Winter 2008 | Issue 12

colostomy association

Tidings

Dedicated to **Colostomates** their **Families** and their **Carers**

inside...

New series
Open Door
A day with Liz HarrisCNS
Royal Berkshire Hospital NHS Trust

Aspects of medical treatment
Stoma Care Professionals write
about...the ostomist and parastomal hernias
and coping with chemotherapy and radiotherapy
and a colostomy

plus...
all our
regular features

- Readers' stories
- Dear Nurse
- Your letters

and more...

Happy New Year to ALL our readers from the Colostomy Association...

Tack & Adhesion
Flexibility
Absorption
Erosion Resistance
Ease of Removal

welcome to WINTER

Tidings Magazine Anniversary Issue
10
YEARS
1998-2008

Left to Right: Ann Leppington-Clarke, Professor R J Heald OBE pictured with Sue Hatton, Chairman of the Trustees Colostomy Association

As Tidings lands on your doormat it will be the beginning of another New Year - 2009! No doubt you will all be recovering from the Christmas and New Year festivities.

The festive season is such a hectic time so many things to think about and too many things forgotten and remembered always at the last minute. So, to get me through the season I always focus on the days between Christmas and New Year because I know that the pace will be more leisurely and less intense for all the family, even the dog! At last the time comes when you can sit down and relax in the company of family and friends. Catch up on news and remember events of the past year.

Looking back on 2008 the Colostomy Association has enjoyed another year of building on its past successes and creating new ones. The highlights this year must be the ten-year anniversary of Tidings magazine. Not to mention the National Conference organised by the Trustees, management and staff of the association and the acceptance by Professor Bill Heald OBE to become President of the Colostomy Association and of his colleague Sister Ann Leppington-Clarke to become Liaison Stoma Nurse.
The fashion show must also be mentioned. Organised by the extremely passionate and energetic Maureen Kelly-Smith of SecuriCare with the kind support of sponsors John Lewis, and the models – who could forget the bravery of the ostomates modelling their chosen outfits courageously and with great expertise.

Lastly, to top off this year the Associations' main fundraising event – the Car Raffle raised an astonishing sum exceeding all expectations over £27,000. Congratulations to those involved and a huge thank you to all who purchased tickets!

As editor of Tidings I hope you have enjoyed the bumper editions this year, this issue being no exception – a massive 56 pages. Our biggest yet.

We are delighted to welcome two new contributors - Julia Williams, Lecturer in Gastrointestinal Nursing at the Burdette Institute writing about Parastomal Hernias and how they affect the colostomate, and Juliette Fulham's article about coping with chemotherapy and/or radiotherapy and a colostomy which is featured on the central pages.

I know from reading your letters and emails to Tidings how much you enjoy the publication - thank you for them and keep them coming.
With this in mind I am launching a Readers' Panel – the hope being to encourage you to comment and write about features or articles in Tidings, or indeed about products you have tried whilst caring for your stoma. As I have said before this really is your magazine. Any reader who is successful and has an article, top tip or wants a particular topic featured which results in publication will see this acknowledgement ►
So, come on get involved let us know about your ideas and experiences.

Reader
PANEL
contributor

I hope you enjoy reading Tidings - winter edition and would like to take this opportunity to thank our advertisers for their ongoing support and to wish all our readers...

A healthy, prosperous and peaceful New Year.

Jane

Jane Wood **Editor**

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EDITORIAL TEAM

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Colostomate & Helpline Volunteer
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The Burdett Institute of Gastrointestinal Nursing in partnership with Kings College London and St. Mark's Hospital, Harrow

FROM THE EDITOR

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Spring Edition advert booking space by 20 February copy by 27 February publication early April

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

Freephone: 0800 328 4257

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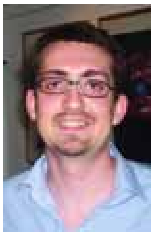
Special thanks...

Tidings would like to thank Kevin Young who got in touch with the CA regarding the use of apostrophes in the autumn issue of Tidings. We invited Kevin to proof read this issue and he took up the challenge with great gusto whilst recovering from his operation...thanks again Kevin.



About Kevin...

Kevin Young is 33 and was given an ileostomy in November this year. He has suffered from Crohn's Disease for fifteen years and the operation became unavoidable when his symptoms worsened. He had been dreading the prospect of surgery for years but now feels it has given him a new lease of life. Kevin works as a radio and online journalist and lives in London.

Tidings is your Magazine...

Submissions:
If you have a story, article, letter or any other item you would like to appear in Tidings, please send them with any relevant photos or pictures to:

The Editor
Colostomy Association
2 London Court
East Street Reading
Berkshire RG1 4QL
or e-mail:
editor@colostomyassociation.org.uk.

We will do our best to include them. Don't forget to supply us with your name, address, phone number and e-mail address, if you have one.

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 (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 hope you have enjoyed this edition of Tidings and look forward to bringing you the next edition...We are always trying to improve your Magazine and welcome your feedback.

colostomy association

How to contact us...

By post: Colostomy Association
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E-mail: cass@colostomyassociation.org.uk
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WCET (UK) Conference

20-22 October 2008 Glasgow

The Conference for the World Council for Enterostomal Therapists (WCET) UK represents the annual educational opportunity for stoma nurses to network with colleagues, and with the stoma companies who fund much of their research work. There are some 450-500 stoma care nurse specialists (known as clinical nurse specialists) in the UK.

WCET is a worldwide organisation and registered charity with 2000 members, providing support, care and education to nurses and patients within the specialist areas of ostomy, wound and continence care. These specialist nurses know the value of providing good, evidence-based, quality care to their patients, and to do this effectively it is vital that they have access to continuing education, both generally and within their own specialist sphere of nursing. The Council enables them to expand their knowledge, keep up to date with political issues that may affect their practice, and be able to share ideas and experiences through networking with peers.

Representatives from the CA, the IA and UA were asked to attend this year's Conference and to give a ten-minute presentation. It was the first time that we had all been invited to contribute. We usually man our space in the foyer alongside the other patient associations. This year 398 delegates were registered, and we all congregated at the Thistle Hotel in the heart of Glasgow for the first evening's reception. The Ballroom foyer had been taken over by the stoma companies and their magnificent exhibitions stands. Giveaway bags were being distributed and I soon located the fudge on offer from Dansac and the delicious fruit cocktail drinks magnificently shaken by two lovely lads who were definitely not stoma reps!

Ray Goddard, Robin Mills and I were hosted by CliniMed and taken to a superb restaurant where we had the chance to get to know the nurses who are sponsored by CliniMed, and work all over the country.

The following day, the majority of the delegates listened to some thirty-three different presentations, among them being:

- Paediatric stoma care nurse group UK/NI and paediatric stoma care standards
- IBD and stoma care management for the adolescent
- Keynote speaker on ileal-anal pouch (stoma vs. non-stoma in pouch surgery)
- Practice-based commissioning and the importance of SCN involvement with the process

The Associations spent the majority of that day networking, meeting the stoma companies, swapping experiences, and using the time to get to know one another better and sorting out our presentations for the following day.

In the evening we and all the 'girls', that is the stoma nurses, dressed up to the nines and were taken via bus to the Kelvingrove Art Museum where a sumptuous gala evening had been organised. It was incredible to have the whole Museum to ourselves and to be able to walk around sipping champagne gazing at the incredible works of art. Ray and I felt very honoured to be seated at the top table with Philip Salt from Salts Healthcare and WCET committee members Julia Williams, Carol Katte and Jo Sica. Ray had told me very definitely that he did not dance, but once the Scottish Dancing started Jill Dean from Coloplast whisked him onto the dance floor accepting no excuses. I did challenge Philip, but he trembled so much that I took pity on him and admitted that my new knee prevented me from promenading around the dance floor with him.

The following morning, I very nervously took my seat next to Caroline Stammers and Anne Demick of the IA, who gave a very slick portrayal of the IA's support for patients. All ten presenters kept strictly to their slots. I gave a brief resumé of what the CA had achieved this year, and then focused on Irrigation as a choice of bowel control for those who were able to use this method of clearing their bowel. It is well known that stoma nurses do not often suggest this as an option for their colostomy patients, and I urged them to liaise with their surgeon to discuss the patient's ability to irrigate and to offer the patient a choice.

After this presentation, we were inundated by nurses eager to pick up our literature, and who admitted that they didn't have time to offer Irrigation as a choice to their patients after they were considered fit for home. I hope to be able to present another paper for the Nursing Times which will urge stoma care nurses to be more positive about Irrigation and to try to get the patient irrigating within the first 3 months if possible. To help with my presentation I had been able to use a brilliant research paper on Irrigation written by Jill Dean, a Clinical Nurse Specialist who works for Coloplast; the paper proves that patients who are able to irrigate have a better quality of life than those who don't.

The Meeting finished at 1.30 pm, when the Chairman Alison Crawshaw expressed the hope that the meeting had been both educationally stimulating and memorable. We certainly came away feeling very positive, fired up with ideas and enthusiasm, with the certain knowledge that we have met stoma nurses who value the Colostomy Association's input into their patients' lives.

If you would like to learn more about the WCET (UK) or see a list of all the speakers and their presentations, they can be found on the WCET UK website www.wcetuk.org.uk under the heading Programme.

Sue

Sue Hatton
Chairman of the Trustees
Colostomy Association


NEW
V. SOFT
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we think you'll like it
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NEW ADVANCED FILTER PROTECTION SYSTEM
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A day with Liz Harris CNS

team member of the Stomatherapy Department at the Royal Berkshire Hospital NHS

Over the coming year Tidings will feature a new series of articles called Open Door, which we hope, will become a regular feature in the magazine.

In each issue we will be following a chosen individual and focusing in on a 'day in their life'.

For instance, we may choose a member of staff at the Colostomy Association, a reader, or a support group organiser.

Liz checks her busy diary

Editors Comment

A big thank you to Liz and her patients for opening the door to Tidings, for demonstrating her professionalism and dedication and for providing a real insight into how much care and effort goes into the management of each stoma patient and his or her needs.

In the first of our series we follow Liz Harris - Clinical Nurse Specialist who opens the door on her busy schedule

Liz Harris works within the busy Stomatherapy Department of the Royal Berkshire Hospital NHS Foundation Trust situated in Reading. She is part of a dedicated team of health care professionals. Her role is that of a Clinical Nurse Specialist or CNS.

A Clinical Nurse Specialist is a trained nursing specialist dealing with a particular type of illness, such as bowel cancer, lung cancer or other diseases not connected with cancer.

As a CNS, Liz is able to offer support to patients and their families before, during and after treatment. This may take the form of emotional support, advice about health problems or the provision of educational information, but most importantly the teaching of stoma care to patients, relatives and carers.

The Stomatherapy Department provides continuity of care for patients with a stoma and is made up of the following:

Pre-operative advice, post-operative advice and follow-up care in the community, which is done mainly at nurse-led clinics within the Royal Berkshire Hospital or externally at one of the local community hospitals within West Berkshire. These are four times a month at West Berkshire Hospital in Thatcham, twice monthly at Wokingham and twice monthly at Townlands Hospital in Henley-on-Thames.

Liz – along with colleagues, Gilly Tomsett, Tessa Martin and Marlene Ellis, who are also Clinical Nursing Specialists – work very closely with each other. Gilly is the only member of the team who is full-time.

From left to right - Liz Harris, Tessa Martin, Gilly Tomsett. Front Marlene Ellis

Liz is a mum and although her working day begins at 8:00am she is up and about beforehand getting the family ready for their daily activities.

Getting into the department and settling herself at her desk, Liz consults her diary. Her diary shows Liz all her weekly activities, forthcoming appointments, patient clinics and meetings. Her daily duties include monitoring and responding to patient telephone calls, liaising with her colleagues, caring for patients on the wards and running patient clinics Mondays to Fridays within the department and also at the community hospitals. Liz and her colleagues share patients and provide each other with detailed handovers and patient write-ups so that they each know the patients' full history. Administration is a very important part of Liz's day and because of her busy schedule is often hard to fit in, but still must be done even if it is out of working hours. All new patients are offered one home visit, which is usually done in the first week after discharge from hospital. ►

> "daily duties include monitoring and responding to patient telephone calls, liaising with her colleagues, caring for patients on the wards and running patient clinics"

Visit to the Stoma Care Outpatients' Follow-Up Clinic Henley-on-Thames Townlands Community Hospital

Liz very kindly offered Tidings the opportunity to observe her working with her patients at a follow-up clinic situated at Townlands Hospital, Henley-on-Thames.

Liz left Reading to travel the short distance of just over eight miles to start her clinic and arrived just before 1:30pm. The five patients attending clinic were all asked if they would agree to Tidings magazine observing their appointments. They all bravely agreed.

In clinic, Liz is able to review each patient's stoma care needs; she always checks the skin around the stoma and re-measures the stoma. The patients attending Liz's clinic were aged between mid-sixties to late eighties and were all from the local area.

"A follow-up clinic gives me the opportunity to assess how each patient is coping with their stoma care," she said. "I like to make sure they are happy with their stoma appliance and the accessories they are using. "I can see if they are using them correctly and ask if they are experiencing any difficulties. It is important for me and invaluable for my patients."

Liz also encourages patients to attend the follow-up clinic. "It's good for their morale and gets them out and about, giving them something to focus on." Patients are asked to bring with them their current stoma products.

Five patients in conversation with Liz

Peter – Urostomate Operation 2007

Peter talked about being poorly on holiday and said that he had been diagnosed with gastroenteritis but recovered well and was able to enjoy the rest of his holiday.

Liz also asked about Peter's diet. Peter explained that he had porridge for breakfast, soup and toast for lunch and a cooked dinner in the evening. Liz said it was important to have a regular flow of food going through the body and encouraged him to keep drinking cranberry juice. Cranberry juice is important to help reduce the production of mucous, which the stoma produces and also helps in the prevention of urine infections. Liz also mentioned probiotic yoghurts and suggested Peter have one a day. She explained that they replenish the stomach with good bacteria which can help keep you healthy.

Liz asked Peter how his conduit (urostomy) was performing, Peter said things had been good and that everything felt OK. Liz then asked Peter if she could take a look at his stoma – he was using a one-piece convex drainable bag with a belt to help pull it in and a half moon seal. Liz checked the seal and stoma. Then she examined his urine. "The colour of the urine is very important," she said. "In fact the paler the better. If it was darker it would indicate that Peter was not drinking enough".

Liz asked Peter if he had any issues with the bag he was wearing. Peter said that the tap had leaked twice and said: “I was getting a bit wet and I wondered why. Then I realised where it was coming from.” Liz said that he should mention this to his supplier and suggested it might just be a faulty bag and to order some more.

Liz said that Peter was well supported by his family and was coping very well.

Elsie – Colostomate
Operation 2001

Liz greeted her next patient, Elsie, who was accompanied by a friend. Elsie had come to the clinic for her six-monthly check-up. After a chat about how Elsie was coping at home Liz asked her how her colostomy was behaving. Elsie said she called her bag Horace and wished the “poo would drop down into the bag but it just sits there.”

Liz said: “This is a good example of pancaking.” Liz suggested Elsie could try covering the filter with one of the small stickers that come in the box with her appliances. She said: “By doing this you can keep some flatus in the bag which may help to prevent pancaking.” Elsie said she had seen the stickers but had no idea what they were for.

Liz explained that Elsie was wearing a two-piece system with a convex base. “Don’t you mean my landing pad,” Elsie joked. She was also wearing a panty girdle to help support her hernia. Liz asked Elsie if she could take a look at her stoma. Elsie complained of some little blisters.

Liz also suggested she measure Elsie’s hernia to see if it had got any bigger. The hernia can stretch the parastomal skin, explained Liz, and good skin care is essential. The use of a skin barrier, protection wipes or spray may help to resolve skin problems. The hernia may also require a stronger support garment.

“Any other problems?” Liz enquired. Elsie replied that she had a problem with one of the parcels containing her stoma supplies. It was delivered partially opened and this had worried her. She said she had contacted the supplier to let them know.

Liz and Elsie chatted some more. Elsie told Liz that she was off on a cruise again soon, and that she had really enjoyed the last one, all round the British Isles. She said that the cabin crew were very kind and helpful.

