Summer 2013 | Issue 30

Tidings

colostomy association

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

Cover story...
Paul fundraising for the CA

Feature
Adhesions and blockages

CA Open day update

Happy Summer Holidays to our readers from the Colostomy Association...

welcome to SUMMER

A couple of requests...
If you can bear to part with your copy of Tidings please consider passing it on to your local GP surgery, Healthcare centre or local government health and social care community outlets (you may have to become a bit of a detective to find out who and where to take it – let me know how you get on!). Further copies of Tidings can be obtained from the Editor.

Also, we are considering a Dear Surgeon or Dear Doctor feature similar to Dear Nurse so please write in with your thoughts or queries. If you are a Surgeon or GP and you are reading this and want to get involved please do get in touch. Here's how...

How to contact the Editor

By letter write to:

The Editor
Colostomy Association
Enterprise House, 95 London Street
Reading RG1 4QA

By telephone:
0118 939 1537

Via e-mail:
editor@colostomyassociation.org.uk

or alternatively e-mail:
jane.wood@colostomyassociation.org.uk

Welcome to the summer issue of Tidings...

Summer is here it's official, the longest day and of course the Tennis! Coverage of Wimbledon is on the gogglebox and we mustn't forget the strawberries and cream or the Pimm's! But where's the weather to go with it…coming soon, no doubt! Let's hope so!

Again kind thanks to everyone who has written in, emailed or telephoned the Editor, it's great to know your thoughts about Tidings Magazine – you keep it fresh and relevant so please do keep your ideas, queries, stories, letters coming in – you make Tidings what it is – your magazine!

Just between us and by 'us' I mean YOU of course! Yes! I'm speaking directly to YOU! The Tidings reader! Your submissions are always eagerly anticipated, in fact my Editorial team and I can't wait to open and read your letters and emails as they always bring something different! But I feel I must let you into a little secret – each submission goes through an editorial process so if you don't see your submission in this issue of Tidings it's because it will be held over for a future issue or is being reviewed! If you would like to contribute to Tidings and I would wholeheartedly encourage you to do so, but feel you need some help with your article – either myself or a member of the Editorial team will be only too happy to help! As Paul writes in this issue, 'if this helps just one person then I'll be a very happy man'.

If you are a regular reader of Tidings – and I really hope you are – you will have read in the last issue of Tidings that CA was moving…check out the CA News pages to see pictures of our Grand Opening! Everyone who attended the day thoroughly enjoyed it – look out for the celebration cake, it's a beauty, cut by the Mayor of Reading Councillor Jenny Rynn!

This issue of Tidings includes a feature called 'Roadblocks and Assumptions' kindly supplied by the IA (Ileostomy and Internal Pouch Support Group) at the behest of Sue Hatton Executive Trustee – your feedback would be very interesting as always.

This July the CA hosts its Patient Open Day at the Royal Berkshire Conference Centre in Reading, be sure to book more details can be found on Page 53 or on the CA website: www.colostomyassociation.org.uk. Contact Susan Hale – General Manager to book your place on 0118 939 1537 or email: cass@colostomyassociation.org.uk.

Now I want tell you about a new series in this issue – 'Additional Ostomy Products' – this series of articles will give a ostomate's bird's eye view as to why each product is a necessary essential! The idea for the series came from your responses to the form 'Are you having problems with your prescription?' Many of you took the time to write in and explain what's happening in your area with your prescription from your GP surgery, Healthcentre or Pharmacy. The information gained has helped CA obtain a clearer perspective around the UK. There were many references to 'accessories' and an apparent lack of knowledge on the GPs part, which has led to restriction of supplies and in some cases, deletions from prescriptions altogether. Theses types of products, often considered optional extras, are in fact, very necessary essentials for many colostomates and support well-being and confidence!!!

On behalf of the Editorial team enjoy this issue of Tidings. I would encourage EVERYONE to get involved with Tidings...YOU make it what it is...YOUR Magazine!

Jane

Email:
editor@colostomyassociation.org.uk

PS. For details of how to get in touch with the Editor of Tidings and the Colostomy Association – please turn to Page 6.

inside……

all your regulars

cover story

Paul Smith...
Real Lives
featured on page 18

...this issue

& special features

update...

Colostomy Association Patient Open Day
Saturday 20th July 2013

Royal Berkshire Conference Centre
(Madejski Stadium)
Reading
See Page 53

real lives...

health...

travel...

colostomy association

Travel Certificate
for people with
a colostomy

Freephone helpline
0800 328 4257

www.colostomyassociation.org.uk

Don't forget your travel certificate this Summer...

Contact CA office on
0118 939 1537 or
cass@colostomyassociation.org.uk

support...

interest...

How to get in touch...with the Colostomy Association and Tidings...

About...the Colostomy Association

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

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

Simply contact us by post:
Colostomy Association
Enterprise House, 95 London Street
Reading RG1 4QA

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

By E-mail:
cass@colostomyassociation.org.uk

Find us on FACEBOOK:

Find us on Facebook

Join our 'closed' group today... simply put Colostomy Association into your FACEBOOK search bar, click on Group and click on 'Ask to join' you will be assured of a warm welcome!

Visit us and **register** at:**www.colostomyassociation.org.uk**

Don't delay... Donate Online today!

There are **NOW two ways** to **donate online...**

①

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

JustGiving ②

Visit the **Just Giving home page** you will see a search panel **'Find a Charity'** type in **Colostomy Association.**

Tidings is YOUR Magazine...

Editorial Submissions:
Tidings is a quarterly publication. Your contributions to Tidings are always welcome. If you have a story, article or letter that you would like featured in the magazine we would like to hear from YOU!

If you have an idea for an article and would like to discuss this with the Editor or would like help writing your story please get in touch. We will always do our best to include your contributions in the next issue of Tidings or will hold them back for a future issue. When submitting your information don't forget to supply your name, address, phone number and e-mail address if you have one.

Please include any relevant photos or illustrations as these really help to bring YOUR magazine to life! You can send these as prints or digital images.

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

How to supply 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 1500 pixels x 1200 pixels at 300 pixels per inch (equal to 12.5cm x 10cm).**
- **File sizes not less than 10Mbytes uncompressed**
- **Images in Tiff with LZW compression or JPEG format.**
- **For scanned images please set at 300ppi in RGB mode and scan original @100%.**

Advertising Enquiries:
For a media pack and advertising rates.
Contact Jane Wood: 0118 939 1537

Publication:

Spring	April	2013
Summer	July	2013
Autumn	October	2013
Winter	January	2014

How to contact the Editor

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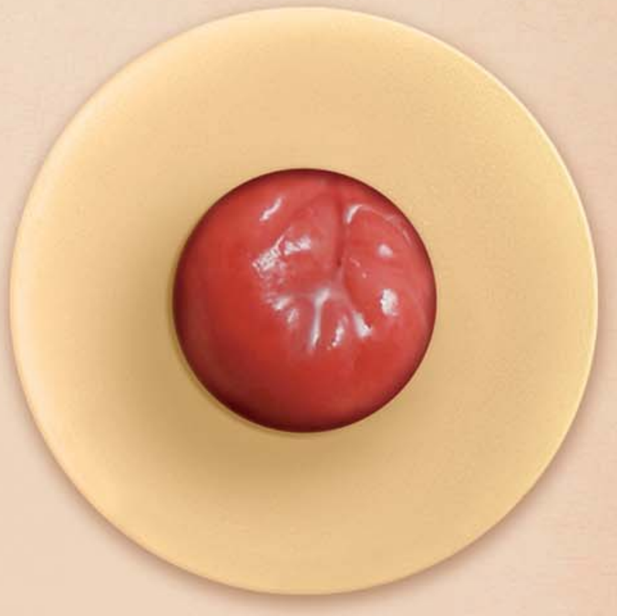

Dear Readers... The Colostomy Association continues to reach out via its trustees, staff, volunteers, support services, Tidings magazine, website and increasingly through its 'closed' Facebook group...to make a difference to the 'real life' experiences of those 'living with a colostomy'. (Joining the group is easy...put Colostomy Association into your Facebook search bar, click on Group and click on 'Ask to join' where you will be met with a very warm welcome). The CA office continues its pivotal role – providing information, support and reassurance to colostomates, family members and carers. There are now 115 trained CA volunteers across the UK. All our volunteers have the skills to chat with new colostomates, attend open days, assist SCNs, listen and support callers on the helpline.

The Right Worshipful the Mayor of Reading Councillor Jenny Rynn with honoured guests, staff and volunteers of the Colostomy Association gathered to celebrate the Grand Opening of the new office premises in Reading in April...

L to R: Mr Monty Taylor with the Mayor of Reading Councillor Jenny Rynn

The CA is delighted to report the success of its Grand Office Opening Event in April. The day started well blue skies and warm breezes. The Right Worshipful the Mayor of Reading Councillor Jenny Rynn along with honoured guests, staff and volunteers of the Colostomy Association gathered to celebrate the Grand Opening of the new office premises in Reading.

Mr. Monty Taylor – Chair of Trustees welcomed everyone to the new offices

of the Colostomy Association. He especially thanked Councillor Jenny Rynn for attending saying: 'how kind it was of her to take time out of her busy schedule to officiate at the celebrations'. He also thanked: 'Mr Edward Richardson for his generous donation of office furniture, which has transformed the workplace environment for staff and CA volunteers'. Mr Taylor also thanked the attending stoma care companies/suppliers for donations towards the office move and reception furniture. He then introduced The Right Worshipful the Mayor of Reading Councillor Jenny Rynn who made a wonderful speech: 'I am delighted to be invited here today to open the Colostomy Association's new offices and to learn more about the support and reassurance this dedicated charity provides to colostomates, their families and carers. Colostomy and stoma care are subjects not openly discussed in the public arena – but it is obvious to me that the Colostomy Association works hard to raise awareness and dispel myths that surround these subjects, which is both brave and heartening'.

Mr Taylor handed over to Mrs Jackie Dudley – CA Trustee and Volunteer who had some special words for a particular guest. Mrs Dudley explained: 'amongst you today is a very special lady – Mrs Celia Waters. In 2004, the then Manager of the British Colostomy Association (BCA) – Mrs Celia Waters – faced the threat of the charity's closure. Macmillan who had supported the BCA over many years decided to withdraw its funding due to restructuring – it was Celia's vision and enthusiasm that prevented the demise of the charity – that is so successful today – now known as the Colostomy Association. We owe a great debt of gratitude to Celia for having the vision, the enthusiasm and the organisational skills to take a group of keen volunteers and make them into a team of Trustees – able to work with her and take the new charity forward.

Celia has since moved on but we all remember and appreciate her

Mrs Celia Waters past manager of the British Colostomy Association devotion to the charity and her most valuable contribution to forming the new charity – the Colostomy Association'. Mrs Dudley then presented a beautiful bouquet of flowers to Mrs Waters who accepted graciously. Celia thanked Mrs Dudley saying: 'she was delighted to be present at the Grand Opening and wished the charity well for the future'. Chairman Mr Monty Taylor then asked everyone to raise their glasses to celebrate the opening of the new offices of the Colostomy Association. There was a break in proceedings and a buffet lunch was served. The new offices buzzed with conversation. Mr Taylor then invited The Right Worshipful the Mayor of Reading Councillor Jenny Rynn to cut the celebration cake (made by Mrs Joyce Rawlinson, Tadley).

CA Website: Our web pages contain a large range of useful information both for new and more established ostomates and their carers. Please note you can download all our literature and factsheets there, as well as check the details of your nearest support group.

Tidings Magazine: CA would like to encourage you to pass on Tidings Magazine and any back copies you may have to fellow ostomates, to your local GP surgery or Healthcentre for the benefit of others. We understand many of you keep each issue for reference – if you can't bear to pass them on that's absolutely fine.

The CA's Purple Iris Award:
Encouragingly, we've received several suggestions for the best UK Stoma Care Department or Community setting and the nomination process has now closed. The winner will be announced in the Autumn issue of Tidings. Thank you to everyone who sent in a form – it's wonderful to hear how many patients have received excellent care.

New Support Groups: Another new ostomy support group will be starting up in Northallterton shortly called Dales & Vale and if you're interested please contact Carol on 01677 988150. We're always pleased to hear from people wishing to set up a new support group as we can help by sending a publicity flyer to our supporters in specific geographical areas. For further details of support groups in your area, please refer to our website or the support groups listing at the back of this issue of Tidings.

Don't forget...The CA Open Day 2013:
We hope you'll be able to join us at our Patient Open Day in Reading on Saturday 20 July!

Open Days: Manufacturers and hospitals run patient information days throughout the UK and ostomates benefit greatly from attending. These events are an ideal opportunity to find about the latest products or to discuss any concerns with the CA representative at our stand. Look out for the details of all open day events which appear on our website or when they are issued by post.

Sam has a Stoma: This story colouring book is an ideal pictorial resource for those caring for children with a stoma to explain what is happening to them (or to depict to a child that a parent has a stoma). A copy can be downloaded from our website from our 'Young Ostomates' web page or ordered by phone/email from the CA office.

Photo ID Card...

The CA photo ID card is proving very popular as it can be useful if challenged when entering or exiting accessible toilet facilities.

If you would like to apply for a Photo ID card, please complete the form opposite and return it to the CA for processing with the various enclosures listed below:-

- **A copy of your prescription or delivery note as proof of eligibility**
- **Passport photo x 1**
- **Payment – cheque**

Note: Payment can be taken over the telephone if preferred.

Alternatively, the form is downloadable from our website: www.colostomyassociation.org.uk

Please allow 10-14 days for delivery – thank you

National Key Scheme (NKS) Radar Key and optional Photo Identity Card...

To obtain a **key or a photo identity card** please **complete the form and declaration.** Make your **cheque payable** to the **Colostomy Association**. Return all required items to: **Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA**

(If you have any queries please contact the admin team at the CA office via the following methods:- Telephone: 0118 939 1537 or Email: cass@colostomyassociation.org.uk)

National Key Scheme - Key and photo ID card purchase

Title:

Name:

Address:

Postcode:

Tel:

Email:

DECLARATION: I declare that the individual named above is chronically sick, has a disabling condition or has had a bowel or bladder diversion that necessitates the use of disabled toilet facilities. The key is for the personal use of the above named and their designated carer only.

Please **tick** the following as appropriate:

☐ I would like to receive a key for a charge of £3.50 (including postage and packing).

☐ I would also like to receive an optional photo ID card for an additional charge of £6.50 and enclose a passport photograph.

☐ I attach a copy of my prescription or recent delivery note as proof of eligibility and a cheque made payable to 'Colostomy Association' in the sum of £3.50* key only/£6.50* ID card only/£10.00* both the key and ID card (*Please delete)

Signature of self or carer: Date: / /2013

The misuse of any public or private conveniences constitutes an offence. Please note that there are penalties for making false declarations. Key holders' details are stored in accordance with the Data Protection Act and may be randomly checked by the Association

Please cut along the dotted line and return to the address on this form - thank you

Pathways to a Colostomy...

Bobbie Minshull...shares her story of how she came to have both a urostomy and a colostomy. Now, after living abroad for many years, she is back in the UK and has become a volunteer for the CA and set up a local support group in Northumberland...

It was in 1985 while I was living in Germany with my husband, who was serving in the RAF, and our two girls that I was diagnosed with cervical cancer. I was sent back to the UK for a hysterectomy. Unfortunately the cancer was at the edge of the removed part and so I had to have radiation treatment. In those days it was not as refined as it is nowadays; it basically fried my insides and I began to suffer from bladder incontinence.

A surgeon recommended a urostomy and this was formed in 1991. Unfortunately the operation damaged my bowels and caused adhesions. Over the years I had several operations, but the adhesions still caused problems with pain in the abdomen. Then my brother in law who is a pharmacist suggested I try an antispasmodic. When I asked my GP he said, 'Oh that's a good idea'. And it was. I no longer had attacks every ten days or so. Instead it would only be once or twice a year. Much better. It made life much more bearable. However, I did suffer with bowel incontinence.

When we moved to Maastricht in The Netherlands I was sent to see yet another specialist. Three weeks later I spent the whole day in the hospital having five different tests. My husband was there as the Dutch encourage partners to attend too. I found some of the procedures upsetting but he supported me throughout. The surgeon said he felt I would be a candidate for an artificial sphincter. He sent us away to research it. We felt the fact that the only surgeon doing this operation in The Netherlands was ten minutes from our house was fate. So we went for it.

The artificial sphincter involved an operation to insert a three piece device. A cuff went around the anus. This was attached to a reservoir and a pump. I then had to pump this to move silicon fluid from the cuff into the reservoir, which opened the cuff and allowed the faeces to flow out. It was a very uncomfortable operation but I recovered and life got better. The artificial sphincter worked reasonably well, apart from when I had diarrhoea.

A couple of years later due to stenosis (a narrowing of the stoma) my urostomy had to be revised. The operation to create a new urostomy went on twice as long as it should have done because of the adhesions. It took me a long time to recover but I did. However, I suffered with chronic diarrhoea and it got worse and worse. Finally it became intolerable and I was feeling at rock bottom. I went to my GP and asked for a colostomy. I just couldn't bear living with the incontinence any more. I was going to the toilet fifteen times a day and my anal skin was so sore I couldn't wipe it.

Despite being nervous of how long it would take me to recover from another operation, I went to the operating table with hope that my life would be better. When I woke up in the recovery room I felt incredibly alert and phoned my husband. He asked why the op hadn't been done - it had only been an hour since he left me to go down to theatre. ‘It has,’ I said. ‘I have a new stoma but no scar. Come and see me.’ I could talk to my husband and felt fine. I even had a sandwich for my tea! Two days later I was home.

However, I started to get very tired. I went to see the hospital stoma nurse and told her I had a lot of output and it was totally liquid. She said to use thickening sachets in the bag. Then one day I felt terrible. I could hardly think and my urostomy stopped working even though I knew I had drunk a lot. My husband dragged me to the hospital. After numerous tests, including a camera pill, they came to the conclusion that I only had 1.2 metres of small bowel left. I was not absorbing nutrients from food, which was why I was so tired.

They tried all sorts of things to help me. Then I was referred to a specialist, newly arrived at the hospital. He saw me every six weeks and together we worked on getting my body working. We got on so well that one day he asked if I would talk in front of a meeting of 34 gastroenterologists, the next day. When I said I couldn't make the morning he moved the schedule around so that I could do it in the afternoon! I was already a volunteer for the students in the teaching university so I had got used to talking about my stomas to students in Dutch. (We learnt Dutch when we went to The Netherlands and it was one of the proudest days of my life when I passed GCSE with an A*). Eventually the specialist managed to get my output down, from the 3700mls measured in hospital, to around 1500mls. It meant a very expensive injection every month and loads of tablets.

As my husband was due to retire after 38 years of RAF service, we then returned to the UK. We moved reasonable close to our youngest daughter so we could be involved in our granddaughter's life, and baby sit two days every fortnight.
I also wanted to do something to help others with stomas and became a volunteer for the CA. What I liked most about the training was being in a room with other people with stomas, something I had never experienced before.

I decided to try to start a support group locally, because there was nothing between Edinburgh and Newcastle. I got in touch with a community stoma care nurse for Northumberland and she agreed to support me. I contacted all the stoma associations and asked them to drop flyers to anyone with relevant postcodes. The local hospice agreed to hire me the room for a couple of hours. The stoma nurse laminated lots of posters and I put these up in GP surgeries, pharmacies, libraries, post offices and supermarkets. I also emailed the local paper to ask if they would be willing to publish a letter about the group and they offered to do a piece on it. They came to my house and did an interview which took up a half page spread that week. Several of the ladies I play golf with commented on it being a very good article. I had never hidden my stomas from them and they have been very supportive.

