to continue our work of giving support to colostomates...

Donations When sending your donation/s please mark your letter/cheque with Tidings Issue 18.... Thank you!

## Special thanks goes to... the Estate of Mrs Constance Alexandra David

Thank you everyone for your kind donations

who sadly passed away in December 2008. The Colostomy Association has been gifted a very generous legacy of £37, 443. 46 it is greatly appreciated.

## Kind thanks to ALL who wrote in with donations...



Gloria Hadfield, a volunteer with the CA, is seen here accepting a cheque for £700 from Bro Harry Johnson, Secretary of the Gardeners Lodge RAOB, at the Coronation Club, Clay Cross.

The lodge has eight members and they fundraise throughout the year by holding raffles, games nights and donations by members. The Colostomy Association was their chosen charity for 2009.

The **Colostomy Association** would like to take this opportunity to say a **BIG THANK YOU** to **everyone who donates and fundraises on our behalf.** We try to publish as many letters as possible - to those of you not mentioned here you are not forgotten - we would not be here without you - **So, PLEASE keep up the GOOD WORK!** 

## 500 Club - April Draw

Mr P Smith	£340.00
Anon	£170.00
Mrs I Scott	£ 85.00
Anon	£ 85.00
Mr A E Rowcliffe	£ 85.00
Anon	£ 42.50
Miss S Alder	£ 42.50
Mrs S Birrell	£ 42.50
Mrs A Campbell	£ 21.25
Anon	£ 21.25
Anon	£ 21.25

## The High Wycombe Round Table

donated £500 to the CA in April this year, as CA was one of several charities supported during 2009.

#### **Dear Sir/Madam**

We are a group of Ostomates with around 30 members. We meet once a month as a social support group and invite speakers. Most of the membership has had some contact with the Colostomy Association to their benefit. Therefore please accept our donation of £30.

## Southampton Ostomates Support Group (SOS) Group

#### Dear CA,

On behalf of my husband and myself please accept this donation £110.00. The sum raised was instead of receiving presents for our Golden Wedding Anniversary. Since having my colostomy operation last year I have received Tidings magazine and have found it very helpful. I hope this donation will help to continue the work of the Association and help other Ostomates.

Kind Regards MM

**Don't forget...the recycling appeal!** We need your old or unwanted mobile phones...telephone: 0118 939 1537 or email: cass@colostomyassociation.org.uk and we will send you a FREEPOST envelope. Simply place your phones in the envelope and return it to the recycling appeal. We will receive money for every phone sent on our behalf!



## **Charity Flowers...**

The Colostomy Association have teamed up with Charity Flowers www.charityflowers.co.uk to receive 15% of any orders placed with them.

Guernsey Flowers Limited are based on the Channel Island of Guernsey and have been involved in the flowers by post business for many



years. Guernsey Flowers manage the Charity Flowers website and call centre. They also provide and pack the flowers from their own purpose built premises.

The bouquets are really beautiful! You can choose by occasion, type of flower or type of gift.

To order, either log onto their website: www.charityflowers.co.uk or call the order hotline 0870 5300 600. Delivery is included in the price covers the UK. At the checkout quote COL as the source code, this will ensure the CA receives the commission. If you do not have access to the Internet we do have a few brochures available at head office.

By choosing to purchase a bouquet from Charity Flowers you will not only be giving beautiful flowers you will be helping the Colostomy Association raise much needed funds.

## 500 Club notice...

Thanks to everyone who has returned their new mandate. If you haven't already done so and would like to remain in the 500 Club please return as soon as possible. If you have any queries please contact the Head office in Reading on 0118 939 1537.

## In Memory...

Mr Edwin C. Geary	£ 194.50
Mr William B Morgan	£ 350.00
Mr David W. Cox	£ 395.00
Thank you	

Congratulations to Owen and Madeline who recently walked the southern section of the Offa's Dyke Path raising funds for the Colostomy Association on their way!

## His partner Madeline writes...



The Offa's Dyke Path runs160 miles from the Severn Estuary to the north coast of Wales at Prestatyn through the most glorious countryside. Owen and I set out to walk the southern 80 miles of the path from Sedbury to Knighton in the hottest spell of the year so far with temperatures topping 29°C.

Walking with a party of thirteen, mostly young school friends in their mid-60's and their partners. This was our second walk after walking the Isle of Wight Coastal Path last year. Our friends had already knocked off the Coast to Coast and the West Highland Way in the previous two years to celebrate becoming 60! An idea came to us why not take the opportunity to raise funds for the Colostomy Association at the same time as walking the Offa's Dyke Path which

is just what we did! We set up a page on the Just Giving website with a target to raise £500.00 and have been delighted with the response. To date we have raised £800.00 taking us well over our original target!

Thirteen was obviously a lucky number for Owen; he led the field to the finish at Knighton. Brilliant for someone pushing 74 and just four months after undergoing parastomal hernia surgery. However, it was an unlucky number for me, after a 13-mile trek to Hay on Wye, I got overheated and my ankles and feet swelled up like two balloons, so I had to follow the luggage van after that, unable to walk the last 30 miles.

Strenuous. Now what does that word conjure up for you? A grassy slope? A narrow path into the valley? We thought our training in the Chilterns and the Lambourn Downs was just about pitched right. Wrong! Think 1-in-2 precipice, scree, tree roots, mud, potholes, loose boulders, ruts, and you'd come somewhere close. To get to our overnight stop in Tintern, we had to negotiate the 'path' from the Devil's Pulpit (its name says everything) then had a nightmare on Caswell Wood! Owen got leg cramps and was in agony on the descent where every step and foothold had to be carefully considered and made - that was only Day One!

The walk was so beautiful, with riverbank, bluebell woods, moorland ponies, buttercup meadows, steep country lanes, undulating sheep fields, dry stream beds, cider apple orchards and high heathland, all picture perfect in May. Owen has a real sense of achievement, knowing that he managed to walk such tricky terrain and for such a good cause.

Donating through JustGiving is simple, fast and totally secure. Your details are safe with JustGiving – they never sell them on or send unwanted emails. Once you donate, they send your money directly to the charity and make sure Gift Aid is reclaimed on every eligible donation by a UK taxpayer. It really is an efficient and effective way to raise funds.

Thank you to all who supported us and gave such generous donations.



If you are thinking of fundraising for the CA like Owen and Madeline why not visit their fundraising page www.justgiving.com/Owen-Hawes.

The Colostomy Association is registered with JustGiving visit: www.justgiving.com/colostomyassociation and as Madeline states JustGiving makes fundraising simple and secure.

## Gardening as an Ostomate written by Jackie Dudley

With all the weather we have been having lately, my garden has needed a great deal of attention lately.

While it is tempting to get out and work hard in the garden, we need to take a little time to consider our body especially if we have not been used to doing regular exercise for a while. To prevent any strain to our back and more especially the area around our stoma we need to remember to take care. The advice given to me stated quite clearly, 'not more than one hour at a time'. I have to admit that at first I tended to ignore this advice but soon changed my mind! I found that having a break for a 'cuppa' certainly helped, it allowed me to take time completing garden tasks that have since given me a great deal of pleasure - and no pain!

So, what can we do to help prevent strains to our body and at the same time protect the vulnerable area surrounding our stoma and the stoma itself? The answer to the first point is to do some gentle warm up exercises that will help blood flow to the muscles, your GP or stoma care nurse will be pleased to advise you. Secondly, invest in a good support garment. These are specialist garments available on prescription and will give extra support to your tummy muscles as well as additional protection to your stoma. (Your stoma care nurse will be able to measure you and help you find what suits you best also CA has an information sheet available listing current suppliers of support garments).

Wearing a support garment may take a while to ge used to and produce 'pancaking' but that is a small price to pay for the satisfaction of good support for the weaker areas of the body. If you do have a hernia it must be protected and supported. If you are lucky enough not to have a hernia then it is even more important to safeguard against that possibility by taking those extra minutes to put on your support garment or belt. This should help prevent a hernia forming.

#### Here are a few of my top tips...

 Bending – When bending over always bend at your knees not your waist. Instead of flowerbeds at ground level why not try introducing raised flowerbeds into your garden, this will ease the amount of bending. You may need help with making a raised bed, if possible try to incorporate built in seating for that ever important, cup of tea! Raising ornamental pots on bricks or stands means you will not have to bend to plant, weed or water! Try growing a mix of evergreens and perennials in ornamental pots as these will look good throughout the winter and you will have flowers every year. You can now buy wheelie pot stands for ease of movement.

 Stretching – To prevent stretching why not simplify your garden. Increase or decease the depth of your borders so you weed or plant out without too much effort. If you already have deep borders plant shrubs at the back of the border that are variegated or evergreen source varieties that require little maintenance. Only plant the border edges with bedding plants. Introduce shingle or bark to cut down on weeding. Consider doing away with flower beds altogether and replace them with lawn, shingle or paving. Position container grown plants at regular intervals to attract the eye and grow plants that are both bird and insects friendly.

• Pushing – If you are using a hand push mower take great care, as you will be using your tummy muscles. It may be a good idea to replace it with a rotary mower, or better still ask someone else to cut the grass for you. If you use a wheelbarrow remember you are lifting as well as pushing. Try not to fill the barrow too full although it may take longer to transfer the contents it is better than the risk of a pulled muscle or strain.

• Lifting – This is something we often do automatically without thinking only to wake up the next day with an aching neck or shoulder. Remind yourself before picking up a pot or lifting a watering can to think about your position to avoid straining yourself. If you are watering your garden with a watering can fill it midway or better still use a hosepipe unless of course there is a ban in your area. Better still ask someone else to do it for you!

• Helpful Tools – Walk around any garden centre these days and you will find items that will ease the pain of gardening. High kneeling pads that are also a seat, a new type of wheelbarrow that can be pulled – not pushed, a garden tidy (rather like a shopping trolley with pockets) long handled small garden forks and trowels, garden refuse sacks, multipick garden tools for picking up small branches etc.,

• Garden Plant Supports – There are also a plethora of plant supports hoops, arches, stakes and pyramids as well as good old trellis. We are all being encouraged to grow our own vegetables. Why not grow your tomatoes, peas and beans up against a trellis making them easier to pick. Start off your seeds or buy raised seedlings and plant them out in grow bags placed on an old table or stand – ask for help with any lifting.

 Start an Exchange Club – for the over abundance of crops and with the economic climate affecting us all – why not try the barter system. If you are unable to cut your hedge or mow the lawn why not offer your services to your neighbour – baking cakes, repairing items, ironing, in exchange for their gardening skills?

Gardening is physical work but with a little forward thinking it can be easily managed and is highly rewarding and good for the soul. The best part of gardening is sitting in a comfortable chair on a warm summers day admiring the fruits of your labour (or that of your neighbours!).

The weather forecast is good for this summer – and I am sure we shall all be out in the garden enjoying the sunshine. I would love to see photos of your gardens in full bloom do write in and tell me your best gardening tips – if you share them I am sure we will all benefit!

## **Editors Comment**

If you would like to share your gardening hints or tips

write to: Jackie Dudley - Trustee Colostomy Association 2 London Court East Street Reading RG1 4QL

or contact the editor via e-mail: editor@colostomyassociation.org.uk

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Name (Mr/Mrs/Miss/Ms): ..... Address:



## A Colostomate Comments...

A regular column from a colostomate's perspective, which raises, researches and discusses issues associated with living with a colostomy. If you would like 'Tidings' to focus on a particular topic or issue that affects you day to day or would like to comment, please write in or email: associate-editor@colostomy association.org.uk. We look forward to hearing from you.

#### One of those "unreal" moments...

I am on a ship sailing through the Coral Sea, North West of Australia... at the Chief Engineer's cocktail party. Other guests sip cocktails and nibble on canapés but I am talking to the Chief Engineer, himself...about toilets!

So how has this come about? Well, while on holiday I decide to continue my investigations into whether the flushable liner of toilet-disposable pouches can be flushed down the loo on a cruise ship. I wrote to the Chief Engineer, sent him samples of the two flushable products on the market, and in return he invited me to his cocktail party. As the party goes on all around us, we speak of appliances, narrow bore pipes, maceration units, sludge and black water, but neither of us mention the words "colostomy" or "toilet".