Roger – Colostomate
Operation 2008

Liz introduced Roger and explained that he was a new colostomate. Roger’s stoma had been formed via keyhole surgery (laparoscopy). He had also had radiotherapy and chemotherapy. Roger had contacted Liz via telephone and she had managed to squeeze him in to the clinic. Roger was wearing a one-piece bag. Liz asked him what the problem was. He told her that he had been having problems with drying his skin after showering and that his bag wouldn’t stick. Roger was using Safe Skin, which Liz said was fine. She then asked Roger if she could have a look at his stoma, suspecting he might have sensitive skin or a skin allergy.

The skin around the stoma was quite red. Liz described it as angry and removed the bag and applied a skin moisturiser. It was amazing how quickly the redness seemed to disappear. Liz showed Roger how to apply a skin barrier cream. She said it would soothe, moisturise and nourish his skin, and advised Roger to wipe off any excess. Liz also advised Roger to use lukewarm water when cleansing around the stoma especially if he continued to have skin reactions.

Ann – Colostomate
Operation 2008

Ann had been rushed to hospital as an emergency because she had “a blockage in her bowel”. She had stayed in hospital for five weeks and then spent three weeks in Townlands. Ann had been wearing a two-piece system, which she had mastered, but had been put on to a maxi one-piece because of a prolapse and hernia. Liz measured Ann for a support belt because of the hernia. Smiling and looking down at the area around her stoma, Ann said: “I had a satsuma. Now I’ve got a grapefruit.”

Liz had brought a sample support belt with her for Ann to try on and showed her how it needed to be positioned on her body so that it gave maximum support. “You really have to be measured to obtain the correct fit,” she said, and measured Ann carefully. Liz advised Ann that she needed to obtain a prescription from her doctor for the belt. Liz was very concerned about Ann as she knew Ann relied on taxis to get around, so contacted a supplier directly to arrange delivery. Ann was very grateful and thanked Liz very much.

Frank – Urostomate
Operation 2008

Last but not least, Liz welcomed Frank and his wife to the clinic. Liz began by asking Frank how he was coping. Liz produced a small zip-up bag and gave it to Frank; it was pocket-sized, just right for carrying stoma supplies while he was out and about. Both Frank and his wife were very grateful.

Liz wanted to find out about Frank’s diet and if he was drinking his cranberry juice. Liz then asked if she could have a look at Frank’s stoma. “It’s been a bit itchy underneath the bag,” said Frank. As Liz removed the bag it was clear that there was a red rash, possibly a fungal infection. Frank had quite a hairy stomach and Liz said: “The adhesive from the bag can get stuck in the hair which can make the area difficult to clean.” She suggested that Frank should shave the area around the stoma, which would enable the skin to be cleansed more effectively. Both Frank and his wife looked at one another and said together: “You can do that.” We all laughed. Liz cleaned the area around the stoma and applied a moisturising cream and barrier cream before putting on a new bag. She gave Frank some barrier cream and wipes to take home with him.

Liz also checked that Frank was managing to cut the hole in the bag to the correct size and asked whether he had mastered applying and positioning his appliance over his stoma. Liz also checked the colour of Frank’s urine and said that it was a bit smelly and quite dark. She advised Frank to take a sample in to his doctor to check that it was clear of infection.

At the end of clinic Liz went on to the wards to check up on her two other patients who were recovering from their operations. It was nearly the end of another busy day in her schedule.

Editors Comment

If you would
like to be featured in our
Open Door Series please
contact us
e-mail:
editor@colostomyassociation.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4 QL

Update on **new stoma care products** and **services**

Tidings has had numerous requests from readers to learn more about stoma care products.

The following pages will be set aside in future issues of Tidings to showcase new products and services

Have you tried a new pouch or other stoma care product or service recently?

If you have found it to be superior to what you were previously using or it solved a stoma related problem, please write and tell us about it or email: cass@colostomyassociation.org.uk

Bullen Healthcare

Bullen Healthcare have introduced Trio Diamonds™ super-absorbent gelling sachets with ActiveOne™ odour control technology, which has been proved to eliminate or reduce unwanted odour, and eliminate or reduce ‘ballooning’.

Trio Diamonds™ are quick, clean and easy to use, and give you all the benefits of a normal gelling sachet, ie. greater comfort, a flatter and more discreet pouch, less emptying, reduced noise, and reduced leakage. The product is available now on NHS prescription (order code TR105 for a jar of 100 sachets in a re-sealable bag), or you can order free samples from Bullen Healthcare on 0800 888 501. A sample request form is also enclosed on the insert within this copy of Tidings.

CliniMed Ltd announce NEW manufacturing facilities - Diamond Point

CliniMed Ltd, is pleased to announce the opening on October 29th of the Welland Medical extended manufacturing facilities at Diamond Point, in Crawley, West Sussex.

The opening ceremony was attended by The Worshipful the Mayor of Crawley Councillor Dr Howard Bloom and Diamond Point was officially opened by Mr Nigel D Piercey, Chairman of CliniMed Holdings Ltd, parent company of CliniMed Ltd and Welland Medical Ltd.

Overall, 2008 has been a busy year for Welland Medical Ltd. Earlier on this year it celebrated its 20th Anniversary and 2008 has seen the exciting UK launch of the new range of FreeStyle® Vie closed and drainable ostomy products, distributed by CliniMed Ltd. Therefore, the opening of Diamond Point comes as a triumphant close to a very busy and successful year.

Part of the ceremony included a guided tour of the new facilities for staff and invitees; facilities of which house the machinery which is responsible for producing the latest product ranges Welland has to offer. Sean Farbrother, Managing Director of Welland Medical Ltd said:

“This has been an extremely busy year for Welland and we are proud and excited to have expanded our business to the benefit of employees and patients alike. The new manufacturing facility will enable us to focus on new product development whilst increasing our manufacturing output to keep up with demand.”

For further details on Freestyle® Vie, please contact CliniMed on: 0800 036 0100

ConvaTec

Now available from ConvaTec is the extra large **ConvaTec Mouldable Technology Skin Barrier** for stomas that are quite large. The new design especially on the extra large has an oval starter hole and so it can fit stomas that measure between 33-45mm one way and 45-56mm the other. It is available on the 70 mm Natura range.

If you would like to know more about ConvaTec Mouldable Technology, please contact the Helpline on 0800 834 822 or email: stoma.webcare@convatec.com

Update on **new stoma care products** and **services**

OstoMART Ltd

OstoMIST Mint Drops Odour Neutralising Drops - highly effective odour neutralising drops and not a masking agent! The drops are effective with the worst odour problems as they contain the active enzyme Nanozyme. The 50ml Dropper Bottle is ideal for those who are reluctant or not able to use a spray.
OstoMIST Mint Drops
Product Code:
SPN5 x 50ml Dropper Bottle

New Product Presentation
OstoSORB – Odour Neutralising Absorbent Gel is now available in a Box of 150 x 3grm sachets. OstoSORB sachets are the only discharge solidifying product to contain the highly effective enzyme – Nanozyme. The sachets dissolve on contact with liquid and effectively neutralise odour as they absorb the fluid inside the Stoma appliance. OstoSORB does not alter the colour of the faecal content of your appliance.

OstoSORB is the original sachet presentation and still the best! OstoSORB is suitable for Ileostomy and Colostomy use where the output is fluid. 15 re-sealable packs of 10 sachets in a box.

Product Code:
PFW6 Box of 150 x 3gm sachets
PFW5 Box of 30 x 3gm sachets

Packaging Change
OstoCLEAR – Medical Adhesive Remover - containing Tea Tree and Lavender essential oils is now available in a new easy to use spray bottle.
OstoCLEAR is highly effective in cleaning and removing flange adhesive and stubborn residual adhesive. The Tea Tree oil may help to keep fungal and bacterial infections away from parastomal skin. Trialists loved the fragrance and many said it was the most effective adhesive remover they had ever used.

OstoCLEAR is available in a 100ml spray bottle for home use and in convenient sachet form for use whilst out and about.

Product Code:
MRW1 Box of 30 sachets
MRW2 100ml Spray Bottle
Samples of all of these products are available now!
Call OstoMART Ltd
FREE on 0800 220 300

Support Garments from Ostomart have changed!
We have added up to the minute technology to our range.

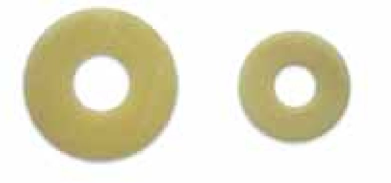
Hi Line have taken the opportunity of improving the value of their garments using licensed technology for your benefit without increasing the price to the NHS.

Silpure™ - Silver based Antimicrobial coating - silver is safe and efficient and used in many medical applications. It is environmentally harmless, non irritating, non sensitising and effective in controlling bacteria. This means a Hi Line garment with the coating will remain MRSA resistant for 50 washes at 40ºC.

We have also added an extra coating to all of the lining fabrics. Advanced Teflon® a dual action fabric protector - with repel and release action it combines the best of two stain fighters in one finish. Repellent products lower the critical surface tension of the fabric so it doesn't attract stains or soil. Release products increase the likelihood that ground in stains will come out in the wash. So your Hi Line garment is less likely to stain should you have an accident.

Peak Medical

Peak Medical has launched an addition to the popular Varimate range of products. Varimate Resist 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.

The washers are available in two sizes: small and large, in packs of 20. Varimate Resist Washers are available on FP10 prescription.

If you would like to receive samples, please see the advert on page 19 or simply call the Peak Medical helpline on Freephone 0800 652 0424.

Pelican Healthcare

NEW – Pelican Select 2-Piece range

Pelican Healthcare is pleased to announce the launch of a new complete range of 2-Piece appliances which are available on prescription now.

The Pelican Select 2-Piece range of products has been specifically designed to enhance comfort, whilst ensuring maximum security coupled with ease of connection.

Select 2-Piece is available in three sizes of Mini, Standard and Maxi to suit your requirements, along with a choice of closed and drainable pouches. Select 2-Piece has an improved filter system with controlled flow for greater comfort and confidence.

The Select base plate is available in two sizes: 50mm and 70mm dependent on your stoma size. The Select base plate is unique and extremely flexible offering you the ultimate in comfort with additional features to aid removal of the base plate and a simple, secure attachment of your pouch.

Please see the advert included within this edition to request your samples today or simply send an e-mail to: contactus@pelicanhealthcare.co.uk alternatively you can call the Freephone helpline on: 0800 052 7471.

Pancaking

with comments and tips from Tidings readers

Tidings Contributor
Louise Taylor
Stoma Care Nurse Specialist
OakMed

There is very little literature, which states how common a problem pancaking is for the colostomist but a problem it certainly is. Pancaking (or pattycaking as the Americans call it) occurs when the stool sits on or around the stoma and fails to drop down into the appliance. As more stool comes out there is nowhere for it to go so often it pushes its way underneath the flange. This causes problems with sore skin (where the skin is exposed to the stool), unpleasant odour and leaks. This in turn can lead to a fear of venturing out in public due to potential accidents.

Pancaking is believed to be caused either by the filter on the appliance being too effective, i.e. it lets all the gas out very quickly and leaves the bag flat against the abdomen, or because the stool is too 'sticky'. It is a tricky problem to resolve but here are a few things for you to try.

The most important thing to try over a period of time is to increase your fluid intake. If the stool is very sticky try altering your diet, particularly your fluid intake as this can often make a difference to the consistency of your stool.

'My experience with pancaking very much depends on the consistency of the stoma output which varies with my diet.'

'Increasing your daily intake of water seems to be the number one home remedy for pancaking.'

Increase your fibre intake – this can also help alter the consistency of the stool.

'Really you need to keep the consistency of the faeces softer by increasing the fluid and perhaps fibre.'

Just as you apply your bag blow a little bit of air into it to prevent it from being completely flat. Towards the top of the appliance there is a filter, which allows the gas to escape. Sometimes the filter works too well and causes the bag to suck together it is worth placing a filter cover over this (they are the little stickers that come in the box with your bags) This allows the gas to create a bit more space for the stool to move down in the bag.

'I cover the filter on the pouch with the little plaster like stickers that come in the box. By covering the filter any gas is trapped inside the pouch and usually preceding every bowel motion is a little wind, which inflates the pouch slightly allowing the motion to pass freely into the pouch (especially if it is oiled inside). This also has the dual benefit of giving you total control over odour. With the pouch filter no odour can escape and when you have wind in the pouch you can go to the bathroom, peel the plaster back a little and press the pouch to release the wind then reseal it. Make sure the plaster is left off the filter at nights to avoid ballooning.'

Another way to help the faeces pass in to the bag is to place a wet or scrunched up tissue into the appliance. This helps hold the sides of the bag open. Alternatively, Opus has a product called Clearway that is a foam cube that can be stuck inside the bag to help hold it open.

You can also grease the inside of your bag with oil (olive oil or baby oil – although this can sometimes lead to shorter wear time). This helps the stool to slide down inside the bag. Alternatively, try using a lubricating deodorant, which is now available from both Hollister and Ostomart and does the same thing.

'If it's relatively solid it can be manipulated externally to help it fall into the bag. In this case applying one of the various lubricants to your bag it can help.'

If the problem persists try taking one sachet of Fybogel a day. This is a drink with extra fibre in which can be purchased from your chemist. Always make sure you discuss this first with your stoma care nurse.

'Manipulation can help a bit but I must say I haven't found a really good solution to the problem except removing the bag (I use a two piece system) and after clearing the problem replacing it'

'A small amount of laxative helps me but this ought to be prescribed by your GP'

'I have dealt with it by lifting the plastic at the front of the bag, lower down than the stoma and then pushing down on the pancake with the plastic to get it away from the stoma. This seems to do the trick and allows further emissions to drop into the bag more easily'

You might be also be interested to learn that Oakmed have been informed on many occasions that when a colostomist has changed to an Oakmed appliance this has often resolved their pancaking problems.

A Stoma Care Department in Portsmouth has had a 100% success rate when choosing an Oakmed bag for any colostomists who are experiencing pancaking problems over the last few months. We believe that it is due to the filter and lining The filter is designed to control the slow release of gas from the bag over a period of time, rather than it all being released at once causing a space to be maintained for the free passage of faeces. Also the lining is highly polished helping the faeces to slide down away from the stoma.

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Pathways to a colostomy blown up...

Duncan Wells is the voice behind many well known Television and Radio advertising campaigns from Nescafe to Ariel Automatic, Renault Cars to the Daily Mail. As well as campaigns recorded from his ISDN studio direct to studios around the world. Duncan is also a Royal Yachting Association Instructor and has his own sailing school, Westview Sailing this is his story...

Twenty laparotomies, five plastics operations, one tracheostomy, one skin graft, endless procedures to insert lines into my chest, neck and arms. The removal of the spleen, the loss of all bar seven inches of my large bowel, some of my small bowel and a section of pancreas. And the addition of a stoma. That's what you can expect when you get shot by a faulty warning flare.

I was in hospital for nine months, four of them in ITU - six weeks in an induced coma - and then nursed privately at home for a further four months. My wife Sally was by my bedside every single day encouraging me to get better, helping with the nursing, supporting me in every way. Which makes me worry a bit when I hear her say "She will not be subscribing to the vows about 'in sickness and in health' in her next marriage." I suspect that she may not be keeping me fully in the picture. I had so many X-rays, CT scans, ultrasound inspections and MRIs that I started to glow in the dark. Any more exposure to x-rays would have been dangerous. As for my medical notes, well they run to five volumes, each six inches thick. And I am a very popular case history. By the time I left ITU no fewer than six doctors had me down as their specialist subject.

I am a voiceover actor who has been behind many TV and Radio campaigns from Nescafe to Ariel Automatic, Renault Cars to The Daily Mail. I am also a Royal Yachting Association instructor. I have my own boat and in a feeble attempt to defray the huge cost of boating, I have my own sailing school. On this day we were filming safety flares for a distance-learning DVD.

The Pains Wessex Mk 7 white collision warning flare burns very fiercely indeed. The magnesium and strontium compound reaches 3000ºC and burns for 60 seconds. I fired the flare and there was a fizzing for a second, then a tremendous flash followed by a huge explosion. I felt a terrible pain in the left side of my abdomen. The shock of the thing knocked me to my knees. I looked down and saw my right hand soaked in blood. I didn't realise it but the flare had torn my hand apart. There wasn't any pain from it at the time, all I could feel was the pain in my abdomen. I couldn't see the flare and then realised that it must have gone in to me, presumably to burn at 3000ºC for the advertised 60 seconds.

Being in a coma and immobile for six weeks I went from 14 stone down to 9 stone and when I came round was so weak that I couldn't move. I couldn't lift my skeletal arms, or my legs or my feet. Nurses had to turn me every few hours. I was incapable of anything. I was in pain and no amount of morphine helped and because I was on morphine I was being sick all the time which caused stress and pain to the abdomen. A vicious circle. A vicious circle that stayed with me throughout the nine months.