A couple of weeks before the meeting the hospice told me they would not be charging rent for the room at first, which was wonderful. The stoma nurse and a representative from a stoma company subsidized the tea and biscuits so I just had to buy the raffle prizes. Come the evening of the first meeting as I set up all the CA leaflets and teas, I wondered how many people would come. Six or eight, maybe.

My wonderful husband hugged me and told me how proud he was of me and then they started to come through the door, and they just kept on coming. I welcomed 26 people that evening, all local and all grateful for someone starting up a group. The noise of people talking about stomas spread throughout the room for two hours. It was a wonderful chaos. I asked people to leave their phone numbers purely in case I ever had to cancel the meeting and I asked if anyone would consider helping. The stoma nurse, my husband and I went from person to person and hopefully between us we managed to help and encourage everyone. I told the attendees that the hospice was donating the room free and asked if they felt able to donate a bit in their charity box as I felt it was only fair. The morning afterwards I was still on a high and got two phone calls thanking me for organizing the group.

And so that's where I am now. My first meeting under my belt and really feeling I might be helping people, hopefully they even may be able to miss out some of the steps I have taken over the years. I am happy with my stomas, I enjoy being a volunteer and I still have my wonderful husband standing by my side. What more can a girl ask for?

Bobbie Minshull

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

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

New Soft Convexity Extra Large Size Pouches...now available from Peak Medical

Peak Medical Ltd, exclusive UK distributor of the EuroTec range of ostomy products and accessories is pleased to announce the arrival of their extra large size soft convexity pouches.

Now available on NHS prescription in a closed and drainable pouch in a cut to fit option: 13-54mm.

Designed with the wearer in mind, the integral, soft, flexible inserts provide the optimum depth and profile to manage most problematic stomas without the discomfort and rigidity associated with traditional convex barriers.

Made from a traditional skin friendly 0.9mm thick hydrocolloid adhesive, the barrier is backed with a protective layer of SuperFlex stretchable foam for noticeable comfort and flexibility.

For more information and to receive your complimentary sample* please call Freephone 0800 652 0424 and quote code M62. Alternatively, please visit Peak Medical's website: www.peakmedical.co.uk for more information.

***All convex products should be used upon the advice and guidance of a Stoma Care Nurse.**

NEW products from OstoMART and HiLINE available on Drug Tariff NOW

Following the success of OstoZYME Odour Neutralising Pouch Lubricating Gel, we have now launched a new 90 sachet size pack to complement the existing 30 sachet size. OstoZYME lubricates the inner surface of your stoma pouch encouraging waste to slide to the bottom of the pouch to prevent pancaking whilst at the same neutralising pouch odour.

OstoZYME is the original pouch lubricating deodorant.

For further information about OstoZYME, see our main advertisement on the outside back cover of this publication.

Our sister company HiLINE is pleased to announce that the popular Res1 Cotton, Res1 Satin and Res2 Lace range of ostomy pantie brief hernia support garments are now available in a choice of Black as well as White. Both colours are available on prescription and in sizes 8-30.

For a FREE sample of OstoZYME Odour Neutralising Pouch Lubricating Gel or further information about the complete range of HiLINE Prescription Support Garments, please call freephone 0800 220 300, email us at enquiries@ostomart.co.uk or visit our website www.ostomart.co.uk

Na `Scent Ostomy Odour Eliminator

Size	'PIP' Code	Product Code
2oz (59mls)	376-4735	02-NOOEWS
8oz (236mls)	376-4727	9901-NOOEWS
12oz (354mls)	376-4719	0112-NOOEWS

Na `Scent Ostomy Odour Eliminator – the new standard in odour eliminator. For use in colostomy, Ileostomy and urostomy pouches. Available now in the UK from Bullen Healthcare.

"It's amazing how much confidence this gives you when you are out and about and having to use public toilet facilities, it takes the paranoia away completely as I can empty my bag and leave the bathroom odour free for others to use," Annette Keenan, Ostomate and Senior Sales Manager, Vanilla Blush.

It is not simply a deodorant it actually eliminates the odour by creating an oxygen rich environment that's kills odour causing microbes in the pouch. Na Scent can give you the freedom and peace of mind you need to confidently go about your day to day life without those worries or stresses slowing you down or feeling a burden on your daily choices.

For further information or samples call our Customer Service Team on Freephone 0800 888 501 or alternatively visit us at www.bullens.com


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

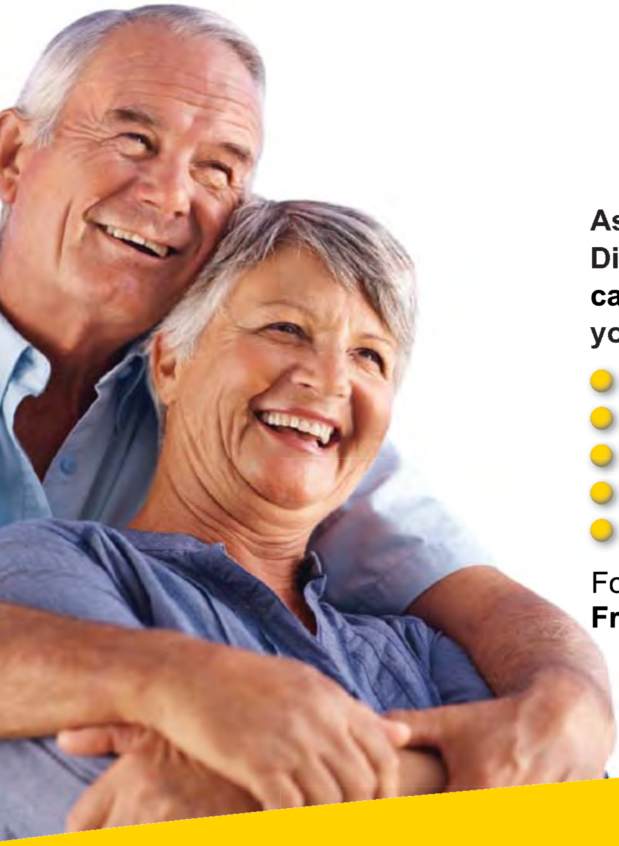
Tidings is always **interested to learn about new stoma care products and services**...from **manufacturers and suppliers. Colostomates**...if you have found **a stoma care product** or **service beneficial to 'living with a colostomy' please let Tidings know. YOUR findings could make ALL the difference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

Stay Put Waistbands...

with silicone strips for extra grip, keeping your waistband exactly where you want it. New improved version of the seamless breathable waistbands, with small strips of silicone inside the hems top and bottom, helping the garment stay put all day and night. Reduces movement when waistband could potentially ride up or roll. Available in 7" and 10" depths and up to 5 sizes from S/M to 2XL/3XL to suite most needs.

Available to purchase from £10.00 or on prescription. For more information visit www.comfizz.com or telephone the Comfizz team on 0113 266 2096.

Another great innovation by Comfizz helping to improve life with a stoma just that little bit more.



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

Donations
When sending your donation/s **please mark your letter/cheque** with **Tidings Issue 30....**
Thank you!

Dear Tidings

Our local pub, which was in sharp and almost terminal decline, was taken over by new landlords about six months ago and is, once again, thriving as a community pub.
One of the projects to improve business was to instigate a charity quiz on the last Tuesday each month, the first of which was in April. It was announced that the winning team each month would then nominate their chosen charity for the following month's competition. I am delighted to say that the Colostomy Association was the recipient of the May proceeds. Please accept our winnings £120 as a donation, which we know, will be put to a good use.

D&S.P

Girlguiding Northamptonshire Corby & Rockingham Forest Trefoil Guild

Please accept our donation of £100 from the Corby & Rockingham Forest Trefoil Guild, based in Corby, Northamptonshire. We held a small Coffee Morning stating that the proceeds were for your Association and were pleased with the response. The work that you do is very much appreciated. Thank you.

G.S.G
Secretary

Dear CA

Please accept a donation of £200, from the Wall Village Lunch Club!

R.T

Dear Colostomy Association

Recently, I very happily celebrated my 70th birthday having had bowel cancer and a difficult time in hospital 5 years ago. I asked family and friends to make a donation to CA, in lieu of presents. Please accept this donation of £200 for all the good work you do.
With best wishes,

M.F

Dear Colostomy Association

Please find the enclosed my donation of £447.30. I raised these funds in April this year to celebrate Winnie's 1st Birthday. In April 2012, I had an operation for bowel cancer, which was very successful – I received a colostomy. To help me recuperate after the operation, I held a competition to name my stoma. I raised £194 for the stoma nurses at Lincoln County Hospital. My stoma's name – Winnie after Winnie the Pooh!

Thank you everyone for your kind donations

I have now made a full recovery and although I sometimes get upset with Winnie, I have come to terms with my stoma. That being said I decided that I would raise money on the anniversary of my operation by getting together all my relatives and friends. I booked the local Scout HQ (I have been a Scouter for 32 years!) and held a coffee afternoon with cakes, a raffle and a Bring and Buy stall. Everyone had a great time celebrating Winnie's birthday and raising money for the CA!

Thank you so much for the Tidings magazine you send out, it has been a godsend! I have had so much help from reading all the articles and stories from the people who have had the same operation as me.

Keep up the good work!

C.B

Don't forget...

CharityFlowers.co.uk
Provided by Guernsey Flowers Ltd

Guernsey Flowers Limited is based in the Channel Islands of Guernsey and have been involved in the Flowers by Post Business for many years. Guernsey Flowers Limited manage the **www.charityflowers.co.uk** web site and call centre and provide and pack the flowers from their purpose built premises.

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500 Club... March 2013 Draw Winners!

Mr K Omar	£	279.00
Mrs H Vickers	£	139.50
Mrs A Wilson	£	55.80
Mr R Walker	£	55.80
Mrs J Weiner	£	55.80
Mr R G Jones	£	27.90
Mr T Woodhouse	£	27.90
Mr T Middleton	£	27.90
Mr P Walsh	£	13.95
Mrs Y Vickers	£	13.95
Anonymous	£	13.95

Note: The following winners donated back to the CA...this is much appreciated – many thanks

Mr Omar: **Donated £50 to CA**

Mr Vickers: **Donated £10 to CA**

Ms Weiner: **Donated draw prize back to CA**

Mr Walsh: **Donated draw prize back to CA**

In Memory

Mr Pat Fitzgerald	£	303.76
Mr H F Sheppard	£	271.47
Mrs C Palmer	£	529.00
Mr S Heginbotham	£	500.00

Thank you

In Memory - Apology:
Mr P T Fitzgerald funds listed in the Spring Issue of Tidings were incorrect. (The Editor has relisted the correct funds above). Our sincere and deepest apologies go to Mrs Jenny Fitzgerald (Pat's wife) for the print error. The total donations made to CA in Pat's name were £303.76 not the £60.00 listed in the magazine.

Legacies...

Mr A Conn	£25,662.00

Thank you

Volunteer's Tandem Parachute Jump raises much needed funds for the CA!

I am delighted to say that funds from my Tandem Parachute Jump amount to over £747 so far. I like to think of you all at CA as a part of my family, and I know from chatting with other ostomates – the work you do – really does make a difference! As I have said before, I know you will put these funds to good use, and I will now try and think up a fund raising scheme for next year. You really do to make living with a colostomy so much easier.

M.R

From Ed: If you have any fundraising ideas or suggestions please send them in! Contact the Editor via: 0118 918 0500 or by email: editor@colostomyassociation.org.uk

Help CA raise funds...

For your FREE donation box simply contact the office – telephone: 0118 939 1537 or email: cass@colostomyassociation.org.uk to order yours today!

Virgin London Triathlon fundraiser...

Ian completed the Virgin London Triathlon, last september. The event entailed a 750m swim in the docklands, 20km cycle ride finishing with a 5km run around the Excel Centre – no mean feat.

Ian raised £1,110.00 for the Colostomy Association which is fantastic! He says: "I chose this charity because my mum's cancer reappeared which resulted in two major operations. The second operation was an emergency one, that had some complications and as a result my mum now has a colostomy.

It's not easy accepting and living with a colostomy, especially when its not widely known about, however my mum has proved yet again that her strength and positivity has meant she can live a normal life.

Mum is a major inspiration and strength to the Scott family and to her friends and has received invaluable information from the Association. I know my family and particularly my mother would like to thank everyone involved in the organisation, it offers a major lifeline to so many".

Total raised: £1,110.00
Gift Aid: £257.50

JustGiving

Don't forget our Recycling Appeal...

Recycling Appeal is a multi-product technology appeal...raise funds for CA. Freepost envelopes are available or collections can be organised simply call: 08450 75 58 82 or 08451 30 20 10

What can be recycled?

Unused and Un-pulled ink cartridges
Mobile Phones
Laptops
DVD
DS/Wii games consoles
DS/Wii games
Cameras

A tough ride...home to family and friends... my business...and cycling for the CA?

Paul Smith tells us his story...back to good health and explains why he came to take the ride of his life across the 'Way of the Roses – a spectacular 'coast to coast' cycle route from Morecambe Bay (the Irish Sea) to Bridlington Bay, on the North Sea coast, with fellow work colleagues...

In October 2010, I was admitted to hospital with uncontrollable bowel problems. I couldn't walk for more than 10 yards with out the inevitable happening. I stayed in hospital for three weeks I was given all sorts of injections and intravenous drips to try to stem the flow. (The long and short of this experience – the ward I was on – was shutting down due to cuts). I was discharged and advised that I was fine and progressing well, I disagreed so far as to say, the week post my discharge, I found myself having lost a stone in weight and writhing in agony for prolonged periods during the day. At this point I was very weak and could not bring myself to eat, my wife was hand feeding me. I had taken enough, and contacted the surgeon who had performed an exploratory sigmoidoscopy (bearing in mind she had advised at that point the bad state of my colon). I advised that if I was not attended to I felt I wouldn't last much longer, my voice failing and all my bodily functions seemed like they were shutting down.

My wife rushed me to the hospital where my consultant advised, 'you're a poorly man and we've neglected the issue.' They did the usual tests and sent me to a ward to wait for the ambulance. I waited for a few hours' all the while losing blood and bodily fluids. I was taken to The Royal Oldham hospital under the care of Mr Rate and his staff. I was advised I was too poorly to operate on and I needed 4 pints of blood and 3000 calories of protein. I was told that I may not be strong enough for the operation but if I waited I may not last the weekend, the choice was mine. What choice?? I dug deep and did as asked albeit unpleasant all the while thinking – is this my last stand? With my family around me in tears, the last memory

JustGiving

Total raised: £1,028.13
Gift Aid: £237.50

before the op was my daughter screaming "daddy" (very gut wrenching) but I assured them all I would be OK. But inside I wasn't too sure.

I awoke from the operation to find the surgeon and staff around me advising that my full colon had collapsed as they had begun the surgery, I was in agony with a strange feeling on my sides I had a ileostomy bag on one side and a drain pouch opposite, my finely tuned torso ruined but hey I'm alive! The three months ahead were difficult, coming to terms with this trauma and life changing event, leaking pouches in meetings or wherever, often six times in a day, a business to run. How was I going to cope? Some days low some not so.

But onwards and upwards as 'they' say! I had my family…friends and colleagues who all played a very big part in my recovery – not forgetting myself of course and my positive mental attitude (PMA), this blow wasn't going to stop me, No Way! The first question I asked at my three month review…When can I go back to the gym? After listening to some very sensible advice from my stoma care nurse, I did go back to the gym – back to building up my fitness, playing 5 aside football again (and holidays). The second question…how do I wear my shorts so high to cover my bag? I didn't. I just folded down the top section of the bag, taped it down – now I was 'normal' – I wore a belt to support the bag so it didn't readily peel off, not always successful but in the main I managed! I carried on like this for just over two years, no pain just the inconvenience. A small price to pay looking back.

After my third operation my bag has now been removed and I have a J-pouch. This was done seven months ago and I must admit it's been a heady climb. (Difficult to have to visit the loo between 8 and 18 times a day). To this day quite severe but be positive – it will improve – I keep saying!

I took a lot from Tidings – advice and tips, all of which were good, reading other people's stories is humbling to say the least. I wanted to help CA so I gave myself a target, something I wanted to achieve personally. My accountant suggested a cycling trip – I thought it a great call! I began training with him. He was tough with me and trained me long and hard.

I was ready after six weeks to achieve my aim. The 'Way of the Roses' – Coast to Coast – was my goal! Cycling 170 miles in three days with two of my employees with my co-director in the back up vehicle . We all succeeded although it was a tough ride – we experienced all four weather seasons during our three day ride! My company employees were so supportive; as were clients and friends – all who knew me – gave to the cause. Humbling and grateful that we could do the trip for such a worthy charity.

If anyone finds themselves in similar circumstances to myself – try to keep positive – all things are possible. I have succeeded in carrying on with my business along with my co-director and staff of over 20 people who embraced my situation. I play football, go to the gym, have a drink with the lads and enjoy the other things life brings – like cycling the Coast to Coast! Having a stoma may seem like an uphill struggle at first but remember my mantra PMA – positive mental attitude! I'm here telling my story and if this helps just one person I'll be a very happy man.

Paul





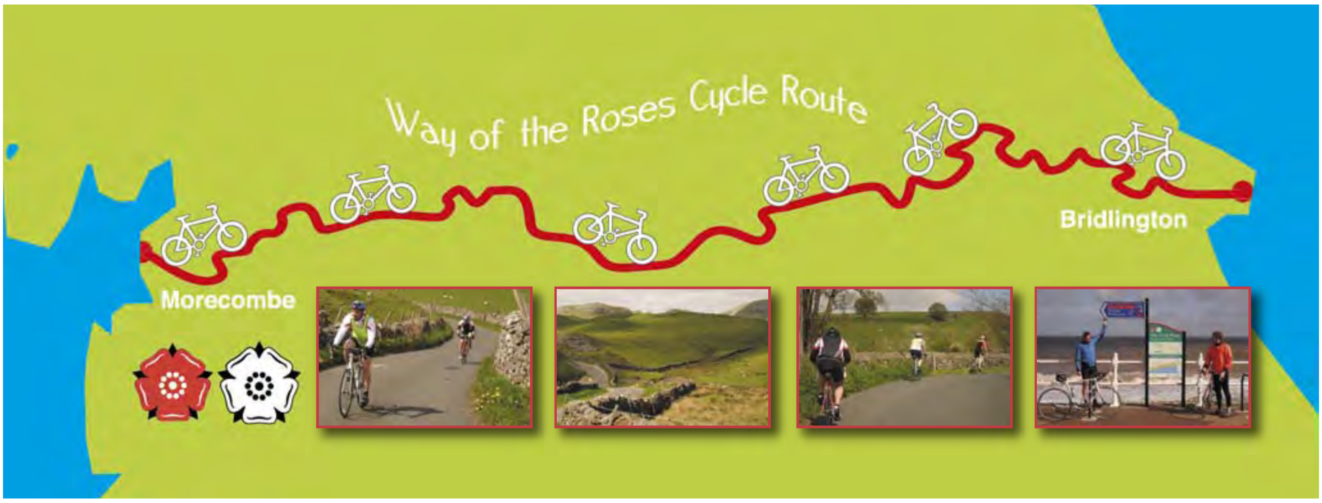
Way of the Roses...riding out to Bridlington!

Day 1: Was a cold start from Morecambe sea front through to Lancaster which was very flat and easy, as the day went on we cycled through The Trough of Bowland and picturesque villages and country roads until we reached Settle where we had a break for half hour. Straight back into the saddles we then had a very difficult climb to the top of the hills out of Settle into open countryside towards Malham. The scenery was breathtaking and the weather was glorious. The open country roads here were quiet and a pleasure to cycle on especially having just had a tortuous climb towards the end of day one.
We finally got into Grassington mid afternoon.

Day 2: Saw us starting out in Grassington and within 2 miles we were heading for the most difficult part of the journey, the weather was freezing and we were hit with hailstorms and heavy rain, this however didn't dampen our spirit.