He doesn't directly answer my questions. However, I get the distinct impression that it is not the liner, but only the flange that might possibly cause a problem – not just in the pipework, but also by clogging up the macerator unit which results in quite an unpleasant task for "the lads down below".

#### Two readers have also contacted us to tell us about their experiences using flushable pouches aboard cruise ships.

David Dungate - "Since the operation I have been around the world three times, travelling to all parts of the globe... More recently, these travels have involved cruising, first on the Celebrity Cruise vessel "Summit" through the Panama Canal, and then on the P & O ship, "Arcadia", from the UK to Australia. However, my preferred bag is a Welland Freestyle Flushable, and, contrary to some of the advice you have received, I experienced no problems on either ship, disposing of the bags in the toilet with no ill effects to the system. Indeed on the British ship I spoke to an engineer, who was aware of disposable colostomy bags, and he advised that they presented no problem as long as they were not accompanied by any non-degradable items like the outer bag, or wipes, etc."

John Ellis - "I have had a colostomy for just twenty years and cruised annually almost ever since. In the early days it was exclusively standard pouches which I emptied - often messy and time consuming.

When the flushable pouch appeared it made the daily changing easy, quick and effective. It did worry me sometimes when a used pouch did not flush at the first attempt, especially when very full, but that was rare. It was usually easy to overcome with a quick snip of the pouch material, where air would be trapped, before a second flush.

My first experience of the flushable pouch on a cruise worked, but only just. The adhesive flange was a rather substantial component to be sucked into the modest exit aperture of the toilet bowl and on one occasion it blocked, out of sight in the small bore plumbing. Yes, it was embarrassing to find a ship's engineer working on the pipework behind a door just down the passage from my cabin a while later, with an ominous odour in the air, and to be reminded that only loo paper should be put in the bowl. I believe about a dozen cabins were put out of action on that occasion.

My loathing of putting used pouches in the bin in the miniscule en-suite shower room and a determination to make the clever flushable pouch work demanded an alternative solution. I decided that I would snip the flange at 'fifteen minute' intervals round the rim towards the centre to make it less of an obstruction. It worked reluctantly! To make sure it had gone I added some extra water to the bowl and flushed again and all was well. However, I felt it would be better to separate the flange completely from the pouch and add a little extra water to the bowl in future. I have never had a problem since. The separated flange can be wrapped in a disposal bag to make a very compact disposal in the small bin supplied.

I have not tried the only other flushable product available today, the two piece item, for cruising nor tested my preferred brand without removing the adhesive flange because I was content with flushing just the biodegradable pouch and its contents. I would be interested in the experience of other colostomates. My modest scientific knowledge and observation tells me that the liner does not breakdown usefully in the short time in the water in the bowl and before passing into the pipework to make much difference to the package being sucked through the vacuum system. The less flexible flange must be an added load on the system and I prefer to remove it. My scissors do sometimes become slightly soiled in the cutting process but a wipe with loo paper followed by short soak in some diluted Dettol should be enough to keep the bugs at bay. For added hygiene you could use disposable gloves.

Don't be put off converting to flushable products. They are improving all the time and soon there will be many more users passing them through the sewage systems without blocking up the works."

#### Monty Taylor (CA Chairman of

Trustees) - has also recently been cruising. When he spoke to an engineer on the Azamara, he was also told that that no flange should be put down the loo but if the flange is detached and put into a disposal bag there would not be a problem as the rest is bio-degradable.

#### Written by

Rosemary Brierley Associate Editor

#### **Editors comment**

If you would like to have your say or contribute to the above debate or would like Rosemary to focus on a particular topic or issue that affects you please e-mail: associate-editor @colostomyassociation.org.uk or write to: Associate Editor, Tidings Magazine, Colostomy Association, 2 London Court, East Street, Reading, Berkshire. RG1 4QL

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## Irrigation and you...

Sue Hatton Executive Trustee writes...There has been another wonderful mixed bag of responses on Irrigation from the last edition of Tidings. Maybe that is not quite the right expression! Thank you all for your valuable contributions please keep them coming. We would especially like to hear from stoma care nurses who promote irrigation to their patients.

I had a calamity, when I went to Reading for a recent editorial meeting. Arriving after the meeting in Swindon for my granddaughter's Christening the next day, I realised I had left my base plate behind at my accommodation! I found to my dismay that I could not irrigate. Adding to my misery and realising it was a Friday I was unable to get anything posted in time.

Now, how would you cope in this situation? I had to go for three days without irrigating, something I do every morning! I was extremely uncomfortable and even more fed up when everything started to explode in the middle of the night - ARGH!

I also had an inquisitive two year old asking me, 'What you doing Granny?' Has anyone else got a good retort to satisfy little people!

**Note:** Irrigation equipment is very light - so if you go away regularly why not take a spare set of equipment with you. I wish I had!

Well, enough of me here's what you had to tell me...



I had a fascinating call from Richard Farrow who sent me a sample of his prototype sleeve (see left) and described his method of reusing the sleeve and

doing without a base plate. Maybe, if this had been in my overnight kit I would not have been so uncomfortable!

Another call was from a very stoical lady who has had her colostomy for 20 years, but has had to have a urostomy as well because of failing kidneys. Her stoma care nurse suggested that she try irrigation! She was on her third day of 'giving it a go' and wanted to chat about it. She was given half an hour of instruction by her stoma care nurse, who seemed to be more intent upon urging her to reuse the sleeves than ensuring that the water was at the right temperature etc., This call accentuates the need for an irrigator buddy system. My suggestion a stoma care nurse asks an experienced irrigator to help someone new to the procedure. I would be pleased to have your feedback on my suggestion! I was very pleased that the CA stoma care nurse asked for my advice, she admitted that she felt a little out of her depth giving confidence to a new irrigator involved in the irrigation process.

A couple of points came forward from these calls...

'Pam' didn't like the smell in her ensuite. I suggested that she light a scented candle or use an air freshener.

Pam admitted that she didn't think the water was warm enough as she could feel her bowel contracting when she tried to insert the cone and the water. She also resented the time sitting by the loo; I suggested a good book, radio, magazines or facemask and manicure!

She also disliked rinsing out the sleeve and reusing it. The stoma care nurse had only given her three sleeves to last ten days. I suggested a large jug of water next to the loo, so that the sleeve is unravelled and rinsed out into the loo while still attached to the belt, this means that there should be no faeces going into the sink.

A few queries - Reusing sleeves... Perhaps some of you have the answers?

- How many of you reuse your
- sleeves?Is there a recommended reuse for this product?
- Should we be asked to pay if we do not want to wash out the sleeve?
- How long should we retain the water bag before renewing?
- How many people steralise the equipment after use, what is recommended?

Note: The CA does not endorse reusing sleeves due to the possible risk of infection via contaminated equipment.

Triumphant! - Irrigation works...



In October 2007, Richard (pictured centre with son Tim and wife Rosamond) was diagnosed with rectal cancer.

#### Richards takes up the story...

It was a major shock to the system as can be imagined but I had magnificent support from my family and friends. Having had to undergo radiotherapy, chemotherapy and surgery I was left with a permanent colostomy. Six months of further chemotherapy left me pretty low. I felt the only way forward was a major challenge so I applied for, and got a place in the 2010 Virgin London Marathon. My son, Tim, joined in running for the RNLI and my wife Rosamond became Team Manager! (If you decide to take up any form of exercise always check with your GP before hand.)

The GREAT day arrived - 25th April 2010. Was I fit enough – No! Was I going to get round – YES! With help! Sure enough we did it! But what about my colostomy bag. Did the irrigation hold up? I had not checked the bag for some time so what would I find? NOTHING! Irrigation works! No residue left behind, no problems, and no worries during the run.

We received our medals – what a great moment! I had completed 26.2 miles. I was exhilarated if somewhat overwhelmed.

My thanks go to my stoma care nurses Jan Beard and Anna Wallace from Beckenham Beacon Hospital for their initial instruction and for their help in getting me started with irrigation.

**Richard Allardyce** 

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## Pathways to a colostomy

## Diverticular Disease with readers' experiences

For about one in ten people with a colostomy, their stoma was formed following a severe attack of diverticulitis. For some the stoma may be permanent, others may be offered a reversal

> Christine has written many articles and also co-authored the book pictured below with her friend and colleague Pat Black



This article was written by **Christine Hyde RGN CNS** in partnership with Jane Wood Editor Tidings Diverticular Disease is very much a Cinderella Disease in as much as there is some research but no answers just theories. Diverticular Disease first became recognised at the beginning of the 20th century and although the incidence of the disease is unknown, it is considered to be an older person's disease. Very often people are unaware that they have the disease and as yet there are no magic cure-alls that will prevent it or prevent further episodes of diverticulitis occurring. For those of us searching for answers to medical conditions such as Diverticular Disease, the Internet has become an invaluable information resource. however, offers of cures for medical conditions should be treated with some scepticism. It must be remembered that there is no substitute for professional medical care and advice given by your Consultant, G.P or Colorectal nurse.

## What is Diverticular Disease?

The term Diverticular Disease includes diverticulosis (the presence of small pockets or sacs or diverticula, in the intestine wall) and diverticulitis (inflammation of these small pockets or sacs). Diverticular Disease occurs in the bowel from problems relating to the presence of diverticula and/or diverticulitis. Diverticular bleeds, and long-term effects of recurring episodes of diverticulitis, may result in narrowing, thickening and poor function of the bowel in a specific area.

Research into Diverticular Disease is yet to produce precise evidence as to the causes associated with the disease. However, it is thought that several factors may contribute to changes in the wall of the colon. These include:-

- Diet related e.g. a low-fibre diet
- Ageing
- Internal and/or external pressure on the intestine
- Internal physical differences
- World population differences e.g. those from western countries have left-sided disease whereas those from Africa and Asia have right-sided disease

## What are the Symptoms?

The symptoms vary depending on the level of the disease. If there is mild disease where the symptoms are vague for example lower abdominal pain may be felt usually on the left side. Any further features of inflammation, such as a temperature could mean Diverticulitis. Pain is generally associated with eating and is relieved by passing faeces.

In Diverticulitis the symptoms are similar, abdominal pain, fever, a change in bowel habit, feeling sick or being sick and in some cases passing blood.

• **Bleeding** - Diverticular disease can account for over 40% of lower intestinal bleeding episodes. Severe haemorrhage can arise in 3-5% of patients with Diverticular disease. The site of bleeding may more often be located in the lower colon (large bowel). The bleeding is usually abrupt painless bleeding. The patient may have mild lower abdominal cramps or the urge to have their bowels open, followed by passage of a large amount of red or maroon blood or clots.

• Acute Diverticulitis - The Patient will be admitted to hospital with acute abdominal pain, fever, possibly bleeding. They will have had symptoms for several days that have not resolved either from own remedies or that of the General Practitioner. The first treatment will be antibiotics.

• Severe Diverticulitis - Patients are admitted to hospital with severe abdominal pain, a high temperature. They usually arrive in A&E in the middle of the night. They are then rushed to theatre where the on call team operate and a Hartmann's procedure is the operation of choice. This involves a laparotomy (opening of the abdomen) the part of the bowel affected is removed and a colostomy is raised. The patient usually then goes to the intensive care unit.

There is a move to reduce the number of emergency operations by offering patients a chance to have surgery following two episodes of diverticulitis. This is happening more for the younger patients but is becoming more acceptable for other patients. It may mean that they do not need to have a colostomy and more importantly they are not as ill as they would otherwise have become.

## **Patient Treatment**

Patients will have their abdomen examined for tenderness, swelling, and guarding to detect any unusual mass around the intestines. Other tests may also be carried out on blood, urine, and stool for signs of infection or blood. Computer tomography (CT) scan, ultrasound, and other imaging techniques may help locate diverticula and any inflammation, fistulae, abscesses, or other abnormalities. Today more patients are aware that they have Diverticular Disease because of investigations for a range of bowel problems. This means that although there appears to be an increase in the disease what it really means is more people are aware of the disease.

Nutrition may play an important part in prevention and treatment of both Diverticulosis and Diverticulitis. The advice given is to eat more fibre but this in its self may cause more problems. Patients should be advised to eat foods that suit them and their symptoms rather than follow a list of specific do's and dont's. A food diary can help the patient to determine what foods suit them and perhaps more importantly learn what foods to avoid. This in itself may well help to improve patient outcomes. Regular exercise may also have a part to play always seek medical advice before starting any exercise regime.