More or less as soon as I was out of the coma the physiotherapists struck. I wanted them to leave me alone. I felt too ill. Every time they tried to get me up I felt sick. I just wanted to lie down. They told me that I would only be allowed to leave the hospital and go home when I could walk out on my own. I couldn't imagine that. I couldn't even imagine being able to sit up. Of course over time I was made to sit out in a chair – they lifted me off the bed using a hoist and lowered me into the chair - and then they tried me out on a standing frame and I collapsed right through it. The fact that I'd just had major surgery the day before and I had open wounds and drains and were attached to every machine going didn't stop the physical terrorists. I'm glad they didn't give up though.

I was unique. There was no instance of any person being shot by a shell or a flare and surviving. The doctors were frantically looking for some previous case that they could refer to but there was nothing. All of which meant that we were right on the medical edge, from surgery to medication to dressings. In the early days the staff at the hospital were fairly sure that I wouldn't survive and prepared Sally for this. I came very close to it on many occasions. Either I was leaking bile inside and poisoning myself or I was haemorrhaging, or I was running a temperature of 40ºC – which is inadvisable. My heart fluttered and beat arhythmically but it kept going and I held on. Even after eight months in hospital when I had my final major operation to stitch the bowel back together there were complications and I started leaking and had to be rushed back into surgery.

The head of ITU said later. "I think it's virtually unprecedented. Certainly in the twenty-five years I've spent in clinical intensive care practice I've never seen anybody survive the magnitude of both the initial injury and then all the following complications."

On arrival at hospital, they removed the flare casing and the handle and the burnt and necrotic large bowel. They were left with several ends of unconnected small bowel – fistulae - so they ran up a quick stoma for later which was a good idea. They made the stoma out of a little piece of large bowel up near the ileum, so we are just in colostomy territory. With three unconnected sections of small bowel I had to be fed parenterally through my vein. And once they had stopped me from dying, which took some time, their attention turned to trying to get my small bowel to absorb.

It was a major plumbing exercise. I was still on TPN (Total Parenteral Nutrition), as it is known, when I left hospital just before Christmas 2006 and would have remained that way for some time had I not got a dose of line sepsis – poisoning of the TPN line – and had it removed. Now without the TPN would I be able to absorb food? Not absorbing would mean a life on TPN – not much fun. A little scrambled egg here and a little avocado there and the stoma started to work. I was on my way back. Food tasted disgusting – I hadn't eaten for nine months – and the nutritionists were balancing my diet most carefully. Too much potassium would be the cry, better drop the avocados. Too much sodium, and so forth. And Sally, devoted as ever, measured every drop that went into me and every drop that came out. I have taken to this eating business so well that now I am overweight but at least I am absorbing.

Editors Comment

You may like to know that Duncan together with his wife Sally raised over £50,000 for a ventilator fund for Wexham Park Hospital. It was his wife Sally's idea to buy the hospital a ventilator as a way of saying 'thank you'.

If you would like to be featured in our **Pathways series** please contact us
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What kind of **food** should you **eat after surgery?**

Many ostomates are able to return to their previous eating habits without much alteration after surgery...

However, ostomy surgery that affects the large or small bowel may change how your body processes food. Therefore, you should exercise some caution and common sense when eating after you leave the hospital. This applies as well to those who have undergone radiation to the pelvic area, as portions of the remaining bowel can be irritated by this treatment. You need to learn how your new body reacts so, if possible try to stick to regular mealtimes as this can help you understand your body's behaviour patterns.

After surgery your appetite can change and food may just not have the same appeal. Your taste buds seem altered - just the sight of foodcan be enough to put you off eating.

Prior to having surgery some people may have had to lose weight in order for them to have surgery. It is quite common to continue to lose weight after leaving hospital. However, by eating little and often you will be able to maintain a good calorie intake.

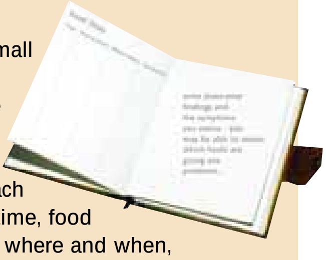
Many people will continue with their previous eating patterns without realising that certain foods may have an effect on their stoma. Which foods will vary from person to person.

Trial and error can often be the only way to find out if a particular food upsets you. Although this may seem like a difficult and irksome task it is well worthwhile and may help you in the long run.

Keeping a food diary is often a necessary and important part of stoma care.

The diary will help you to detect which food is upsetting you and more to the point affecting your output. It will help to highlight any problems relating to your diet.

Food Diary... here's what to do



- Take a small notebook and divide into four columns
- Name each column - time, food and drink, where and when, symptoms
- Write down your findings and the symptoms you notice

After a few days, you may be able to assess which foods are causing you problems and then try to take steps to avoid including them in your diet.

Getting back to eating well - when people receive their stoma, many are unsure of what to expect. They may even be surprised when the stoma starts to work and their pouch begins to fill for the first time.

The key to eating well after surgery is not to eat large meals but to eat smaller amounts regularly. You may find it difficult at first to eat six times a day – three small meals with nourishing snacks in-between – but it really is worth a try.

Eat slowly and try to chew your food thoroughly. This will help to prevent the intake of air with your food and will aid digestion and prevent you feeling full too quickly.

You will gradually get to know what amount of food to eat before you feel uncomfortable.

Try to relax while you are eating; make sure eating is an enjoyable experience. If possible, you should try to sit up at a table because this also aids the digestive process. However, you may prefer to sit in an armchair with a tray on your lap.

Some people often need something to help stimulate their appetite – you may find some of the following tips helpful:-

- Exercise. It does not have to be a formal workout, or even high intensity.

- Take a look at cookbooks, health magazines, or cooking websites. Simply observing pictures of food can stimulate your appetite and physically prepare your body to eat.

- Try new foods, or make old favourites more interesting by adding to the recipe.

- Experience your food. Take time to savour the smells, tastes, and textures as you eat.

- Plan your meals. Anticipation of good food can increase your appetite.

- Have a very small snack before your meal. If you have gone too long without food, you will tend to "tune out your hunger and actually reduce your appetite".

As your appetite returns you will feel more like eating, your weight should start to increase and your energy return. You will feel more able to cope with your stoma and with the added information from your diary you will have the confidence to choose foods you know you can enjoy - meal times will become a pleasure not a worry.

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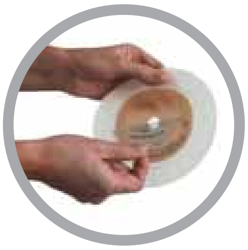

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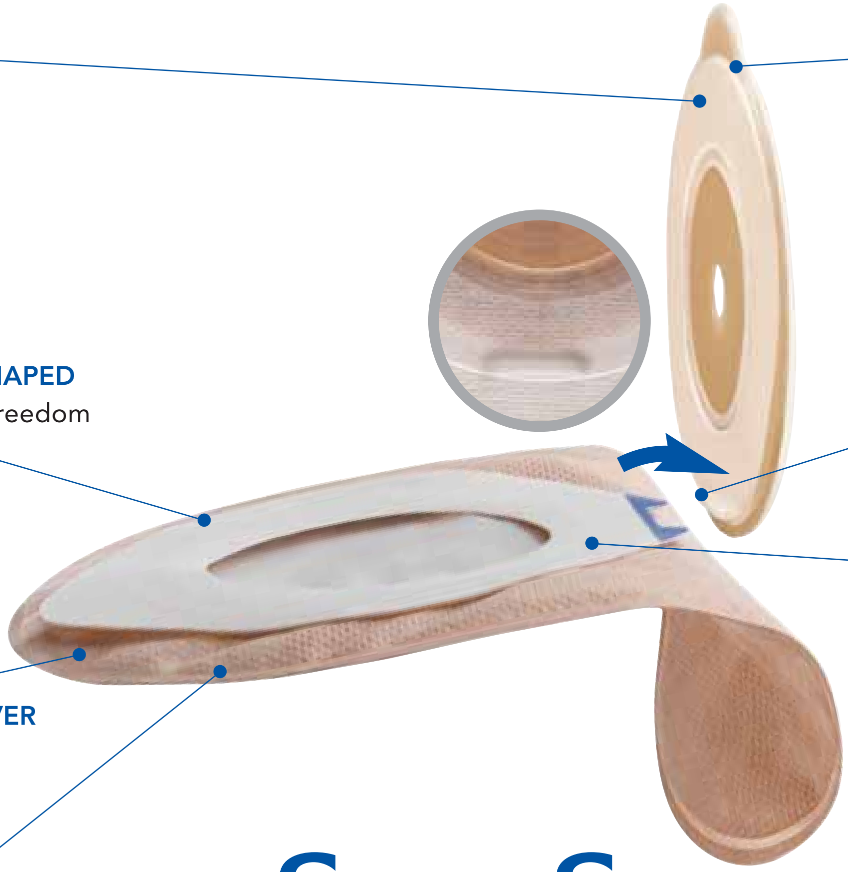

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Parastomal hernia
battle of the bulge

Parastomal hernia is a common complication associated with stoma surgery, leaving the surgeon with surgical dilemmas, the stoma nurse with practical solutions to solve and the ostomist with the stress of disguising its visibility from beneath their clothing as they battle the bulge.

This article aims to discuss the plight of the ostomist with a parastomal hernia by exploring the reasons for herniation, the signs and symptoms related to hernias, the surgical management and the dilemmas that may ensue whilst considering suitable stoma management.

A parastomal hernia is described as "an abnormal amount of intestine in the subcutaneous or intestinal tissues causing a swelling or bulge". It may occur with any stoma but is more common in end colostomies. Initially a slight, painless swelling develops causing little or no management difficulties for the ostomist. However, this swelling has the potential to get larger and as it does, it also brings about many other associated complications.

Fig. 1

When the parastomal hernia becomes large, the pressure of the bowel protruding through the abdominal wall causes much discomfort, which is often described as a dragging sensation. This is further complicated with changes in the size and shape of the stoma, the skin around the stoma may become fragile and uneven giving rise to skin problems, consequently posing difficulties with everyday activities.

It is widely acknowledge that a parastomal hernia is a late complication of stoma surgery. The incidence of herniation varies throughout medical literature but it mostly states that at least 20 – 30% of colostomists are likely to be troubled by a hernia whereas the incidence is less for the ileostomist and urostomist.

The main reason for the development of a parastomal hernia is assumed to be weakness in the abdominal wall at the site of the stoma but this is not always the case. Other contributory factors thought to lead to the development of a parastomal hernia include obesity, malnutrition, chronic cough, sneezing and straining in constipation; all of which may increase pressure on the abdominal wall. There has been much debate amongst surgeons as to how the stoma is initially constructed. If a defect arises in the construction of the stoma, the potential of a hernia occurring increases. One of the main theories is that the stoma should be placed within the rectus muscle of the abdomen (See Fig. 1), as this muscle will act as a support to the bowel but further debate arises with which route the bowel should take prior to being pulled through this muscle. Some surgeons feel that it is unnecessary to position the stoma through the rectus muscle particularly as with age the rectus muscle becomes thinner and weaker and therefore not able to provide adequate support to the stoma and that this is more common in women. A defect in the ostomists' skin collagen may also play a part although there is no study to support this view.

Preferred treatment or management of parastomal hernias is non-surgical however extreme cases will require surgery. Surgeons are reluctant to surgically repair parastomal hernias as there is a 50% recurrence rate following any surgical intervention particularly when a local repair has been undertaken. This is when the dilemmas begin for the ostomist and the nurse specialist as attempts are made to manage the hernia conservatively, resulting in some ostomists wearing support garments such as a girdle or belt.

From my own clinical experience ostomists with parastomal hernias, not only become distressed due to the unsightly bulge or swelling that develops but many express difficulties managing their stomas. As the parastomal hernia enlarges the stoma function becomes progressively more unpredictable. Many are extremely embarrassed as wind (flatus) seems to increase and becomes more noticeable, whilst the output appears to fluctuate between sluggish (small pellets) to explosive (diarrhoea) making appliance fitting extremely difficult. Some ostomists have expressed difficulties when buying suitable clothing, as they often feel lopsided and would have to opt for a larger size.

As the stoma nurse makes her assessment of individual cases ostomists not only require advice in order to support the parastomal hernia but also require advice as to how to manage a dysfunctional stoma. When managing the appliance, a one-piece system would be considered better than a two-piece system as it is less bulky. Of the one-piece appliances available it is recommended to use a large circular or oval shaped adhesive or a product with two adhesives so that the appliance will have an opportunity to stick better. However these are not always suitable for the individual because an appliance with a large adhesive area usually comes with a large bag, which is not everyone's choice.

Whilst assessing the stoma function it may be necessary to consider the dietary habits of the ostomist. Taking a dietary history could help identify the dysfunctional problems, amount of fibre and type of food eaten. Sometimes fibre can lead to a blockage, resulting in further pain and discomfort but it also has a role in thickening the stoma output. Therefore it might be necessary to keep a diet diary for a time in order for the stoma nurse to make an assessment with regards an individual's dietary intake.

The mainstay management for parastomal hernia is that of a girdle or belt. There are several types available however the individual must be measured and fitted appropriately prior to use. Up until recently most girdles and support belts would come with a reinforced hole for the stoma and appliance to be fitted through. Reports now show that a hole in the corset or belt is unnecessary, as it will only exacerbate the very problem it seeks to correct. Some stoma nurses feel that without the hole in the girdle or belt the stoma output is unable to flow freely thus leading to 'pancaking' where the faeces does not fall to the bottom of the appliance.

Currently preventative measures are being explored, suggesting those at high risk of hernia development be assessed and offered preventative management such as a support garment, dietary advice and advice on re-establishing activities such as lifting and playing sport. Current research is also exploring whether it is appropriate for all ostomists with newly formed stomas to undertake abdominal exercises in order to strengthen abdominal muscles and thus prevent hernias occurring in the first place.

Tidings Contributor
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In conversation with BreakAway

Rachel Clarkson and Julie Bastin - organisers of BreakAway - (the UK's first adventure activities break for young people with bladder or bowel diversions/dysfunctions and their families) tell us why Breakaway is so special plus two young people Max and Fergus write about their experiences.

Question:
What makes BreakAway special?

Answer:
Because it is the only organisation that offers the chance for young people with bladder or bowel diversions/dysfunctions and their families to meet, share experiences and have fun!

Question:
Why is BreakAway so important to young people with bladder and bowel diversions/dysfunctions?

Answer:
Here are some quotes from young people who have attended a Breakaway weekend.

- "It has been great sharing experiences with other people in similar situations"
- "I enjoyed talking to people about my problem"
- "I enjoyed dancing with my new friends"
- "I have found it an interesting weekend and I have found out about other illnesses too"
- "I thought I was the only one"
- "This was definitely the best holiday ever"

Question:
What does BreakAway offer young people?

Answer:
BreakAway offers a unique environment for everyone, in which to be open and honest about their conditions. It helps to build confidence and also shows that they are not alone.

Question:
Who can go to a BreakAway Weekend?

Answer:
Any young person who has a bladder or bowel diversion/dysfunction.

Question:
Is BreakAway just for children or can their families accompany them?

Answer:
BreakAway is for the whole family. It is a chance for the family to come together having been through tough times.

Question:
How is a BreakAway weekend structured? Is there an itinerary?

Answer:
We start off by splitting people into groups with people they don't know (little children with their parents of course). We devise team-building games to help them get to know one another.

Activities during the weekend are designed to build confidence and show the young people that having a diversion/dysfunction does not stop them from doing anything. These are things like climbing, canoeing, coasteering, gorge walking etc.

On the final evening we have the traditional breakaway party. Stoma care companies and patient associations are invited to offer advice and display their products on the final morning.

The itinerary and kit list is sent to all families around a month before the event.

Question:
Does BreakAway cater for special diets or medical needs?

Answer:
BreakAway is able to cater for special dietary needs and we ask about requirements on the booking form. Medical needs are taken into account and the programme is devised accordingly.

Question:
Does BreakAway provide insurance cover?

Answer:
BreakAway does not provide insurance cover, however we do have details of insurance companies available on request.

Question:
If families do go on a BreakAway trip do they join in with their children's activities?

Answer:
Yes, we feel it is important for everyone to get involved, as it shows the young people there is nothing to be afraid of.