We cycled through Burnsall heading up the hills towards the notorious climb to Pateley Bridge, a winding steep steady climb for circa 4 miles to be

> 'I was ready after six weeks to achieve my aim. The 'Way of the Roses' – Coast to Coast – was my goal! Cycling 170 miles in three days with two of my employees with my co-director in the back up vehicle'.



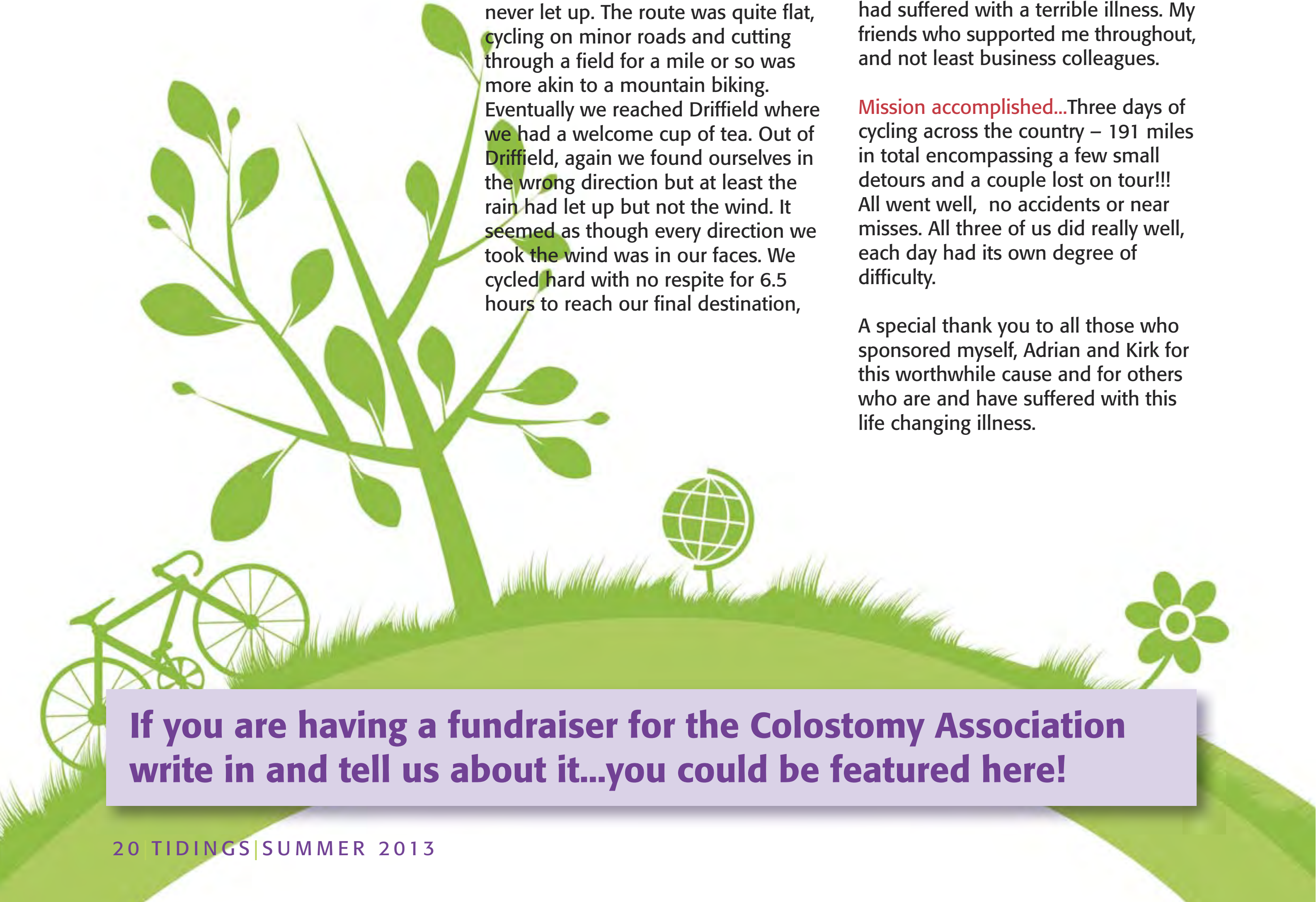
welcomed at the top with a very steep and tricky descent. The weather was against us here and we had to ride with caution on the downhill as the roads were both slippy and very steep with tight bends. There are warning signs here to be ultra cautious. We got into the village of Pately bridge to find yet more climbs to get to our next point, Fountain Abbey – a lovely village where we grabbed a cup of tea before stopping at the Abbey to take a few pictures and have a closer look. We rode through the national park on to Ripon and through the centre, a couple of quick snaps at the cathedral, sheltered from the hailstorm before our last jaunt towards York, where we arrived mid afternoon.

Day 3: What should have been the easiest day of the 3, relatively straight forward with only a minor 200m climb over a 10 mile stretch. The weather was atrocious, heavy rain and howling winds in our faces. Getting out of York wasn't the easiest, having to take detours and getting lost for around an hour didn't bode well for an easy last day. The rain subsided but the wind never let up. The route was quite flat, cycling on minor roads and cutting through a field for a mile or so was more akin to a mountain biking. Eventually we reached Driffield where we had a welcome cup of tea. Out of Driffield, again we found ourselves in the wrong direction but at least the rain had let up but not the wind. It seemed as though every direction we took the wind was in our faces. We cycled hard with no respite for 6.5 hours to reach our final destination, Bridlington. A sense of achievement. Six months ago I had my reversal to now riding nearly 200 miles across the country.

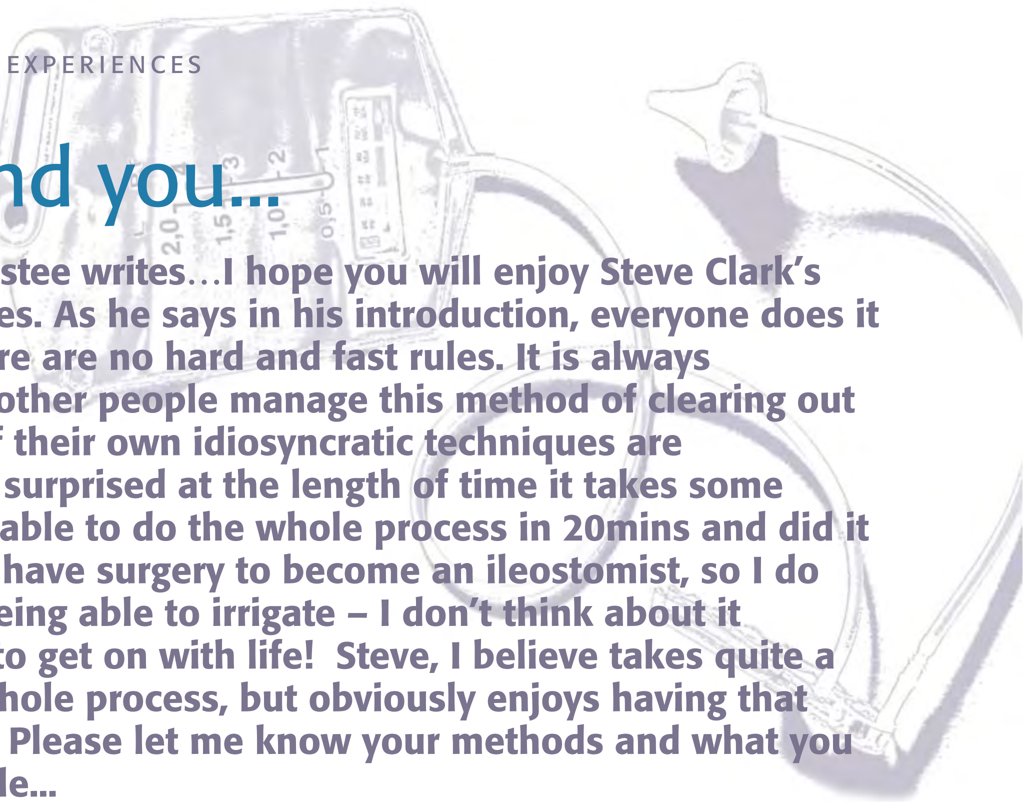
The ride was not easy and you have to have a base of fitness for sure. I would like to thank:- Kirk Lusty and Adrian Radcliffe who cycled with me. The camaraderie was great, each one of us kept the others pushing on. Jeff my business partner for being with us all the way with the supplies and spares in the crew van. His contribution was invaluable. My wife and family who supported me through the years That I had suffered with a terrible illness. My friends who supported me throughout, and not least business colleagues.

Mission accomplished...Three days of cycling across the country – 191 miles in total encompassing a few small detours and a couple lost on tour!!! All went well, no accidents or near misses. All three of us did really well, each day had its own degree of difficulty.

A special thank you to all those who sponsored myself, Adrian and Kirk for this worthwhile cause and for others who are and have suffered with this life changing illness.



If you are having a fundraiser for the Colostomy Association write in and tell us about it...you could be featured here!



Irrigation and you...

Sue Hatton Executive Trustee writes…I hope you will enjoy Steve Clark's article on how he irrigates. As he says in his introduction, everyone does it differently. It is true, there are no hard and fast rules. It is always interesting to read how other people manage this method of clearing out their bowel and some of their own idiosyncratic techniques are fascinating. I am always surprised at the length of time it takes some people to irrigate. I was able to do the whole process in 20mins and did it daily. I have now had to have surgery to become an ileostomist, so I do not have the luxury of being able to irrigate – I don't think about it anymore, you just have to get on with life! Steve, I believe takes quite a while to complete the whole process, but obviously enjoys having that time to sort himself out. Please let me know your methods and what you think about Steve's article...

Colostomy Irrigation - One way of doing it...

Steve writes...I am not medically qualified and only offer this as a guide to my technique.

I'm going to attempt to explain my procedure for irrigation. Don't forget, we are all different and what works for me may not work for you.

Firstly, you must get permission and training from your stoma care nurse. I have an end colostomy but I don't know how much has been removed. As I understand it, the greater amount of colon that remains, the easier irrigation becomes but I believe people successfully irrigate with a descending colostomy, so don't be put off, persevering and honing your technique. One day it will suddenly come together and work for you.

Before I start, I make sure I'm well hydrated. As a general rule, I try to drink about 2 litres of water a day to keep everything working right. The colon absorbs water back into the body so, if I am dehydrated, the water that goes in doesn't come out.

To begin, I remove my bag and attach a sleeve. I then fill the water bag to the correct level and temperature, as detailed below, attach the cone and hang it up above shoulder height. I have a folding chair from Asda (currently £7 at March 2013), which I place close to the WC so my sleeve will hang into the bowl. A useful touch to my chair is the cup holder. This is useful for putting wipes, peg, spray in while you are virtually immobile during the procedure.

The first consideration for a successful irrigation is water temperature. I've been through the temperature ranges from 34/35 deg up to above 40 deg. I've found my greatest success is a starting temperature indicated on the bag of 39/40 deg. Obviously, as the procedure progresses, the temperature drops and I often complete my last infusion at about 35/36 deg. If the water is too cool, the colon can spasm. If too hot, you risk hurting yourself and damaging the equipment.

Infusion volume: I fill the bag to 2 litres. I then infuse about 500ml at a time, with the flow indicator wheel just turning above dead slow/stop. It takes about 3 minutes to infuse 500ml. If there is trouble 'turning the wheel,' it is because my bowel is not relaxed enough. I take a very deep breath in, which normally starts the wheel turning, and exhale slowly, allowing my abdomen to 'flop' at the same time so I end up flopped back in the chair. This relaxation generally keeps the flow going.

Output: Eventually, I get an uncomfortable feeling of fullness and water tries to escape past the cone. At this point, I enter 'extreme relaxation' mode in an attempt to relive the water pressure. After a couple of seconds I remove the cone and start reading my book. By this time the wench has delivered the cup of tea! A few seconds later, I get a gush that is sometimes clear, sometimes mixed with formed matter. I carry on reading and after about 5/10/15 minutes, I get another long, sustained gush that is usually made up of looser matter, having been mixed with the infused water. After about another 5 minutes, I repeat the infusion process again, and at the end of the cycle, for a third time. By now I have infused about 1500ml total in 3 lots of 500ml.

Clearing up: After I've had no output for about 10/15 minutes after the last secondary burst, I remove the sleeve and clean all the equipment, hanging it all to dry. This is the risky bit because at this point, 'Fred' is au naturel. Assuming no 'inconvenient afterthought,' it's into a nice hot shower, slowly reducing the temperature until it's a nice cold shower!! After that, out, dry, smellies and bag. The whole procedure takes me between an hour and 90 minutes, depending on my motivation. I have cut corners and done it in about 40 minutes, with success, but I've always had the nagging doubt of incompleteness in my mind.

Conclusions: The major barrier to successful irrigation I believe is relaxing. Relaxation is crucial to successful irrigation, in my opinion. I take a very deep breath which generally sets the wheel spinning. The difficult thing is relaxing the abdomen as I exhale. Sometimes, I can feel the tightness still. I found that by 'slumping' my abdomen, it seems to relax me. It's one of those things that you will know exactly the sensations and feelings when you do get it right and, after practice, will repeat again and again without problems.

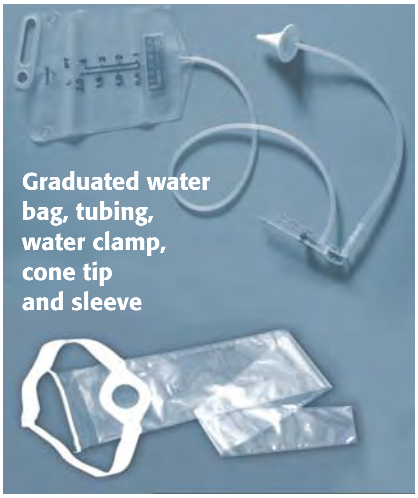
I've tried various changes to routine and found that what I have detailed above works FOR ME. Don't forget, we are all different and special in our own way. Please feel free to pull my ideas to bits and debate them.

There are many manufacturers supplying equipment for irrigation but this is the equipment I use:

- **Dansac Irri-drain adhesive (box of 20) Item Code: 950-35**
- **Coloplast Irrigator Bag Item Code: 1511**
- **Colotip Item Code: 1110**

Thanks to Sarah, Shirley and Duncan for their assistance in correcting this. Any errors that remain are mine.

Steve


Graduated water bag, tubing, water clamp, cone tip and sleeve

Why opt for Colostomy Irrigation?

Irrigation can give the colostomate a new sense of freedom and control. In general, irrigation is a safe and effective method for achieving a continent bowel. It is not a technique, which suits everybody, although for colostomates who suffer persistent problems with their colostomy it may be an appropriate option. Patients suitable for irrigation are identified by their stoma care nurse. She/he will discuss irrigation to find out if the patient is happy to try it. If all is well the stoma care nurse will teach them the procedure which should adhered to at all times. Patients who are suitable for irrigation should have a left-sided colostomy either in the descending or sigmoid colon, with an output of formed faeces.

What is Colostomy Irrigation?

Colostomy Irrigation is used to manage faecal output by cleansing the bowel; irrigation does not wash out the entire bowel but clears the lower (distal) colon of faeces - this enables the bowel to perform the function normally performed by the rectum of storing faeces until they are evacuated.

What type of equipment is needed?

Irrigation involves the use of specialist equipment, referred to as Irrigation sets. Sets include a graduated water bag, tubing with regulating clamp, cone tip and sleeve.

The Colostomy Irrigation procedure

A colostomate who regularly irrigates will gain an understanding of their body and overtime will identify the best time of day to irrigate - a time that suits them and fits in with their lifestyle. Organisation at the outset of the irrigation procedure is key to keeping relaxed and in control.

Gather together the items needed prior to irrigating:-

- irrigation set (see pic)
- tissues/wipes
- bowl of warm water
- 1 litre of tepid tap water (36-38°C)
- a non-sterile measuring jug
- stoma pouch or cap
- clothes peg
- disposal bag

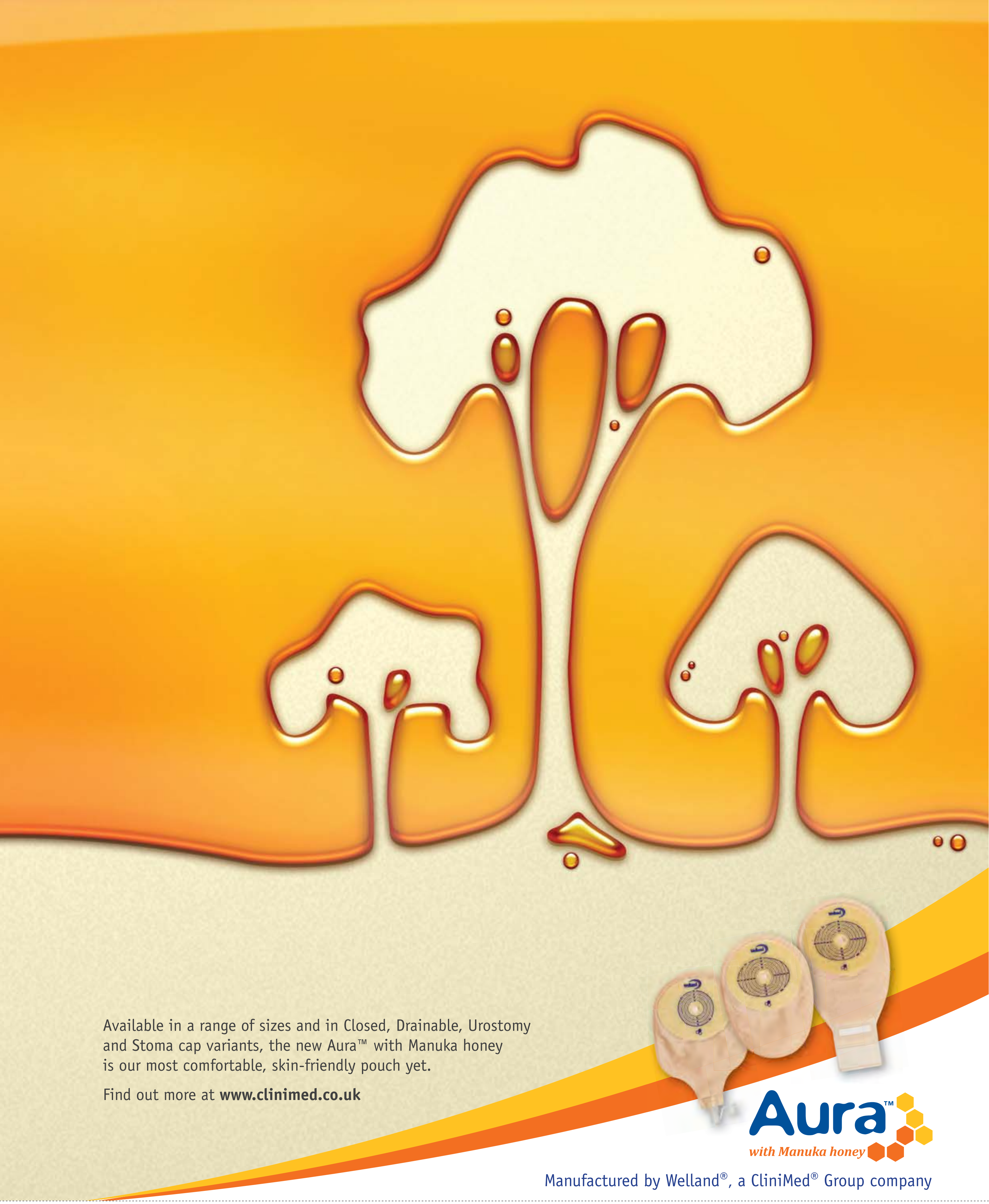
To start the procedure make sure the environment e.g. bathroom/toilet is warm, comfortable and private. Layout your items and wash and dry your hands, ensure everything is within reach. Fill the jug with approx. 500ml tepid tap water 36-38°C (body temperature is 37°C) pour into the graduated water bag. The bag should be hung on a hook preferably behind the toilet bowl, with the base of the bag at shoulder height. When ready remove your clothing and position yourself on the toilet ready to irrigate.