## **Explanation of terms... Diverticula, Diverticulosis and Diverticulitis**

### What are Diverticula?

Diverticula resemble pockets or sacs and occur in the intestine, usually the large intestine or colon. The diverticula or small pockets bulge outward through weak spots (like an inner tube that pokes through weak places in a tyre) in the bowel wall. The pockets or sacs trap faeces in which bacteria multiply, resulting in inflammation. It is not known whether one diverticulum (pocket/sac) presents singly and then spreads or whether they occur all at once. They can be found in any part of the bowel. However, they occur predominantly in the sigmoid colon.

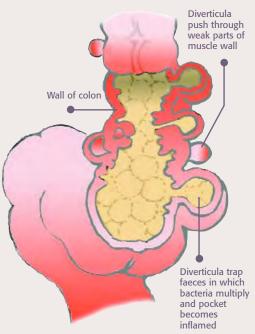
#### What is Diverticulosis?

If diverticula are present in the colon, the condition is known as

Diverticulosis. This 'symptom free' form of the condition is sometimes known as Asymptomatic Diverticulosis. Diverticulosis is a very common condition with 50% of people being affected by the condition by the age of 50, and 70% by the age of 70. Approximately 75% of people with diverticulosis will not experience any symptoms associated with Diverticulitis.

#### What is Diverticulitis?

Diverticulitis is a condition in which diverticuli in the colon rupture. The rupture results in infection in the tissues that surround the colon.



## **Diverticular Disease** - readers' experiences

Two readers tell us of their experiences: Carol who has now had a reversal and Wendy who still has a stoma and is back living life to the full.



## Carol writes...

In November 2007 I was diagnosed with diverticulitis after just a couple of unpleasant bouts of stomach pain accompanied by constipation - nothing too serious. At the beginning of February 2008 I was very well. I had had friends for dinner the previous

evening and was just about to go to the hairdressers when I was gripped with agonising pains and diarrhoea. After an hour or so, I was able to phone a friend who came over straight away. I remained in severe pain and was vomiting too so she called a doctor. When he arrived he said it was probably an infection due to the diverticulitis and gave me antibiotics and pain killers but to go to A&E if it didn't get better.

To be honest I felt so ill that I couldn't face getting out of bed to go to the hospital and the painkillers helped. The following Monday my GP phoned to see how I was and asked me to go to the surgery. She took one look and sent me straight to the hospital. After a scan and some tests I was rushed to theatre as I had an abscess which had burst causing peritonitis. I had no time to be prepared so I didn't even think of the consequences of waking up with a stoma.

I was still very ill of course having had a Hartmann's procedure. I truly believed I was going to die and it was four weeks before I was discharged and even then I was very weak and had to be cared for at home. But I had a wonderful surgeon, Miss Donellan, at The Conquest Hospital in Hastings and an excellent stoma nurse, Sue Field, who helped me tremendously and although I didn't like having the stoma I realised it had saved my life.

They said I could have a reversal six months later and at first I couldn't wait but as the time drew nearer I was very apprehensive. I'd coped quite well with the stoma and had even been abroad. I'd also been reading an article on people who'd had a reversal and wished they hadn't. At the end there was a piece written by a surgeon who said most were successful, so I wasn't sure what to do. I decided to delay it, partly because I was about to become a grandmother and wanted to be able

## **Pathways** to a colostomy **Diverticular Disease** - readers' experiences

to help, also I wanted to visit some friends in Florida and Christmas was coming up. In the end I decided to go ahead. I am a widow and have a new partner and thought it would be nicer if I didn't have the stoma to worry about. I had the reversal last February. It all went very smoothly although there were a few hiccups when I first came home, but after a few weeks there was no looking back and I am so pleased I had it done.

I am getting married in April and am very grateful for my new life.

## Wendy writes...

At the time of my operation, I was an active, healthy sixtyfive year old and still working part-time as a dispensing technician for a big supermarket chain. About two years or so before surgery, I had really bad stomach pains and on visiting the doctor was diagnosed with diverticulitis, subsequently

The doctor prescribed strong antibiotics and also Mebeverine, and told me that were the attacks to continue it could, in time, lead to surgery and the possibility of, horror of horrors - A BAG. He also said that should a further attack occur I should 'take the tablets'. This I was perfectly happy to do and yes, the tablets worked both the first time and then as further attacks subsequently occurred.

As one of my activities, I enjoy walking but was always a bit anxious wondering, "will I need to 'go' urgently" and if so, would there be a handy convenience. Occasionally, when there was no nearby loo or even convenient hedge, the worst happened with pretty dire consequences.

One morning, however, a Wednesday, I had got up to go to work, had my breakfast, and then somehow managed to crawl back upstairs to the bathroom with the most agonising pains I had ever had. I woke my husband, John, who eventually got me undressed and back into bed and phoned for the doctor. When the doctor came, he examined my tummy and wondered if I might have a touch of food poisoning as these were pains like I had not had before when the diverticulitis had flared up. He said to call him the next day if I was no better. Well, I wasn't! He came, took my temperature, then said the dreaded words, 'ambulance' and 'hospital'.

Once in hospital (Southampton General) various questions were asked and tests done including a CT scan. On Friday morning it was off to theatre, where due to an eruption of the diverticula it was found that peritonitis had set in. Nine inches of bowel was removed, a Hartmann's Procedure performed and when I woke up in HDU, there was my stoma all ready and waiting.

A couple of days later I was moved on to an ordinary ward, where I met a lovely stoma nurse named Diana. She talked to me about what had been done and then about the stoma, after which she showed me how to look after it. A couple of days after this she watched whilst I changed the bag myself, then after that I managed very successfully on my own; always knowing, however, that Diana would be there to answer any questions and help if necessary. By now, I was eating once more and my stoma was beginning to function. Whilst in hospital I lost a stone in weight which, by all that is wonderful, I have kept off.

Before going home I was given a second CT scan as a tumour had been discovered necessitating the removal of my spleen, part of my pancreas and also, of course, the tumour. I know it is thanks to having had to be admitted originally for diverticulitis, that the tumour was discovered. I therefore feel that my stoma is, in a way, my life saver.

After a week in hospital it was time to come home, and then just over a week later John and I went to Devon for a holiday which was a really quick way of showing me how little trouble a stoma is to cope with. Since then I have made three short-haul flights, and am looking forward to my first long-haul. I am back at work- usually cycling there, a distance of three miles each way; and also back walking without fear of accidents or wondering where the nearest loo is. This year I took part once more in the Race for Life - this year, of course, without any anxieties as there are no loos on the 5km. course. I have learned that there are some things my stoma doesn't like such as spicy food, garlic, onions, swede or Shreddies; and that corn flakes tend to make me constipated. Fortunately I like Weetabix so enjoy that at breakfast time. I cope perfectly well with fruit, cabbage and even a few sprouts are no problem; I have also had the odd glass of wine.

At the moment my stoma sits quite happily on top of a parastomal hernia which is no bother. It is usually very well behaved, but when pancaking occurred my stoma nurse recommended a small bridge be put in the bag which has helped considerably. I sometimes put a small amount of baby oil or gel into the bag which also helps. When I change my bag at home, I use soft baby wipes with aloe vera, and have had no skin problems. If attention is needed when we are out or I am at work, I use ordinary 'wet ones' which I carry in my small handbag-size kit. This also contains a Radar key a couple of spare bags plus an adhesive remover, tissues and disposal bags.

I live happily with my stoma and, having had two big operations in the space of three months, I am not looking to have a reversal. I have since been seen by my surgeon, and he also feels that as there are no problems to leave well alone, and he has discharged me.

Life with a stoma, then, can be easy and straight-forward and be lived fully and satisfactorily without anxiety, unnecessary awareness or embarrassment - enjoy it.

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## An ostomate's travelogue downunder...

Written by Moira Hammond

Moira, Michael and Chris Hammond on Christmas Day at Bucklands Beach, Auckland

Reader PANEL contributor

Since my permanent colostomy was formed five years ago due to rectal cancer when I was 62, I've taken several holidays overseas. I have gained courage and advice from others who have managed. I thought I would share some of my recent adventures in Australia and New Zealand with you all...

My husband Chris and I visited New Zealand on two occasions prior to my surgery to visit our son Michael, who lives in Auckland. However, we had always promised ourselves a trip to Australia to visit friends and relatives there, so we eventually booked a twomonth trip. The first hurdle was sorting out the insurance, which was now a little more complicated as Chris had had a minor heart attack last year. However, we got a good annual policy from Columbus, which gave us 60 days cover (many only give 30).

We spent many hours pondering our holiday route round Australia - we wanted to visit an old college friend of Chris's who lived in Sydney and some distant cousins in Canberra and Leeton, and then journey to Melbourne and Adelaide if possible, travelling to Auckland in time for Christmas with Michael and a tour of the South Island afterwards. From experience we have found a break in the journey such as a two-night stopover in Singapore and a three-day one in Bangkok really helps conquer jet lag.

The next decision was whether to hire a car or a motor home for our adventure. The advantage of a motor home is of course, no daily unpacking of suitcases; the advantage of a car is that it is much cheaper! We did our sums and decided to go for the comfort of a motor home. We would economise by cooking in the van and picnicking.

So much planning to do...Trying to pack lightly! Sorting summer clothes (with a few warm ones just in case), shutting the house down, writing early Christmas cards and letters, ordering medication, plus all the other necessities, not to mention how many pouches to take! My distributor was good enough to agree to post a month's supply out to Michael in Auckland; even so the first month's supply (plus extras in case there were any delays leaving Australia) meant a fair number. Would the heat mean that the hydrocolloid adhesives might come off? I took OakMed microskin ones as extras as well as Coloplast plugs for swimming, plus of course some drainables in case of a tummy upset. All this doubling up meant a considerable number of pouches! The main supply was to be carried in our hand luggage of course (liquids in the obligatory plastic bag) and extras divided between both suitcases in the hold

So the great day comes, an 11.00am departure from Heathrow meant a 6:30am flight from Manchester. Oh, how I hate early mornings! A couple of Loperamide tablets to slow things up on the bowel activity front are useful.

No problems with airline security and I wasn't subjected to the body scanner, but on one occasion (Melbourne to Auckland flight) I was called to one side for a 'random' body check. They gave me a written explanation and I explained I had a colostomy. The check-over with an 'electronic wand' and 'frisking' was all done in a reassuring, friendly and efficient manner. They then checked my hand luggage and wished me a happy journey and goodbye - I wasn't at all bothered by any of the procedures. It could be a co-incidence but on this occasion I had shortly before made use of the disabled toilet to change my pouch. Perhaps airport cameras thought it strange that an able bodied person should spend so long in that toilet! Otherwise, it was just the usual metal detector arch.

The flight to Singapore was uneventful with my bowels behaving well. Flights on this trip were trouble-free: the feared, but illogical, wind in the bag situation doesn't occur I didn't have to change my pouch while in flight, though I have done so before now.

We arrived at our Orchard Road Hotel at 8.00am, and after checking-in, had a four hour sleep. Orchard Road was brilliantly lit with Christmas decorations, Rudolf and Jingle Bells playing, so strange in all that heat. Back at the hotel the combination of tiredness, heat and I suspect, a very cold dessert that evening, hit me. I started being sick, 'Oh dear', I thought, 'A tummy upset already. What a start'. However, after an hour or so it all settled down and I awoke the next morning feeling fine! What ever it was didn't get to my bowels.

We left Singapore on an evening flight to Sydney where our friends met us. We did the obligatory visit to the Opera House and a day trip to the Blue Mountains with a walk at a nature reserve. It all made for a very pleasant stay with good friends.

Our 17 day motor home journey then commenced... All mod cons included: sink, cooker hob, microwave, fridge, shower and toilet. First to Canberra where it was lovely to meet relatives and see the city. As we travelled on towards Leeton the countryside became a bit more arid. However, the Murrumbidgee River has been developed to provide crop irrigation, as it is a big fruit growing area. Herein lies a story.