Question:
Do children/families need to bring anything special with them?

Answer:
All specialist equipment is provided, and a kit list is sent out to the families prior to the weekend.

Question:
If children/families don't have their own transport how can they get to a BreakAway weekend?

Answer:
We try to organise BreakAway weekends close to public transport links.

Question:
Is there a nursing professional on hand?

Answer:
We have several stoma care nurses who join us for the entire weekend.

Question:
Does BreakAway provide any emotional support?

Answer:
We are not trained counsellors, but having the support and experience of likeminded people is hugely beneficial to the young people and parents alike.

Question:
How is BreakAway supported?

Answer:
BreakAway relies solely on donations. In the past these have come from stoma care companies, private donations and fundraising by friends and family.

Both myself and Julie work on BreakAway completely voluntarily in our own time.

Max writes about Breakaway...

Before Breakaway in 2007, I felt that I was alone and that there was no one to turn to for help, or anyone to talk to who understood my problem.
I have an ACE stoma that was created around three years ago, which was when the doctors first realised I had bowel problems. That was after twelve years of complete misdiagnosis. I just did nothing because I was scared people would laugh at me if they found out about my problem, and that I'd never get any true friends. But then one day, during a hospital appointment, I was told of this new group Breakaway that has just started up for young people with bowel and other problems.

The first Breakaway I went to was in 2007. I was nervous and scared, but when I got there I was welcomed with open arms and met an amazingly great group of people who have the same sort of problem as me. I was shy, but still I enjoyed the activities we had to start off with. ►

In conversation with...

BreakAway

The group activities were to get people to communicate and start talking. I was the only boy of my age (14) there. The rest were very young or a couple years older, but I was able to fit in with the older people and they were so nice and friendly. They talked to me about our problems and how we deal with it, they gave me advice and it really helped, as I was new to the ACE, very confused about what I should do with it, and how I should go about using it.

I opened up a lot, and on the last night we had a party/disco. I loved it! Everyone danced, as did I. I just felt so relaxed. It was one of the best times I've had in my life. The last day came to an end, and I went home with the confidence to tell my friends at school that I have bowel problems. I started going to school more, as I felt safer. My mates started to protect me because they cared. I would never have found out if I hadn't gone to Breakaway. It opened a door for me to change how I was, the scared and nervous person, to a more open and willing person.

When the 2008 Breakaway came I was so excited, I almost felt ill. As I got to the place where Breakaway was hosted, I saw loads of new people, and some people my age. This made my day because I got to learn how they deal with school, their lives and their problems.

Young people can really benefit from going to Breakaway because it shows them that there are people with the same problems, and there are people they can talk to without having to worry. It also lets them get away from school and home life for three days, allows them to hang out with people that know the problem and can help with confidence, and they will meet friends that really understand.

I've got loads of friends because of Breakaway. They differ in age, but they are all understanding and very nice people. I must say that I'm not going to stop going to Breakaway for years to come. It just helps me calm down, relax and escape from the world of misunderstanding where bowel problems are concerned. Breakaway has helped me a lot, and it can help other children with bowel and other disabilities. It's the best! Thanks to Rachel and Julie and everyone else who helps Breakaway, plus the people who go to Breakaway for all the help and support.

Fergus writes about Breakaway...

Whilst I was packing for the Breakaway Christmas Weekend I said to my Mum that the people from Breakaway were more like a second family to me rather than friends. I can't believe that the first time that I met everyone was only two years ago! My name is Fergus I am 13 years old I got my colostomy when I was just 12 hours old so I have no idea what it is like not to have a colostomy. I was 11 years old when I met other children at Breakaway, up until then I had never met another child with a colostomy. Having a colostomy made me feel different from my friends at school because the only other people I knew with colostomy's were people who were adults.

The first time that we all got together was at a Youth Hostel in North Wales It rained all week end but that did not stop us all enjoying ourselves. We had rowing races on the lake and then we climbed up a rock and jumped in to the freezing cold water of the lake. It was brrrilliant!!!!! At Breakaway we did lots of activities so that we got to know one another very quickly and became friends and then we were able to talk about things. The good thing about Breakaway is that there are children and young people of all different ages and because of our different experiences we are all unique but joined together because of our problems.

This year we went to the National Forest in Moria. We had a great time there just like we did last year. We went canoeing which was great fun because we had a water fight. Of course I was winning, but then everyone got jealous so they decided to get me drenched (because I was stone dry) AT THE VERY END!!!!!!!! We all had a great time. Even before the canoeing it was great. We had a lesson in archery and yet again I was the best (JOKE!!!) but I was in the top five!!!

The best opportunity came on the last day, just as everyone was about to leave there was a chance to gather information about colostomies and ileostomies. You could also get free samples to try and decide which one was best for you. Also another opportunity which nearly everyone if not all people took hold of was to get information, hints and tips about how to cope with your illness and what people think of you.

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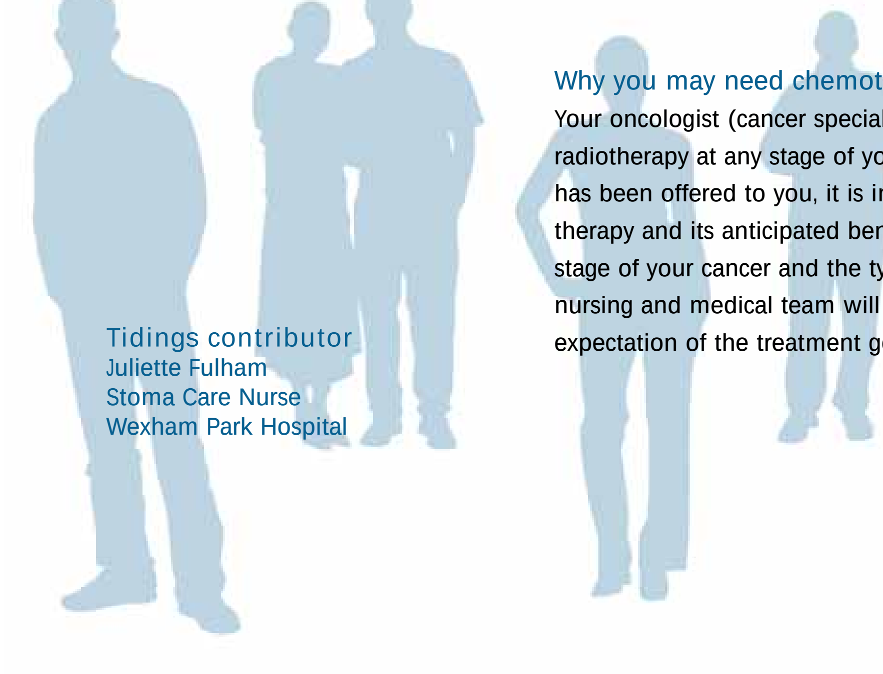
Pembrokeshire, South Wales
from May 22nd for 3 nights

Visit:
www.breakawayvisit.co.uk/2009.php

Coping with **chemotherapy** or **radiotherapy** and **a colostomy**

If you have undergone or are undergoing stoma formation due to cancer, surgery may not necessarily be the only form of treatment you will receive.

Although surgery is the main mode of treatment for the majority, some patients may still need to receive additional treatments such as chemotherapy and/or radiotherapy



Why you may need chemotherapy or radiotherapy?

Your oncologist (cancer specialist) may recommend chemotherapy and/or radiotherapy at any stage of your cancer treatment. If either of these treatments has been offered to you, it is important that you understand the aim of the therapy and its anticipated benefit to you. This will depend upon the current stage of your cancer and the type of tumour you have. Your oncologist and his nursing and medical team will discuss this with you so that you have a realistic expectation of the treatment goals and the possible side-effects of treatment. ►

Tidings contributor
Juliette Fulham
Stoma Care Nurse
Wexham Park Hospital

Coping with **chemotherapy** or **radiotherapy** and **a colostomy**

In the main, chemotherapy and radiotherapy are given for the following reasons:	
Neo-adjuvant therapy: (Before your main treatment starts)	This aims to downsize your tumour before your main treatment starts. For example, a combination of chemotherapy and radiotherapy is sometimes given before surgery to reduce the size of a rectal tumour. This aims to reduce the size of the tumour to render it operable or so that less radical surgery may be required to remove it.
Primary treatment: (Your main mode of treatment)	For most cancers where a solid tumour exists, surgery is the main treatment (in terms of trying to effect a cure). However, for certain cancers (e.g.anal cancer) chemotherapy and radiotherapy are given as the main treatment, with the intention of hopefully curing the cancer.
Adjuvant treatment: (After your main treatment)	This is generally where chemotherapy (and occasionally radiotherapy) may be given after your surgery to treat any cancer cells which may remain. It aims to reduce the likelihood of your cancer recurring.
Palliative treatment: (When your cancer cannot actually be cured)	Even though it may not be possible to cure your cancer, chemotherapy and/or radiotherapy may be given to help relieve the effects of the cancer, to improve your quality of life. It may also aim to help prolong your survival.

How does chemotherapy work?

Chemotherapy involves having cytotoxic drugs (this literally means drugs which are toxic to cells) administered (usually intravenously or as a tablet) which aim to cause any cancerous cells in your body to die. Although normal cells in your body will still be affected by chemotherapy, they have a greater ability to repair themselves, whereas cancerous cells are more vulnerable to the effects of chemotherapy.

There are many different types of chemotherapy drugs. Different drugs have been found to be effective at treating different types of cancer. The drug or combination of drugs you receive will depend upon the type of cancer you have and the stage of your disease.

Chemotherapy is usually given in cycles – this means a series of treatments at set intervals (for example, every three weeks for a set period). The reason for this is so that the normal cells in your body have an opportunity to try and repair themselves between each treatment while a larger proportion of cancerous cells can be targeted over a longer period of time. Spacing out the cycles of chemotherapy in this way aims to reduce the extent of its side-effects whilst increasing its effectiveness at actually treating the cancer.

How does radiotherapy work?

Radiotherapy is given to directly target a specific area in your body, usually the cancerous tumour itself or an area where the tumour has been. Radiotherapy involves using radiation to damage the cancerous cells, to try and cause them to die. As with chemotherapy, radiotherapy is usually given at set intervals, known as fractions. This means a series of smaller doses over a pre-determined length of time. This is so that more cancerous cells can be targeted over the duration of the treatment and (as with chemotherapy) it allows normal cells the chance to try and repair themselves between treatments.

Sometimes, particularly when given for palliation of symptoms, radiotherapy may be given as a single dose, or over a shorter period of time.

What side-effects or problems may I experience and how will it affect my stoma care?

When receiving chemotherapy, the side-effects of treatment will depend upon which drugs you are receiving. Side-effects vary between individuals, even though they may be receiving the same treatment. Your oncology team will provide you with information about the specific drugs you are receiving and what side-effects you may experience. It is vital to inform your oncology team as soon as you experience any side-effects to treatment, since it is much easier to treat them if they are identified early, rather than waiting until they become more severe.

The most common side-effects to chemotherapy and radiotherapy which may affect your stoma care, either directly or indirectly, are outlined below.

It is important to remember that other side-effects are also possible, but only those relevant to your stoma care are included here.

Skin damage due to radiotherapy - This can occur within two or three weeks of starting radiotherapy. It is very unlikely that your colostomy will be within the area targeted by the radiotherapy, so the skin around your colostomy should be unaffected. However, some people who have an abdominoperineal excision of their rectum (also known as an APR) for a rectal cancer (where the anus is also removed) may have had pre-operative (neo-adjuvant) chemotherapy and radiotherapy. This can impair the rate at which the perineal wound heals. Try and avoid sitting on the wound for prolonged periods until it has fully healed and ensure that the wound is checked frequently to make sure it is healing normally.

Gastro-intestinal disturbances

Nausea - this is commonly experienced with chemotherapy and can also be a side-effect of radiotherapy to the abdomen or pelvis. Your oncology team will usually give you anti-sickness tablets to take for a day or two after each treatment (and you may well receive them intravenously at the same time as your chemotherapy), but it is important that you inform them if these aren't fully effective. They may be able to offer you alternatives.

If you find you are eating less due to nausea or vomiting, this may affect your colostomy output – you may find you are passing fewer faeces and your colostomy may function erratically because your intake of food and drink is irregular. If your stools become hard, or your colostomy functions less than once every 24 hours, this indicates that you may be constipated. Ask your GP or oncology team to consider prescribing laxatives (enemas and suppositories are not appropriate for colostomists) and try to increase the amount of fluid and fibre in your diet. You may find eating little and often easier, and if the aroma of cooked foods exacerbates your nausea, try eating cold foods.

Diarrhoea - this is a common side-effect of chemotherapy and can also occur after abdominal or pelvic radiotherapy. Your colostomy output may become looser and you may find you need to change your appliance more often than usual because it fills up quickly with loose faeces. If you find you are needing to change your bag more than three times per day, it is usually better to switch to a drainable bag until the loose stools/diarrhoea resolve.

Changing your bag too frequently may cause the skin around your stoma to become sore. Using a drainable bag means that you can empty the contents more easily into the toilet.

If your oncology team tell you that diarrhoea is a likely side-effect of your treatment, contact your stoma care nurse so that he/she can arrange for you to be sent some drainable bags, in case they are needed.
It is also worth noting that fatty or high-fibre foods may make your ►

Coping with **chemotherapy** or **radiotherapy** and **a colostomy**

diarrhoea worse – you may wish to consider alternative foods until the diarrhoea has resolved.

If you do experience diarrhoea during your treatment, inform your oncology team as soon as possible. They may wish to give you some anti-diarrhoeal medicine to help reduce your symptoms.

Positioning during radiotherapy

Sometimes, people receiving radiotherapy may need to lie on their front to receive the treatment. Although each treatment will only last a few minutes, it's a good idea to ensure your bag is empty before each session and to make sure you bring a few spare bags with you.

Sore mouth/mucous membranes (known as mucositis/stomatitis)

This is a possible side-effect of some chemotherapy drugs, where the mucous membranes of your mouth and lips can become sore and inflamed. This can make eating and drinking difficult (causing the same potential problems for your colostomy as for nausea and vomiting). Make sure you alert your oncology team immediately if you experience this problem so that they can treat it quickly to try and prevent it worsening.

Similarly, your colostomy may become swollen and may bleed easily. Take extra care when changing your bag and when cleaning around your colostomy. If your colostomy appears larger, you will need to enlarge the hole in your stoma bags. If necessary, your stoma care nurse can help you with this.

Sore hands and feet (known as palmar plantar syndrome) or numbness (known as peripheral neuropathy)

Some chemotherapy drugs have the potential to cause short or longer-term numbness in your peripheries. Flaking, sore skin to the palms of your hands (and the soles of your feet) is a potential side-effect of 5-FU (also known as capecitibine or Xeloda) a chemotherapy drug commonly used in the treatment of colorectal cancer. Although the numbness usually reduces over time, either of these side-effects may temporarily affect your dexterity so that (amongst other things) you may find it harder to change your bag and carry out your stoma care. Contact your stoma care nurse if you are experiencing problems with your stoma care due to this – they may be able to suggest an alternative appliance which you may find easier to use while the problem persists.

Reduced immunity (known as neutropoenia)

Your oncology team will carry out regular blood tests throughout your course of chemotherapy. If your team suggests that you are neutropoenic this means you have a reduced number of white blood cells and are more vulnerable to infection. Make sure you clean around your colostomy gently and remove your bags carefully to avoid injuring the skin, since breaks in the skin could serve as a route for introducing infection.

Who should I contact if I experience any problems?

For any advice relating directly to your stoma care, contact your stoma care nurse.

