


Winter 2011 | Issue 20

Tidings

colostomy association

Dedicated to Colostomates their Families and their Carers

A photograph of two men in suits and ties, engaged in conversation. The man on the left is wearing a dark suit and a red tie, while the man on the right is wearing a light-colored striped shirt and a pink tie. They are both wearing glasses and appear to be at a formal or semi-formal event. The background is slightly blurred, showing other people and warm lighting.

Reaching out
Building awareness
CA Open Day 2010
Heritage Motor Centre

Open Door...Focus on
CA Volunteer in Scotland

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

THE **Natural** CHOICE FOR A PERFECT FIT

NEW Natural fit

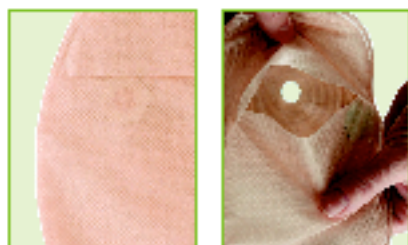
Excellent flexibility and adhesion, to fit closely to any body shape, ideal if you have a hernia



Flexifit® wafer on a hernia

NEW Natural comfort

Soft edges for increased comfort



NEW Natural softness

Infused with Aloe extracts for softer skin



NEW Natural shape

Unique Flexifit® wafer bends and flexes with your body



NEW Natural protection

Skin-friendly hydrocolloid, research into which is validated by The British Skin Foundation



As a colostomist, who has ever suffered from an ill-fitting pouch, leaks or sore skin, it's time you discovered NEW Confidence® Natural. Now, users can have all the comfort and convenience of a one-piece closed or drainable pouch with a range of natural benefits.

NEW Confidence® Natural features a unique, five-sided Flexifit® wafer, so it offers greater comfort, flexibility and fits more securely to the body's natural contours. It's even infused with extracts of Aloe Vera for smoother, softer skin.

AVAILABLE IN CLOSED AND DRAINABLE



For free samples or further information, please call FREEPHONE 0800 626388 or visit www.saltsstomacare.co.uk

Confidence®

Natural
WITH ALOE EXTRACTS

SALTS
HEALTHCARE

welcome to WINTER



Welcome to the winter issue of Tidings... A Happy New Year to everyone! I hope you enjoyed the festive season with family and friends and that you greeted the New Year with a clink of glasses filled with your favourite tipple!

The beginning of a New Year is always such a special time! It's a time for renewal, for taking stock, a time when we can cheerfully say, 'out with the old and in with the new'. Whatever your resolutions this year, I hope Tidings remains top of your reading list in 2011!

With your help throughout 2010 each issue of Tidings magazine has been packed full of information, inspirational stories, practical advice and fundraising activities! Kind thanks to everyone! There has also been an increase in the number of submissions to Tidings magazine not only from its dedicated readership but also from new readers who have been given Tidings by their stoma care nurse or by you! We are delighted that this is the case - long may it continue!

Tidings magazine endeavours to clarify, inform and support the ostomate 'living with a colostomy'. It's the Editor's task, together with the Editorial team, to examine and keep in our minds eye the 'bigger picture' and to dispel the negatives where and when they present. So what is the 'bigger picture' I hear you ask? Well, for anyone who is a regular reader of

Tidings you will already know! I'll let Justin Hansen the determined kayaking fundraiser and fellow ostomate tell you... 'It was amazing to meet so many people along the way who asked what the trip was all about, and to find myself talking to total strangers about the pros and cons of varying stoma products. I was also staggered to discover how many others either were or knew an ostomate'. Got it! Yes! That's the 'bigger picture'! There are many ostomates just like you - differing in age, sex, and ethnicity going about their daily activities throughout the UK...so if some days you feel a little down and don't feel very positive always remember the 'bigger picture' you are not alone!

Tidings magazine extends a warm hand to YOU and to everyone involved in stoma care and to the ostomy community in its widest sense. Tidings is proud to provide a discussion platform that reflects and considers aspects surrounding the ostomate and stoma care.

This past year has been incredible! The editorial team has been fortunate to receive a wide variety of articles from readers, stoma care nurses, surgeons and many more - so do please keep them coming! (Just to explain, if you have submitted an article, which hasn't been published, it may well be published in a future issue.)

This year we want to hear from even more of YOU! So don't hold back get involved! New patients, experienced colostomates, irrigators, family members, carers, stoma care nurses, GP's, surgeons, stoma care product manufacturers/suppliers, pharmacists tell us about your events, stories, issues I am sure you all have much to contribute!

Let's make Tidings magazine even better! A rounded magazine that truly reflects the 'bigger picture' for everyone to enjoy in 2011!

A few words...it was a real privilege to meet some of you at the recent CA Open Day at Gaydon. I only wish I could have stopped to chat more, perhaps next time...also to speak to you as editor via Tidings, chat on the phone, read your letters and receive your messages by email. As someone who fully understands what life can be like 'living with a colostomy' I am here for you whenever or however you decide to get in touch, so never hesitate!

I would also like to send out several BIG messages of thanks and appreciation...Firstly, to our 'Dear Nurse' Julie Rust, who always makes time even though she is exceptionally busy to answer your medical queries in Tidings.

To the Editorial team! Thank you for your ongoing support, excellent contributions, ideas, passion, medical observations and proof-reading skills - well done team!