We had stocked our fridge up with fruit and vegetables at Wagga Wagga, (what a lovely name) and set off towards Narranderra when we saw road signs saying "Eat your fruit now or throw it away." 'How peculiar' we thought. Then more signs warning of large fines and a fruit fly exclusion zone. Eventually a lay-by with bins and a large notice 'Stop here and deposit all fruit and tomatoes. \$11,000 fines'. We consumed bananas, apples, tomatoes, cherries and wonderful mangoes and then fearing a bit of a revolt from my insides, reluctantly threw the rest away! What a waste.

Through all this my stoma and pouches behaved impeccably, though my skin did get a bit spotty at one time, due I think to the heat. As my output is pretty predictable I thought an airing would be the answer. Being high up in a van, I was able to travel, Chris driving of course, – pouchless, (no output, despite all the fruit!) with tissues, wipes and pouch to hand. A few days of this treatment with applications of barrier lotion and all was well. (Does this qualify for the unusual pouch change competition?)

Returning towards the coast via the

Snowy Mountain area we continued towards Melbourne stopping off at Phillip Island to see the evening Penguin Parade - about 1000 cute little Penguins come ashore each night to feed their chicks. Another stop was Ballarat, an old gold mining town with notorious extremes in weather. The first night it was really cold but the day soon warmed up as we looked round the town. The next day it reached nearly 38°C as we went round Sovereign Hill, which replicates the life in Ballarat 150 years ago. An entertaining and fascinating place.

On the practical side of travelling with a stoma, it was easy in Australia when camping, as the amenity blocks were so good. The shower cubicles were nearly always in two parts with a dry area with a bench and coat hooks, so I was able to hang my changing bag up and spread all the bits and pieces out on the bench, whilst using a little of the shower water to wipe my stoma. I had been keen to have toilet facilities in the van for changing my pouch, but in fact there wasn't enough room to change.

Disposals were not a problem, I sometimes use a drainable bag which cuts down on the number needed but am in the habit of emptying the pouch in the toilet first, then fold it to stick to itself, pop them in the bag and twist, many times and double it back into the bag before tying. It makes a very small packet which I put in the hotel bin or take out with me to find a bin in a public toilet or I leave them in the sanibins in the campsite toilets, (yes I know it is easier for ladies). I explained to my friends about disposing them in their rubbish just as babies' nappies are disposed of.

Travelling to the Grampian Mountains and camping at Hall's Gap, we were treated to the company of six emus and a group of kangaroos. We then drove along the stunning Great Ocean Road with fantastic scenery and huge waves crashing onto the cliffs. Then finally, we returned our little home on wheels at Melbourne, staying a couple of days exploring the lovely city whilst looking forward to spending Christmas with Michael.

And what a different one that was! We sat on a lovely beach near his home eating crayfish with salad and fruit and swimming in the gorgeous calm sea. After a few days we set off with Michael to the South Island, spending 3 days at Nelson. One of our best outings was a boat trip from Kaiteriteri up the coast of the Able Tasman National Park on New Years Day. We thought of everyone back home battling the snow, it made me realise how lucky we were. We stopped at many beaches; Awaroa, was one of the most beautiful I have ever seen. We enjoyed a picnic and a swim in sparkling clear water before reluctantly rejoining the boat on its return trip viewing seals on the rocks as we went.

A few days later we were walking up the glacial Hooker Valley towards the foot of Mount Cook for a four-hour walk. We spent a couple of days in Christchurch, the most English of cities before travelling to Kaikoura where we had booked a boat trip to watch whales. Sightings are almost guaranteed, as this is where young male sperm whales come to mature. We were lucky to see three whales at quite close range before they flipped their tails and 'sounded'.

On our return we stopped on the volcanic plateau - one of the film locations for Mordor in the film 'Lord of the Rings'. We wanted to see the volcanoes clearly so the following morning we got up at 5.30am to be rewarded with perfect views, but as the sun rose, clouds began to gather and we returned to our motel before travelling back to Auckland.

I guess I'm a lucky ostomate to be able to tackle this journey without any problems, but I have well behaved bowels and enjoy all sorts of food. Michael took us to a lovely Japanese restaurant where we enjoyed sashimi (all raw fish:- scallops, salmon, octopus and white fish). The next night it was a Korean buffet meal, more sushi and oysters amongst other exotic things.

I think Michael was on a quest to get me to do unusual things; we went snorkeling among some quite sizeable fish at Goat Island and body boarding on a surf beach! Having put a plug in my stoma and a support garment under my costume, I ventured into the surf and soon got the hang of catching the waves, only getting knocked off once!

Sadly, the last week flew by and we had to say our goodbyes to Michael, but still a bit more holiday to come as we flew to Bangkok.

So the trip of a lifetime ended, thankfully without unwelcome incidents and I would encourage any would-be travellers to enjoy their holidays whatever they arrange. The trick is to plan well and be positive. We might not like what life has done to us by way of plumbing alterations, but we are still here so "Go for it"!

Good luck to you all! Moira Hammond

## **Breakaway May Weekend 2010** A buzz of activity and excitment...



As the first event of 2010 approached I began to worry as I always do every year! As Breakaway grows a pace so does the responsibility. I find myself asking the same old questions...Will people turn up? Will it be as good as the last one? Will people get on with each other!

However, as usual my worries were all for nothing as on Friday evening families slowly but surely trickled through the door. There was a buzz of activity...families who had attended previously came bounding through the door full of excitment! Children abandoned parents unloading their cars, and went off to check out their new surroundings. New parents with their children arrived nervously , but were soon at their ease as they began to realise they were in the midst of 'families just like themselves'.

I asked Hannah (aged 9) my daughter to keep a little diary of the weekend. The idea being that she could share it with other people to explain what goes on at a Breakaway Weekend!

Breakaway is now in its fourth year, and this was our sixth event. As I said earlier Breakaway is growing a pace and our greatest hope is that it will continue to do so - so that no family has to travel on this journey alone.

## Julie Bastin Chairperson

## Hannah's Breakaway Diary

I am so excited about tomorrow I don't think I can sleep! I am especially excited as I had surgery a few months ago to have a Mitrofanoff, it's all very new and scary!

## Friday 28th May 2010

I had a visit from my nurse this morning; she brought me a Hannah Montana bag so I can carry my catheters about over the weekend. There are lots of new families and some I already know. We had dinner then played silly games outside. One with wellies on the wrong feet and another one with cups of water, one Mummy threw a bucket of water over a Daddies head. It was very funny! Bedtime now I don't want to go but we are up early in the morning - night, night!

## Saturday 29th May 2010

After Breakfast we got on a coach to go to the activity place. I did canoeing first which was really good fun. We got soaking wet through, my Daddy fell out his canoe when he steered it into a bush, everyone laughed at him. After a lovely lunch we went on a huge zip wire which was about 11mtrs high, I was really scared, but the instructors helped me and reassured me and ZOOOOOOM! It was fab! Then we went on the high ropes course, I decided I didn't want to do this, it didn't matter – no one makes you do anything you don't want to do. I stayed with one of the other Mums and had a cuddle out of the wind; it was very funny watching other people fall off. A face painter came after dinnertime, which was great fun, I am in bed now and I still have flowers on my arm.

#### Sunday 30th May 2010

This morning I had 3 goes on the climbing wall that came to the hostel, on the last go I got right to the top! My friend Brett came today. Mummy let me ask him to come as he has been a very good friend whilst I have been poorly recently. We played some games with the instructors, had an ice cream and a mini farm had ben set up with little pigs, lambs, chickens, and a pony - we got to feed the lambs their bottles. The best bit was tonight, we had a BBQ inside as it was cold, followed by a disco and we all had glow sticks. I danced and had fun with all my friends!

#### Monday 1st June 2010

I slept in today and missed Breakfast, one of my new friends; she is only five, came and woke me up by climbing up to my bunk and pulling the covers off me! We had a look at different things from the stoma care companies this morning, which was good. After lunch it was time to go home, I was sad to leave. I just can't wait until the next Breakaway, it's a weekend where I can just be me - it always makes me very happy!

See you again, Hannah

"Great opportunity for families to share experience, gain support, and friendship. The kids get to have fun and develop their independence. It's great!"



## Max (Age 17) writes...

breakaw

Breakaway, well what can I say...I have been to every Breakaway weekend since 2007 - the event really is an emotional roller coaster ride but what a difference it makes to all who attend!

When you get there, you think - finally, people I can share my story with who understand. I can listen to other people's stories and pick up hints on how they get over any problems. You also learn that there's loads of things you can do even with a bowel and/or bladder problems, things that I thought I wouldn't ever do again after having the op.

Without Breakaway to go to I think I would still be a shy closed person scared of people ever knowing I'm different so to get out and see others with a similar problem is heart-warming. Especially when you know that you can speak out without fear of bullying.

Breakaway is a family to me, everyone's so friendly and great fun to be with. Breakaway makes me realise that some of us have to endure really nasty things. One little girl has been robbed of so much, but she still was very determined to have a good time and I enjoyed helping this come true for her.

There's also a very nice emotion that I started to feel for the first time, and I feel confident with it.... love and thanks to breakaway I actually started to feel it. To be honest Breakaway is a very emotional place but it's the best place for young children and teens to go if they have a bowel or bladder problem.

Thank you, Rachel, Julie and the Breakaway team, for helping all these people and for helping me gain the confidence to live with my condition.

"I really love it at Breakaway and would come again. Meeting people who have the same problem as me is the best thing ever."

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## What has **Ostomyland** and **James Bond** got in common? Well, if it wasn't for **Ian Fleming's super spy - Ostomyland** may never have been created!





Jason Dale is thirty-five years old and lives in West Yorkshire. He has a colostomy and is the webmaster/owner of a website called 'Ostomyland'. www.ostomyland.com is an ostomy support community blog/website that Jason funds from his own pocket and it will soon be celebrating its 13th Anniversary online. Jason tells us how it all began...

Picture the scene. It's New Years Day 1998 and I'm sat in the living room with the family. We're all recovering from the large celebratory lunch, and lounging on the comfy chairs in front of the telly waiting for the James Bond movie to start on ITV1. Snores from my parents, and my dog, fill the room, as they contentedly sleep off their belly-busting lunch, and I – out of boredom – pick up a copy of ".net" magazine whose front page promises to spill the secrets of creating your own home page from scratch with HTML code. Soon after starting to read the magazine, I got bored of the Bond movie so I quietly left the room to go to the computer and started to try out the HTML coding projects the magazine had featured.

To my surprise I found the coding quite easy to pick up. However, it's all very well being able to code an internet page but what on earth could I talk about on it? I was new to the Internet. Freeserve had launched about six months previously and so I was still finding my feet online, and discovering what a wonderful resource the information superhighway was. It seemed it had pages on everything...except for a page about life as a "young ostomate" – which was what I had become only six or seven months previous on the June 16th. Most of the books I'd read pre-op about colostomies were all aimed at the older generation, and failed to answer the questions I had as a twenty-three year old faced with this life changing operation. And so, with my copy of ".net" magazine on my lap, and my computer humming away, I thought I'd rectify this by putting my story online.

Twenty-one days later, "Jason's Homepage" was uploaded to my 10MB of free ISP web space - a whopping two whole pages of content. One page focused on me, my hobbies and interests, while the other page focused on what it was like to be a young ostomate. It wasn't a lot, but it was my first site. I was mighty proud of the achievement.

At the time of my stoma operation I wrote a diary of my hospital visits and the early weeks afterwards. I took those notes and wrote a colostomy lifestyle guide aimed for younger people, covering topics that were interesting for all ostomates, but would especially help to allay any fears younger people might have e.g. travelling with an ostomy, sex and relationships, sports and swimming, returning to work or school and so on. I'd submitted the book to healthrelated publishers but always got rejected with comments that the content was too specialized. However, I was utterly convinced that it was in demand and of use to people. So once my new-fangled internet page was online, I dug around in my desk drawers and pulled out the manuscript for the colostomy lifestyle guide book with the idea of publishing it online.

Over the course of the following month I retyped and edited it for publication on the internet and uploaded the whole guide in one large update to my homepage. With that one update the number of pages on my website went up ten-fold. By this time I had ditched the personal homepage idea totally, focused solely on ostomy information and relaunched the site with the title "Living with a Colostomy".

Out of curiosity, I added a free webpage hit counter service to the site, so I could see how many times the pages were visited. I set myself a target of 100 hits in the six months, which I expected to miss by a mile and to lose heart in the project. To my utter shock I shattered that target in the first two weeks and nearly broke 1000 hits in two months.