It is also always advisable to contact your oncology team to report any treatment-related side-effects. If these require treatment, the earlier this is instigated, the greater the likelihood of minimising the side-effects. Your oncology team will provide you with their contact phone numbers at the outset of your treatment. ■

Additional sources of information

The following organisations provide additional cancer-related support and information:

Cancer Backup
Tel: 0808 800 1234
www.cancerbackup.org.uk

CancerHelp UK
Tel: 0808 800 4040
www.cancerhelp.org.uk

Beating Bowel Cancer
Tel: 08450 719300
www.beatingbowelcancer.org

Bowel Cancer UK
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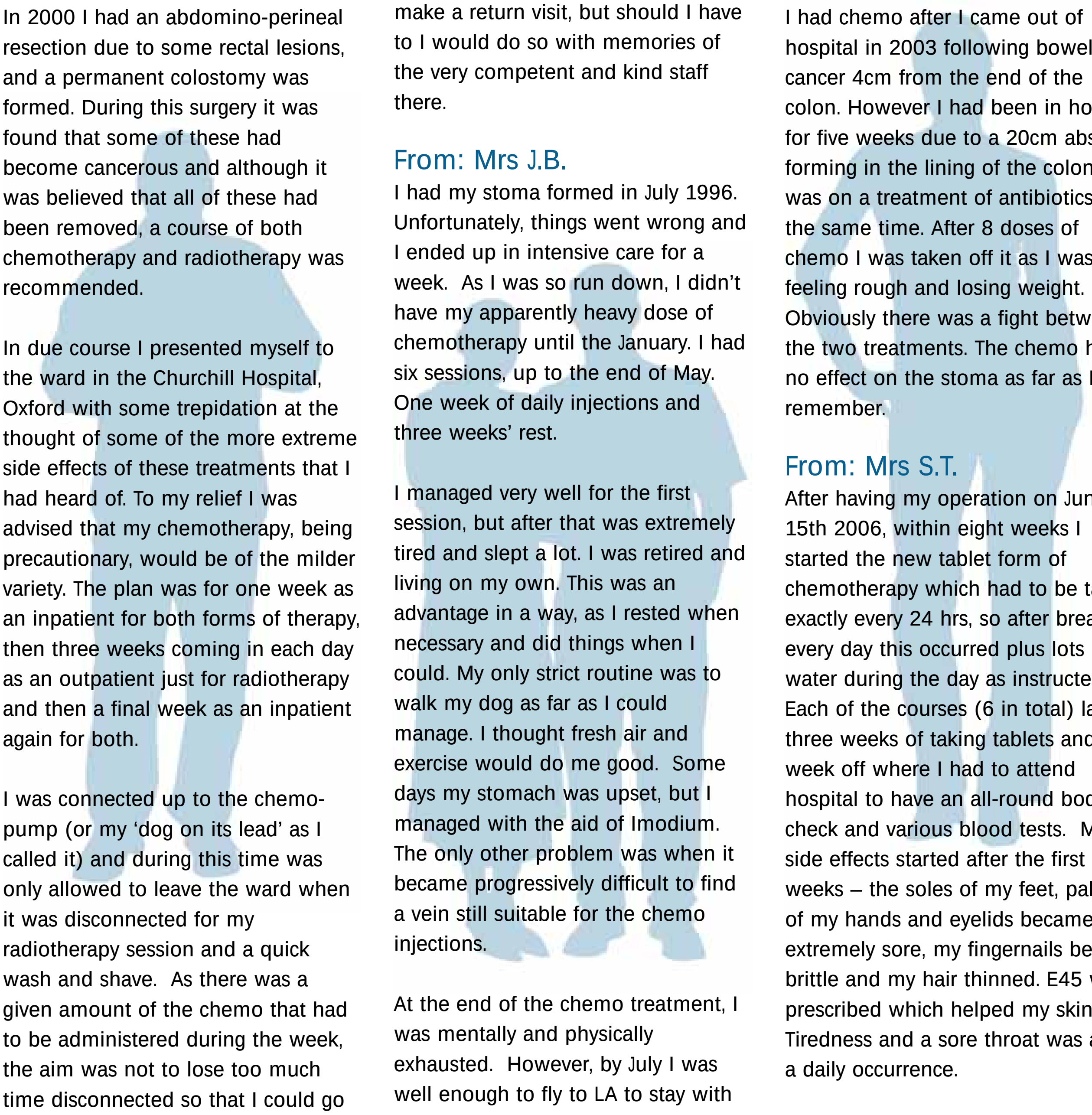
voices of experience

personal voyages in chemotherapy and radiotherapy



From: Mr K.H.

In 2000 I had an abdomino-perineal resection due to some rectal lesions, and a permanent colostomy was formed. During this surgery it was found that some of these had become cancerous and although it was believed that all of these had been removed, a course of both chemotherapy and radiotherapy was recommended.

In due course I presented myself to the ward in the Churchill Hospital, Oxford with some trepidation at the thought of some of the more extreme side effects of these treatments that I had heard of. To my relief I was advised that my chemotherapy, being precautionary, would be of the milder variety. The plan was for one week as an inpatient for both forms of therapy, then three weeks coming in each day as an outpatient just for radiotherapy and then a final week as an inpatient again for both.

I was connected up to the chemo-pump (or my ‘dog on its lead’ as I called it) and during this time was only allowed to leave the ward when it was disconnected for my radiotherapy session and a quick wash and shave. As there was a given amount of the chemo that had to be administered during the week, the aim was not to lose too much time disconnected so that I could go home on the Friday night.

For me, fortunately, there were no side effects except for a slightly sore ‘tail end’ from the radiotherapy. In my case it was just two rather boring weeks, and some eight years down the line it hasn’t proved necessary to make a return visit, but should I have to I would do so with memories of the very competent and kind staff there.

From: Mrs J.B.

I had my stoma formed in July 1996. Unfortunately, things went wrong and I ended up in intensive care for a week. As I was so run down, I didn’t have my apparently heavy dose of chemotherapy until the January. I had six sessions, up to the end of May. One week of daily injections and three weeks’ rest.

I managed very well for the first session, but after that was extremely tired and slept a lot. I was retired and living on my own. This was an advantage in a way, as I rested when necessary and did things when I could. My only strict routine was to walk my dog as far as I could manage. I thought fresh air and exercise would do me good. Some days my stomach was upset, but I managed with the aid of Imodium. The only other problem was when it became progressively difficult to find a vein still suitable for the chemo injections.

At the end of the chemo treatment, I was mentally and physically exhausted. However, by July I was well enough to fly to LA to stay with friends for two weeks. By the second week, I was able to go sightseeing with a well-behaved stoma. Returning home, I live a completely normal life again.

From: Mr P.M.

I had chemo after I came out of hospital in 2003 following bowel cancer 4cm from the end of the colon. However I had been in hospital for five weeks due to a 20cm abscess forming in the lining of the colon. I was on a treatment of antibiotics at the same time. After 8 doses of chemo I was taken off it as I was feeling rough and losing weight. Obviously there was a fight between the two treatments. The chemo had no effect on the stoma as far as I can remember.

From: Mrs S.T.

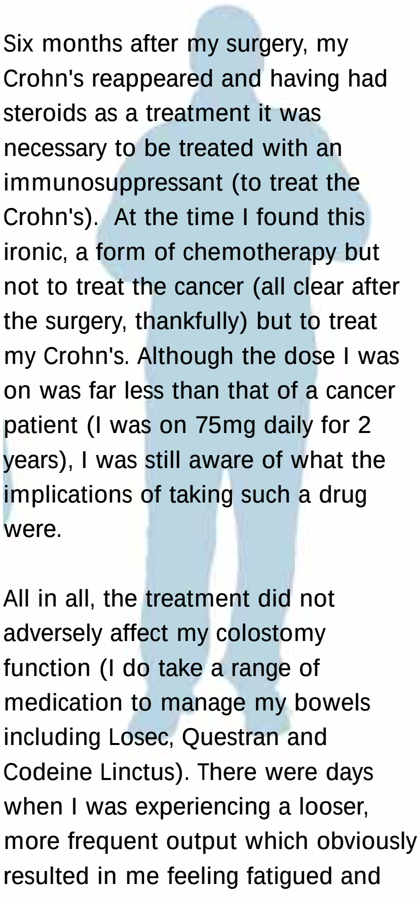
After having my operation on June 15th 2006, within eight weeks I started the new tablet form of chemotherapy which had to be taken exactly every 24 hrs, so after breakfast every day this occurred plus lots of water during the day as instructed. Each of the courses (6 in total) lasted three weeks of taking tablets and one week off where I had to attend hospital to have an all-round body check and various blood tests. My side effects started after the first three weeks – the soles of my feet, palms of my hands and eyelids became extremely sore, my fingernails became brittle and my hair thinned. E45 was prescribed which helped my skin. Tiredness and a sore throat was also a daily occurrence.

Unfortunately, six weeks into the course, I needed a blood transfusion but luckily this sorted out my blood cell count.

Although I was given sickness and diarrhoea tablets, I was very lucky as this only occasionally happened and the stoma worked impeccably even through my various scans. I never had any soreness around the stoma and continued to use my stoma bags as normal; this was important as I didn't have to worry about that part of the operation.

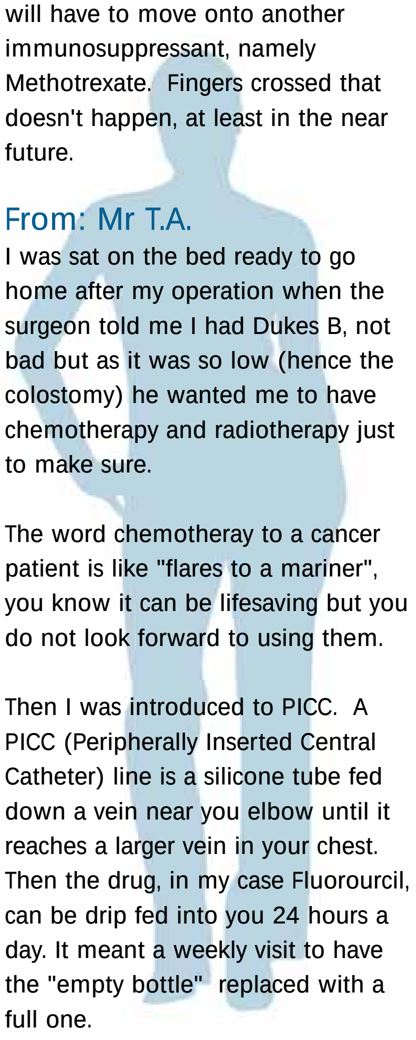
From: Ms. Denvir

Having been diagnosed with Crohn's Disease and subsequently with a Crohn's-related cancer (very rare I am assured), I underwent surgery to have the cancer (rectal) and infected Crohn's bowel removed. This left me with a permanent colostomy which functions like an ileostomy (best of both worlds!).



Six months after my surgery, my Crohn's reappeared and having had steroids as a treatment it was necessary to be treated with an immunosuppressant (to treat the Crohn's). At the time I found this ironic, a form of chemotherapy but not to treat the cancer (all clear after the surgery, thankfully) but to treat my Crohn's. Although the dose I was on was far less than that of a cancer patient (I was on 75mg daily for 2 years), I was still aware of what the implications of taking such a drug were.

All in all, the treatment did not adversely affect my colostomy function (I do take a range of medication to manage my bowels including Losec, Questran and Codeine Linctus). There were days when I was experiencing a looser, more frequent output which obviously resulted in me feeling fatigued and having to try to take things a little easier (try as I might!). Otherwise, the treatment didn't really affect my colostomy, or Grace, as I like to call her. I have been given the all clear for the Crohn's, for the immediate future, and if there is a recurrence, I will have to move onto another immunosuppressant, namely Methotrexate. Fingers crossed that doesn't happen, at least in the near future.



From: Mr T.A.

I was sat on the bed ready to go home after my operation when the surgeon told me I had Dukes B, not bad but as it was so low (hence the colostomy) he wanted me to have chemotherapy and radiotherapy just to make sure.

The word chemotheray to a cancer patient is like "flares to a mariner", you know it can be lifesaving but you do not look forward to using them.

Then I was introduced to PICC. A PICC (Peripherally Inserted Central Catheter) line is a silicone tube fed down a vein near you elbow until it reaches a larger vein in your chest. Then the drug, in my case Fluorourcil, can be drip fed into you 24 hours a day. It meant a weekly visit to have the "empty bottle" replaced with a full one.

As with all these drugs I was warned about the side effects. One such warning was small ulcers in your mouth. Well, I had lots of them but not in my mouth. I surprised myself by being quite "matter of fact" when I had o drop my trousers and pants in front of the radiography nurses every week but revealing my manhood in front of a male doctor to show him the plethora of ulcers on my penis was the worse part of my treatment. Fortunately they disappeared soon after the Fluorourcil bottle 3 months later.

From: Mrs D.
Chemo Therapy
May-July 2008

My chemo course was a low dose, so no hair loss, I only had two months treatment instead of three. Experienced sickness and heartburn, but mostly I felt fine.

From: Mr O'L.
Chemo Therapy started
Nov 2007
Currently 5/8

I am a very positive person, I find it very difficult to be negative.
It was explained to me about the possible side effects of chemo, I am now on session five of eight sessions. I had breathing problems this time, but tried to remain calm and it passed. It is getting more difficult each time, with tingling in hands and feet, and frozen face, try to stay positive, it will soon be over.

Editors Comment

This article will become a Colostomy Association leaflet. If you would like to add any further information or comment please contact us
e-mail:
editor@colostomy association.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4 QL

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* “A service evaluation of the use of silicone-based adhesive remover”. C J Rudoni, BJN, 2008 (Stoma Care Supplement), Vol 17, No 2.


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Chemotherapy a positive treatment outcome

In January 2001, I entered hospital to have a hysterectomy. I woke to find myself in the High Dependency Unit (HDU). The surgeon standing at the end of the bed gave me the news. During my operation he had found cancer attached to the bowel and had therefore performed a colostomy.

A few days later I was visited by the clinical oncologist who informed me that I had a very rare form of cancer that would not respond to any treatment, ie. chemotherapy and/or radiotherapy. The prognosis was not good and I was told to go home and do everything that I had ever wanted to – as my time was very limited.

By April 2001 the cancer had returned – but this time in a very aggressive form which the oncologist thought “might” respond to chemotherapy.

I was absolutely delighted. Here was a chance to beat the cancer. The chemo would destroy the cancer cells and I had a chance to get better.

I knew that the chemo would also affect my “good” cells, so I made sure that I was taking supplements to build up my immune system.

And so the chemo began.

Once every three weeks I would attend the hospital for a day. The chemo was fed into the back of my hand intravenously (into a vein), lasting many hours.

I had been given the choice of wearing an ice cap to save my hair. I wanted to save my hair if I could – and so endured the “tea cosy” look, with its freezing contents. I had to make sure that the nurses covered all the exposed skin areas with cotton wool so that the freezing sides of the cap could not give me freezer burn. It is not pleasant yet not unpleasant as the cap gets warmer – you think, oh good, and then along they come and replace the cap with another cap straight from the freezer. This can happen three or four times during the time the chemo is being dripped into the veins, and it did save my hair.
I had an anti-nausea drip too so I would not feel sick.

I was so happy to welcome the chemo into my body to kill off those cancerous cells. I welcomed my visits to the hospital. Whether it was my positive thinking, I don’t know – but I seemed to get very strong after the treatment. By the time I was due for my next treatment I was feeling tired, but never once did I think anything other than it was doing me good.

The word ‘chemotherapy’ is sometimes feared by those who are given the news that they must receive the treatment. Why? Having chemo is so different now. Many people continue with their usual activities while having chemotherapy, for example working between injections or cycles of tablets. There are a few side effects but none as drastic as they were some years ago. Everyone reacts differently to chemotherapy and some people may have no side effects at all. It really does depend on the drugs and the dose a person receives. The side effects you may experience with your chemotherapy should be discussed with you.

You may experience some sickness – pills or an anti-nausea drip take away that feeling. During your chemotherapy you may start to feel tired and listless. This may be general fatigue or it may be that you become tired more easily after normal activities. This is quite normal and usually occurs with all types of chemotherapy.

However clever the surgeons think they are at removing cancerous growths, chemo is the added belt to the braces.

A friend told me that she marvelled whilst watching the three coloured chemo liquids go into the veins – into the body – knowing that here was the chance to destroy all the cancer cells and get better. The word she used was “brilliant”.

The joy of being able to find a treatment that would cure me was indescribable and I am testament to the fact that chemo works. I had my terminal diagnosis in 2001 and we are now in 2008.

I would encourage anyone who has been told they can have chemotherapy to ask as many questions as they want of the oncologist. It is often the fear of the unknown that causes us to worry – knowledge is power – and the better informed you are about chemo the more confident and positive you will feel towards your treatment. ■

Glossary

Chemotherapy is a treatment of an illness or disease with a chemical substance, e.g. in the treatment of cancer. Chemotherapy is often used as an additional safeguard after surgery or in conjunction with radiotherapy, to destroy any remaining cancer cells and reduce the chance of the cancer returning.

Clinical oncologist medical specialists skilled in non-surgical forms of cancer treatment, utilising radiotherapy, chemotherapy, hormone therapy, radioactive isotopes and other special techniques to treat patients with cancer.