Remove the used stoma pouch/cap and wipe away any excess faeces from the stoma and surrounding skin. Wash the stoma and skin carefully with warm water and gently pat dry.

Allow a little water through the tube via the clamp/flow control to expel air that might be trapped in the tube then close off. Fit the irrigation sleeve over the stoma, place the smallest end between the legs and into the toilet bowl. Lubricate the cone and pass it through the top end opening of the sleeve, then insert the cone gently into the stoma, so that it forms a dam between stoma and cone. Open the clamp/flow control to allow water to run slowly into the bowel (approx 8-15mins). Once the water has been instilled, remove the cone from the stoma, fold over the top of the sleeve and fasten securely with a peg. Wait for around 20mins muscular contractions (peristaltic motion) within the bowel cause the water and stools to flow out of the stoma into the irrigation sleeve then out into the toilet bowl. After the main flush, clean the lower end of the sleeve, fold up, and clip to the top end of the sleeve. After 10mins has passed and no further motion is felt remove the sleeve leaving it hanging over the toilet edge.

Wash the stoma and skin with warm water and gently pat dry. Apply a clean stoma pouch or cap. Clean the irrigation sleeve (if using a reusable one) by holding it over the toilet bowl pouring warm water from the jug into it or add a basin showerhead attachment to a nearby washbasin and use the spray. Hang the irrigation kit up to thoroughly drip dry then store in a cool place. Dispose of the rubbish as normal then wash and dry your hands.

Remember...says Sue... Everyone's body is different and that goes for the colon too! Your body will adapt to irrigation and you will learn what works best for you and your bowel.



I'm Fine...really?!

Sarah writes: Surgery of any kind is a shock to the system, both physically and emotionally and everyone will have their own rate of recovery. We often get asked on the CA Facebook group if it's normal to feel so down 6-8 weeks after a colostomy operation. The simple answer is Yes. By the six week point you may well be feeling much better physically but adjusting emotionally to having a stoma can take some time. How many of you can relate to the title question? I've certainly said, "I'm fine" when actually I've felt pretty damn rubbish. But family and friends have been so good we don't want to worry them further by telling them we are feeling sad because our life has been turned upside down – we feel we should be grateful the stoma has saved our life, or helped our condition. And of course most of us are grateful the stoma has helped our problem, but it is a huge adjustment to come to terms with and it is easy to feel very alone.

The CA and sister charities for ileostomies (IA) and urostomies (UA) offer a huge amount of support, and with it – a community of people who understand 'living with a stoma'.

The CA can put you in touch with a volunteer with similar experiences to you. Talking to someone who has already walked a mile in your shoes can really help! If you have a problem crop up and aren't sure where to turn CA offers its unique 24/7 helpline, manned by trained volunteers, all with experience of 'living with a stoma and colostomy'. The CA 'closed' Facebook group is a safe haven where new ostomates and experienced ostomates can help each other overcome problems, make friends or have a good moan if that will make them feel better! It is often easier to tell people outside your family circle how you really feel. There are many inspirational stories in Tidings. It may be you read them and think you will never get to that point.

I certainly didn't think in the first few weeks that I'd get to a point where I could go on holidays abroad or juggle family life, a full time job AND a stoma. But you will move forward, even if it feels frustratingly slow, after the first few weeks you can hopefully look back and see how you have progressed. The bag change that used to take a good half hour is becoming quicker; getting dressed feels less of a marathon. In the early days you will probably still be feeling very tired always remember to give yourself a break. We all need that even though we feel we must carry on, for the sake of everyone around us. Surgery is an assault on your body and the scars on the outside may not reflect what has gone on inside. Listen to your inner voice and take the time to rest – your body is asking for it – being exhausted can make you feel more down and less able to cope. Time is a great healer.

The six week point is a good time to start being proactive. You may realise that you want to learn more about your stoma and the products you are using. That's a good thing – you are beginning to take ownership of your stoma. You may be happy with the products you are using or you may feel that something is not quite right. You could be experiencing some leakage or the skin around your stoma may look red and feel sore, or your stoma may have reduced in size so your pouch doesn't sit as well as it did. If you have any queries always contact your stoma care nurse – they will be happy to discuss your concerns. Stoma care nurses are busy people as you will remember when you were in hospital but their mantra is – 'please leave a message on our answerphone we will ring you back'.

You could take a look at the many new samples of products with your stoma care nurse and those advertised in Tidings. All of the stoma product manufacturers would be happy to send some samples so take advantage of this to find what works best for you. You may be thinking about colostomy irrigation, or getting back to work. If you've not had a follow up with your stoma care nurse now would be a good time to make an appointment.

Have you read through that pile of literature you were given in hospital? Many of us are so overwhelmed and shocked at the beginning we can't remember much of what the stoma care nurse has told us, and the leaflets were just a bridge too far so they've stayed in the drawer. You may have issues with body image but you aren't alone – most of us look down and think the bag on our side has changed everything. Many people worry about the clothes they wear – will the bag show, will my clothes stop the bag filling? Experiment with your normal clothes but if you are still concerned there are companies that make specialist underwear and swimwear, which might give you that extra bit of confidence to feel better. It's all about getting the best quality of life possible with a stoma and it takes time to adjust to this new norm. You probably didn't want a stoma – I definitely wouldn't have chosen to have one, but now I have it I am determined I am going to have the best life I possibly can.

If you are still feeling low then your GP or stoma care nurse will be able to point you in the right direction for professional support. The support may vary depending on your underlying condition, for example cancer versus a ruptured bowel due do diverticulitis, but your healthcare professional will be able to identify what suits you best. You may be eligible for cognitive behaviour therapy, where problems are identified and strategies developed to help overcome them, or counselling, stress management or even hypnosis. But the main thing is not to suffer alone – the help is out there so speak to someone and find out what is available to you.

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☐ Midi
☐ Maxi

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For extra security use two tapes to surround the base plate.

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Association of Stoma Care Nurses UK

www.ascnuk.com

Formally known as WCET-UK
This is a new national organisation founded in 2013 but remains a charitable trust and continues to work in collaboration with our international association – World Council of Enterostomal Therapists (WCET).

This launch provides an opportunity to raise the profile of stoma care nursing in the UK, which will promote recognition of the organisation by employers, Trusts, patient organisations and individuals with a stoma throughout the UK. The aim of the ASCN UK is to become a stronger force in order to progress and develop the speciality of stoma care. Our outcome would be to enable individuals with a stoma to have access to and be treated by nurses with specialist knowledge, which we believe should be advocated, within the current climate of reduced resources within the NHS. We will continue to work closely with the manufacturers and delivery companies associated with stoma care, in order to offer people with a stoma a choice.

The elected committee and trustees promote the aims of the organisation and encourages new and experienced stoma care nurse specialists to become members.

Members are then supported by;
- Sharing expert clinical practice (both nationally and internationally)
- Promote educational and research opportunities, for example; a national audit to demonstrate the cost effectiveness and value of individuals being regularly reviewed by a specialist stoma care nurse
- Develop and advance the specialist knowledge required to deliver expert care to individuals with a stoma, for example; updating national standards for delivering a consistent stoma care service

Our Annual National Conference will be held on 6-8th October 2013 at Celtic Manor, Newport, Wales. Details of this can be found on our website at www.ascnuk.com

New series...

focus on additional ostomy products

Adhesive removers sprays and wipes...

When we receive our stomas, for whatever reason, it means that we will use an appliance (either a one-piece or a two-piece). The appliance will be placed over the stoma and pressed gently onto your tummy allowing the adhesive to make contact. This area of the body will have reduced exposure to the air, therefore the skin around the stoma, known as peristomal skin, is often very soft and delicate.

Changing a stoma appliance without having a skin care routine in place can be both painful and damaging. An adhesive remover spray/wipe, when used consistently will make the removal of the appliance easier and will help retain your skin's natural integrity. Soap can be used but it can dry the skin so it is generally advisable to avoid using it on peristomal skin, (as colostomates have differing amounts of large bowel, their stomas behave differently and the number of appliance changes needed each day, may vary enormously). Therefore it is very important that adhesive remover sprays/wipes become part of your appliance change routine.

Keeping the skin around the stoma healthy is essential – removing the appliance without an adhesive removal spray/wipe can result in people pulling it too hard, causing skin stripping, pain and increasing potential soreness. Problems such as 'picking' in one area to remove the appliance can result in ulceration of that area.

Top Tip: After changing your appliance check that the slight reddening of the skin, which comes when the bag is first removed, is fading by the time you apply the new appliance. This is just the usual flushing of the skin and not a sign that the skin might be reacting to the adhesive. If the skin stays flushed and red but intact (erythema) for any length of time always consult your stoma care nurse.

There are a number of adhesive remover sprays/wipes on the market and most, once sprayed or wiped gently across the adhesive area, will release the adhesive quickly. Because the skin dries in seconds, a new appliance can be positioned in place almost immediately.

Adhesive removers are alcohol-free, oil or silicone based. It is important to use one that suits your skin type. Take advice from your stoma care nurse. What to look for, when choosing an adhesive remover spray/wipe is one that:-

- Is alcohol-free and skin friendly
- Will dissolve hydrocolloids
- Does not leave a residue of adhesive on the skin
- Does not require a secondary skin cleansing product
- Is easy to use and simple to apply

An adhesive remover spray/wipe that works immediately and takes away any stress that can come when changing a stoma appliance.

It is most important that healthcare professionals recognise that adhesive remover sprays/wipes are just one of a series of important and necessary items required by all ostomy patients and therefore should be readily available and included on their prescriptions.

Seals for Stoma Appliances...

Barrier wafers, rings and seals are used to create a flat surface to seal the area between the stoma and the pouch. A good seal between the wafer (skin protective flexible wafer/barrier joined to the pouch - one-piece appliance), flange (skin protective flexible flange/barrier unit separate with attached pouch - two-piece appliance) and skin is important to prevent leakages. Sometimes this is not possible because the skin around a stoma has dips or creases, crevices and folds in the skin, and even scar tissue. All these can stop the pouch sitting correctly with the stoma causing leakage, which can be very distressing.

Because we need a snug seal around the stoma and the appliance, washers are used to fill in the gaps that make the skin around the stoma uneven. Using a washer means that the output from the stoma will not sit on the skin and cause soreness.

There are many types of washers, which can be adapted to provide protection. Some can be moulded to ensure a snug fit; others can be cut to fit and moulded around the stoma. They are all skin friendly. This product gives us protection from leakage and confidence, security and peace of mind when out and about.

Drops and Odour products...

One of the first questions any new patient who knows they are to receive a stoma will ask is, 'will it smell'. I don't think that very many medical professionals really appreciate the 'huge' importance and weight attached to this question. What is said in response may have a major impact on the patient's adjustment back to good health and wellbeing.

Odour is always of great concern to people with a stoma. Most modern appliances are now odour proof provided they are fitted properly. You should only be aware of odour when emptying or changing your appliance. While there are many products in the supermarket that we can spray in the bathroom after we have changed our pouches – none will actually take away the odour of a changed pouch. Room sprays are not the same as specialist odour reducing products as they do not break down the odour but merely mask the smell for a short time.

Ostomates need to feel confident that there is no odour coming from their pouch. Odour neutralising products, efficient in eliminating odours, available in different forms e.g. gels, drops, tablets and sprays can improve confidence and promote a feeling of wellbeing. Specialist neutralising sprays created with perfumes such as, Fresh Apple, Blackberry and Sandalwood are highly effective. Just a few droplets of odour neutralising liquid placed into the new pouch to eliminate smells whilst emptying the previous one can make all the difference. Additionally, neutralising powder that dissolves over time to absorb fluid in the pouch makes it easier to empty.

Have a discussion with your stoma care nurse about which odour neutraliser would suit your lifestyle. Alternatively, contact the many manufacturers that make these products and request samples to try. If you think odour is excessive, then it would be wise to check with your stoma care nurse.

All these products, available on prescription, give support and confidence to you and fellow ostomates. After all, it's how you feel about yourself and how you manage your stoma that matters! It would be a very dull world if we all drove the same car, lived in the same house and did the same things each day! But with choice comes responsibility – order only what you need, when you need it.

Roadblocks and Assumptions

Mr Nigel A Scott, BSc MD FRCS
Consultant Colorectal Surgeon, Lancashire Teaching Hospitals Trust, Preston
President Association of Coloproctology of Great Britain and Ireland (2011-2012)

Mr. Nigel A Scott, BSc MD FRCS

The ileostomy has been part of the surgical management of intestinal conditions for nearly 100 years. Recently in Cairns I heard Dr Vic Fazio describe how Australian army surgeons (Colonels Albert Coates and 'Weary' Dunlop) used defunctioning ileostomies to save the lives of soldiers with amoebic dysentery in Japanese prisoner of war camps. The stoma appliance was a flattened metal water bottle with an opening placed over the stoma - so the stoma appliance companies have made some progress since then. And talking about history brings us back to Professor Bryan Brooke and the 60th anniversary of his publication of a new technique for constructing an ileostomy (everting or turning the bowel inside out) to reduce ileostomy complications - the Lancet July 19th 1952. As we know his inspired technical advance secured a real leap in quality of life for those with an ileostomy, from 1952 to the present day.

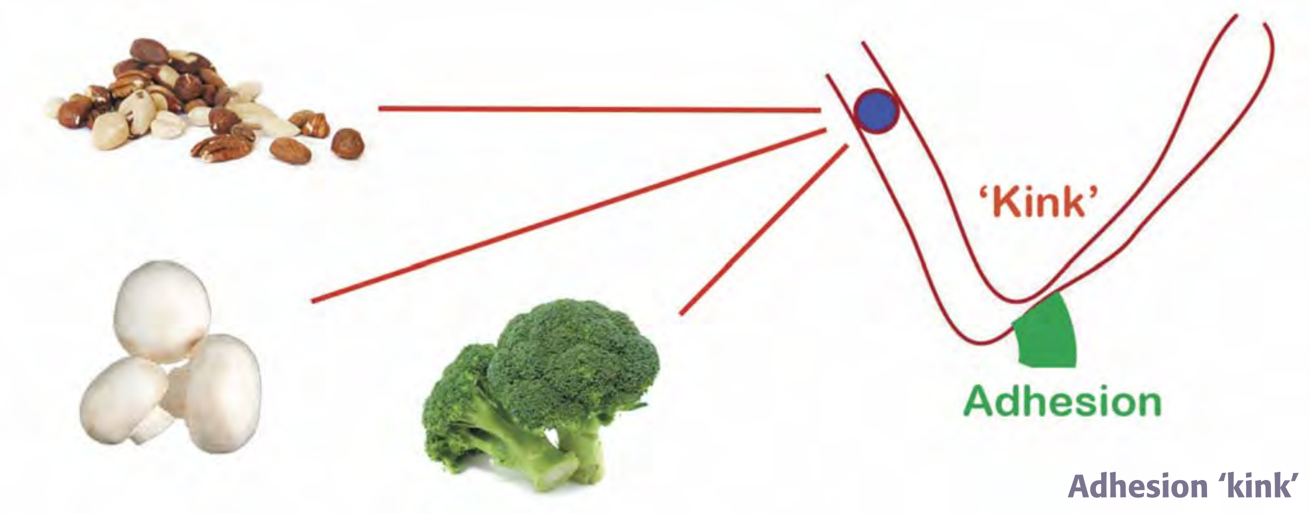
But during all of this surgical development, adhesions have been the constant companion of surgery - causing roadblocks and commonly leading to assumptions- and so this topic. Roadblocks in intestinal surgery are blockages - a not infrequent event in the life of anyone with a stoma. And we blame adhesions for many post-surgical problems, because no matter how big or small an operation on the abdomen, adhesions form afterwards within the peritoneal cavity.

First some anatomy - the peritoneal cavity

Behind the tummy wall muscles, there is a space called the peritoneal cavity. Within this space the small bowel as a 3 metre (10 feet in old money) coiled tube is free to move around. Because the intestine has a slippery peritoneal lining and the peritoneal cavity is also lined by slippery peritoneum, everything slips past everything else. But after an abdominal operation, handling of the bowel and operating on the bowel causes loops of gut to stick to each other and also stick to the lining of the peritoneal cavity. Why the bowel sticks after an operation is not clear, but it seems to be a response to tissue handling and represents some process of healing and scarring. The end result is that inside most abdomens that have had a surgical operation, there are areas of fibrous scarring that hold the normally mobile small bowel stuck to adjacent loops of bowel and the inside of the abdominal cavity.

So adhesions - good thing or bad thing?

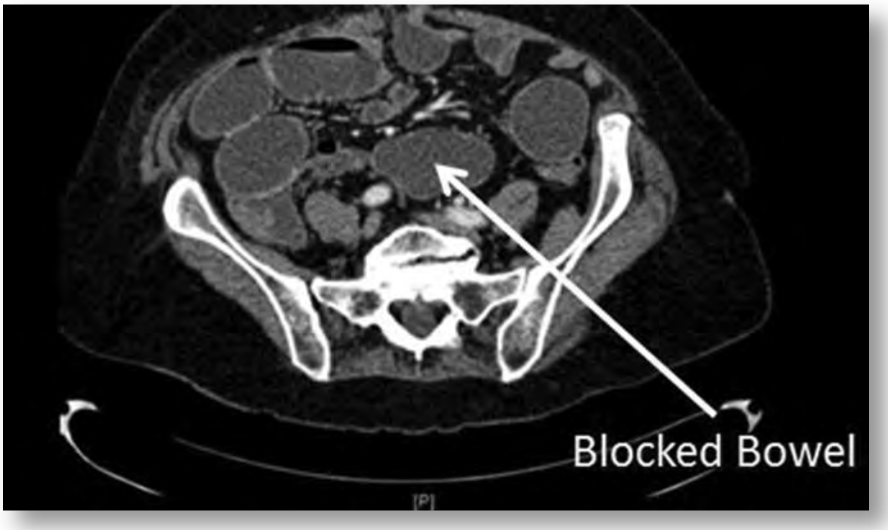
Well we really don't know what adhesions are for. There have been animal experiments where adhesion formation seems to assist the healing of bowel surgery such as when connections or anastomoses are made between two pieces of bowel. But adhesions can be a real nuisance as surgeons have to spend quite a lot of time carefully dividing adhesions to do an operation in someone who has had previous surgery - not to mention the occasions on which we have to look after someone with obstruction caused by adhesions. So adhesions almost certainly have some good biological purpose in the majority of people - but cause significant problems for a minority of surgical patients.



Adhesion 'kink'

Let's look at Roadblocks

The intestine is designed to move food from the mouth along the gut in one direction - out. This is done by peristalsis, the bowel in front of the food relaxes while the bowel behind the food contracts and squeezes the food and the juices onwards. All done under automatic pilot and as long as the gut pipe is reasonably open then all moves forwards and all is well. But adhesions interfere with this process by kinking the bowel tube; instead of a nice smooth mobile tube an adhesion can fix the bowel at an acute angle. Most days food and juices get past the bend, but throw in a bowel of broccoli, an avalanche of almonds or a ménage of mushrooms and oh boy there is going to be a major hold up at that kink; and so we have an obstruction. It is difficult to explain why dietary indiscretions on some days don't cause trouble but on other days they do - but it does seem to be the case that indigestible vegetable fibre increases the risk of adhesion blockage.