Then I discovered IRC chat. I thought to myself that it could be a great tool for getting ostomates to talk to each other, to swap notes, or support each other, or even just to hang out with like-minded people. After some research I found a program on the net that I could install onto my website and allow people to chat there and then. At first there would only be two or three people in the chat room over the course of the night, but they told their friends, and at its peak it wasn't uncommon to have seventy to a hundred people come through the doors on the night, and it would average twenty or so people online at any one time.

Thanks to the inclusion of a message board, the website started to take on the look and feel of a community. People would post supportive replies to complete strangers, make them feel welcome and comfortable enough to vent or ask questions at any time. It is always so satisfying to see people come to the site as an utter wreck, feeling they are alone and helpless, and then over the next year or so be supported to the extent that they would develop into the person who then gives support to others by reassuring them that life does go on and things do get better no matter how bad things might seem at the time.

Soon after this the manufacturers' section of Ostomyland was born. This is where I list the major ostomy

product companies along with their contact details, their best selling products and their new products. I invited the "big four" (Coloplast, ConvaTec, Dansac and Hollister) to have a free feature page on the site, and soon after other companies were asking if they too could be featured. And to this day I'm still adding pages from companies who ask to be on the site.

About six years ago the site started to outgrow its free web space roots and so I had to face a choice – close down the site, or invest in proper commercial web space. The decision was easy, and so the first of my proper web space accounts were leased. The years came and went and I hit my 30s. More and more people started the visit the site looking for information on other ostomies and the decision was made to expand the site from a colostomy site to one that covered all ostomies and so the site name changed from "Living with a Colostomy" to the name of our chat room: Ostomyland.

And so to blogging: many of our members had started their own blogs on various blogging networks and I realised what a great resource they could be for the Ostomyland community and ostomates in general. It has taken a number of years to find a way of getting blogs on to Ostomyland that would deliver a quality feature without risk of destroying the current board database, but it was worth the wait. As many of you know I launched the new message board system in September 2009 and included in that is the ability to create and edit blogs. Hurray!

At last count twelve people help me run the site, be it as a senior admin on the site, or a moderator on the message board, or a chat room operator. Ostomyland couldn't exist without Kathy my "number one" and the other fantastic members who give up their time freely for nothing more than a word of thanks from me because of their love for the community.

To date Ostomyland continues to grow. We've recently broken our six millionth hit, averaging two to three thousand page views a day, and we're welcoming approximately a hundred new people to the main site every single day, some of whom register to be part of the community and stay for years. Whilst it's great to have so many ostomates visit Ostomyland, it is sad that so many people are in need of help, especially those from outside the UK, where it seems so many people do not have access to a Stoma Care Nurse specialist. Although Ostomyland started as a hobby project, it is now very much a full time job squeezed into my spare time. It's a continual work in progress; we've recently revamped our Ostomy Wiki and launched version 2 - at present 225 pages. The site will continue to evolve to try and reflect the new trends that launch on the net - recent examples of this being the Facebook and Twitter groups pages. And, whilst I am at the helm, Ostomyland will always be a free-toaccess/join site.

My parents don't understand why I put all the hours into the site in return for what they see as nothing. My reward is the occasional email of heartfelt thanks that comes in from someone who has received support that has pretty much changed their life. Then I get that warm, fuzzy feeling inside and realise that THAT is why I do this.

I never for one moment thought I would be sat here writing about the history of the website, nearly twelve years on from that boring New Years Day when I picked up the magazine...

And it's all thanks to James Bond... wow!

Jason Dale Webmaster/Owner Ostomyland.com webmaster@ostomyland.com

Jason would like to thank the BCA and CA for everything they've done for Ostomyland over the years.

#### Jason says:

"The single biggest event in the website's history was when the old BCA (British Colostomy Association) asked their webmaster at the time -Ian – if he would get in contact with me and help the site improve and evolve. To this day, I am eternally thankful to the BCA for this, as without that one important event I am certain that my skills would not have grown, and the site would not have become what it is today. In my eyes he is Obi Wan to my Luke Skywalker. He is my mentor. He is my friend. I was so sad to see the BCA close down; my heart literally fell at the news. But it's been fantastic to see the CA rise from the ashes and grow from strength to strength over the last few years."

## NEW SERIES Problematic stomas... Dips and creases

Written by

Melanie Jerome RGN, BSc(Hons), CNS Amanda Gunning RGN, CNS Chelsea and Westminster Hospital NHS Foundation Trust

It is so important to speak to your stoma care nurse if you are having problems with your stoma. There is an extensive array of products on the market in order to cater for each individual's needs. Therefore, finding the right product for you is essential. The following article will highlight some common problems and outline some of the solutions.

Ideally the pouch change should be as simple as possible. However, any complications with the stoma, leakage or the fear of leakage can cause individuals to curtail their work and social life and may often lead to social isolation. Sometimes the stoma does not sit flush with the surface of the skin; in stoma terms this is known as a peristomal dip, crease or moat. This means that the base of the pouch is unable to sit on a flat skin surface, which leads to difficulty in adherence and instability, causing the bag to leak and the skin around the stoma to become broken and sore.

There are several reasons why you may have dips or creases. The surgery may have been an emergency therefore the stoma care nurse was unable to mark the most appropriate place for the stoma, avoiding abdominal creases, previous scars or bony prominences. There may have been a technical difficulty during surgery, which has caused the abdomen to become uneven. The individual shape of the abdomen may have natural dips and creases and any weight gain or loss will cause the abdomen to change shape, this includes pregnancy.

#### So what is a peristomal moat?

The word peristomal describes the skin area around the stoma; the moat is a hollow of skin, which may be partially, or fully, around the stoma. The base of the pouch is then unable to adhere to the skin due to the gap produced by the moat. The solution may be to use a washer, or half a washer, to fill the gap and therefore provide a flat surface for the pouch to adhere to. There are many different washers, or seals, available and your stoma care nurse will help you decide which is the most suitable for you.

## What is a peristomal skin crease?

Skin creases can occur naturally on the abdomen but become problematic if the stoma is sited within one. Again, this may be due to emergency surgery, or as a result of weight gain/loss. The abdominal skin may then overhang the stoma causing a crease. If this is the case it is very important to use a good technique when applying the pouch e.g. standing and using one hand to pull the abdominal skin taught and using the other hand apply the pouch thus smoothing out skin creases. There are creases that cannot be smoothed out and for those you may require a convex appliance, which your stoma care nurse can assess. The base plate of the convex appliance curves outwards to smooth out creases and fill dips. Convexity must always be prescribed by your stoma care nurse as the pressure may cause bruising or soreness and will require monitoring.

#### What is a skin dip?

Skin dips are changing contours in the skin. The skin may have become distorted during your surgery and the place where the stoma is formed may pull into a dip, even if your stoma was sited prior to your surgery. There may be one or many dips around your stoma causing difficulty with pouch adhesion and therefore

leakage. Also available is strip paste, which can be handled and moulded like plasticine is sticky and useful to fill in the creases. Paste may also be used on its own or in conjunction with other accessories. Paste comes in a tube, just like toothpaste, and can be squeezed into dips. It is best to damp your fingertip before you touch the paste in order to mould it, as it is very sticky! This will not inhibit the adherence. Some pastes have an alcohol content that may cause slight discomfort on broken areas of skin.

Your stoma care nurse may suggest a two-piece appliance as the added accessories can make the appliance change more time consuming. A two-piece appliance has a separate base plate that attaches directly to your skin. The second part, the pouch, then attaches to the base plate. The pouch can then be changed leaving the base plate on the abdomen. The two-piece system may be useful if you change your appliance frequently throughout the day.

Stoma construction, body contours and personal capabilities (dexterity, eyesight etc) will all contribute to the choice of accessory your stoma care nurse may offer. Seals, convex appliances, strip pastes, paste and two-piece appliances are available from many different companies.

Everyone is different. Your stoma care nurse will provide you with an excellent service based around sound advice and professional expertise helping you to select the appropriate products for your needs. By keeping in touch with your stoma care nurse and up to date with stoma management you can carry out your everyday activities happy in the knowledge that your appliance won't leak - giving you extra confidence!

# **Readers'** writes

Why not write or email the Editor of Tidings with your thoughts, experiences or hints and tips...

#### **Dear Editor**

I am writing in response to a letter in the Spring issue from a lady who has decided not to go ahead with a colostomy reversal for fear of the uncertain results. I also had to make that decision and I am aware that there seems to be a lot of negative comment and not much positive and I would like to redress the balance.

I had a colostomy performed as an emergency after my bowel perforated in July 2007 - eight days in ICU with severe sepsis and five weeks in hospital. My wound became infected as is common in these circumstances so I was left with an open wound and a new and unexpected colostomy. Tidings magazine was a lifeline in my new world. I also developed an incisional hernia and I felt that, following the trauma I had been though, I would never want a reversal.

However, the hernia became progressively very large and uncomfortable and as a year later I was forced to have surgery for that it seemed I might as well give reversal a go. I read everything I could both in the magazine and on various online forums and a lot of it was very negative with people regretting it and stating that their lives were easier with a colostomy. I realised that it is much more likely that people write to forums or magazines if things have gone wrong whereas if things have gone right there is no need to express your pain. I also felt that I had to give it a go.

So in June 2008 I had a reversal and a hernia repair. The surgeon decided that it would be good to form a temporary ileostomy to protect the new join, and then reverse that in a few months time. I can therefore say from experience that a colostomy is much to be preferred. The ileostomy was reversed in November 2008 and I waited for all the terrible things that had been predicted to happen. They didn't. I had a few days where I was rushing to the toilet several times a day but it settled really quickly, and by Christmas I had a regular pattern of daily perfectly formed bowel movements. As I had nine inches of bowel removed I don't get a lot of warning before I need to go but that has improved and I would now say that my daily morning bowel movements are as normal as anyone else's.

I just wanted readers to know that temporary colostomies can be successfully reversed and if your surgeon's advice is that it can be done there is a chance that it will all go right.

#### B.B. (Mrs)

I am so pleased that your reversal has been successful. Thank you for letting us know because, as you say, it is those people for whom things have not gone as well as they'd hoped who usually write to us, so sometimes the articles and letters can seem a bit negative. Ed.

#### **Dear Editor**

I have just read the item Forty Years On by Michael Rose in the winter issue of Tidings. This takes me back thirty-three years to March 1976, when we lived in Essex and I had my colostomy operation at Basildon Hospital.

I was a member of the Colostomy Welfare Group and went to meetings in Eccleston Square. In the late 1970's Essex Radio held a week of programmes on Self Help groups and I represented CWG. It was the longest five minutes of my life! Then I answered phone questions for thirty minutes.

In 1984 we moved to Cheshire with my husband's work and I continued to be a voluntary visitor for CWG. I still sometimes attend open days in Macclesfield.

I am also a member of IA and have made many friends at their meetings.

Carry on with your splendid work.

Yours sincerely M. B. (Mrs)

#### **Dear Editor**

Following my diagnosis of anal cancer in early 2007, I had a temporary stoma formed prior to undergoing an aggressive course of radiotherapy and chemotherapy. In November 2008 I had an operation to form a permanent stoma and also to carry out a parastomal hernia repair. My rectum was so scarred from the radiotherapy that a reversal was impossible.

I was not too disappointed as I had got used to my stoma, but following my discharge from hospital, I had some problems with infections and was quite poorly for a while. After being told that another parastomal hernia was unlikely to happen, I of course got another one, but I am reluctant to have another repair as they may have to re-site my stoma and there are no guarantees it will not happen again.

I had an operation to dilate my rectum to ease the passage of mucus late last year and am due to have another one in a couple of months. The first one helped a tremendous amount.

I know I would not have got

## **Readers'** writes

through the last three years without support of family and friends and the marvellous medical staff at Chatterbridge and Arrowe Park Hospitals. I am sixty-two now and feel so lucky and blessed to have been given a second chance. Last year I holidayed in Bournemouth, Croatia and Tenerife and had a great time – big bumps and all.

Thanks also to Tidings and the CA. Hearing other people's experiences and getting information about new products is invaluable. You feel like you are not alone which can be a great comfort at a very difficult time.