Cytotoxic 'Cytotoxic' means that the drug destroys rapidly growing cancer cells. Cytotoxic drugs are useful in the treatment of many forms of cancer. There are over 200 types of cancer and more than 50 chemotherapy drugs currently licensed to treat the disease, either on their own or in combination.

External radiotherapy uses high-energy rays that are directed at a specific area of your body.

Fraction The term for radiotherapy treatment.

Internal radiotherapy can be given in two ways, and may involve a short stay in hospital depending on the type of treatment used. Radioactive implants are solid radioactive wires or needles that are placed into the area that needs to be treated. Radioactive liquids can also be given which you drink, or have injected.

Radiotherapy is the safe use of controlled doses of radiation to treat disease, especially cancer. It is commonly used alongside other treatments such as chemotherapy (taking drugs to treat cancer), and surgery to remove a tumour (an abnormal mass of tissue).

Readers’ writes

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

Dear Tidings,
IS ANYONE IRRIGATING WITH A HERNIA?

I had my colostomy in November of last year. After six weeks I started irrigating and it went perfectly, forty-five minutes, done and dusted and out of the house! In March I discovered I had a hernia. So I stopped irrigating for a while and then started again in August. However, although I can just about get in two litres of water (some of which spouts out of the side of the cone however far in I insert it) nothing of any note comes out, not even the water. Within eighteen hours of doing this I get a migraine (visual disturbances only now not the pain and vomiting I experienced in my 30s). My senior stoma nurse says I should stop irrigating, as it is a waste of time. I desperately want to get back to irrigating efficiently, not only because of the cost of bags but also because I got a lot less pain.

Has anyone else had better experiences irrigating with a medium-sized hernia? Should I just persevere and try to get more water in after the initial two litres? Is it going to be all right for me to put more water in than comes out? On only one occasion did I nearly faint whilst irrigating. Was this anything to do with an excess of water in the bowel? I would like some feedback please from anyone who has had similar problems.

Thanks.

E.P
Southampton

If you can help E.P or have experienced this please contact us and we will forward to E.P - thanks

Ed

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

Look out for our new Reader Panel Button (opposite) in the next issue to see where readers have been involved.

Reader
PANEL
contributor

Dear Readers,
SUPPORTING A PARASTOMAL HERNIA

I had a colostomy in late 2004 following a bowel perforation – it cannot be reversed because of my age (82) and other medical considerations.

Soon after the colostomy I developed a parastomal hernia, which my stoma nurse described as spectacular. She recommended a ‘support garment’, which was duly supplied. As a male I can only relate them to some of the garments I had issued when I was in the army! They were most uncomfortable, designed I think by a woman crossed in love.

Eventually it was felt that they gave limited or no support and I was told I needed a corset. The ‘corset lady’ arrived eventually and I was measured. After a considerable wait the corset arrived just in time for me to take them away on my cruise. It was soon apparent that the corsets had been made the wrong way up and were pretty useless. So back they went!

I finally received some that were wearable and gave some support. Having used them for two years or more they are now worn out and give me less and less support. My stoma nurse visited me and agreed, saying I should have had two new ones each year and arranged for the ‘corset lady’ to call again.

I saw the ‘corset lady’ last June and I’m still awaiting a fitting. Goodness knows when I will get the finished article. In the meantime I am struggling with worn-out Velcro, and garments that have shrunk and give limited support.

Surely it shouldn’t be so difficult to get these support corsets. I get the impression that there are very few manufacturers; surely I can’t be the only patient in the country needing them. I wonder if any other patients are experiencing similar problems.

Fortunately the hernia, although very large, doesn’t bother me too much, just drags a bit at the end of the day. As I tell my consultant, it and I co-exist.

Thank you for your time,

E.A.A (Mr)
Middlesex

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Readers' writes

Dear Editor
FASCINATED BY TOMMEE

When I read a letter in the autumn issue of Tidings I was fascinated by the one about Tommee Tippee Nappy wrappers. I live up on the 3rd floor of our building and it is such a drag to go down to get rid of the "Bag" in the communal bin after every change; the alternative is to keep them in the flat but I have a real dread that any visitor may be able to locate the "smell."

So I decided I would go on to the Internet to look for more information and pricing for the Tommee Tippee Nappy wrappers. I couldn't find any information from Mothercare or Boots but found that Amazon sold them at £24.99 plus postage, bringing the total to almost £30. So a trip into town was the next move to find one to inspect for myself. I found one in Boots priced at £29.99 and one of their own make at £39.99. Not wanting to pay out that much my friend and I went to Wilkinsons, which was not too far away. Well, it pays to shop around. We found one with no difficulty at all, and wait for it – just £14.99. I was delighted as it is really the same product and is a lovely white and lilac colour, and "it does exactly what it says on the tin" at half the price. Even the refill bags are a £1 cheaper. I was really pleased, as I'd just come from the opticians after spending nearly £200 on new glasses, so I thought I'd pass on my excellent find to you all. The only drawback is that I may have to consider changing my colour scheme in the bathroom to match.

With every good wish and thank you
for an excellent magazine

A.B
Swansea

Dear Editor

I would like to endorse the letter from K.R. (Mrs) concerning the 'Tommee Tippee Nappy Wrapper'. It is a boon for disposal of bags – simple to assemble and very easy to clean. It is also available in a larger size from Boots.

Great magazine.

Yours faithfully
J.L (Mrs)
Slough

Dear Editor
MOST INTERESTING

Thank you so much for a most interesting 'Tidings magazine'. I have just received my fourth issue and feel I must write to say how much I enjoy reading about fellow colostomates. It certainly helps me to realise I'm not the only one with a bag.

I became a colostomate on July 19th 2006 when I was suddenly taken ill. I was in great pain and was rushed into hospital as an emergency. I had my operation that day having suffered a diverticular perforation. I will be forever grateful to those dedicated doctors and nurses in critical care. They worked so hard to bring me back to life again. Now two years on I am living with a colostomy and enjoy a normal lifestyle at 86 years.

Yours sincerely
E.F
Norfolk

Dear All,
ENJOYING TIDINGS

I just thought I'd write in to say how much I enjoy Tidings magazine. Being a comparatively new colostomate it's been so informative and helpful. Thank you very much and the same thought goes to those responsible for the super service received.

Please keep up all the good work.

Sincerely
C.T (Mrs)
Essex

Dear Editor
WHILST CHANGING MY BAG

Two years ago I had a colostomy. I explained what I had had done to my granddaughter, then aged 8 years. She seemed curious but didn't ask any questions. Last week I stayed overnight and she walked into the bathroom whilst I was changing my bag. She looked at it and said, "yuk, how horrible." I replied, "If I hadn't had the operation, I wouldn't be here." I know what I prefer! She just nodded and disappeared. We have a good relationship and I think she appreciated my reply. Your magazine is great and very informative. I also attended the conference in Reading and was unsure of what it would be like. What a surprise, a very friendly and lighthearted meeting. Thanks, and as for the fashion show, much better than the professionals!

Yours faithfully
C.N
Berkshire

Comment
Readers' writes

Sincerest apologies - to C.M

We would like to offer our sincerest apologies to C.M if a letter in the Autumn 08 edition caused any upset.

Dear Editor

A POSITIVE NOTE

I wrote a letter to you in 2004 stating I had just had three colostomy operations in hospital, and feeling really done, and thinking, like a lot of people, why did this happen to me?

But as I wrote in my last letter about this, something happened to pull me around. I had my golden wedding anniversary whilst in hospital, my family and hospital staff made it such a beautiful day. I thought to myself, 'come on what's wrong with you, it's not so bad having a colostomy, at least you are here to enjoy this special day, and that's what I wanted'. It put a smile back on my face. Since then life's been sweet.

Now in 2008, a lot more sweetness has come to us. I just feel I have got to write and tell you our wonderful news. On the 4th November this year we were blessed with our first beautiful great granddaughter (Katy Susan). I can't express how we are all feeling in my family. We've been waiting a while for this to happen, she has given me a new lease of life (my colostomy – I have forgot I have one).

I feel sure that many readers who take the magazine will have, or have had, the same joy of new life in their families. I just wanted to share my joy with the readers of Tidings. Thank you for all the magazines throughout the year, they have been very helpful to me. Thank you for all the good work you do for us. Please keep it up – this proves to me that life can be sweet for people like us.

D.B
Bury

Editors Comment

Dear All

Thank you for your letters and emails we welcome them all. Whether you are a new or regular reader of this section you will appreciate the comments and experiences contained within - anyone can contribute and it is essential that you keep your letters and e-mails coming as they give help, support and comfort to all who read them.

We will always do our best to print them. Editing may be required for reasons of clarity or space. In the interests of confidentiality we will publish only your initials, not your full name, unless you give us permission to do so.

Ed

Follow up on Brooke's story in autumn Tidings - "having a colostomy doesn't bother me at all"

Brooke writes about her colostomy

and how she did a **'show and tell' to her teachers and friends**

Following my short article in the last edition of Tidings, I've taken a massive step in sharing the fact I have a colostomy with all my friends at school


Brooke standing on a wooden frame with a friend

"Brooke is a brave little girl with a sense of humour who will always have a place in our hearts"

I recently received a present of a rag doll with its very own stoma – just like me. I decided my new doll might be a good way of letting all my class know about my stoma.

Mum and Dad didn't quite share my enthusiasm at first. For two years I'd only told special friends what I had hidden under my jumper. They wondered if it might be best to keep it that way. They were worried people may laugh at me, but knowing my class I really didn't think that would happen.

I don't have a problem with my colostomy so I figured everyone else should be the same about it. It did make me realise though that I'd have to be prepared for questions. Dad suggested we spoke to school to see what their thoughts were before I took my doll in.

On talking to my teachers they seemed quite keen for me to do a 'show and tell' activity. Mummy raised her concerns but they agreed with me. They didn't see there would be a problem with anyone picking on me, which gave Mum and Dad the reassurance that I would be supported if any matters did arise.

It was quite scary standing up in front of the whole class but as I'd guessed, everyone was great. I showed all my friends my doll's tummy bag and explained that she had a colostomy, which was something I had. One of my friends asked what it was for so I replied quite simply by saying: 'It helps people do a number two.' Another question was 'how do you go to the toilet?' I explained the routine of changing my bag using wipes and water, including the bit about putting my base plate under my arm to warm it up!

The question I'd really been waiting for was 'why do you have a stoma'. I love to baffle people with big medical words so I give the reply 'I was born with a Sacrococcygeal Teratoma – a huge tumour attached to my spine'. No more questions asked.

From: Brooke's Mum & Dad

When Brooke announced she was taking her doll into school we had a chat and told her some home truths about children being cruel etc., We asked her to sleep on it then decided to seek her teacher's opinions, which much to Brooke's delight were all positive.

Brooke had the confidence to tell her classmates about her stoma, no matter what the consequences. She made her own decision based on her experiences and was happy to confront it head on. For that we are very proud parents and thank her school for the support, which has enabled her to share her experiences.

Brooke's Special Educational Needs Coordinator (SENCO) at School – Mrs Margaret Hartley

Brooke is an inspiration to all who know her and the previous article she wrote was sensitive and informative about her very busy social life. It drew many positive comments in the staff room and was a 'talking point' for quite a while afterwards.

Brooke participates in all aspects of school life and is fully supported to cope with any changes regarding her personal needs. She has built strong relationships with staff and feels comfortable in their care.

The children and staff at Ladybridge C.P. School admire and respect the mature approach she has when sharing her innermost feelings. Confidence and trust in her friends, teachers and school was proven when she felt able to explain to her class, in detail, about her colostomy.

Brooke is a brave little girl with a sense of humour who will always have a place in our hearts here at Ladybridge.

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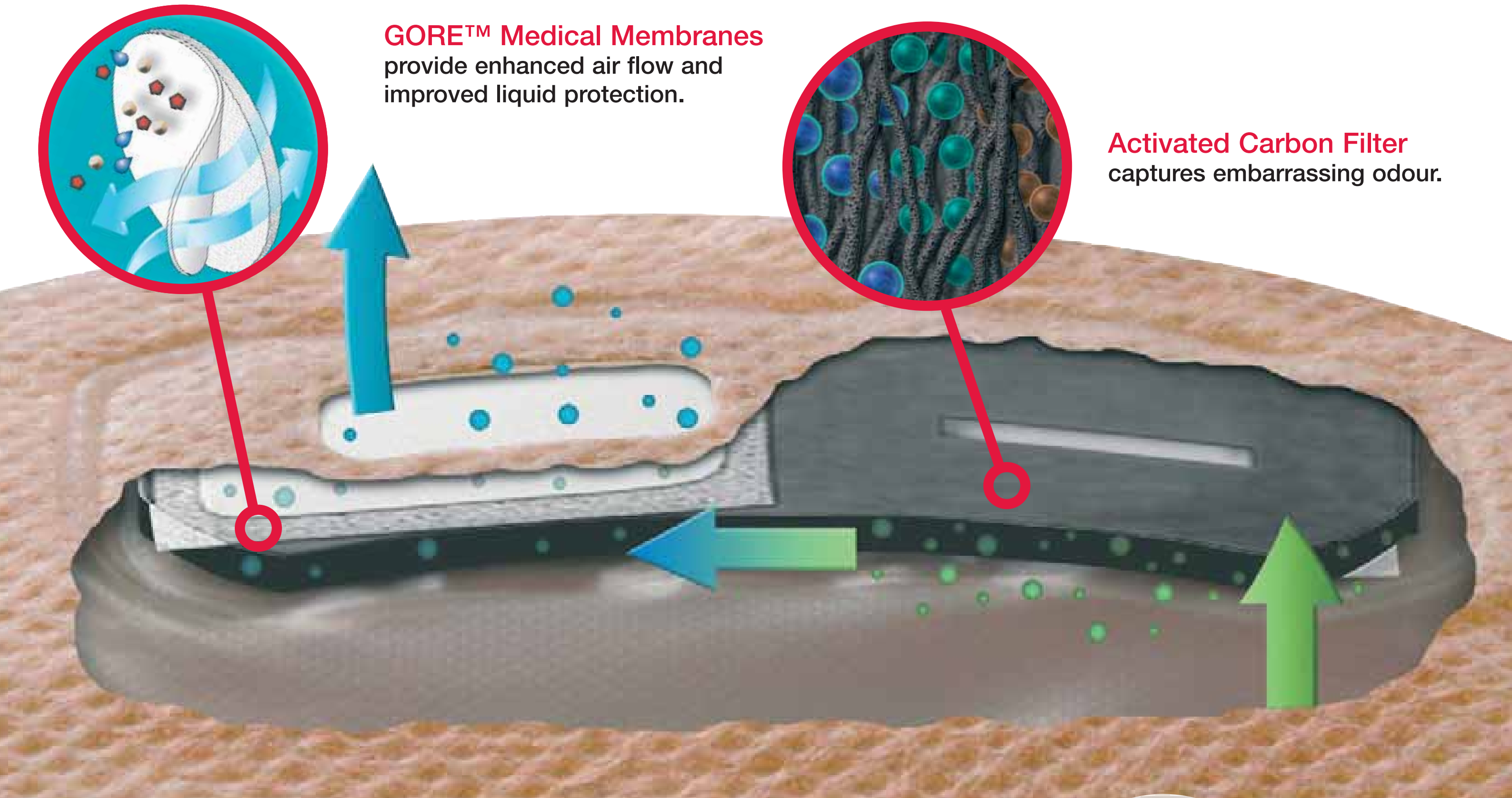

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llister

Attention to Life.

Dear Nurse

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

Q: I am having a few problems with my bag leaking. When I eat certain foods it causes excessive very loose stools and this leaks from the bag. Can you give me any advice on how to prevent this happening; I find I am being over-cautious with my choice of food to avoid it.

A: You do not say which sort of stoma you have, either a colostomy or an ileostomy. The output varies dependant on the stoma type. A left-sided colostomy would have a formed motion, whilst an ileostomy would have a more paste-like output. Certain foods can impact on the consistency of the output and this can vary from person to person. For this reason it is important to identify which specific foods affect you individually, so that you can then maintain a varied diet which does not cause major problems. However if you have done this and are still getting problems it may be worth trying some of the other remedies. For colostomists foods such as rice, pasta, potatoes and bread can help to thicken the motion, whilst ileostomists can try jelly cubes or jelly sweets to thicken the motion. You can also try some of the products that go in the stoma pouch such as Moreform, Gel-X and others which will thicken the motion once it is in the bag but do not slow the output from the stoma down. If you speak to your local stoma care nurse she will be able to get you some samples of the different products which are available. The final thing you may wish to try is to have something to thicken the stool by slowing the intestine down and this is available on prescription from your GP.