As the intestine is a single lane carriageway if it blocks there are no diversions and everything stops. So the stoma stops, the belly swells as gas and fluid cannot go through and get out and there is pain. This is the colic of intestinal contraction trying to force things past the blockage. Finally there is vomiting, as if the intestinal fluid cannot leave the bowel through the stoma then it comes back up as vomit. Now it has to be the case that many, many blockages clear themselves at home and never see a doctor. The real roadblock pros (you know who you are) just restrict themselves to fluids and pain killers and over 12 to 24hrs the blockage shifts and normal service is restored, often with more fluid output than normal in the stoma bag.

But if the roadblock does not spontaneously clear, then a trip up to the hospital is required. The diagnosis of obstruction is made on the plain abdominal X-ray or CT scan and the gut rested by drip (the intravenous fluids for rehydration) and suck (the nasogastric tube to takes off the fluid above the blockage). And again with 24-48hrs of patience the majority of blockages clear and the stoma works and all is well.

However, a minority of patients with adhesion obstruction do not settle and so need an operation. One way we identify who will and who will not settle is to do a gastrografin follow through X-ray. For this you drink a radio-opaque dye and we do X-rays to see if the dye drink will go through the bowel. If the dye doesn't go through the bowel, the blockage has not resolved and then an operation is required to free the bowel by dividing the adhesions.

These operations are very variable from just a simple snip of a single adhesion to hours of painstakingly freeing of the entire small bowel. So all abdominal operations produce intra-abdominal adhesions, but obstruction that will not resolve spontaneously is rare. The lifetime risk is estimated to be about 2% - so 2 out of every 100 people that have had an abdominal operation may require surgery for obstruction at some future date.

Now the assumptions

Even if adhesions don't cause obstructions they must be bad, as adhesions cause abdominal pain – don't they? While this is certainly an assumption commonly made about adhesions, there is no real evidence to back up this view. Because many people with masses of abdominal adhesions never have abdominal pain and further, the surgical division of adhesions does not get rid of abdominal pain. One trial designed to answer the adhesion-pain question looked at the effect of the laparoscopic (telescope inside the tummy) division of adhesions in gynaecology patients with abdominal pain.

Half the patients simply had a telescope examination of the abdomen but the adhesions were left alone and the other half had a telescope inspection and then the adhesions were divided. Nobody - patients or doctors - knew who had what done. Both groups of patients had abdominal pain before the trial and after the trial both groups of patients had the same level of abdominal pain. So in this comparison dividing adhesions gave no obvious relief from abdominal pain.

It seems strange to conclude that adhesions have no role in abdominal pain - given all the attention that pain and adhesions gets on the internet. But let's get down to considering what pain actually is. In the end pain is simply an electrical signal we receive via nerves from a part of the body that is then 'felt' or perceived as pain in our brain. The electrical impulse sent up to the brain is the same no matter what the sensation responsible for the impulse. It is how the signal is processed in the spinal cord and the brain that determines whether or not an impulse is felt as pain, or feels like a touch or even if the impulse is completely ignored by our consciousness. (Remember Agent Smith in the film Matrix - our entire reality is a series of electrical signals reaching and being processed by the brain.)

Stimulation of the gut by acid perfusion of the gullet in some people can cause much more pain than in 'normal' people. This means that in some people the gut can be hypersensitive and send more 'painful' information to the brain than is normal. In other circumstances when we get a lot of pain from the abdomen, it could be that the brain for some reason is looking for trouble and reading normal nerve messages from the gut as pain messages - when all impulses sent are just about routine information.

Brain scans can show different parts of the brain 'lighting up' with activity when the gut is stimulated - but the pattern and degree of brain activity is affected by a person's emotional state. So pain is complicated - what messages are being sent to the brain and how the brain perceives or feels the information - and gut pain is very complicated. Surgeons only have one tool - cutting someone open and looking inside ('to a man with a hammer, everything looks like a nail'.) And when a surgeon is asked to operate just for adhesion-pain, it seems likely that no matter how many adhesions are cut the pain problem will not be resolved. More research in this important area is required.

Cutting holes into the abdomen in order to correct and remove disease is quite a remarkable achievement of mankind - since surgeons began to get the measure of appendicitis in the mid-nineteenth century. However, all abdominal surgery seems to lead to adhesions and within limits the bigger the surgical problem the more adhesions we see - which indicates that adhesions are a healing response for the patient's benefit. True there is a downside and a significant number of people need conservative (bowel rest) management of adhesion obstruction - with a few requiring an invasive operation. But abdominal pain without symptoms of obstruction (absent stoma output, distension and vomiting) not only doesn't mean a roadblock but often leads to an assumption about adhesions causing the pain. This assumption has not been substantiated and we need more research to understand tummy pain in the long term after surgery.

Finally a thank you to the IA for granting me the honour of delivering the 2012 Bryan Brooke lecture. I am especially proud that I could make this presentation at NC12 as both the President of North West Lancashire & Cumbria IA who hosted this meeting and President of the Association of Coloproctology (note the chain). It is the case that the battles and successes of people overcoming disease and moving on, can only come about by the strong partnerships we witness in this meeting; the bringing together of patients, families, specialist nurses, industry and surgeons in a common purpose.

Reproduced courtesy of the IA (The Ileostomy and Internal Pouch Support Group)

Your Travel Checklist...

On top of all the normal precautions...like making sure your travel documents are in order, taking copies of important documents with you in case the originals get lost or stolen...the ostomate needs to remember to:

- Take sufficient supplies for your stay
- Take all supplies and travel stoma kit as hand luggage
- Ask the airline in advance if you need extra hand baggage for your supplies.
- 'Check in' online 24 hours before departure to secure your preferred seat.
- Avoid food and drink the day before you are to travel that are likely to cause upset or excessive wind.
- Take medication to firm up or loosen output.
- Carry your Travel Certificate with you especially when passing through immigration or security areas.
- Take some form of electrolyte replacement solution in case you become dehydrated.
- Drink bottled water in foreign countries, avoid ice in drinks and use bottled or boiled water to clean around your stoma area.
- Store your supplies in a cool place, out of direct sunlight.

CA Booklets, Leaflets and Factsheets are available...

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Monday to Thursday
9am – 5pm and
Friday 9am – 3pm

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cass@colostomyassociation.org.uk

or download from our

Website:
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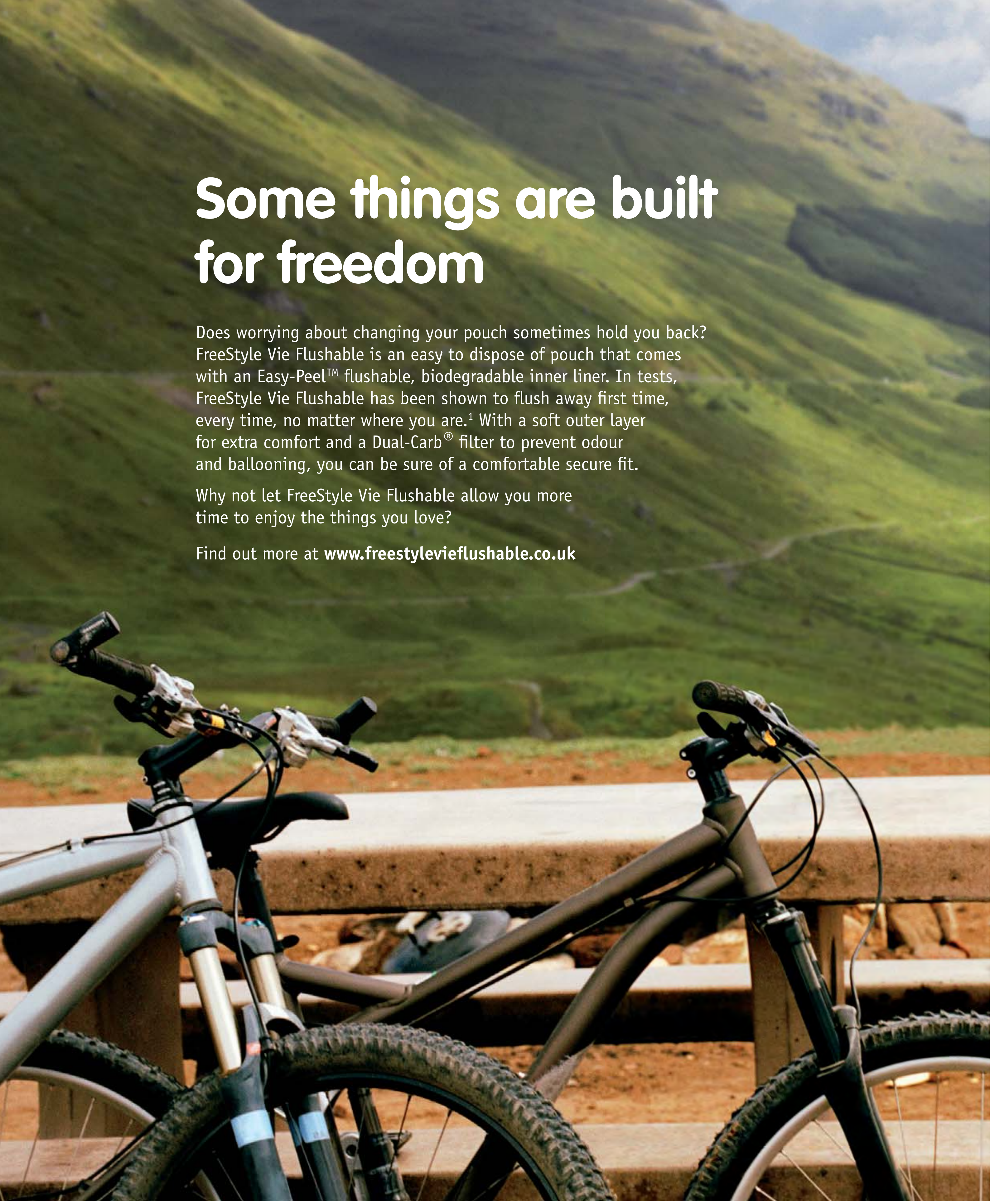
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Breakaway...goes from strength to strength!

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Breakaway offers support to children who have bowel and bladder diversions/ dysfunctions and their families. We offer unique support all over the UK!

Our events include family activity weekend, where you and your child will take part in confidence building adventure activities, meet other families in the same position as you, share your stories and gain comfort and support from knowing that you are not alone. You will also have the opportunity to speak with our professional volunteers about your child in a question and answer sessions.

"Only Kids Allowed"... is what it says! We offer the opportunity for school year 7 and above aged children to have a few nights away from home with Paediatric Nurses, leaving Mum and Dad at home, and having a taste of independent living*. Centre Parcs in Sherwood Forest is this year's venue. **Information Days**...we plan to take Breakaway all over the UK this year, holding short, but fun information days! We aim to bring families together, in a relaxed environment, and show them the work of Breakaway.

For more information on any of our events please contact;
Info@Breakaway-visit.co.uk
www.Breakaway-visits.co.uk
07903220040

Or follow us on facebook
https://www.facebook.com/Breakaway.visits

What our Families Say:
I discovered Breakaway while chatting on a forum for parents of children like mine. I then got in touch with the Founder Julie and haven't looked back! Breakaway has opened so many doors for us as a family.

We were keen to get in touch and be involved with Breakaway as we knew of only a few families online that could relate to what we were going through. At the time (summer 2010) we had 3 children aged 9 months, 3 and 5. The younger two were both born with imperforate anus. The baby had a colostomy and our 3 year old was waiting to have the ACE procedure. We had also not long had the confirmed genetics diagnosis of Currarino Syndrome, which had come down my husband's side of the family. So after multiple surgeries with both children and more ahead of us, Breakaway was a way to meet others face to face and share our experiences and learn and find comfort and support from others in the same boat, so to speak.

Breakaway has in fact done so much more for us than we could have hoped. The children are growing up knowing that although they may be different to their peers, they are not alone and there is always someone we can turn to for things we are unsure about. They have made friends and stay in touch between Breakaway events and although still young, (now 7 months, 3, 6 and 8 years, yes there has been another addition to the Breakaway family!) this will I am sure be a huge help in the future as they become more aware of their condition and the difficulties that they conquer every day. As parents, Breakaway means we are now, never more than a text, call, private message or social media status away from help, comfort and support when the going gets tough or we just want to share a milestone!

The kids love the freedom that breakaway gives them, from everyday problems, a day out with school is far different from a day out with Breakaway. Which in turn makes it a different day for me too, not having to worry about what might happen, how many times we visit the toilets, etc.

Everybody understands and everybody helps and supports each other. It is always a sad day when a breakaway event comes to a close, but we always make new friends and know that we are all only a few clicks away, while waiting until the next one!!!

More importantly we know that we are no longer alone!

Julie Bastin
Founder and Trustee

*to be eligible to attend a Breakaway event which doesn't include parents, you must have attended a Breakaway family event prior to this.

Breakaway...
Putting Smiles on Young Faces...
www.youtube.com
http://www.youtube.com/watch?v=5ga9xtwxXgI

Breakaway May 2013 - Kids' Feedback

Why did you want to come to Breakaway?

- To have fun!
- Because I could have friends with the same problem.
- So my brother can socialise with people like him.
- Because I thought I would make lots of new friends and I did!

What did you enjoy the most?

- Doing activities that I didn't think I could do.
- The snow tubing and toboggans.
- Disco and hide and seek in the dark.
- I enjoyed the tobogganing and the zip wire the most.

Can you write a few sentences about the weekend?

- This is my third time at Breakaway. I really enjoy coming because I no longer feel that I am on my own. I met some great friends that I keep in touch with outside of Breakaway.
- My favourite thing was tobogganing. I also liked the disco especially Gangnam style and the cannons at Beaumanor.

Breakaway May 2013 - Parents' Feedback

How did you find out about Breakaway?

- Through a friend of mine who saw me so upset I couldn't even think of googling for help, she did it for me and came across the Colostomy Association who then signposted me to Breakaway.
- From a stoma nurse originally but a local organisation sponsored us to come.

Why did you want to come to Breakaway?

- To meet other parents and children with the same stomas.
- We came on the weekend to try and meet people in similar circumstances so we didn't feel so isolated.

What did you enjoy the most?

- Being together and sharing our experiences of the activities and social events.
- Everything! Perfectly well balanced.

More information about Breakaway...

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www.breakaway-visits.co.uk

Breakaway NEW events for 2013...
23rd - 26th August 2013 at Woodrow High House, Cherry Lane, Woodrow, Amersham, Bucks HP7 0QG

What's up Doc...diagnosis a problem...?!

Susan writes: In 2008 I had a Deep Vein Thrombosis in my right leg and was prescribed warfarin, later in the same year I went on holiday to Spain, still on medication but with the doctors approval. It was while on holiday that I first had blood in my stools. I thought this was because of the warfarin and didn't mention it to my husband. After returning home there were a few times when it happened again. In fact, it was getting worse. Eventually I went to the doctor and by now I was off the medication. He thought it could just be piles and told me to monitor the problem and go back if it didn't improve. Well, it took a turn for the worse. One day I had terrible diarrhoea and was passing nothing but blood. I was sent to have an endoscopy and a polyp was found in my back passage.

Things moved quickly from then on. Because the polyp couldn't be removed, I then had a colonoscopy and a biopsy, which proved to be sinister. I was sent to see the surgeon who decided to do a more in-depth biopsy which involved staying in overnight. The result was not good, I would have to have a major operation and would have a colostomy bag; my back passage would be removed because of where the tumor was. I started radiotherapy and chemo in January 2009 and had my op in May that year followed by more chemo. It was a long road to recovery, but I got here thanks to a very good surgeon, nurses and my husband. I returned to work the following year and have had the all clear. I still have regular check ups, my bag hasn't stopped me having a life and I've just started irrigation, which is marvelous and totally liberating. I would say to anyone who can irrigate, "give it a go". I've always thought there are people worse off than me and we have to take what life throws at us, I feel lucky to be where I am today!

From Ed:
It would be interesting to ask this GP Practice if they felt they had done their very best for Susan. Was diagnosing piles the very best medical opinion they could have given her? Did the initial diagnosis put her, the patient, first? Or was it simply incompetent?

It is clearly not an easy job to be a GP but 'blood in the stools' is a classic indicator of something: dark, perhaps something serious, bright and fresh, perhaps something less serious. Either way it would have been wiser to investigate further at the outset.


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"My stoma has to live with me; I don't have to live with it"

Christina Hammond, a 61-year old colostomate living in Bristol, had her stoma formed in 1986, following a difficult child birth. She initially had concerns over the operation, as she wondered how the stoma would affect her active lifestyle particularly with her having a new born baby and one other child at the time.

Following a successful operation, Christina quickly found an ostomy product that was right for her, "I was pleased with my pouch", she says. However, she still had concerns that it would limit her lifestyle and achievements, so determined to prove to herself that she could still do anything, Christina signed herself up for a deep-sea-diving course in Thailand and became a qualified diver. "It was great fun and I'm really pleased that I did it. I showed that my stoma doesn't have control over what I can and can't do."

"In February 2012, out of the blue, I was told my product was being discontinued and that I needed to find a new one. I had been using the same pouch for 25 years, so I was distraught. I had found a product that worked for me, it was comfortable and more importantly it worked with my routine. I felt really let down, I felt that the company didn't care", Christina explains.

Christina had an exciting journey coming up, giving her extra motivation to find a reliable replacement pouch quickly. She says, "I was set to travel to Australia in January 2013 for 3 months and wanted to not only find a new pouch, but to be confident with it when I was away, so that I could enjoy myself."

Even with this 12-month window and Christina's proactive attitude, she struggled to find a pouch that worked for her. She contacted different stoma care companies directly for samples, but had little luck. "It was a real challenge. There were so many different products, but I struggled to find one that worked as well for me as my old one did", she says.

"Natura® Plus gives me the confidence to live my life how I want to live it"

Christina was becoming increasingly frustrated, as her stoma started to have an impact on her life like never before. "The difficulty with trying a new pouch is that you have to fit your life around testing it. I started to worry about leaving the house in case I had an issue with the pouch while I was out", she explains. "I had all sorts of issues, like getting the pouch on and off, it not sticking to me properly and problems with the filter. I was also constantly worrying about leakage."

"After months of struggling, I met Sue Peckham from ConvaTec in 2012 through a support group I help to run. She recommended Natura® Plus Mouldable Technology™ and I've never looked back. Natura® Plus helped to ensure I had a fantastic time in Australia.
The pouch even stayed secure when I was splashing about in the sea!", she says.

"If I want to eat a vindaloo then I will"

Christina is relieved not to have to worry about particular problems any more.
She says, "I used to have big issues with pancaking, where the pouch stayed flat and waste couldn't move down the bag, which was incredibly uncomfortable. With a convex product like Natura® Plus there is always air in the pouch so you never experience this issue." She adds, "with some of my old products the baseplate used to come unstuck from my skin, but with Natura® Plus I've never had this problem. I also no longer need an adhesive remover, as Natura® Plus doesn't leave any adhesive deposits on my skin."

Expressing a very positive attitude, Christina says, "for the last 27 years I have lived by this motto: my stoma has to live with me, I don't have to live with it. It's so important to me that I'm able to go about my life as normal; if I want to have a vindaloo curry, then I will! It's just a question of being sensible and not eating it the night before I have a big day out."

Christina runs the Bristol Ostomists Self-Support group to help others that have been in a similar situation. "It's so important to have these support groups as nobody talks about stomas. At our group, ostomates can ask those awkward questions without the embarrassment, as they know that everyone else has been through it too. New ostomates take great comfort from seeing how other ostomates have continued to live normal lives", Christina explains.

Please be advised that the testimonials above reflect only the experience of the user who has provided the testimonial. Results referred to in the testimonial may not be typical and individual results may vary.

If you are experiencing any issue similar to Christina, please contact ConvaTec on the number below and see how we can help you from our extensive range of products suited to individual needs.