#### Yours faithfully

#### D.B. (Ms)

#### **Dear Editor**

I have been a colostomate since 1998 and I began to use Welland Freestyle Vie flushable pouches five months ago. The medication I am taking for the pain caused by a slipped vertebra in my lower back is making my faeces dryer and firmer and sometimes of larger volume than it used to be. I am therefore using mainly maxi pouches and only use a midi pouch if I know I will be changing it after a short time.

Just once have I had difficulty flushing the inner pouch and contents down the toilet. The pouch was very full and the water in the toilet rose up almost to the top, before slowly going down. I flushed the toilet again and this time all was well. So the pouch had been too full. Since then if the pouch has been very full I have emptied some of the contents from the top of the pouch into the toilet and then dropped the pouch into the toilet.

After taking the pouch off I have always cleaned around the edge of my stoma with toilet paper and warm water. I used to then dry it with a swab and put the swab and the more or less emptied nonflushable pouch and the plastic circle which had covered the flange into a blue disposal bag which went to landfill. Now I no longer use disposal bags or swabs. I dry around my stoma with toilet paper or a towel. The clean outer pouch and plastic flange cover go with other plastic items to recycling. What I like about flushable pouches is that everything goes either down the toilet or to plastic recycling, rather than mostly going to landfill or possibly incineration. There is just one improvement I would like and that is to have a tab on the flange to help its removal from around the stoma.

#### G. C. (Ms)

#### **Hello All**

I am so pleased that I was given the CA phone number. I called and got such reassurance from someone who knows what it's like to have a colostomy and the problems that sometimes occur.

I have only had my colostomy for one year after all else failed to help with colitis, diverticulitis and complete incontinence – even rectal muscle tightening failed after a while. I had the colostomy operation by keyhole to start with, but the stoma retracted and after three weeks it was decided a laparotomy be performed to get things right. Unfortunately I got an abscess on the scar tissue site.

After three weeks I was allowed home. I didn't feel my stoma was right: all the pictures I had seen showed stomas that stood out from the area. Mine was and is almost flat to the skin. The stoma nurse suggested I use a convex style bag, but I still sometimes get pancaking.

Another problem I seem to be experiencing is an offensive discharge of mucus from my rectum. I went to see the surgeon who performed the operation and he said there is nothing nasty going on and he would contact the stoma nurse who would be able to show me how to use an enema to wash out the offending mucus. Are there other colostomists who have experienced this problem of mucus in the rectum?

The Tidings magazine you sent me is so informative and I have read it from cover to cover. It does help to know that I am not alone.

Thank you again

M.G. (Mrs)

We frequently get calls on the

Helpline from colostomates who experience problems with a mucus discharge from the rectum. The CA have a leaflet, "About Rectal Discharge", which explains why this occurs and how other people deal with it. Ed.

Thank you for your letters and e-mails. Please keep them coming. We will do our best to print them or we may hold them over for a future issue.

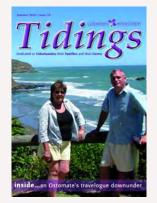
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> If you want to be involved in the next issue of Tidings magazine - simply drop us a line via email: associate-editor@ colostomyassociation.org.uk or write to: Associate Editor Colostomy Association 2 London Court, East Street, Reading RG1 4QL

Look out for our Reader Button to see where readers have contributed to Tidings

Reader PANEL contributor

Yours Rosemary Brierley Associate Editor



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## **Laparoscopic Bowel Surgery**

Written by Mr John Lengyel - Consultant Surgeon University Hospitals of North Staffordshire NHS Trust Stoke-on-Trent

#### **History**

Would you believe it but the very first laparoscopic or 'key hole' operation was performed as early as 1902 by a German surgeon Georg Kelling on dogs by insufflating air into the abdominal cavity to view the bowel.

It wasn't until Raoul Palmer a Swedish-born French gynaecologist published the first 250 cases of visualisation of the uterus and ovaries that lead to a revolution in gynaecological laparoscopic surgery.

When a general surgeon from Germany, Erich Muhe, adopted and developed the technique for removal of the gallbladder (cholecystectomy), he published his series of 97 cases. All of his work was discredited and he was criticized for his work for many years by the German Surgical Society, and it wasn't until 6 years later they had to eat humble pie and admit his work was pioneering in the field.

As techniques, technology and instruments improved, an American surgeon Moises Jacobs was the first man to remove the right side of the colon using the keyhole method. This was 20 years ago and the uptake has been slow. There were worries about safety, especially when the operations were done for cancer. From 2002-2007 3 major clinical trials were published which compared the standard large incision operation to the keyhole method in 2864 cancer patients. They all concluded that although laparoscopic surgery cost a little more and took a little more time to do, the benefits to patients in the short term were better if done keyhole.

Many more studies have shown that the risk of the cancer coming back in the long term was the same as if done the traditional open way. In 2006 the National Institute for Health and Clinical Excellence (NICE) published its guidance outlining a clear role for 'keyhole surgery' in colon cancer.



'Laparoscopic surgery is fast becoming the gold standard in colorectal surgery'...

## Can I have keyhole surgery?

The National Cancer Peer Review (NCPR) is a national quality assurance programme for NHS cancer services has issued clear guidance that any patient requiring an operation to remove a cancer should be offered the option of laparoscopic surgery. In 2009 only 25% of all colon cancer was done using the keyhole method.

The problem has been that most Colorectal Surgeons trained in the UK have had no training in the technique. In order to adopt it safely they have to go through a number of courses and undergo a period of supervised operating. The knock on effect of this has been that the new consultants wanting to learn the technique have found it difficult to find someone to train them.

There has been industry partnership (Ethicon Endosurgery) and part government funded (Lapco) initiatives to train surgeons in this technique to be able to deliver it in the UK. I was one of the few surgeons lucky enough to get specialist training in the form of a fellowship prior to starting my consultant post and mentoring two of my colleagues to independent practice. With 20 years experience between them this was a very weird experience, as two years previously they were teaching me how to take the colon out through a large incision! Within a year of starting at the University Hospital of North Staffordshire 9 out of 10 operations are now performed keyhole. With determination delivery of the highest standard of care is possible and hopefully will occur across the country.

#### So how is it done?

Well, first you need a good team and some important pieces of kit. The patient who has consented for the procedure and understood the benefits and risks is put under a general anaesthetic. The first step is to see what you are doing on the inside, and to create space between your tummy muscles and the bowel, carbon dioxide is pumped in under a small amount of pressure. The bladder has to be empty to visualise the bowel and reduce the risk of injury so all patients have a catheter. Actually looking inside is done using a laparoscope, a sort of elongated

magnifying glass. Light is directed down fibre optic cables to the end of the scope and the whole instrument is linked to a high definition camera and TV monitor.

A number of working ports are then used to do the procedure. These are usually 3 in number and approximately 5 to 10mm in size. On the inside the bowel doesn't just float about but is tethered in certain places and has a blood supply. Running with the blood supply is the lymph glands. These are important in cancer surgery as the harvest of these can allow a pathologist to tell us if cancer cells have spread from the tumour which may indicate the need for chemotherapy after the operation.

During the procedure we use the very latest technology. I favour a device called the harmonic scalpel that cuts tissue and seals blood vessels. It is virtually a bloodless procedure. Another clever advance has been a specialised staple gun. This instrument allows us to seal and divide large blood vessels and bowel easily, safely and quickly.

Once a piece of bowel has been isolated that has a tumour in it for example, we need to make a slightly larger incision to get it out. This is approximately 5cm in length. After the tumour hits the bucket and sent off to the lab for analysis we can then, hopefully get the ends of bowel together. This is done again using a specialised staple device. If a stoma is necessary this is done at this point. All the wounds are closed with stitches and 'frozen' with local anaesthetic so when patients wake up they hopefully experience minimal and sometimes no pain at all. The operation is over.

I have described a typical cancer operation here but we apply the same techniques for non-cancer surgery, diverticular disease, prolapse operations or Crohn's disease. Occasionally removal of the entire colon and rectum can be done for Ulcerative colitis and a specialised ileal pouch constructed to restore the gut continuity. All through minimal skin incisions.

#### **Benefits**

There are several benefits of the keyhole surgery. The first is that the bowel is handled less and unlike open surgery does not get a chance to become cold and traumatised through the 2 to 3 hour procedure. This means less fluid loss, less need for a drip after the operation as the bowels kick back into action a lot sooner. Therefore unlike the traditional diet and fluid restriction that used to occur, patients are encouraged to drink and eat hours after surgery rather than days.

Smaller incisions also mean less pain. This has got to be the biggest bonus. Less pain is great for patients, but it also means patients' get up and about sooner. This has the added benefit of reducing the chance of a chest infection, clots in the legs and lungs, which in turn leads to shorter stays in hospital. Of course when out of hospital recovery is also quicker so this means patients can return to normal daily activities of shopping, exercise, driving and other pleasures in life.

At this point it is always worth mentioning another linked health initiative called Enhanced Recovery. This is a collection of all the above ideas bundled together with education, stoma teaching and planned discharge that aims to reduce the length of stay. For the traditional open operation a patient would typically be in hospital 10 to 14 days. With the keyhole surgery alone this can be 6 or 7 days, but when combined with a good Enhanced Recovery Program, patients can be home in 3 to 4 days after major abdominal surgery.

#### Summary

Laparoscopic surgery is becoming the gold standard in colorectal surgery. We can do almost every operation through small incisions that we previously did through one large one. As with any surgery there are risks, but the benefits to the majority of patients when they are sat out of bed with minimal pain, enjoying a full breakfast the very next day after major bowel surgery is immensely rewarding.



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Julie Rust RGN. Dip, N. MSc. Clinical Nurse Specialist Stoma Care University Hospital of North Staffordshire

Q: I am looking for some advice with regard to the following problem. I had a colostomy carried out December 2009 for diverticular disease and also an incompetent sphincter muscle. My stoma care nurse advised me that I would pass mucous from the rectum at intervals. The first post op month there was nothing then I started passing foul smelling discharge every few weeks. This has now increased to the point where the discharge is constant and I am using pads. It still doesn't smell nice. In fact when I last saw my stoma care nurse I told her that this discharge smells worse than anything, which comes from my stoma. At times the discharge is also streaked with blood. I don't know if this is normal but it's making me miserable. I am due to see the consultant shortly as I developed a hernia immediately post op while I was still in hospital, which I am going to have corrected. However, I wonder if I should mention the other problem. Can you please give me any advice as to how to remedy this situation? I feel I am still new to 'living with a colostomy' and not knowing anyone with one I have no experience or advice to fall back on.

A: You do not say if the surgeon is planning on reversing the stoma for you at some stage, although with an incompetent sphincter muscle this may not be appropriate. If he is not planning on a reversal he may consider removing the rectum completely, which would solve this distressing problem for you. Alternatively, it may be that you need a rectal washout/suppository to

## Dear Nurse



Your medical questions and queries about stoma care management are always welcome and important to us. Queries received by the Editor or CA are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma Care for Julie to review and answer. Answers are published in the next issue of Tidings. We are also interested to learn how you resolve your stoma care problems and how Julie's advice has helped you!

remove the debris. I would suggest discussing all the options with your surgeon at your next appointment.

**Q:** My husband is an 87-year-old, five-year survivor of primary liver cancer. As a result of an errant liver ablation procedure that burned a hole in his stomach and small intestine, it became necessary to perform a colostomy.

Recently the stoma has retreated, causing leakage at the abdominal site, irritating the skin to the point of painfulness, despite the use of barrier creams. The leakage causes embarrassment and has increased the frequency of appliance change by four times the previous norm. We are using the 'Sur-Fit Natura' distributed by Convatec.

To date, we have consulted two general Surgeons, both of whom have ruled out surgery due to Allan's age and general health. We are thus asking you for suggestions as to what alternate measures can be employed in order to mitigate the identified problem, as there are no Enterostomal Therapists in Bermuda.

A: This sounds like a retracted stoma causing the problems. It may be useful to try something for the sore skin such as Orahesive Powder from Convatec, use this with a large seal such as a Cohesive Seal from Salts or the Adapt ring from Hollister. I would also suggest using a convexed pouch as this will help to push the spout of the stoma out towards the skin surface. Many of these can be used with a belt. It is difficult to know what to suggest you order, as I am unaware of what products are available in Bermuda. However, it may be useful to speak to the companies there to see if they can send you some samples to try.