Q: My husband, who is 64, recently had a colostomy for a cancerous tumour that cannot be operated on. He is also undergoing chemotherapy and being given quite a lot of painkillers to combat the pain.

All went well after the operation and we are coping with the bag very well. There was a little somewhat gelatinous discharge from the anus for a week or so after the operation but not a lot. However in the last couple of days there has been more discharge but mixed with what seems to be fecal material – it's brown! He did seem to have a bit of a blockage causing liquid output but the bag is now filling normally. Is this cause for concern, or could anything have come adrift internally.

A: Obviously I do not have the specifics regarding you husband's surgery but from what you have said it appears that the rectum remains in place. Due to this it is not unusual to pass a mucous discharge, which may be discoloured. Also if your husband has a loop stoma rather than an end there can sometimes be a small amount of overflow from the active end of the stoma, which will then be passed from the anus; again this is normal. Obviously if your husband is in pain, and the stoma either stops working or the output becomes excessively watery with his abdomen swelling and even vomiting, then you would need to seek advice from your GP as this can be a sign of a blockage.

Q: I had a colostomy in November 2007 for a non-cancer condition. I developed a parastomal hernia in March 2008. I am still taking Tramadol and paracetamol/co-codamol for pain and an overactive bowel. How much longer do you think I will have to take painkillers? My GP is quite happy for me to continue with them but surely I should not be dependant on medication eleven months on from my operation? Has anyone else had the same experience? I would love to hear from them.

A: You can continue on painkillers for a significant period of time depending on the reason for the pain. Without knowing the specifics of your surgery I cannot say whether you need them for the underlying condition or whether you are taking them because of the pain from the parastomal hernia. If the pain is due to the herniation there may be other things, which may help. An abdominal support will help to ease the discomfort caused by the hernia and it may be worth contacting your local stoma care nurse to see if she offers a service where you can be measured for a support or if not she can put you in touch with a company which offers the service. Also dependent on the size of the hernia and the resulting problems you may be having there may be the possibility of having the hernia repaired surgically. To discuss whether this is an option for yourself you would need to speak to your surgeon who will be able to tell you if this is possible and what the operation would involve.

Q: *I am 16 years old and I attend Sixth Form. I have a colostomy and my main problem is when I am in an exam, an assembly, or just a quiet room, I have a phobia about my colostomy being overactive and making a noise, which would be incredibly embarrassing. This has become a real annoyance as I have an assembly at least once a week and exams at the end of the year. In one assembly I nearly fainted due to being so scared. I find during assembly I am constantly pressing against my stomach to suppress my colostomy but that just ends up with my stomach rumbling very loud, which is also embarrassing.*
I sometimes skip assembly because of my problem and end up getting into trouble. I have tried using Imodium Instants, which sometimes work but as you can imagine this is very expensive. I really need an alternative option, because I am growing up and am nearly an adult. I hope you can help, thanks.

A: You don't confirm if you have an end colostomy but I am presuming it probably is. If you do, you have a couple of options. The first is to try the Coloplast Conseal Plug, which is a small device similar to a tampon and is used to 'plug' the colostomy and prevent it working. Usually, we suggest a trial starting with wearing the plug for approximately four hours for a few days and then gradually increasing the length of time it is worn until you can manage twelve hours. This then prevents the colostomy, from working until you remove the plug and wear a pouch for 12 hours – usually this is overnight. This system also helps with reducing wind noise as it allows the wind to be released slowly.

Secondly with an end colostomy you are able to use irrigation. This is when we teach you to insert water into your stoma and then to release it, bringing the motion with it. This again prevents the stoma working by removing the stool from the bowel so there is no output there. It can be time-consuming as it needs to be done regularly, usually every 24-48 hours, and takes approximately 30-60 minutes each time.

I would suggest a visit to your local stoma care nurse to discuss both these options and to see if you are suitable to try them.

Hope this helps and good luck at college.

Q: *I use a Dansac Novalife colostomy bag, but find that due to my MS, my elbow presses on the stoma itself. This stops the faeces from entering the stoma bag, causing a build up, and gives me quite a lot of pain. It also causes the faeces to be pushed out underneath the adhesive part attached to my skin. At the moment I am using micropore as an added safety precaution. Can you suggest any type of guard to help me with my predicament?*

A: What you have described is known as 'pancaking.' There are several remedies for 'pancaking', including using a filter cover, Hollister Adapt Gel in the pouch and even the use of flange extensions instead of the micropore (several companies make these including Salts Healthcare and Welland). However, your main problem appears to be the positioning of your elbow pressing on the stoma itself due to your MS. It may be worth trying the Stoma Guard available from Convatec. This is a hard plastic guard, which sits over the stoma but does not prevent the output dropping into the pouch. It is held in place with a thin elastic belt. It is available from Convatec on prescription so it may be worth contacting them for all the details.

Have you got a question for Julie...

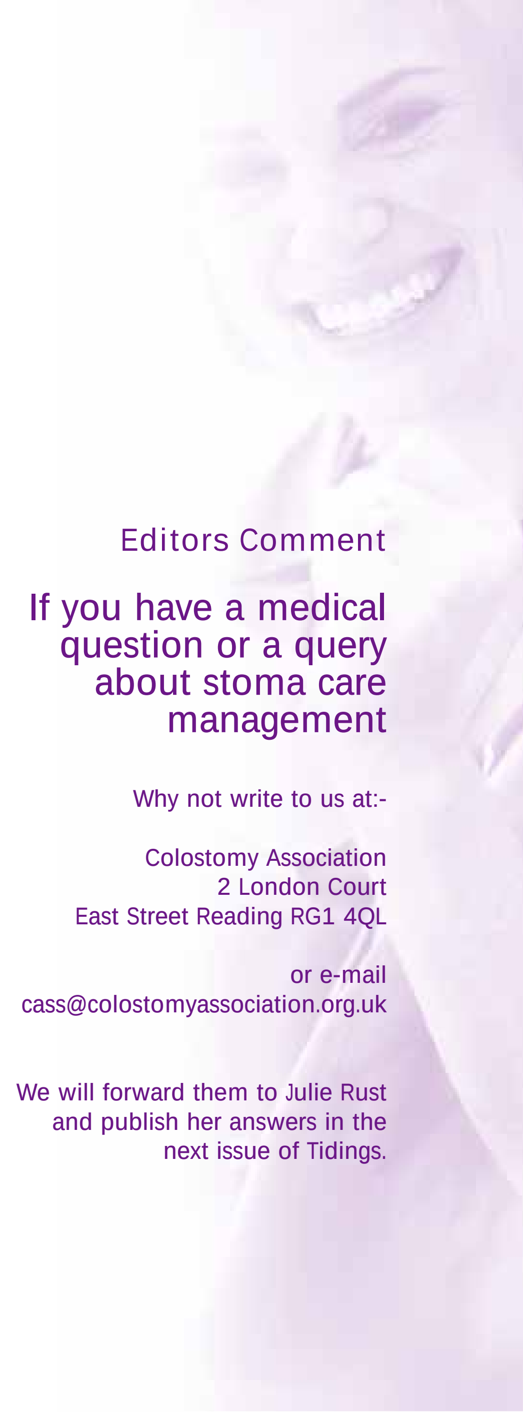
Dear Editor
Whilst I am in contact with your good selves, I would like to ask your resident nurse Julie a quick question, which may help other colostomates.

Having a colostomy during September 1998, I have learnt to live with my pouch very well, with the odd problem along the way, but over the past eighteen months I have developed a sickness-type cough first thing in the morning, which continues through breakfast and in the shower. After changing my pouch I dress for the start of the day, helping my wife around the house doing the daily chores.

Strangely enough the cough subsides as the day continues, why is this?
I await your reply in the Tidings magazine with interest.

Yours sincerely
B.E.L (Mr)

Comment from Ed. If you have experienced a similar problem why not write in and tell us...



Editors Comment

If you have a medical question or a query about stoma care management

Why not write to us at:-

Colostomy Association
2 London Court
East Street Reading RG1 4QL

or e-mail
cass@colostomyassociation.org.uk

We will forward them to Julie Rust and publish her answers in the next issue of Tidings.

Marketplace

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If you have anything to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20. Please contact Ray Goddard at Head Office on 0118 939 1537 for more details. Advertisements received before 27 February 2009 will be considered for inclusion in the next issue of Tidings.

Nurses, did you know…?

Stoma Care Open Days are organised by nurses working within the NHS, where several manufacturers and suppliers are represented, (are included on Marketplace free of charge.)

Annual bowel awareness open day
This open day will be held at:
Venue: Upper Room, The Crossing at St Paul's, Darwall Street, Walsall, WS1 1DA on
Date: Wednesday 29th April 2009
Time:12noon – 4.00pm

This is the annual bowel awareness open day organised by the Manor Hospital in Walsall. This is a health promotion event designed to raise public awareness of bowel disease.

For a complete list of Stoma Care Open Days visit our website: www.colostomyassociation.org.uk

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East Berkshire **Ostomy Club**

Interview with
support group organiser
Jackie Dudley

Why and how was your support group set up?

Well, a stoma care nurse working at Wexham Park Hospital in Slough approached me and asked me if I would be interested in starting up a support group. She was concerned about new ostomates; she wanted them to be able to meet and talk to fellow ostomates.

I thought carefully about her request and decided to ask the committee of our local community centre for the availability of their small hall, suggesting I would be interested in holding a meeting once a week. I discovered they had a vacancy on a Monday afternoon 2.00-4.00pm. They were very generous and allowed me to use the hall each week at no cost whatsoever.

What happens at your support group?

Members arrive at about 2.00pm and the first thing on the agenda is tea and biscuits. A register is taken just in case there is a fire drill and for me to find out if there are any absentees who might need to be sent information about future meetings. I set out a display of Colostomy Association literature plus samples and literature from different stoma care companies. At the end of each month we hold a raffle with prizes.

What other ways does your support group help its members?

I offer a venue where they can meet – free of charge. It provides an oasis of calm. Support is always offered, and members help just by listening and talking to one another. The group offers people the opportunity to meet people who know how they feel. It is very interesting to listen to them swap ideas on “cures for ills”, whether it be for an ileostomate, urostomate or a colostomate. It is a chance to air their views about anything and everything. The group is always helpful and they share everyday experiences both negative and positive. Through groups like this members learn that they are not the only ones coping with a stoma.

Do your members relate personal experiences? If so what concerns them?

We have a wonderful cross-section of people. Members love to tell stories about their backgrounds, in London during the war etc., their personal experiences of family life and we always take time to tell Brown and Bush how to run their countries. We discuss what’s on TV and in the papers. We also discuss anything and everything to do with problems concerning our stomas – and members chat about recent visits to their stoma care nurse or consultant. We also offer advice and support.

Are you in touch with health professionals or stoma product company representatives?

Yes. We have representatives from Dansac, CliniMed, Securicare, PALS, ACORN, Stoma Care Nurses and Life coaches who come and give presentations at our meetings.

Do you offer talks from outside individuals?

Yes. I have organised a presentation from David Orton who presents slide views to music and I have had a life coach come in to talk about five ways to beat stress. PALS also come along plus other voluntary groups – and I invite anyone that I think the group might find interesting.

How can people find out about your group?

I have access to Radio Heatherwood who run a short “advert” about the club. (the club has only recently changed its name and is now the East Berkshire Ostomy Club so I will have to update them). I place news items and posters on the exterior noticeboard of the Community Centre. I also ask SecuriCare to use their database to send out my newsletter about forthcoming meetings. The support groups are always advertised in ‘Tidings’ magazine and Ostomy Lifestyle mentions my group on their website support group page.

Editors Comment

Why not get your **Support Group** published in Tidings if you contact us before 27 February 2009 we will publish the date and venue of your next Stoma Support Group meeting.

If there is no **Support Group** in your area **YOU** may be interested to learn that head office can help you set up your own group and put you in touch with other ostomates who have their own local groups

For more information
contact head office
telephone:
0118 939 1537
e-mail:
cass@colostomy association.org.uk
or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4 QL

colostomy association

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...**

Tell us more about your fundraising events...for CA

From: M.D (Mrs) On July 1998 I was diagnosed with bowel cancer and very soon I had my colostomy operation. Due to the excellent skill of my consultant, and the very professional care I received from the hospital staff, my stoma nurse, and the help and support of my family and friends, I made a rapid recovery. Happily since then I have led a very active life and enjoyed the best of health.

On Monday 29th September my husband and I celebrated our golden wedding anniversary with our family and friends. In our invitations we stated 'strictly no presents but a donation to the Colostomy Association would be appreciated if so desired'. I am delighted to be able to donate the sum of £1,030.00 to the Colostomy Association.

Long may your valued and very much appreciated work continue.

Quiz Evening - the Padbrook Residents' Association...

The Padbrook Residents' Association in Oxted, Surrey held a quiz evening in October and raised £157.29, which they kindly donated to the CA. A big thank you to Derek Oakey, Donald Mycroft and everyone who supported the event.

Thank you for you kind donations

A much-needed 'Henry'...

Vic King, a member of the Optimists Support Group in Cornwall, kindly provided the CA with a much-needed vacuum cleaner, 'Henry'. It was supplied through 'Numatic International', the company that Vic works for - our grateful thanks for this valuable workhorse.

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- Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region while wearing the belt.
- Used by ostomists with a pasastomal hernia (a bulging around the stoma) the belt will also help prevent muscle damage and enlargement of the hernia.
- Ideal for work, sports, gardening, housework, DIY or at any time stomach muscles require a firm support.
- With support from the Sash belt and periodic consultations with a consultant some Ostomists are delaying, maybe permanently, the need for hernia surgery.

Ref. no. S1

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SASH stoma support and parastomal hernia belts are suitable for Colostomy, Ileostomy, Urostomy, Umbilical and waistline Insisional hernias. The SASH stoma hernia belt has been designed and developed by an ostomist to give support to a hernia that surrounds the stoma without restricting normal body movement or limiting muscle use.

For more information:
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Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111
E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com

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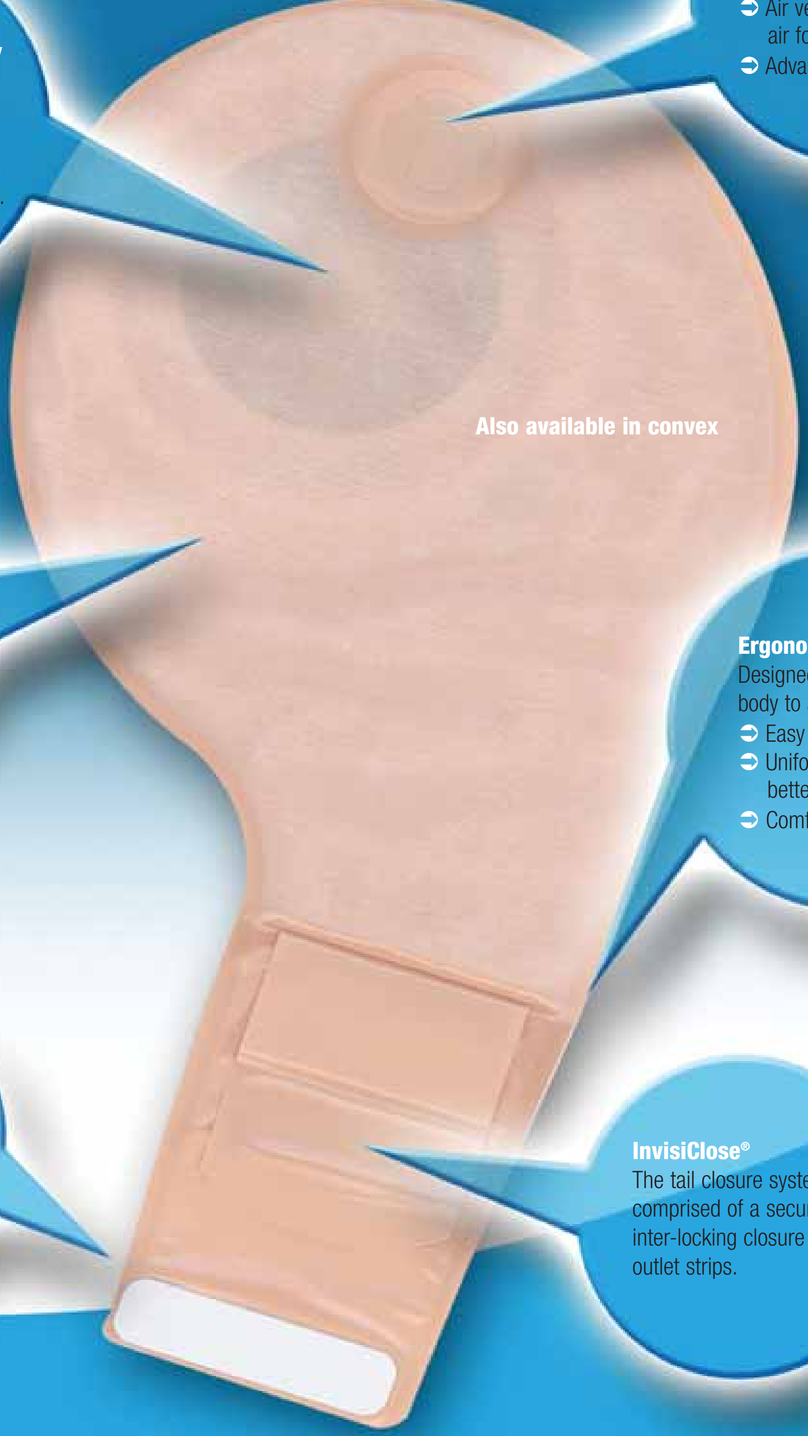

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- Deodorizes
- Air vent to filter maximum air for more comfort all day
- Advanced membrane

Also available in convex

Comfort Backing
Soft fibrous backing available one side or two, which is easy to dry after a shower or swimming and reduces noise and friction.