ConvaTec MOULDABLE technology™

Experience the confidence.
To learn more, call 0800 282 254,
ROI 1800 721 721 or email us on
stoma.webcare@convatec.com

AP-013598-GB
April 2013

A Reader's Reply… about Travel

Following Bob Adamson's article and his "Travel Tips for Ostomates" in the last issue of Tidings, John Bradley wrote to tell us about his experience.

I had my stoma in November 2010 after being housebound for ten months. In that time I had to give up my job as a hod carrier and cancel a holiday in Tunisia. When I was fit to work I was lucky enough to get a job as a domestic at the same hospital as I had my surgery. In 2011 I went on holiday with my wife, daughter, son-in-law and our two fantastic grandchildren for a week in Scarborough. We had a fab time although I was still getting used to having a bag.

I asked people I have met at my local stoma meeting about going abroad, as some of them go all over the world, without problems. My wife and I decided to go abroad this year. We got our holiday dates from work and went to our local travel agent and booked to go to Tunisia. We had a five week wait before we flew out so I started asking my stoma nurses and friends about what I should be taking away with me. I ordered extra pouches, flanges, wipes and sprays. I phoned around for insurance and got a good deal with the Co-op at no extra cost and took a travel certificate with me just in case I got stopped at the airport. As the holiday got closer I was becoming quite concerned as people were telling me about getting an upset stomach and problems with the heat etc.

The flight was at 6am on the 8 July 2012. I went through security OK and had all of my stoma things in my hand luggage, no questions asked. I wore a shield over my bag to protect it from the seatbelt on the plane. There were no problems during the flight. I went to the toilet once; it was a bit tight but I managed OK. That was the first obstacle out of the way!

Next was the heat. We stepped off the plane to 20° at 9:30am and all I was thinking was, will my pouch fall off? As the day wore on, the temperature was over 40° with the highest day being 51° and still my pouch did not budge. That was obstacle number 2 out of the way!

Next was the food and upset stomach. The food was really nice and I ate nearly everything – tomatoes, sweetcorn and rice, all of the things I normally stay clear of at home. I even drank fizzy pop! That was the final obstacle out of the way!

All the worries I had about the pouch coming off with the high humidity or while I was in the sea or the swimming pool were unnecessary, same with the flight and the food! So nearly two years after we had to cancel our holiday, we went and had a fantastic ten day break. So if you think you can't go on a foreign holiday, please don't be put off as there is a lot of help and advice out there.
Having a stoma has given me my normal life back. You can overcome all of your obstacles with confidence and positive thinking.

John Bradley

Are you going abroad this summer?

Do you have your travel certificate?

colostomy association

Travel Certificate
for people with
a colostomy

Freephone helpline
0800 328 4257

www.colostomyassociation.org.uk

The CA produces a travel certificate which can be shown to security staff at airports etc. to prove that you have a stoma. It explains what a stoma is, that you will be carrying spare appliances in your hand luggage, and that if a body search is necessary it will have to be carried out in private.

This information appears in French, German, Italian, Spanish, Portuguese, Greek, Turkish, Croatian, Polish, Russian, Arabic, Mandarin. Hindi, Thai and Vietnamese.

When you are going through security at the airport, it is best to have the certificate in your hand, not in your suitcase or bag which will be on the conveyor belt! If you are at a foreign airport it is also a good idea to have the certificate folded open at the translation into the local language.

The certificate can be obtained FREE by telephoning CA on 0118 9391537 Make sure you request it well in advance of your holiday as it needs your GP's signature and the practice stamp. Some people have found that when they asked the GP to sign and stamp it during a routine appointment they weren't charged for this service.

Lift Plus Citrus now available

Gentle
adhesive removal

Lift Plus non-sting adhesive remover reduces the pain associated with the removal of pouches and flanges, drying quickly with no washing required. The wipes also contain aloe vera to promote healthy skin.

Lift Plus Citrus contains a fresh citrus scent for added discretion.

Available on prescription as a handy spray or disposable wipe.

For a free sample and further information on our range of stoma care products please get in touch: **0800 458 7605 www.opus-healthcare.co.uk**

Job bag: AL/1376/10.12/0.001 Date of prep: Mar 2013

Opus healthcare
A Division of Alliance Pharmaceuticals Ltd

Dear Nurse

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

Q: *I read with interest, the letter to nurse Julie in the spring edition of Tidings, regarding anal discharge being a dark colour. I have had this for the 4 years since I had the Hartmann's procedure and was told it would clear up in time, which is not the case. I cannot get to the cause of this, having seen my stoma nurse who suggested it was an infection, so doctor prescribed antibiotics, which hasn't helped. I asked at the 6 monthly review clinic I attend and the doctor shrugged his shoulders and said I could extend my reviews to yearly as I was doing so well. I then contacted the surgeon, who organised a CT scan, this being two months ago, and I have no feedback yet. I was wondering if any of the readers have this problem. There is no join (anastomosis) in the bowel as far as I am aware so cannot understand this.*

A: Discharge from the remaining rectal stump left following a Hartmann's Procedure is due to mucous production. This is a normal function of the bowel, with mucous acting as a lubricant to allow the stool to travel smoothly through the bowel. When the output is diverted out through a stoma, as in a Hartmann's procedure, the mucous is still produced by the redundant bowel. This mucous may be passed regularly out through the anus or it may collect over a few days before being passed. Patients usually describe a feeling of needing to pass a stool through the anus and if they sit on the toilet and push slightly a mucous discharge or plug may be passed. If patients struggle to pass this discharge and the feeling of fullness is uncomfortable a Glycerine Suppository can be prescribed by the GP. I hope this helps to explain why a discharge may be present even when there is no anastomosis (join) in the bowel.

Julie Rust became Tidings Nurse in December 2004. She has answered readers' letters and e-mails in every issue which has been published since then. We look forward to many more years of publishing her very sound advice.

Your medical questions about stoma care management are always welcome and important to us.

Questions received by the Editor or CA are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma Care to review and answer. Answers are published in the next issue of Tidings.

Q: *I had a colostomy about 10 years ago and I'm glad to say that the top end has worked very well. I enjoy playing squash and fell walking so the operation itself has had little effect on my lifestyle.*

Following the operation, an abscess formed somewhere near the top of my rectal stump and eventually this started draining through a fistula that discharges quite close to my anus. I understand that an abscess happens in about 5% of colostomy procedures.

I manage the discharge with non-sterile dressings changed 2 or 3 times a day and this again has little/no impact on my lifestyle.

I am a little anxious however about the existence of the abscess, whether it's growing in size, whether it might "burst" and whether there might be some new treatment that has evolved over the last few years that might deal with it.

Or should I just stop worrying about it! I'd welcome your advice.

A: It is possible to assess the size of the abscess and therefore its progress with the use of scans. You do not state if you are reviewed regularly by the consultant but from your letter I presume not. If you are concerned or you want to look at the options for treatment you may have with regard to your abscess I would ask your GP for advice or for them to refer you to the hospital for a review. I hope this helps to ease any concerns you may have.

Q: *I have had a urostomy for some time; recently I have had to have a colostomy. I am in quite a lot of pain and have very little appetite. If I eat fruit or vegetables I just get diarrhoea – I often feel sick. Can you help?*

A: You do not state why or when the stoma was fashioned and without all your medical information it is difficult to answer the question. I would however suggest that with the symptoms you are describing it might be worth a review by your GP or Consultant. Immediately following surgery a little discomfort and a reduced appetite post operatively is normal, however this should settle over a period of time. You do not state if you are having issues with the pouch holding in place or not but if you are it may also be worth asking your stoma care nurse for a review.

I'm sorry I can't be of more help but a full medical review will be needed to sort this out.

Q: *My Dad is thinking about having a colostomy to treat fecal incontinence, which is affecting him very badly. He just can't face going out at all no matter how much I coax and encourage. My question is this – would a colostomy help him?*

A: This is a very big decision for your dad and there are many options to treat faecal incontinence, including stoma formation. I would suggest you ask your dad to contact his GP and request a referral to a Consultant Colorectal surgeon who has a specialist interest in treating people with this condition. He really requires investigating to obtain a full medical history and to ascertain the actual cause of the problem, which will then dictate the treatment that is best, suited for him. It may be there is an alternative treatment such as Biofeedback, Sacral Nerve Stimulation, Percutaneous Nerve Stimulation or Rectal Irrigation, which may help. This is obviously only suitable for certain patients and conditions and your dad may or may not be a potential candidate for these options. A review by a specialist will help to clarify the possibilities.

Q: *I have had my colostomy quite a while and it has helped me live a better quality of life. However I have noticed a change in the skin that surrounds my stoma it looks different, drier and a bit lumpy in places. The skin in these areas tends to bleed a little as well. What could be causing this change – everything has been fine – up until now?*

A: These changes could be due to several things such as a change in your skin integrity, damage due to the type of pouch you are using or a change in size of the stoma requiring a template change. I would suggest a review by your local Stoma Care Nurse to assess the cause and to prescribe the relevant treatment. Hopefully this will be a simple solution and you will go back to enjoying a full and active lifestyle again.

Q: *I returned home from hospital having only changed my bag once myself under supervision. My stoma care nurse had marked up my flanges with a pen as to where I should cut them but I'm just not sure about it at all! I tried to do one and made a complete hash of it – I think! Are there any guidelines available? Or could you give me a few tip – many thanks. I feel like a complete novice.*

A: It is important to assess the size of your stoma and therefore the necessary template size on a regular basis to ensure the pouch is fitting correctly at all times. It is recommended that there is a 1mm gap between the stoma and the pouch but as a new ostomate this is often difficult to assess yourself.

Did your stoma care nurse give you a template to draw around on the pouch, which would be the correct size when you left hospital? Hopefully they did, you will be able to draw around this template to guide you when you are cutting the pouch. If you are finding it difficult maybe your relatives could help to cut a few at a time for you to use. If this is not possible then you may be able to get them pre cut by the delivery company if you use one. This is not ideal as a stoma will change shape and size quickly in the early days but it is possible. The stoma care team will review you regularly in the early days following stoma formation and therefore they can assess the size of the stoma for you and change the template accordingly. Once the stoma has settled you will be able to have your pouches pre cut so you will not need to cut them yourself.

Q: *I had my colostomy in February this year and have been advised to eat low fibre foods. I have heard of high fibre but not low fibre. Could you tell me a little more please? Here's hoping!*

A: With a colostomy you can eat a normal healthy diet although we do suggest that you are careful with high fibre foods in the early days. You do not state if you were given specific dietary advice for any other reason but if you were then you need to follow the advice, possibly asking for clarification from the person who suggested a low fibre diet. It may be that you could be referred to a dietician as well if needed.

Q: *I had my colostomy in February this year and have been advised to eat low fibre foods. I have heard of high fibre but not low fibre. Could you tell me a little more please? Here's hoping!*

A: With a colostomy you can eat a normal healthy diet although we do suggest that you are careful with high fibre foods in the early days. You do not state if you were given specific dietary advice for any other reason but if you were then you need to follow the advice, possibly asking for clarification from the person who suggested a low fibre diet. It may be that you could be referred to a dietician as well if needed.

Q: *I had a Hartmann's procedure six months ago – I'm so unhappy and fed up as my bags keep splitting and bursting. My skin around my stoma is so sore – what should I do? Would I be better using a two-piece product?*

A: There are many reason why you can get leaks from a stoma pouch, such as 'pancaking' where the faeces do not drop into the pouch but sits at the top or the stoma changing size, requiring a change in the template size. Once pouches start to leak they can cause skin soreness, which then prevents the pouch sticking again, leading to further problems. A review by your nurse will be able to help identify the cause and therefore be able to advise regarding the solution and provide you with advice as to product usage and/or accessory products. I hope this helps.

Q: *I'm due to return to work shortly – I had my colostomy due to cancer. I am very apprehensive about returning to my workplace. I don't know how I will cope. Do you come across other patients who feel the same way? Could you suggest any helpful hints that would put me at ease? If so it would be much appreciated!*

A: Many patients feel very apprehensive when it the time comes to return to work following a cancer diagnosis, surgery and a stoma formation. You do not say what job you do but some employers, especially if the job is a heavy, will allow staff to return to work on a phased return. This may be a possibility for you but you would need to speak to the Occupational Health team at your place of work. You can also speak to other ostomates via the Colostomy Association who will be able to chat to you about how they felt and managed their concerns with regard to their return to work. There is no reason why you should not be able to return to work and lead a full and active lifestyle with a stoma. What you are experiencing are normal feelings and talking to people about it and getting support from your employers should be of help to you. Good luck and do write in to Tidings to let us know how you get on.

Q: *I had my colostomy due to Crohn's Disease, which caused abscesses and fistulas. When I chatted to my surgeon he suggested I go for a permanent colostomy and mentioned 'colostomy irrigation' as an alternative method of* *bowel management. This seemed very interesting to me however when I mentioned it to my stoma care nurse she said that it was highly unlikely – had I known this at the outset I would have opted for a temporary colostomy – I wonder if you could explain why my stoma care nurse reacted in such a way. Is there more to it than I understand?*

A: Colostomy Irrigation is a method of controlling when the action from the stoma occurs. It involves using an irrigation set (water reservoir bag, soft rubber cone, clear tubing, water regulator, sleeve, ostomy belt and clips), the water reservoir bag is hung at shoulder height, gravity pushes the water down the tubing, the flow is monitored by the regulator, water enters the stoma via a cone, which is inserted gently into the stomal opening. Once the allotted water is inserted the cone is removed from the stoma and the water and the bowel contents are expelled into the toilet via the sleeve. Colostomy Irrigation is usually performed daily to start with but many people are able to change this to alternate days. Your stoma care nurse may be reluctant to undertake irrigation if you have active Crohn's disease as this could cause problems with the Crohn's causing it to flare up. You may be able to use something called a Plug, which is a method of controlling the output. It involves inserting the plug into the stomal orifice and leaving it in place for up to 12 hours. You do need to do this under the guidance of your stoma care nurse who will advise as to suitability and also on how to gradually increase the length of time the plug is left in place, as it needs to be introduced slowly. The plug is worn for 12 hours and a pouch is worn for the remainder of the 24 hour period, usually at night. This enables you to prevent the bowel activating during the day but allows it to work at night. The plug is not suitable for everyone and again you need to speak to your stoma care nurse who knows your individual circumstances.

Q: *I am in my early 40's and have been told I will require a colostomy. I have read so much information – I'm really undecided. What should I do next?*

A: It would be of great value to go and meet with your stoma care nurse prior to your surgery to discuss in depth the surgery and resulting stoma formation. She will be able to use a variety of methods, books, imitation stomas, pouches, videos and diagrams, to explain the surgery and resulting stoma and also prepare you for life with a stoma by training you to change a stoma bag before surgery. She will also be able to identify suitable websites for you to access and introduce you to people who have already undergone the surgery. This can be extremely useful as, although they will not be able to answer the medical questions which are for the consultant and stoma care nurse, they will be able to talk to you from a patients perspective which is very important. I do this with my patients and they report it to have been extremely useful in helping them to fully understand what and why things are happening. I hope you find this helpful.

Q: *I am 86 years old and had my colostomy in September 2009. I have managed quite well and have dealt with the obvious problems. However about a year ago I developed a parastomal hernia (about the size of an orange but it has grown rapidly and is now approx. 9" in diameter). It gives me no pain, and little discomfort and I can cope with its appearance. However, I now have to wear a support garment, which is quite uncomfortable – I can't help wondering if I am wearing it correctly. Any advice or help would be greatly received. Many thanks.*

A: You do not say if you were measured for your support garment or if it was one you obtained yourself. A properly measured, correctly fitting abdominal support should improve things for you. If you were not measured for the support I would suggest you contact your local stoma care nurse who will be able to arrange this for you. If you were measured for the support but still find it uncomfortable I would suggest you contact the company or department who measured you for it to arrange for a review and a further demonstration on how to wear it correctly. I hope this helps and you are able to wear the support in the future to reduce the discomfort you are getting.

What kind of stoma do you have?

When food leaves the stomach it enters the small intestine, a long coiled tube about twenty feet long. The last part of the small intestine is called the ileum. If the ileum is brought out through the abdomen to form a stoma (ostomy), this is called an **ileostomy.**

Five facts about an ileostomy

- The name comes from combining the words ileum and ostomy.
- It allows faeces to leave the body without passing through the large intestine (colon).
- It is usually on the right hand side.
- The output tends to be fairly liquid – the consistency of porridge or thick soup.
- A drainable bag is used and emptied four or five times a day.

Normally digested food passes from the small intestine directly into the large intestine or colon. If the colon is brought out through the abdomen to form a stoma (ostomy) this is called a **colostomy.**

Five facts about a colostomy

- The name comes from combining the words colon and ostomy.
- It allows faeces to leave the body without passing through the anus.
- It is usually on the left hand side.
- The output tends to be formed and firm.
- A closed bag is used and changed as necessary.

The above applies in most cases, but there can be exceptions For example, sometimes it may be easier for a surgeon to create a colostomy on the right hand side. The output from some colostomies may be fairly liquid particularly if only a small amount of colon remains. Therefore some colostomates may prefer to use a drainable bag.

Editors Comment

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

If so write in and tell us:

The Editor
Colostomy Association
Enterprise House
95 London Street
Reading RG1 4QA

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


FREE delivery
24/7 advice
Phil
Nurse visits*
Charitable donations
FREEPHONE orders
All makes and brands supplied

CA ‘Closed’ FACEBOOK Group...

Nicola...a case history

Hi everyone, my name is Nicola. I have a colostomy. I was given a bag seven months ago as a result of bowel cancer. The surgeon had told me prior to my operation that I might have to have a bag as a result of the operation he and his team were going to perform to remove the cancer. And he was right. He also said that I might be able to have a reversal, so fingers crossed.

I had chemo after my operation and found that caused my output to be very loose, I had a lot of trouble with leaks and then soreness around my stoma – I found it was impossible to get a bag to stay on for very long. My skin was red and very sore. I tried to contact my stoma care nurse but found it was very difficult to get hold of her or anyone in the department. They never seemed to be there and they never returned my calls. Eventually I did get through and got an appointment and was given something for my skin – some sort of cream. It helped a little but when I applied it to my skin it never seemed to be completely absorbed. Certainly not enough to leave my skin dry, ready for my next bag. So with the bag not sticking on properly, I ended up with more leakage and my skin not healing properly.

In desperation one evening, I went onto the Internet and came across the Colostomy Association. I noticed they had a ‘Closed’ Facebook Group. I found it and asked to join. That was at 8pm. I was accepted and received a warm welcome. I told them what the problem was and within an hour I had a huge list of remedies that other people had tried and that worked for dealing with sore skin. It was incredible to realise that there were others out there who understood and who had been and were going through the same thing!

I couldn’t go out to the shops at that time of night but did have some Calamine lotion in the cupboard left over from when my son had some terrible midge bites and so I thought I’d try this. Someone had recommended it. You put on a layer of Calamine lotion and let it dry. Then you apply further layers until you have sealed the skin. The fact that the Calamine lotion sets means you can get a bag to stick to it. I got a bag to stick on for 8 hours doing this, before this I was only getting a few hours. The group members also said to make sure that the hole for the stoma was cut correctly around the stoma leaving a 1mm gap so as not to restrict it but enough to reduce leakage. The holes that I had been cutting were a bit too big. Someone also said I could ask the supply company to cut the holes for me, all part of the service apparently. By the end of a week my skin had started to calm down. I kept going with the Calamine lotion. Actually I ran out and had to buy another bottle.

Now thanks to my Facebook friends, I have been able to get the attention of the stoma nurse - they encouraged me to write a letter - and I have some very handy remedies for sore skin. I am not sure I’d ever try the one where you put egg white on the skin but someone swears by it! My supply company are cutting holes in the flanges to the correct size, the size that my stoma care nurse measured me when I went to see her last week. I still hate the look of my stoma but I am beginning to get the hang of it and the leaks have reduced. This is partly due to the fact that my chemo has finished and so I am not nearly as loose as I was.