**Q:** Today, I found a brochure on the Internet, which your Association wrote regarding rectal discharge. Over 10 years ago, I had an elective colostomy due to being quadriplegic from an SCI. Since then, I always had some slight white or clear discharge. Sometimes it would be brown and smell foul but it was a very small amount and of a jelly-like consistency. One time in hospital, I did pass a rather large firm ball of something but that was because a nurse gave me a rectal suppository.

About two months ago, I passed a very foul smelling brown liquid discharge. It happened again yesterday. It was a lot of liquid. Both of these times happened after I had

#### HEALTH YOUR QUESTIONS ANSWERED

bathed. I sit in a wheelchair so no one noticed. What could this be? I certainly don't want this to happen again. Could this be rectal or anal cancer or an infection of some kind? Please just be straightforward and let me know what I may be dealing with.

A: The most common cause of this discharge is often just a build up of mucous and this can be easily treated with regular Glycerine Suppositories given by the District Nurse if you cannot manage yourself. However, it is obviously difficult to be sure what is causing the problem without examining you so I would suggest a review by either your surgeon or your GP with a view to getting you referred to a consultant if appropriate.

**Q:** I have a colostomy and am also a diabetic. I irrigate and also wear a pouch. I am currently on medication and have found undissolved tablets in the pouch. Does this mean they are not working and is there anything I can do about this?

A: If the medication you are taking is appearing in the stoma pouch undissolved then it is not being absorbed and therefore is not entering your system. I would suggest a review by your GP to investigate if the particular medication is available in another format such as syrup or powder as this may be absorbed better.

**Q:** I suffer from quite a lot of what I call 'morning sickness' since I had my colostomy, and wondered if there is anything I can do or if any other readers also suffer from this.

**A:** This may not be related to the stoma at all and therefore I would suggest a review by your own GP with a view to investigating the cause of the sickness.

**Q:** I have a query about my colostomy. I had a Hartmann's procedure in 2008 and for the last four weeks when I eat my evening meal my pouch fills with liquid. It's like having the runs all the time. I'm becoming very concerned at such loose motions for so long. What do you think? I've been on a healthy eating plan since the end of January to lose weight for a reversal op. I've had abdominal pain and scans and

#### nothing showing up. Should I be worried? There's no blood that I can see but it's making my stoma sore and bleed sometimes.

A: This may be related to the diet you are on at the moment to try to loose weight. It may be worth keeping a diet diary to see if it is related to any food in particular. Alternatively, it may be that you need to see your GP and obtain something to try to slow the output down. Something such as Fybogel may help, as it will bulk the motion without the risk of constipation. You also say the skin around the stoma is getting sore. If it is wet I would suggest trying Orabase Powder and a seal such as Salts Cohesive Seal to try to heal the skin area. Once the soreness is settled I would suggest using Cavilon Spray as a barrier to protect the skin from further soreness.

**Q:** Firstly I've only had my stoma (Bertie as I call it) for three month's and it was emergency surgery caused by Diverticulitis, which I didn't know I had. I'm in a very small percentage as my consultant told me yesterday being aged 39, having no previous symptoms and finally the surgery. He advised me to further increase my fibre intake and I do try but I don't seem to tolerate vegetables very well anymore and fruit plays havoc too. So I'm at a loss, as I don't know what to do next? When I've asked I keep being told to have a balanced diet, this doesn't help me and I'm beginning to stress about it which will not do me any good either, I hope you can point me in right direction.

A: If you have spoken to your stoma care nurse and consultant regarding this and have tried all their suggestions I would suggest a referral to a dietician to see if they can give you more specific information. Usually with a colostomy we suggest a normal healthy, well balanced diet but if you are struggling the dietetic department may be able to help.

**Q:** I am a colostomate and also a paraplegic. There is a lot of talk about irrigation. I have, in my five years with a colostomy, had 3 or 4 sessions of diarrhea and wondered about trying out irrigation before going on leave but I gather that most users carry out the procedure daily, sitting on the loo. I can't and do not

want to risk sores by getting onto a loo and also, losing the great beauty, for me, of speed - changing a bag is 15 mins max. compared with daily sessions on the loo of 30 to 90 mins. It also cuts down the number of holiday possibilities. I assumed that irrigation cleared out one's system for some days and not as a daily routine. Have I got it all wrong and can I perform the irrigation as a one-off without sitting on a loo?

A: Colostomy irrigation can be done sitting in front of the toilet in a chair with the long drainage bag going into the toilet basin. I have taught patients in wheelchairs to perform the procedure quite well. It is usually done daily at the start of the training to try to re-train the bowel to accept the irrigation. However I do have some patients who manage to do the procedure every other day without any problems from leakage in between. This works for some people but not everyone. It may be worth discussing the procedure with his own Stoma Care Nurse who can explain in detail and show him the kit/procedure.

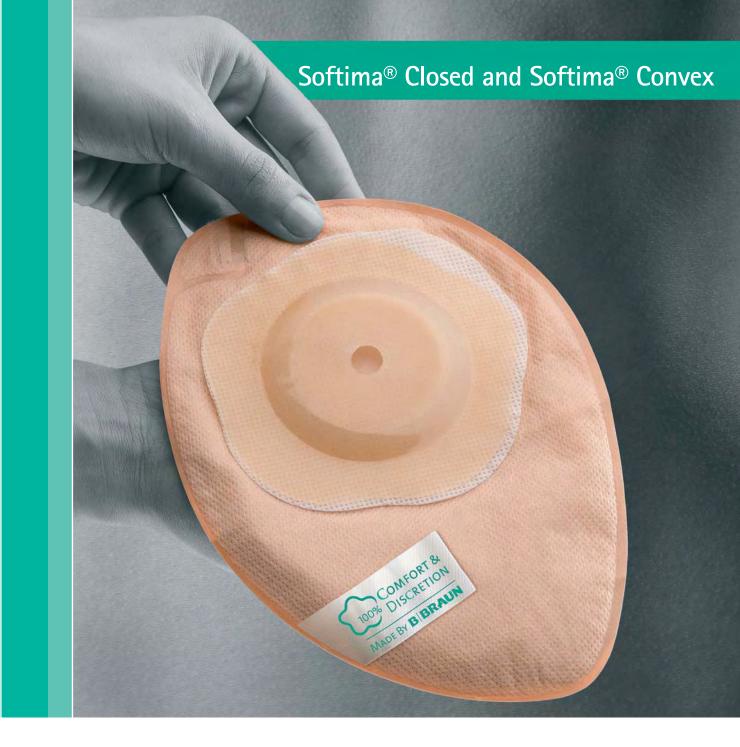
**Editors Comment** 



Have you got a medical question or a query about stoma care management for Julie?

> If so write in and tell us: Colostomy Association 2 London Court, East Street Reading RG1 4QL

or e-mail your query to: cass@colostomyassociation.org.uk editor@colostomyassociation.org.uk



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### Stoma Care Open Days...

Open days give ostomates the opportunity to meet and share experiences with other ostomates. Many people attend with friends and family and they can be very sociable events. Open Day events are posted on the Colostomy Association website throughout the year - visit: www.colostomyassociation.org.uk/get-involved/open-days

#### List of forthcoming Open Days:-

Date:	12th July 2010	Date:	8th September 2010	
Venue:	Midland Hotel, Morecambe, Lancashire	Venue:	The Moorings Hotel, Fort William	BRADAR
Time:	11am – 3pm	Time:	11am – 3pm	the disability network
Organiser:	Fittleworth	Organiser:	Salts Healthcare	NATIONAL KEY SCHEME
Date: Venue:	16th July 2010 Hilton Tree Tops, Aberdeen	Date: Venue:	10th September 2010 Jarvis Hotel, Livingston	How to obtain a key to gain access to toilets for the disabled
Time:	11am – 3pm	Time:	11am – 3pm	Colostomates are entitled to
Organiser:	Salts Healthcare	Organiser:	Salts Healthcare	a key which will open 8,000+ locked toilets around the UK.
Date:	28th July 2010	Date:	15th September 2010	Some local councils will provide
Venue:	Wicksteed Park, Kettering	Venue:	Lindhurst Rooms,	this key free, or for a small charge.
Time:	11am-12.30 & 1.30pm-3pm		Mansfield Civic Centre	Keys can be obtained from the
Organiser:	Salts Healthcare	Time:	10am – 3pm	Colostomy Association at cost of £3.50.
Date:	1st September 2010	Organiser:	NHS Stoma Care, Mansfield	Contact head office: 0118 939 1537 for an application form.
Venue:	Park Hotel, Rugby Park,	Date:	4th October 2010	Keys can also be purchased for £3.50
venue.	Kilmarnock	Venue:	Northern Gen Hospital,	from RADAR:
Time:	2pm – 7pm	venue.	Sports Hall/Spinal Injuries	Tel: 020 7250 3222
	NHS Ayrshire and Arran		Unit, Sheffield	Web: www.radar-shop.org.uk
		Time:	10am – 3pm	New from RADAR - coming soon
		Organiser:	Stoma Care Dept	National Key Scheme Guide 2010 Pre-order Price: £9.49

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that we have your full name,	Address:								
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thank you		Pos	stcode:						
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	(Please tick.) <b>Yes I would lil</b>	ke to make <b>an single donation</b>							
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	I enclose a cheque/postal order form made payable to the C.A. Ltd - Thank you!								
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	Account number:	Sort code:							
	Please pay: NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP								
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	the sum of £	amount in words:							
	Date of first payment:	and thereafter on the same o	lay every month/quarter/year)*						
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Our findings show there are approximately 60,000 colostomates living in the UK and with over 6,400 permanent colostomy operations being performed each year - we need to be here for them!

## The Association continues, with **YOUR help**, to **give support** and **reassurance** to both experienced colostomates and those who are new to 'living with a colostomy'.

Here's how your donation helps us make a **difference...** to **fellow colostomates** 

#### The Association provides:

- advisory literature, written by colostomates and health care professionals.
- a quarterly magazine 'Tidings' especially written for colostomates, their families and their carers.
- a telephone helpline 0800 328 4257 manned 24 hours a day every day.
- over seventy contact volunteers covering the UK, fully trained and experienced, (who are themselves ostomates) these dedicated individuals bring a human touch.
- a volunteer at the request of a stoma care nurse can visit a patient/s before their colostomy surgery, and afterwards in hospital. Home visits can also be arranged.
- attendance at organised stoma care nurses 'open days', that you can visit and where you can learn more about your stoma, in a friendly atmosphere and discuss any problems.
- attendance at manufacturers' and suppliers', 'open days' and exhibitions. This allows us to update you on stoma care products, accessories and services via 'Tidings'.
- a voice for your opinions at on going consultations with the National Health Service and keeps you informed of issues that may affect you.

Here's how **YOU** can continue to support us... simply by making a donation you will ensure our survival

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Your donation to the Colostomy Association today...will mean we can reach out to other colostomates their families and their carers with support, reassurance and encouragement. With your help we really can and do make a difference - thank you



Office Address: 2 London Court, East Street, Reading RG1 4QL Tel: 0118 939 1537 Helpline: 0800 328 4257 E-mail: cass@colostomyassociation.org.uk Web: www.colostomyassociation.org.uk Registered Office: 2 London Court, East Street, Reading RG1 4QL 5RW Registered Charity No: 1113471 "no one except another person in the same situation or with a similar experience can really truly understand what 'living with a colostomy' brings and means to one's life"...

## Claire Loaiza writes about a new support group making a difference in the North East of England



## It's in the Bag

### Hull and East Riding Stoma Support Group



Back row - from left to right: Rose Grimsby, Jane Armstrong, Cliff Williams, Pete Smith, Jo Lorenz, Claire Loaiza, Pete Rennard. Front row: Malcolm Woollass, Chris and Norman Pearl.

After arriving back in the UK after a seven-week stay in a Costa Rican Intensive Care Unit, I found myself at the age of 36, with my second colostomy bag. Having previously had a successful reversal during the summer of 2008.

Once I was strong enough to make the long journey home, I arrived to bleak weather and a rather grey outlook knowing what was ahead of me. I couldn't believe it was happening again, I felt low, depressed and most of all completely alone.

It was my mother who said to me, after a visit to the stoma care nurse at Castle Hill Hospital in Cottingham, that she thought there should be more emotional support. Certainly, no one except another person in the same situation or with a similar experience can really truly understand what 'living with a colostomy' brings and means to one's life.