Ergonomic Shape
Designed to sit centrally on the body to allow:
- Easy & natural drainage
- Uniform containment for better discretion
- Comfort

Drainage
Tail designed for natural drainage whilst seated.

InvisiClose®
The tail closure system is comprised of a security flap, inter-locking closure and outlet strips.

What more do you need...

If you would like more information please call our Customer Care Line on: 0800 834 822
or email us at stoma.webcare@bms.com

ConvaTec
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Tidings 10th Anniversary - Car Raffle

a **runaway success** raising in excess of **£27,000**

Pictured - Monty and Sue Taylor, Paul Mullin, Steve Hawkins, Nick Robey, Malcolm Paine

Monty Taylor pictured with his wife Sue (who drew the winning ticket), Paul Mullin Director of Sonning Common Garage and his staff who kindly supplied the 'Agila' raise a glass to the winner of the Tidings 10th Anniversary Car Raffle...

The Colostomy Association would like to 'congratulate' all those who supported and were involved with this year's main fundraising event - Tidings 10th Anniversary Car Raffle.

The Association would like to thank the following - the management and staff at the Vauxhall Dealership, Sonning Common Garage for offering a brand new Vauxhall Agila Club as the prize for the raffle. Monty Taylor (Trustee) for his vision, planning and management and the behind the scenes team at CA Head Offices - Office manager and Trustee Ray Goddard, Beryl, Gill, Jo, and volunteers who all helped the event run smoothly and successfully.

The raffle was drawn on Saturday 15th November at Sonning Common Garage around 1pm Monty's wife Sue drew the winning ticket. Monty opened a bottle of champagne and along with staff from the garage, Jane and Mike from Art Direct and Gill and Jo from the office, toasted the winning ticket holder, Mrs Green of Birmingham. After the draw Monty tried several times to contact Mrs Green but there was no reply. However at 4.30pm in the afternoon she finally answered the telephone. Mrs Green was shocked and amazed when Monty told her she had won the car. Monty discovered that she was a colostomate of some 20 years. She told Monty that unfortunately she didn't drive and that her sons were unable to drive due to illness, but she said she had a daughter "who could probably do with a new car as she has just returned from missionary work in Africa".

The Tidings 10th Anniversary Car Raffle really has been a runaway success, indeed it has exceeded the hopes of all involved. Our grateful thanks go to the hundreds of you who bought tickets. Thank you!

You have all made a invaluable contribution to the work of the Colostomy Association.

The approximate figure raised is an amazing £27,300 however it seems likely it will be more - we will keep you all posted as to the final amount raised in the next issue of Tidings.

Interview with Sonning Common Garage

Question:	Answer:
When did the Colostomy Association approach you regarding the potential of offering a car for their fundraiser?	June 2008
Who within your company helped the Colostomy Association to organise a car for the fundraiser?	Paul Mullin and Steve Hawkins
Who decided which type of vehicle to offer and why?	Steve and Monty. Because it is a brand new model and predominantly purchased by the over 50's
Did you help in any way with this fundraising activity?	Yes. All our salesman and staff at the petrol station sold raffle tickets.
Would you consider helping the Colostomy Association again in the future?	Definitely

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...**

Tell us more about your fundraising events...for CA

Volunteer in Doncaster - Roger Barrett receives a cheque on behalf of the Colostomy Association for £400 from Colin Brookes...

The Co-operative Social club in Doncaster hosted a presentation evening on Friday 5th December 2008 for their Golf Section which comprises in excess of 40 members, who hold various competitions throughout the year at different venues.

The captain of the golf section during the 2008 season was Mr Colin Brookes, a member of the CA who had his colostomy close on 5 years ago. Colin is a very active member of the club and it is customary for the golf captain, who holds office for a year, to give the proceeds of the raffle which is held annually to his chosen charity. When Colin was asked where he would like the proceeds to go, he had no hesitation in nominating the Colostomy Association.

Thank you for you kind donations

Our volunteer in Doncaster, Roger Barrett, was invited along for the evening with his wife Yvonne and accepted a cheque for £400 on behalf of the CA. The photograph shows Roger receiving the cheque from Colin Brookes and expressing thanks on behalf of the CA.

From: C.G (Mrs)

I was diagnosed with cancer in November 2005 and Cancer Backup helped me by providing me with vital information and support. The Colostomy Association has also been a great help in my battle against cancer and so when my daughter was running the Berlin Marathon on 28/9/08 she decided to use it as an event to raise money for these two charities on my behalf. Laura raised a total of £2370.75. I am happy to be able to donate £661. I hope that this money will be of some assistance to the valuable work that your charity does. I know personally that the Colostomy Association will do their utmost to help fellow colostomates with their problems.

Donations - In memory

Mrs E M Howells	£130.00
Mrs N K Dickinson	£1500.00
Mr R V Cilia	£230.00
Mr F R Darby	£225.00
Mrs J Lamb	£206.35
Mrs M Fox	£350.00
Mrs M Ord Johnson	£120.00
Sharon Barrett	£70.00
F J Vidmar	£165.00
Joan West	£270.00

Pelican Healthcare introduces . . .

Pelican Select 2-Piece

- Ease of connection
- Improved filter system
- Full range of pouch sizes

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Select Convex

Select Afresh Closed

Select Afresh Drainable

To obtain your FREE sample of the Pelican Select 1-Piece or Pelican Select 2-Piece pouches please return this coupon to:

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or e-mail: contactus@pelicanhealthcare.co.uk

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

Address: ....

.... Post Code: ....

Preferred pouch (please tick one)

1 Piece: Convex ☐ Flat ☐

2-Piece: 50mm (cuts to 35mm) ☐ 70mm (cuts to 55mm) ☐

Stoma Cap: Minuet 10-40mm ☐ Minuet Plus 10-55mm ☐

Pouch size (please tick one): Maxi ☐ Standard ☐ Mini ☐

Pouch type (please tick one): Closed ☐ Drainable ☐

Stoma size .... mm

Select Minuet

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HEALTHCARE

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an eakin company

BCA 01/09

Campaign for change...

Support the Colostomy Association today

Learn how we make a difference to colostomates and how **YOU can help us** continue to make that difference

The Colostomy Association

is an independent charity, financed solely on donations. This means that we must seek ongoing support to ensure our important work can continue.

We really can make a difference...

Our findings show there are approx. 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!

How we help colostomates...

The Association continues to help colostomates who are experienced and those who are new to ‘living with a colostomy’.

We have a range of advisory literature, written by colostomates and nursing professionals, readily available on request. Plus our quarterly magazine ‘Tidings” especially written for colostomates, their families and their carers.

We have over seventy contact volunteers covering the country they are fully trained and experienced volunteers who are colostomates. Our volunteers are dedicated individuals who bring a human touch, to what can sometimes be a delicate and emotional time. Our contact volunteers are often asked to visit patients before their colostomy surgery, and afterwards in hospital, usually at the request of the stoma nurse. Home visits by our contact volunteers can also be arranged by request.

We attend organised stoma care nurses 'open days', where you can come and learn more about your colostomy, in a friendly atmosphere, and discuss any problems. We give these events our full support.

The Colostomy Association also attends manufacturers' and suppliers', open days and exhibitions, keeping you up to date on stoma bags, accessories and services via ‘Tidings’.

Importantly, we are involved in ongoing consultations with the National Health Service on your behalf and will keep you informed of issues that may affect you.

Here’s how YOU can make a difference to US...

Single or Ongoing Donations...

Single donations from individuals and fundraising events are always welcome and greatly appreciated. Your financial support has never been more important. You can help the Colostomy Association support other Colostomates by making an ongoing donation via standing order - simply fill in the form overleaf or on line at: www.colostomyassociation.org.uk

Become a ‘Friend’...

We would like to invite anyone with a colostomy, (permanent or temporary) and/or members of their family to become ‘Friends of the Association.’

A ‘Friend’ is asked to make a regular commitment of £12.00 (or more) to the Association each year, either by standing order, cheque or postal order. This will ensure that we are able to continue to produce four issues of Tidings per year - full of the latest news, product information, hints and tips and real-life stories from other colostomates.

This regular payment will ensure that there is always a helping hand for those who need it, now and in the future – including some colostomates yet to be born. There are many thousands of adults and children, who, now and in the years to come, will receive a life saving colostomy.

Donate via Payroll Giving

Payroll giving is a scheme that enables employees to give to any UK charity straight from their gross salary (before tax is deducted), and to receive immediate tax relief of up to £4 for every £10 donated.

To set up a regular gift contact your employer’s payroll department. If they do not have a suitable scheme in place they can set one up free of charge, simply by contacting an approved Payroll Giving Agency.

Legacies - a gift in your will

Legacies are an important source of funds for charities. Some of the larger charities, such as Macmillan Cancer Support, receive up to a third of their income from legacies. So, if you are about to make a will, or are considering making a change to your current will, spare a thought for the Colostomy Association and consider making a legacy to help us to continue to support colostomates countrywide.

colostomy association

I would like to make a single donation or ongoing donation or I would like to become a ‘Friend’

☐ I would like to make a single donation. I enclose a cheque/postal order made payable to Colostomy Association Ltd.

☐ I would like to become a ‘Friend’. I enclose a cheque/postal order for £12.00 or more, made payable to Colostomy Association Ltd.

☐ I have completed the Standing order form on Page 46 (please complete the standing order form overleaf)

☐ Please tick here if Gift Aid applies to your donation (see overleaf for details)

Please note: Please ensure that we have your full name, address and postal code - thank you

Your donation to the Colostomy Association today...will mean we can continue to reach out to other colostomates, their families and their carers with support and encouragement.

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: Mill Cottage Polwheveral Constantine Falmouth Cornwall TR11 5RW
Registered Charity No: 1113471

Donations & Standing Order Authority

colostomy association

Please help the Colostomy Association to support other colostomates by making a donation - thank you

Please return this form to: Colostomy Association 2 London Court, East Street, Reading RG1 4QL

Title: First Name: Surname:

Address:

Postcode:

Tel: Email:

Instruction to your Bank/Building Society to pay by Standing Order

To the Manager (Bank or Building Society)

Address:

Postcode:

Name(s) of Account Holder(s)

Account No: Sort Code:

Please pay:

NatWest Market Place Reading Branch

13 Market Place Reading RG1 2EP

Account Name:	C.A. Ltd
Account No:	88781909 Sort Code: 60-17-21
The sum of:	£

Amount in words:

Date of first payment:

and thereafter on the same day every **week/month/quarter/year** (delete accordingly) until further notice. Please cancel any previous standing order in favour of this beneficiary.

Name: (IN CAPITALS)

Signature: Date:

giftaid it

I would like the tax to be reclaimed on any eligible donations that I have ever made or will make to the Colostomy Association until further notice.

I confirm that I pay an amount of income tax and/or capital gains tax at least equal to the tax that the Colostomy Association reclaims on my donation in the appropriate year (currently 28p for every £1 donated).

Signed: Date:

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WHY CHOOSE THE RESPONDER SERVICE?

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We will always use an **OVERNIGHT DELIVERY** service working through a **NATIONAL NETWORK** of professional couriers.

Prescription appliances will arrive discreetly and efficiently at your home, place of work or any other chosen address

We can cut personal templates accurately from both pouches and flanges with our **COMPUTERISED CUTTING MACHINE**.

So you can DEPEND on us to give the most accurate machine cut available

Our Customer Service is recognised internationally guaranteeing our Quality Service.

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0800 220 300 OstoMART Ltd

WE NOW OFFER WET WIPES!

OstoMist

In Pouch Odour Neutraliser
With NANOZYME

new

Mint Drops

- Use directly into the pouch/bag when changing an appliance
- Just place 1 or 2 Drops in the pouch/bag prior to use
- Contains Nanozyme, which neutralises faecal odour
- Effectively neutralises odours quickly and efficiently

OstoMIST Mint Drops are for use with faecal stoma pouches!

The powerful odour neutraliser breaks through the worst odour problems. It is NOT A MASKING AGENT!

Need More?
No guesswork needed with the see through container!

Try OstoMist Mint Drops now!
We know you will like them!

Available on Prescription from your local supplier

OstoMIST MINT DROPS
50ml Dropper Bottle
Order Code: SPN5

OstoMist works!
Why not try it for yourself!

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OstoMART Ltd

500 Club **Winners**

As well as raising funds for the CA the **500 club** gives members a chance of winning a quarterly cash prize of up to £500.

Summer prize winners...

£367: Mrs Oldman from North East Lincolnshire

£183.50: Mr Carson from Bangor

£73.40: Mr Pateman from Hitchin, Mrs Singer from Bushey Heath and Mr Butcher from Stoke on Trent

£36.70: A member from Berkshire, Mr Lilley from Wolverhampton and Mrs Hadfield from Sheffield

£18.35: Mr Williams from Llandudno, Mr Tolman from Carmarthen and Mr Dickson from Tamworth

Autumn prize winners

£381: Mr Drayton from Lynton

£190.50: Mr Marsden from West Deeping

£76.20: Mrs Fox from Luton, a member from Gloucester and a member from London

£38.10: Mrs Dugdale from Kendal, Ms Korn from Enfield and Mrs Bentley from Darlington

£19.05: A member from Brampton, Mrs Roberts from Caernarfon and Mr Pimm from Castle Bromwich

The next draw will take place around the New Year so we will not publish the winners details until the Spring edition.

2009

colostomy association

JANUARY

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Ostomart	0800 220300
Peak Medical	0800 6520424
Pelican	0800 0527471
Salts	0800 626388
Sash	0800 3893111
UCI Healthcare	0800 731 4376
White Rose Collection	01202 854634

Helpful Groups & Organisations

Other Ostomy Support Associations...

- IA (The Ileostomy and Internal Pouch Support Group)
  Freephone: 0800 0184 724
  www.the-ia.org.uk
- Urostomy Association
  Tel: 01889 563191
  www.uagbi.org
- IOA International Ostomy Association
  www.ostomyinternational.org
- Gay Ostomates
  Tel: 0844 414 2356
  e-mail info@gayostomates.org
  www.gayostomates.org

Support organisations for medical conditions...

- 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

Although Macmillan Cancer Support and Cancerbackup are merging 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
- Incontact
  (Incontinence & Diverticular disease)
  Tel: 01536 533233
  Web: www.incontact.org

RADAR
the disability network

NATIONAL KEY SCHEME

How to obtain a key to gain access to toilets for the disabled

Colostomates are entitled to a key which will open 7,000 locked toilets around the UK. Some local councils will provide this key free, or for a small charge.

Keys can be obtained from the Colostomy Association at cost of £3.50. Contact head office: 0800 328 4257 for an application form.

Keys can also be purchased for £3.50 from RADAR:
Tel: 020 7250 3222
www radar-shop.org.uk

RADAR also publish a guide which lists all the NKS toilets throughout the UK (cost £10.25).