> “Now thanks to my Facebook friends, I have been able to get the attention of the stoma care nurse - they encouraged me to write a letter - and I have some very handy remedies for sore skin”.

I have an appointment with the surgeon in two months to discuss reversal. I wonder what he will say. The CA Facebook group have given me quite an insight into ‘living with a stoma and colostomy’, and reversal. Several group members have been reversed. For some it is a success, for others, where they have to visit the lavatory many times a day and take a lot of Imodium it’s not so great. I will take the advice of the surgeon, see what she has to say.

Many thanks to the CA Facebook Group. They are a great bunch. I have made many new friends - they’re always there when you need them - and I am looking forward to the next group meeting to get to know some of them in person!

Joining the group is easy... put Colostomy Association into your Facebook search bar, click on Group and click on ‘Ask to join’ where you will be met with a very warm welcome!

Readers' writes

We want to hear from you...learn about your experiences, understand your concerns, read your hints and tips...so write, email or phone the Editor today!

Dear Editor

I was wondering if you would have any advice for me. I am a former colostomate and receive your magazine which is really interesting reading and I am really amazed at the courage of some of the people. I will detail my history below.

In January 2010 I had back surgery four days later unfortunately I had a perforated colon and peritonitis and was apparently very seriously ill, this resulted in me having a Hartmann's procedure, as you can imagine a huge shock to the system, after which I was in hospital for six weeks. My recovery was very slow and I had three procedures to re-fashion the colostomy as it was not functioning correctly, I understand that because the operation was done so quickly as an emergency there was no time to mark out a proper site etc. Eventually in November 2010 I had a reversal, which thankfully was successful with the exception of an abscess that formed on the site on Christmas Eve 2010 and had to be excised.

All was going reasonably smoothly after that but I then developed four massive hernias which eventually were operated on in May 2011 resulting in a mesh being inserted over the whole of my abdomen.

Although being successful in restraining the hernias from re-appearing this is extremely uncomfortable most of the time and over the last six months I have had steroid and anaesthetic injections to try and relieve the pain, which has helped.

That being my recent medical history in connection with my colon I cannot say that I feel 100% due to the fact that I still have diverticulitis, I am still suffering flare ups with diarrhoea on many occasions, at the moment these seem to be in the middle of the night, which is causing sleep disturbance therefore making me feel really tired the next day. I still suffer from left sided lower abdomen pain on quite a few occasions.

I was discharged some months ago from the gastroenterology department and was wondering whether I should be re-referred or maybe speak to the stoma care nurses who are really well informed, or if you have any words of wisdom for me. I have been on a dairy free diet now for about a year and only have milk occasionally in tea and have found this helps. I cannot really get to the bottom of why these flare ups occur, it could be if I have eaten too much, or it might be if I have hardly eaten, nothing seems to make sense. I wonder if I just have to put up with it and get on with it. My surgeon did say at one time if things got really unbearable that he would be prepared to give me a permanent colostomy, but quite honestly things really are not that bad, just a nuisance.

Since my operations and all the problems following I have lost a lot of my confidence and I am always worried about going out should I need a toilet quickly and panic if I have to go anyway that I do not know, I am gradually overcoming this, but it is a real problem.

Yours in anticipation,

J.S

Dear Editor

I was delighted to read in the Spring edition of Tidings magazine ('Len's Story') that the bowel cancer screening test worked for him but I think it's important to point out that this test does not always work. I have heard of many people having false positive results but I think I may be in the minority as I received a false negative result and shortly afterwards (after a minimal amount of bleeding which I could easily have dismissed as piles) I was told that I had bowel cancer. I am now left with a permanent colostomy and feel very let down by the screening process. My advice would be by all means take the test if you wish but also take the results with a pinch of salt.

Best regards,

I.L

Dear Editor

Having just received the spring issue of Tidings I must advise that I have recently undergone a successful colostomy reversal and as such no longer have a need to receive the quarterly magazine. However I would like to thank you and the team for your dedication in supporting colostomates, and to let you know I found the magazine not only informative, but of a great comfort when reading the stories therein and realising that I was not alone in the wide range of mixed emotions resulting from having a bag.

I don't know if my experience would be of any worth to other people but just in case here it is...

Following emergency surgery for a blocked bowel (caused by bowel

Readers' writes

cancer) four years ago I underwent an attempted colostomy reversal of a Hartmann's procedure at Scunthorpe thirty months ago, but this was aborted because of a large amount of scar tissue around the original operation site. When I was coming round in the recovery room, one of the theatre team doctors suggested the surgeon had been keen to proceed but the rest of the team had dissuaded her from going ahead because of the risks associated with the scar tissue.

For the next two years I was constantly told in hospital follow- up visits and by my GP that there was no possibility of reversal, however this niggling doubt had been put in my mind by the comments made in the recovery room and eventually I asked for a second opinion. I was referred to Hull Castle Hill hospital and within six weeks I had seen the consultant there (Miss O'Grady) who, after reviewing my file, said she could see no reason why not to try again. Within a further six weeks I had my surgery, this time undergoing a successful reversal, being fully reconnected. Six weeks later I was back at work and have to say that (touch wood) I am delighted with the result.The down side is I don't have a great deal of rectum left which means I don't have a lot of storage space and need to visit the toilet around 4 to 6 times a day, but I have good control and mostly can hold it and go when it's convenient (forgive the pun) for me rather than as a matter of urgency. I don't know if any other of your readers have had a similar experience to me, and have not pushed for a second opinion. However in my case asking for a second opinion has been a major turning point in my life.

With best regards,
M.B

Dear Editor

I have been a member of the Colostomy Association for the last few years and I have sent a donation ever since to support this great association and another donation is on it's way!

I have wanted to send an email to you to say I think the 'Tidings Magazine' is fantastic!! I have a had a Colostomy for three and a half years and a Urostomy for five years and both are permanent and both carried out in emergency circumstances hat has left me traumatised. I have Short Bowel Syndrome with my colostomy and everyday is a challenge and the large amounts of medications to take to control this on a daily basis.

I am a very private person and have a great network of support from my loving, family, friends and a great Stoma Care Nurse. My heart goes out to all the courageous people who write their stories and one day I hope to share my experiences with you and the magazine.

I have found it very, very hard coming to terms with both my 'Little Friends' but to read the stories in the 'Tidings Magazine' is an 'Inspiration!' People cope in so many different ways.

Thanks once again for this great and inspirational magazine and for taking the time to read my email.

Kind Regards,

T.W

From Ed:

Thank you for your kind words which I have shared with the Editorial team. From everyone involved with Tidings we encourage you to share your story as Paul says on page 19 – 'if this helps one person I'll be a very happy man'.

Before acting on suggestions from other ostomates you are advised to check with a doctor or stoma care nurse that this course of action is suitable for you.

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

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

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:
The Editor
Colostomy Association
Enterprise House
95 London Street
Reading RG1 4QA

Readers'
PANEL
contributor

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

Colostomy Association Patient Open Day Event in Reading on Saturday 20th July 2013

Come along and enjoy the Colostomy Association Patient Open Day Event in Reading on Saturday 20th July 2013 – meet your President and Trustees, the Office Team and Fellow ostomates…help CA to make this event a great success – one to remember!

Building on the previous Colostomy Association Patient Open Days in Swansea, Gaydon, Warwickshire and Leeds. The Colostomy Association is delighted to announce that this year's Open Day event will take place at the Royal Berkshire Conference Centre, Madejski Stadium Complex, Reading, Berkshire RG2 0FL on Saturday 20th July 2013. (http://www.rbcc.org.uk/location.php).

The event will introduce attendees to the work of the charity – the changing face of stoma care and the innovative world of stoma care appliances and additional products. The focus – reaching out, building awareness and moving the Colostomy Association forward.

Ultimately, attendees will take away much by attending this information driven event. Improved knowledge of their stoma and its care, a greater awareness of stoma care appliances and additional products plus an increase in confidence and a sense of belonging to a charity which encourages, supports and reassures – people 'living with a stoma and colostomy'. Stoma care companies and suppliers already signed up to exhibit include AAH Pharmaceuticals (Medi), AmCare, B.Braun, Bullens Healthcare, ConvaTec, Fittleworth, iMedicare, OstoMart, Opus/Alliance Healthcare, Pelican Healthcare, Suportx and Wilkinson Healthcare. Presentations on the day will reflect the positives and practical issues associated with 'living with a stoma and colostomy'.

The Colostomy Association will be inviting VIP guests, sister charities – the IA, UA and Breakaway – as well as other local support groups.

The event will open at 9.30 am, giving time for registration – tea/coffee and biscuits in Windsor Lounge (Exhibition area). The presentations will take place in the Princess Suite. There will be one break - for comfort during the morning and then lunch (on a first come first served basis) – attendees will be encouraged to view manufacturers and suppliers stands, attend workshops and SCN/Patient One to One's in the afternoon – an appointment system will be in place on a first come first serve basis.

Book Today!: Please email your name, contact details and how many people will be attending to cass@colostomyassociation.org.uk or contact Susan Hale General Manager on: 0118 939 1537

What you can expect…
Brief Outline of Agenda*...

Registration: From 9:30am
(Includes Tea/Coffee/Biscuits)

- Exhibitors stands will be available throughout the event – all refreshments will be served in the Windsor Lounge (Exhibition Area) on a first come first served basis.

Morning: 10.30 – Welcome
- Introduction
- About the CA raising awareness
- Patient story
- Stoma Care Overview
- Awards Ceremony

Lunch: 12.45pm – 1.30pm

Open session: from 1.30pm onwards

Exhibition Area
- Exhibitors stands

Patient One to One appointments
- Stoma care nurses available for attendees to chat with. CA Specialist Discussion/Workshop topics
- Irrigation
- Exercise and well-being
- Insurance and travel
- Parastomal Hernia Workshop

Close: 4:00pm

* Agenda may be subject to change

Accommodation: A hotel is on site if accommodation is required – The Madejski Millennium Hotel – Reading Football Club – Stadium Complex. Reduced rates are offered for Friday 19th July and Saturday 20th July – Double room/single occupancy/B&B = £55.00 + VAT. Double room/double occupancy/B&B = £65.00+ VAT. Please quote Col: 190713. Contact the Hotel Reservations Team on: 0118 925 3817. (Note: Cancellation of room/s must be before 2pm on Friday 19th July/ Saturday 20th July 2013).

By Car: Sat Nav Postal Code - RG2 0FL From M4 Junction 11, take the A33 to Reading through the traffic lights. Straight ahead at the mini roundabout, at the second roundabout turn left, at the next round about and take the second turning up the hill towards the stadium. Follow the road around the stadium over the two mini roundabouts and pass the hotel entrance on your right. Car parking is available in the blue car park in front of the Football Mega Store, entrance to Conference Centre to the right of the Football Club Mega Store.

By train to Reading, then by Taxi: Once arrived at Reading Central Station, leave the station by the town side exit the taxi rank is located opposite the Station and in Garrard Street.

Madejski Stadium Park and Ride:
Greenwave Buses – Service No 50
This bus service operates every 10 minutes from the Old Bus Station in Reading (just a short distance from Reading Railway Station) to and from Madejski Stadium/Royal Berkshire Conference Centre.
Reading buses Customer Services Team 0118 959 4000 - Mondays to Friday, 9.00am to 5.00pm
http://www.reading-travelinfo.co.uk/park-and-ride/madejski-stadium.aspx

Bus fares
Cash fares (exact change required):
- Adult single £1.80
- Adult return £3
- Child single (aged 5-18) £1
- Child return (aged 5-18) £1.50

Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group
  Freephone: 0800 0184 724
  www.iasupport.org
- UA Urostomy Association
  Tel: 01889 563191
  www.urostomyassociation.org.uk
- IOA International Ostomy Association
  www.ostomyinternational.org
- Stomadata & Stomafr
  www.stomadata.com
  www.stoma.fr
- Macmillan Cancer Support
  Tel: 0808 808 00 00
  Mon - Fri: 9am - 8pm
  www.macmillan.org.uk
- Crohn's and Colitis UK
  Tel: 0845 130 2233
  www.nacc.org.uk
- The Gut Trust
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.theguttrust.org
- Bladder and Bowel Foundation (B&BF)
  Formerly Incontact and Continence Foundation
  General enquiries: 01536 533255
  Web: www.bladderandbowelfoundation.org
- Bowel Cancer UK
  Tel: 020 7381 9711
  Email: admin@bowelcanceruk.org.uk
  Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK
  Tel: 08450 719300 (Lo Call rate)
  Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)
  (The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)
  Web: www.glo-uoaa.org
- Ostomy Lifestyle
  Tel: 0118 324 0069
  Email: admin@ostomylifestyle.org
  Web: www.ostomylifestyle.org

Stoma Care Patient Open Day event dates...

For a comprehensive list of Patient Open Days events...visit the CA website. Details can be found on Page 6. Listings are updated throughout year.

If you are not online contact CA on: 0118 939 1537 to find out if there is an event near you.

Don't forget the CA Patient Open Day Saturday 20th July!

SASH

Stoma Support and Hernia Belt

- The Stoma Support and Hernia Belt is made of a 50mm (2") non elasticated webbing attached to a restraining flange that fits between the bag and the adhesive section of the pouch.
- The SASH Stoma Support and Hernia belt is designed and manufactured by an Ostomist and gives support to the muscles surrounding the stoma.
- 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 parastomal 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. HB102

Freephone 0800 389 3111

Website:- www.sashstomabelts.com

SASH

- Sash belts are available on prescription for a Colostomy, Ileostomy or Urostomy and suitable for both male and female.
- All belts are custom made from information given on the enclosed Order Form. A hole will be cut into the belt flange to fit the pouch you normally use.
- No fittings are required. Belts are processed and mailed within two working days.
- For further information call Freephone : 0800 389 3111 or visit our website: www.sashstomabelts.com

Security and Leakage Belt

- The Security and Leakage Belt is made of a soft 32mm (1.25") elastic belt attached to a retaining ring that fits between the bag and the adhesive section of the pouch.

"the ring of confidence"

- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
- The belt also gives added confidence and security against the pouch becoming detached and will help to support the weight of a full pouch

Ref. no. SR103

Sash Medical Limited
"Woodhouse", Woodside Road, Hockley, Essex, SS5 4RU.

Marketplace

advertise...your events • messages • services here...

Mid Devon Ostomy Group Advance notice

The Boniface Centre, Crediton is booked for meetings for Crediton Support Group the 3rd Saturday 2-4 every as follows:-

- **July 20th 2013**
- **October 19th 2013**

Contact Janice Parkyn via CA at cass@colostomyassociation.org.uk

Holidays... Beesands – Devon

Holiday Apartment
Self–Catering Accommodation
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Contact: Mrs J Seal
Tel: 01548 581 163
Mob: 07968 370498

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Royal Derby Hospital Stoma Care Nurses Open Day...

Thursday 24th Oct 2013
10.00am till 2.30pm

Venue: The Spot,
Wilmot St West,
Derby DE1 2JW

All enquiries to:
Stoma Care Dept
01332 787465

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Designed by Ursula Naish

Ursula Naish designs and produces pouch covers and waterproof mattress and wheelchair covers.

As Secretary of the UA Kent Branch she offers this service to raise funds for her local group.

For further information please contact:
Ursula Naish, 9 Oast Meadow, Willesborough, Ashford, Kent TN24 0AS
Tel: 01233 640 863 Email: ursulanaish620@btinternet.com

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living with a stoma and
colostomy in the UK

colostomy association

contact CA:
telephone: 0118 939 1537
email: cass@colostomyassociation.org.uk

stronger **together...**
forward together

The **Colostomy Association** is an **independent charity financed solely by donations.** Your **help and support today** is **more important** than ever in this **changing world...**

Our findings show there are approximately 60,000 colostomates living in the UK and with over 6,400 permanent colostomy operations being performed each year - the CA needs to be here for everyone 'living with a colostomy'.

Here's how YOUR donations help CA make a difference...

- **A telephone helpline 0800 328 4257** manned 24/7 365 days a year by fully trained volunteers experienced in living with a colostomy.
- **An Outreach Programme** CA's own Patient Open Day event for ostomates. Come and visit us it's a full day packed with information and friendly faces.
- **Patient Advisory literature,** written by colostomates and health care professionals.
- **A quarterly magazine 'Tidings'** especially written by colostomates for colostomates, their families and their carers.
- **Over one hundred contact volunteers cover the UK** fully trained and experienced, (who are ostomates) these dedicated individuals bring a human touch. A volunteer can discuss emotional or practical problems with you and be matched to a patient by age, sex, location or by problem
- **Patient visiting** a volunteer can at the request of a stoma care nurse visit a patient/s before their colostomy surgery, and afterwards in hospital. Home visits can also be arranged.
- **CA attendance at organised stoma care nurses 'open days' around the UK** – that you can visit and learn more about your stoma, in a friendly atmosphere and discuss any problems.
- **CA attendance at manufacturers' and suppliers', 'open days' and exhibitions.** These allow you to come and see us and we can update you on stoma care products, accessories and services via 'Tidings'. Display our literature and chat to ostomates.
- **A voice for your opinions at ongoing consultations with the National Health Service** keeping you informed of issues that may affect you.

Donate and make a difference to CA..today! Here's how...simply dial 0118 939 1537 to donate over the telephone • visit www.colostomyassociation.org.uk and donate online make a regular donation via standing order • make a single donation of £15 or more • donate online at justgiving • donate a gift in memory • leave CA a legacy in your will – THANK YOU!

colostomy association

Thank you for your support

Regular donation

Your ongoing support means we can plan our services with confidence knowing when donations will be coming in – and reach out to more colostomates their families and their carers with support, reassurance and practical advice. With your help we really can and do make a difference - thank you.

Please use this form to make a Regular donation by Banker's Standing Order. Simply complete this form and return by post to the Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.

Note:
Please ensure that we have your correct contact details: full name, address and postal code telephone number thank you

My Details: Title: Name: Surname:
Address:

Postcode:
Telephone (home): Mobile:
Email:
Optional Information: Date of Birth: Reason for your stoma:
Stoma Type: (Please tick) Colostomy ☐ Ileostomy ☐ Urostomy ☐

(NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)

Regular donation: I wish to make a **regular contribution by Banker's Standing Order** to the **Colostomy Association** in support of the charity and its ongoing work. I have completed the **Banker's Standing Order Form below** ☐ (Please tick.)

Instruction to your Bank/Building Society to pay by Banker's Standing Order

To the Manager: (Bank or Building Society)
Bank Address: Postcode:
Name(s) of Account holder(s):
Account number: Sort code:
I would like to make a **regular donation*** of ☐ £15 ☐ £20 ☐ £25 ☐ £50 or other amount (please state) £
☐ **monthly** ☐ **quarterly** ☐ **annually starting on the** ☐ **1st** ☐ **15th** ☐ **25th of month:** **year:**
thereafter until further notice. *Please state your donation amount in words:
(Please cancel any previous standing order in favour of this beneficiary).
Please pay: **NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP**
Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**
Name: (IN CAPITALS)
Signature: **Date:** / / 2013

giftaid it

Thank you for your gift

Thanks to the gift aid scheme - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of **£15 becomes £18.75 with gift aid,** at no extra cost to you.

☐ 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 25p for every £1 donated).

Signature: **Date:** / / 2013

To donate via standing order...Please fill in the form and return to the Colostomy Association - thank you

Registered Office: Enterprise House, 95 London Street, Reading RG1 4QA
Registered Charity No: 1113471

colostomy association

Thank you for your support

Single donation

Your single donation/gift makes a real difference to the work of the charity – CA can reach out to more colostomates their families and their carers with support, reassurance and practical advice. With your help we really can change lives - thank you.