The next day whilst waiting to see my GP a notice caught my attention. A Stoma Support Group was being established in Hull, possibly offering exactly what I needed. I anxiously called the number provided and spoke to Peter Smith, who had set up the group. Later that week I met him and many others and in the weeks that followed those people helped my life as a colostomate change considerably.

Peter Smith a strong and resilient man (who had part of his bowel removed due to cancer) recognised that he faced the rest of his life living with a colostomy. Peter realised that he may benefit from speaking to other colostomates. After looking in the Tiding's magazine for his nearest support group it became clear that there wasn't one within easy reach.

'I knew I was coping well but I could also imagine some people may well be hiding away after having a colostomy. I wanted to give people hope, to help them embrace life again and realise they had a second chance. I felt I needed to instigate something, to help others.'

Peter went to see the stoma care nurses at Castle Hill Hospital who contacted every stoma patient to inform them of the new group. He also set about putting notices in surgeries and advertising in the local newspaper. The group is growing, and like me, people are making new friends and finding out more information. Experiences are shared, shoulders are offered and most days tears of laughter are shed as we swap stoma stories. One of our members Pete Rennard, known to the group as 'Professor Pete' has had a colostomy for 32 years and his knowledge and experiences are a real asset to us all.

We now have a committee to manage the group and are in the process of building a web site, organising a monthly newsletter and having our 3rd charity-raising event for Ward 11 at Castle Hill. We are also looking into visiting new stoma patients in hospital as well as contacting those on the waiting list and those contemplating reversal.

We meet at one of Peter's public houses, The Ruscadors, Queen Street, Hull, every Thursday at Noon and our contact details can be found at the back of this Tiding's magazine! We will be inviting guest speakers ranging from product suppliers to stoma care nurses, our first speaker, is from Comfizz.

Family and friends of colostomates are very welcome and many attend each week. The support system we have developed is really wonderful and whatever problems there are, whether physical or emotional, we always seem to find a solution.

Often when I am in the supermarket or at the bank I wonder if anyone else has a colostomy. Just a few days ago I went to view a house and the owner to my shock and amazement, also had a colostomy and will be joining the group!

With five people becoming a colostomate every week in Hull and East Riding the support group provides a vital link for those that are just starting life with a colostomy to those that have had one for a number of years. We have members' young and old and we all have something to offer which makes the load a little lighter.

Support Groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

### Stoma support groups in your region...

The following support groups have been revised thanks to your responses from the spring edition of Tidings.

#### Scotland

#### Midlothian:

GOSH

Contact: Alex Topping 01501 772154 Maggie's Edinburgh Timetable Contact: 0131 5373131

#### **Glasgow:**

Fittleworth Glasgow Stoma Support Group

Contact: Christine Daalman 0141 633 0592 or Charlie Sutherland 01698 822075

#### Avrshire:

North Ayrshire Stoma Support Contact: Jim 01292 220945 Stoma Care and Recovery (S.C.A.R) Contact: Rhona 01294 557478 or Maggie 01294 271060 or Mob 0781 7736147

#### Fife:

Fife Ostomy Support Group Contact: Ishbel Barr 01592 772200

#### **England - North**

**Cheshire:** 

Cestrian Support Group Contact: David Burgham 01244 310461 **Countess of Chester Hospital** Contact: Julie Clements 01244 366170 Drop in Clinic Contact: Angela Perks/Deborah Singleton 01625 661598 Stockport Support Group Contact: Angela Simpson 0161 419 5059 TOMAS (The Ostomates of Macclesfield and Surrounding Areas) Contact: Kath Wood 01625 875442 Warrington Ostomy Support Group

## Contact: Jane Shaw 01925 662103

#### **Cleveland:**

**Oops Group** Contact: Julie Morrisroe SCN/Carol Younger 01287 284113

#### **County Durham:**

South West Durham Ostomy Group Bishop Auckland Contact: Betty 01388 814535 Colin 01388 773757 Jen 01325 31266 Maureen 01388 818267

#### **Derbyshire:**

Stockport Support Group Contact: Angela Simpson 0161 419 5059

#### Lancashire:

Oldham Stoma Support Contact: June Wilde 0161 6787086 Trafford Bowel Care Contact: Jackie Carey (Secretary) 0161 7489659 Doreen 0161 9627818 John 0161 7484655

#### Merseyside:

I.C.U.P.S Contact: Stoma Care Nurse 0151 6047399 Liverpool Support Group Crosby Contact: Barbara Percy 0151 5292842 (Afternoon) Olivia Thomas Suite University **Hospital Aintree** Contact: Carmel/Pauline 0151 5292842 (Evening)

#### Northumberland:

Northumberland Cancer Support Contact: Pat Fogg 0191 4102679

#### Teeside:

Bowel Cancer Support (Semi Colon) Contact: Mr G Dickson 01642 563747 Pat Brydon 01642 897903

#### Tyneside:

Gateshead Health NHS Trust (Stoma drop in clinic) **Contact: Sister Heather Wilson** 0191 4878989 Ext 2221 NHS Molineaux Centre Contact: Lesley Brown 0191 2195656 Royal Victoria Infirmary Support Group Contact: Gordon Weatherburn 0191 2341109

#### Yorkshire:

Airedale Stoma Support Contact: Jenny Shaw 01535 652516 or Sue Hall 01535 210483 Bowel Cancer Support Group Contact: Lisa Hall 01422 357171 CROPS (Colo-rectal ostomy & internal pouch support) Contact: Gloria 0114 2879503 Dewsbury & District Ostomy Contact: Janet/Eileen 0844 8118110 Rotherham Ostomates Caring Support Contact: Contact CA for details Scarborough Stoma Support Group Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446 The Hull and East Riding Colostomy Support Group Contact: Pete Smith 07989 565335 and Claire Price 07805 978151

NORTH

CENTRAL

SOUTH WEST

SOUTH EAS

#### Isle of Man:

Optimistics Contact: Stoma Nurse Lynne Webb SCN 01983 534009 Stoma Support Group Contact: Carole Cringle 01624 650212

#### England - Central

**Buckinghamshire:** Milton Keynes Stoma Association Contact: Bruce Pollard 01908 582563

#### Leicestershire:

Moving on (Leicester Royal Infirmary Colorectal Support group) Contact: Wilf Patterson (Secretary) 01455 220344

#### Nottinghamshire:

Nottingham Colostomy, Ileostomy & Urostomy Support Group Contact: Rosemary Brierley 0115 982 7868

Nottingham Stoma Support Contact: Mrs B Heath 0115 966 3996 North Notts Stoma Support Group (Sutton-in-Ashfield) Contact: Tore and Nicky Norman 01773 715460

#### Staffordshire:

Outlook Contact: Ernie Hulme 01782 324441 Joan 01782 710828

#### Worcestershire:

Kidderminster & District Collossus Support Group Contact: Brendon Drew 01299 400843

#### West Midlands:

Colostomy Group Contact: Diana Wick 0121 4242730 Newhall Stoma Support Group Contact: Sarah French 07773 396236

#### **England - East**

**Bedfordhire:** Saturday Social Club

Contact: Karen Richards 01234 792278

#### Cambridgeshire:

Ostomistics Contact: Heather Connor 01733 768332 Mob: 07757167422

#### Essex:

M.E.S.S (Mid Essex Stoma Support) Contact: Clive Blanchard 01245 468750 Jeanette Johnson 01376 511862 N.E.S.S (North Essex Stoma Support) Contact: Mr K Harvey (Chairman) 01206 271425 Brian Waller (Secretary) 01206 540449 **Optimistic Ostomates** Contact: Janet 01702 385510 Angela 01702 385509 South Essex Young Ostomy Group Contact: Paul Gray 01708 501268 STEPS Contact: Jackie Coleman 01268 451937 Redbridge Ostomists Club Contact: Stoma Nurses: Chris/Lisa 0208 9708321

#### Hertfordshire:

Colonise Contact: Gill 01727 851556 Stoma Fellowship Contact: Andrea/Mandy 01438 781133

#### Lincolnshire:

Friends Support Group Contact: Betty 01205 724120/Sheila 01205 364493 Grantham Support Group Bobbie 01476 464822

#### Norfolk:

Ostomy Friendship Support Group Contact: Contact CA Stars Contact: Anne Brown 01603 661751

#### Suffolk:

East Suffolk Ostomy Group Contact: Marion Fisher 01473 311204 James Pagett Ostomy Support Group Contact: Sandra Hutchings 01502 585955 West Suffolk Support group

Contact: Jessica Pitt 01638 515525

#### **England - South East**

#### **Berkshire:**

Monday Pop In Group (Bracknell) Contact: Jackie Dudley 01344 426652 West Berkshire Ostomy Club (WBOC) (Reading) Contact: Jackie Dudley 01344 426652

#### Hampshire:

Southampton Support Group Contact: Carole Summer 02380 446779 Wessex Urology Support Group Contact: David Morris 02392 361048

#### Kent:

Ashford Stoma Support Contact: Chairwoman - Mrs Ursula Naish 01233 640863 Canterbury & Coastal Stoma Support Contact: Marie Culleton SCN 01227 769679 **Dover & District Stoma Support** Contact: Marie Culleton SCN 01227 769679 Maidstone Stoma Support Group Contact: Judy/Kirsty 01622 224305

#### London:

Whipps Cross University Hospital Contact: Christina 0208 5356563

#### Middlesex:

Inside Out Contact: Bob (Chairman) 0208 4284242 Sarah Varma 0208 2354110 Semi-Colon Club Contact: 01895 179391

#### **Oxfordshire:**

Oxfordshire Ostomy Fellowship Contact: Pat Longworth 01235 524163

#### Surrev:

Epsom and District Stoma Support Contact: Jan/Sheena 01372 735232

Sussex:

(SAS) Brighton & District Stoma Care support Contact: Sylvia Bottomley 01273 554407 The Ostomy Friends Group Contact: Jane Quigley 01323 417400 Ext 4552 West Sussex Princess Royal Stoma Support Contact: Tina Walker 01444 441881 Ext 8313

#### **England - South West**

#### Avon:

Bristol Ostomy Self Support (BOSS) Contact: Christina 0117 9075326 Joyce 0117 9558236 Rob 0117 9668021

#### Cornwall:

Ostomist and Carers Support Group Contact: Christine 01208 831471 Optimists Contact: Sue Hatton 01326 340058

#### **Devon:**

Devon IA Contact: Margaret Bond 01392 447374 CAT - Torbay Contact: Donna Ashbrook 01626 854862 **Dorset:** 

Cupid (Colostomy Urostomy pouch Ileostomy of Dorset) Christchurch Contact: CA for details Cupid (Colostomy Urostomy pouch Ileostomy of Dorset) Poole Contact: CA for details

#### Wiltshire:

Swindon IA www.swindon-ia.org.uk Wessex Stoma Support Group Contact: Michael Slater 01722 741233

#### Wales

Blaenau Gwent Self Help Contact: Celia McKelvie 01873 852672 Royal Glamorgan Stoma Care Support Group Contact: SCD 01443 443053 Swansea Ostomy Self Help Group Contact: Glynis Jenkins 01792 418245 Wrexham Ostomy Friendship Group Contact: Mrs R Thomas 01978 359445

#### Northern Ireland

Causeway Patient Support Group Contact: Mary Kane 028 70346264 Daisy Hill Hospital Belfast Contact: Bernie Trainor 028 3883500 Ext 2222 Mater Hospital Belfast Contact: Karen Boyd 028 90741211 Ext 2329 Southern Trust Contact: Mary Jo/Bernie 028 38612721

#### Eire

Bowel Cancer Support Group (Irish Cancer Society) Contact: Olwyn Ryan +353 12310500 Mavo Stoma Support (Castle Bar Hospital) Contact: Marion Martyn 094 902 1733

#### **Editors Comment**

Support groups are very often invaluable to those who are 'Living with a Colostomy'. We support existing groups and help new support groups set up. If you know of a support group not mentioned in our listings please let us know.

#### Here's how you can get in touch via e-mail:

editor@colostomyassociation.org.uk

or write to: Colostomy Association 2 London Court East Street Reading RG1 4QL or email: cass@colostomyassociation.org.uk



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