Please use this form to make a Single donation to the Colostomy Association. Simply complete this form and return by post to the Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.

Note:
Please ensure that we have your correct contact details: full name, address and postal code telephone number thank you

My Details: Title: Name: Surname:
Address:
Postcode:
Telephone (home): Mobile:
Email:

Optional Information: Date of Birth: Reason for your stoma:
Stoma Type: (Please tick) Colostomy ☐ Ileostomy ☐ Urostomy ☐

(NB: The optional information is not mandatory but will help the CA learn more about you – it will not be passed on to third parties)

Single donation: I wish to make a **single donation** to the **Colostomy Association** in support of the charity and its ongoing work. I have completed the **Form below** ☐ (Please tick.)

Single donation/gift: a donation of £15 (or more) will help cover the cost of all our patient services

☐ (Please tick.) **Yes** I would like to make **a single donation/gift** of ☐ £15 ☐ £20 ☐ £25 ☐ £50 or
other amount (please state) £ to the **Colostomy Association**

I enclose my **cheque/postal order form** made **payable** to the **C.A. Ltd** and attach the completed Donation Form in its entirety.

Yes, I require a receipt ☐ (Please tick.)

Single donations from individuals, groups and fundraising events are very welcome and greatly appreciated. So please keep them coming, no matter how small. Just £15.00 (or more) will help cover the cost of all our patient services.

giftaid it

Thank you for your gift

Thanks to the gift aid scheme - we can reclaim money on your donation from the government. **For every pound you give us, we can claim an extra 25p.** For example, a donation of **£15 becomes £18.75 with gift aid,** at no extra cost to you.

☐ 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 25p for every £1 donated).

Signature: **Date:** / / 2013

To make a single donation...Please fill in the form and return to the Colostomy Association - thank you

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Registered Charity No: 1113471

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Flat Top

“I went swimming with this pouch. I was amazed how quick the pouch dried.”

M.H - Leeds

Anatomical

“I liked this smaller size pouch and found it useful when playing golf or going out for the evening.”

V.W - Kent

Soft Convexity

“Skin seems much better since using your pouches. Can’t believe how soft they are.”

H.W - Newcastle-Upon-Tyne

Stoma Cap

“I like the size, the feel of this pouch. The material is soft and quiet. I can forget I am wearing a pouch as it is small enough not to get in the way.”

J.L - Glamorgan

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

Janice Parkyn writes....about the Mid Devon Ostomy Group – a new group for ostomates in the West Country!

Janice writes: I have now had my fourth support group meeting! I decided to set up an informal support group in Crediton, Devon with help from CA and Jackie Dudley – Trustee and Volunteer and support from Ostomy Lifestyle's course – 'Nuts & Bolts of running a Support Group'.

It took a little while to find a venue but I finally found a local hall that was available on a Saturday afternoon, which was great news! I devised a poster with an eye-catching logo and CA sent invites out for me to local members in the Devon area and Sam Robertson – stoma care nurse at the Royal Devon and Exeter Hospital did the same. I put up posters in local Libraries and Doctor's surgeries and asked my local stoma care company reps if they would be interested in coming along to help and cover the cost of the hall and refreshments via a donation – the response has been really good.

At my first meeting in June last year, the weather played havoc, we had torrential down pours but people still came! The theme 'chocolate', quizzes, facts and fun! Linda Matthews from Salts Healthcare, Diane Kay from Pelican Healthcare and Kim Hill from Hollister came along. My next meeting was in September yet another wet day this time with long traffic delays! I had contacted people who came to the first meeting and advertised again locally we all had a good afternoon – Jonathan Tait from Salts Healthcare, Gareth Carruthers from Peak Medical and Moya Westcott from OstoMART came along and Tracy Inch – Community Stoma Care Nurse from Coloplast.

I decided to book the hall in advance for 2013 – every quarter – January, April, July and October! My next meeting was January 20th – we were in the grip of a wintery cold snap that brought snow for most with some exceptions such as Crediton. Claire Hills from CliniMed was the only rep that made it through! All morning I received calls saying: 'sorry, we can't get to Crediton due to the snow'. I thought to myself no one's going to make it! But as it turned out a small group of people made it through and we had some fun and quizzes!

As well as advertising in Tidings, and all my usual places! I contacted Radio Devon who mentioned the April meeting on their Sunday request show. I have just had my fourth meeting, we had a talk from the Blue Cross, which was very interesting, everyone agreed to donate the money raised from the raffle! We were pleased to give the Blue Cross £36.00. This time my son came and helped with the teas and the washing up!

I would just like to say how rewarding it is when people come to each meeting! A big thank you Pat, Marlene and Angela who likes to do the raffle. Thank you also to Cyril Smith who sets up a table for the Colostomy Association displaying leaflets and Tidings Magazines. We do not have any membership fees we just ask for donations towards the food once the hall fee is covered and raffle prizes!

The meetings are for anyone with any type of stoma and family members or friends are always welcome. perhaps I'll see you there at the next one!

Regional Stoma Support Focus...

England - South West

Avon:
B.O.S.S Bristol Ostomy Self Support
Contact: Christina 01179 075326
Joyce 01179 558236
Rob 01179 668021

Cornwall:
Hayle's Angels Stoma Support Group
Contact: Sue Hatton
01326 340058
Ostomist and Carers Support Group
Contact: Christine Davey
01208 831471
Optimists
Contact: Sue Hatton
01326 340058

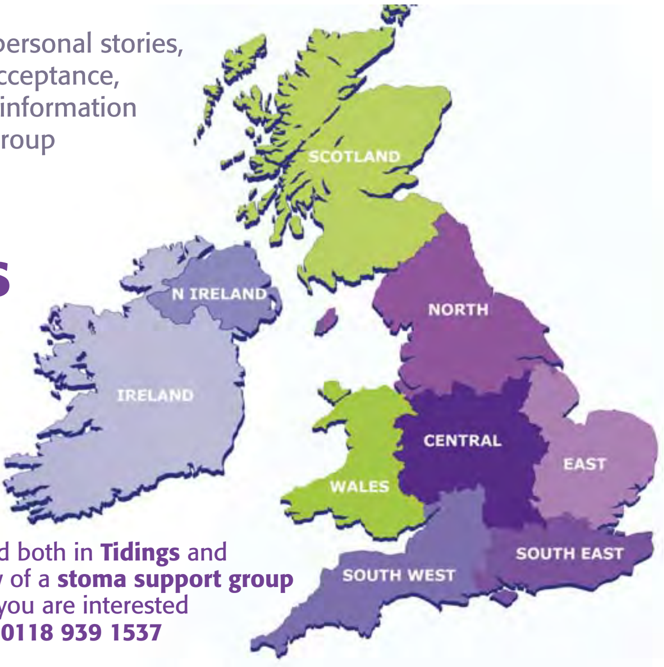
Devon:
Mid Devon Ostomy Group
Contact: Janice Parkyn
01363 776417
Devon IA
Contact: Margaret Bond
01392 447374
Devon Stoma Support Group
Contact: Donna Ashbrook
01626 854862

Dorset:
CUPID Colostomy, Urostomy, Pouch & Ileostomy of Dorset - West Dorset
Contact: Colin Clare
01305 853 288

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

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

Stoma support groups
in your region...



Information about **stoma support groups** is regularly updated both in **Tidings** and **online visit: www.colostomyassociation.org.uk.** If you know of a **stoma support group** near you not mentioned in our listings please let us know...if you are interested in setting up a group the CA can help. Contact the **CA office: 0118 939 1537** or **E-mail: cass@colostomyassociation.org.uk**

Scotland

Midlothian:
Maggie's Edinburgh
Contact: 0131 537 3131

West Lothian:
GOSH
Contact: Alex Topping
01501 772154

Glasgow:
Glasgow Stoma Support Group
Contact: Maureen O'Donnel
01236 436479

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

Fife:
Fife Ostomy Support Group
Contact: Ishbel Barr 01592 772200

England - North

Cheshire:
Cestrian Support Group
Contact: David Burgham 01244
310461
Stockport Support Group
Contact: Angela Simpson
0161 419 5059
TOMAS (The Ostomates of Macclesfield and Surrounding Areas)
Contact: Kath Wood 01625 875442
Warrington Ostomy Support Group
Contact: Jane Shaw 01925 662103

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

County Durham:
Bishop Auckland Stoma
Care Group
Contact: Betty 01388 814535
Jen 01325 311266 or
Maureen 01388 818267

Cumbria:
Grange Cancer Support Group
Contact: Marie 015395 33279

Derbyshire:
Stockport Support Group
Contact: Angela Simpson
0161 419 5059

Lancashire:
Oldham Stoma Support
Contact: June Wilde 0161
312 5538
Tameside Ostomisticles
Contact: Paul Seavers 0777 1359046
Trafford Bowel Care
Contact: Jackie Carey (Secretary) 0161
7489 659 Doreen 0161 9627 818
John 0161 7484 655

Merseyside:
Crosby Support Group
Contact: Stoma Care Nurse
0151 529 2842
Aintree Stoma Support
Contact: Stoma Care Nurse
0151 529 2842
I.C.U.P.S
Contact: Stoma Care Nurse
0151 604 7399

Northumberland:
Northumberland Cancer Support
Contact: Mary Miller 01434 622 392
Jim & Dee - 01434 230 398

Tyneside:
NHS Molineaux Centre
Contact: Stoma Care Nurse
0191 2380011
Royal Victoria Infirmary Support Group
Contact: Gordon Weatherburn
0191 234 1109

Yorkshire:
Airedale Stoma Support
Contact: Jenny Shaw 01535 652516
or Sue Hall 01535 210483
Behind You (Calderdale& Huddersfield
Bowel Cancer Support Group)
Contact: Stoma Care Nurse
01484 355062
Barnsley-Bottoms Up
Stoma Support Group
Contact: Stoma Nurses 01226
432528 or Celia Utley (Chairman)
01226 284262

CROPS (Colo-rectal ostomy & internal pouch support)
Contact: Gloria 0114 2879503
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Rotherham Ostomates Caring Support
Contact: Karen 0788 0575758
Scarborough Stoma Support
Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446
The Hull and East Riding Colostomy Support Group
Contact: Pete Smith 07989 565335 and Pete Rennard 01482 793966

Isle of Man:
Stoma Support Group
Contact: Carole Cringle 01624 650212

England - Central

Buckinghamshire:
Milton Keynes Stoma Association
Contact: Mrs Joanne Dixon 01908 318262 or 07502 226702

Leicestershire:
Kirby Ostomy Support Group
Colostomy, Ileostomy & Urostomy in Leicestershire
Contact: Janet 0116 239 2844

Nottinghamshire:
Nottingham Colostomy, Ileostomy & Urostomy Support Group
Contact: Rosemary Brierley 0115 982 6691
Nottingham Stoma Support
Contact: Mrs B Heath 0115 966 3073
North Notts Stoma Support Group (Sutton-in-Ashfield)
Contact: Tore and Nicky Norman 01773 715460

Shropshire:
Oswestry Stoma Support group
Contact: Irene Constable 01691 238357

Staffordshire:
Outlook
Contact: Ernie Hulme 01782 324441
Moira Hammond 01782 627551

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

West Midlands:
Coventry Stoma Support
Contact: Martin Robbins 07947 385643
Newhall Stoma Support Group
Contact: Sarah French 07773 396236 02476402616

England - East

Bedfordshire:
Saturday Social Club
Contact: Karen Richards 01234 792278

Cambridgeshire:
Ostomistics
Contact: Alan Wright 01354 653290/ 07836 661102

Essex:
Connect
Contact: Lin Hart 01279 505273
M.E.S.S (Mid Essex Stoma Support)
Contact: Paul Foulger 01245 224374
Jeanette Johnson 01376 511862
N.E.S.S (North Essex Stoma Support)
Contact: Mr Bill Hatch (Chairman) 01255 503688
Brian Waller (Secretary) 01206 540449
Optimistic Ostomates
Contact: Angela Taylor/Carol Booth 01702 385509 or 01702 385510
STEPS
Contact: Jackie Coleman 01268 451937
Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa 020 8970 8321

Hertfordshire:
Connect
Contact: Lin Hart 01279505273
Colonise
Contact: Anastasia 01727 760 981
Hertford Stoma Support Group
Contact: Ralda 01992 535311
Stevenage Ostomistics
Contact: Alfred Levy 01767 316958

Lincolnshire:
Friends East Coast Support Group
Contact: Betty 01205 724120/Sheila 01205 364493
Grantham Support Group
Contact: Bobbie/Amanda: 01476 464822
Email: grantham.colorectal@ulh.nhs
March Group
Contact: Maureen 01754 874 485
Sutton Bridge and Long Sutton Ostomy Group
Contact: 01406 351617

Norfolk:
Kings Lynn Ostomy Friendship Support Group
Contact: 01533 691370/768271 or 01533 775698
Stars
Contact: Anne Browne 01603 661751

Suffolk:
East Suffolk Ostomy Group
Contact: Marion Fisher 01473 311204
James Pagett Ostomy Support Group
Contact: Sandra Hutchings 01502 585955
West Suffolk & District Stoma Group
Contact: Jessica Pitt 01638 515525

England - South East

Berkshire:
EBOC (East Berkshire Ostomy Club - Bracknell)
Contact: Jackie Dudley 01344 426652
WBOC (West Berkshire Ostomy Club - Reading)
Contact: Jackie Dudley 01344 426652

Hampshire:
COGS (Colostomy Only Support Group)
Contact: Sarah Anderson 07907 820125
Solent Ostomates Support Group
Contact: Carole Summer 07527 707069
Solent Ostomates Support Group (New Forest Branch)
Contact: Carole Summer 07527 707069
Wessex Urology Support Group
Contact: David Morris 02392 361048

Isle of Wight:
Optimistics
Contact: Stoma Nurse Natalie Sayer SCN 01983 534009
Semi Colon Group Isle of Wight
Contact: Tony Crowson Chairman 01983 559326

Kent:
Ashford Stoma Support Group
Contact: Ron Huckstep 07941 310681

Margaret Webb 01233 628807
Atoms Support Group
Contact: Maria Culleton SCN
01227 769679 or 07827997424
Dover & District Stoma Support
Contact: Maria Culleton SCN
01227 769679
Dover Stoma Friends Group Support
Contact: Julie Bell & Ros Marshall
07771345701/01233616646
Maidstone Stoma Support Group
Contact: Judy or Kirsty
01622 224305
Medway Ostomy Group Support (MOGS)
Contact: Val Solly or Helen or Tracey
07773 605534
Thanet Stoma Buddies Support Group
Contact: Phil (Secretary)
01843 587769

London:

Homerton Hospital Bowel & Stoma Support Group
Contact: Toni Johnson 0208 510 7599
Angela Davy 0208 510 5318
Shepherd Bush Stoma Support Group
Contact: Roslyn 0208 354 0121
or Jackie 0208 740 4790
South Woodford Support Group
Contact: Christina 0208 5356563
Surrey & South London Bowel Cancer Support Group
Contact: Sue Berry: 01737 553134 or
John Amos: 0208 668 0796

Middlesex:

Inside Out
Contact: Bob (Chairman) 0208
4284242 Sarah Varma 0208 2354110
Semi-Colon Club
Contact: Pat Black/Katheryn Foskett
01895 279391

Oxfordshire:

Oxfordshire Ostomy Fellowship
Contact: Pat Longworth
01235 524163

Surrey:

Epsom & District Stoma Support Group
Contact: Sheena 01372 735925

Sussex:

(SAS) Brighton & District Stoma Care support
Contact: Sylvia Bottomley
01273 554407
The Ostomy Friends Group
Contact: Jane Quigley 01323 417400
Ext 4552
West Sussex Princess Royal Stoma Support
Contact: Tina Walker 01444 441881
Ext 8318

England - South West

Avon:

B.O.S.S Bristol Ostomy Self Support
Contact: Janet 01275 472873
Rob 01179 668021

Cornwall:

Hayle's Angels Stoma Support Group
Contact: Sue Hatton
01326 340058
Ostomist and Carers Support Group
Contact: Christine Davey
01208 831471
Optimists
Contact: Sue Hatton 01326 340058

Devon:

Mid Devon Ostomy Group
Contact: Janice Parkyn
01363 776417
Devon IA
Contact: Margaret Bond
01392 447374
Devon Stoma Support Group
Contact: Donna Ashbrook
01626 854862

Dorset:

CUPID Colostomy, Urostomy, Pouch & Ileostomy of Dorset - West Dorset
Contact: Colin Clare
01305 853 288

Wiltshire:

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

Wales

Blaenau Gwent Self Help
Contact: Celia McKelvie
01873 852672
Bridgend Ostomy Patients Support Group
Contact: Anita Brankley (Secretary)
01656 645602 or
Pat Jones 01656 786103
Royal Glamorgan Stoma Care Support Group
Contact: Domenica Lear
01443 443053
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245

Northern Ireland

Antrim Area Stoma Support Group
Contact: Chris Wright
07720 717771
Belfast Royal Victoria
Contact: Sarah Haughey/
Audrey Steele 02890 240503
Ext 3483
Causeway Patient Support Group
Contact: Mary Kane 028 70 346264
Colostomy Association Volunteers Northern Ireland
Contact: Chris Wright
07720 717771
Daisy Hill Hospital Newry
Contact: Bernie Trainor
028 3883500 Ext 2222
Mater Hospital Belfast
Contact: Karen Boyd
028 90741211 Ext 2329
North Down Stoma Support Group
Contact: Adrian Ewing
07850 741511
Southern Trust
Contact: Mary Jo/Bernie
028 38612721
Ulster Hospital
Contact: Hazel/Martina
028 90 550498

Eire

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

"Very effective, does exactly what it is supposed to do. Excellent product."

Mr M.G. (Staffordshire)

OstoZYME

Odour Neutralising Pouch Lubricant

"The OstoZYME is amazing. It is one of the very best ostomy products I have ever come across. Thank you so much."

Ms L.H. (London)

"Found something that stops pancaking at long last. Thank you."

Mrs S.P. (Lincolnshire)

Stop pancaking and neutralise pouch odour in one go!

"It's very easy to use with pleasant odour."

Mrs C.L. (Sussex)

The benefits of OstoZYME:

- Prevents pancaking by lubricating pouch to aid contents to bottom
- Contains active odour neutralisers
- Reduces noise from the pouch
- Gel stays at the top of the pouch where you need it most
- Easier pouch emptying
- Reduces static in the pouch
- Simple and easy to use
- Only one sachet or one pump from the bottle is required
- Minimises risk of accidents and leaks
- Suitable for ileostomy or colostomy pouches
- Pump bottle is ideal if you have limited dexterity
- Sachets are convenient for travel
- Sachets are easy to open with a spout to aid application
- OstoZYME is the most cost effective pouch lubricating deodorant available*

NEW PACKAGING SAME GREAT PRODUCT

Accept no imitations

the original pouch lubricating gel

NEW NOW IN A BOX OF 90 SACHETS

Available on prescription in sachets or bottle

Order Code: TCB3 (30 x 8ml sachets) or TCB3-90 (90 x 8ml sachets) or TCB6 (300ml pump bottle)

Try them now, for a FREE sample call: **0800 220 300** or visit: **www.ostomart.co.uk**

Request a free sample and ask about our free price comparison service to see if switching to OstoZYME will save the NHS money

*Based on a comparison between the Drug Tariff price of a TCB3-90 sachet or TCB6 bottle of OstoZYME versus an equivalent quantity/size of competitor pouch lubricating deodorants.

Innovation as standard

Scan the QR Code to watch the demonstration video

Available on prescription from your usual supplier or direct from OstoMART Ltd.

Drug Tariff Listed – Product Codes:

Order Code: **TCB3** (30 x 8ml sachets)
Order Code: **TCB3-90** (90 x 8ml sachets)
Order Code: **TCB6** (300ml Bottle)

OstoMART Limited