Finally, thank you to the advertisers. Without their continued support, Tidings magazine in its current form would not be possible! And to the unsung heroes who continue to ensure the highest quality of production and print that this publication truly deserves!

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

Email:
editor@colostomyassociation.org.uk

PS.If you haven't done so already please send back the Tidings Feedback Questionnaire from the autumn issue - many thanks!

inside.....

all your regulars

cover story



**Colostomy Association
Open Day 2010...**
featured on page 28

3

Welcome

From the Editor

6

How to get in touch...

About the...
Colostomy Association
Editorial Team
Editorial submissions
Advertising information
Publication Dates

8

CA News

President's Message
Chairman's Message
Greeting from the office...

10

Fundraising

Your donations...
stories and the
500 Club

50

Connections

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

48

Notebook

Updates and events

51

Donations

Making a difference...

...this issue

& special features

update...

14 Taking a look at the latest stoma care products & services
Keep up-to-date with the latest information about stoma care products and services

16 Product Showcase
NEW to Tidings... understanding the ostomy product

real lives...

20 Pathways to a Colostomy
Helen McTurk tells her story...

32 Ten months on...
Follow up from Susan Fifer

34 Young Ostomates
Breakaway...a family affair and more

36 Ostomy Community
Gutless Kayaking
Justin Hansen paddles his way to success...

health...

22 Diet
A balanced view... Losing those extra pounds after Christmas can be difficult when you have a stoma...

42 Irrigation and You
Sue Hatton replies to your responses from the autumn issue

45 Dear Nurse
Your letters and queries

travel...

24 Insurance for the ostomate
Taking on Travel Insurance...Duncan Wells UK voice over artist and ostomate - tracks down insurance providers... and reports on his findings

support...

12 Open Door
Focus on CA Volunteer in Scotland

28 Reaching out
Open Day success at Heritage Motor Centre

53 Support groups
In conversation
Moira Hammond writes about the Outlook Support Group

54 Support group listings

interest...

38 A colostomate comments
a colostomate's perspective

39 Chatback
Readers' writes

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
2 London Court,
East Street, Reading RG1 4QL

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Helpline: 0800 328 4257

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

Find us on Facebook:



Simply visit our **website** and **register** at:
www.colostomyassociation.org.uk
or contact:
General Enquires: 0118 939 1537

**Don't delay...
Donate Online today!**
There are **NOW** two ways to donate online...



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



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 edition 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 300 ppi in RGB mode and scan original @100%.

Advertising Enquiries:

For a media pack and advertising rates.
Contact Jane Wood: 0118 983 6226

Publication:

| | | |
|--------|---------|------|
| Spring | April | 2011 |
| Summer | July | 2011 |
| Autumn | October | 2011 |
| Winter | January | 2012 |

EDITORIAL TEAM

Editor

Jane Wood

Associate Editor

Colostomate & Helpline Volunteer
Rosemary Brierley

Executive Trustee

Colostomate & Helpline Volunteer
Sue Hatton

Trustee

Colostomate & Helpline Volunteer
Jackie Dudley

Office Administrator

Gill Herbert

Office Administrator

Jo McKenzie

Colostomate

& Helpline Volunteer
Georgina Williams

Colostomate & Volunteer

Bob Buckley

Stoma Care Nurse Advisor

Amanda Gunning RGN, CNS

How to contact the Editor

By letter write to:

The Editor
Colostomy Association
2 London Court
East Street Reading
Berkshire RG1 4QL

By telephone via CA Office:
0118 939 1537

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

or e-mail:
cass@colostomyassociation.org.uk

Tidings Magazine:

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

Disclaimer:

The display, description or demonstration of products and services or the inclusion of advertisements, inserts and samples within Tidings Magazine does not constitute an endorsement or recommendation of these products and services by the Colostomy Association.

To avoid the embarrassment of leaks, noise or odour try **AbsorbaGel** the UK's leading gelling agent that makes the use and disposal of pouches safe, simple and perfectly discrete



Available on prescription
in packs of 150 sachets

For free samples and all the help you need
0800 458 7605

www.opus-healthcare.co.uk



Message from our President...

The Colostomy Association is now a thriving and expanding success story. Our Open Day get together at The Heritage Motor Museum and Centre near Gaydon was full of vitality and an evolving sense of purpose.

My own priorities at this time are to foster and develop ways of providing education in alternative methods of stoma care management that may

improve the colostomists' enjoyment of life. The initiative to provide practical training in irrigation received a sharp set back with the death of our much loved Ann Leppington-Clark, but it is wonderful that Amanda Gunning RGN and CA volunteer nurse has dedicated herself to this cause. It is my hope that in the future irrigation masterclasses will be available to those who are interested.

It goes without saying that this has nothing to do with the money that would be saved for the National Health Service if irrigation were more widely adopted, and that the Association's approach is based entirely on championing the various causes of the colostomist and his or her long-term well being in every facet of life.

It is a huge pleasure to welcome as Vice-President of the Colostomy Association Mr Ian Daniels, Consultant Colorectal and General Surgeon at The Royal Devon and Exeter Hospital, where he is also a lecturer in the up and coming Peninsular University. He and I have worked together in the

past and will be visiting various parts of South Africa together to perform demonstration surgical operations in relation to bowel cancer early next year. He has formerly agreed to take forward the concept of a specialist centre to handle the problems of colostomy, hernia, stricture, prolapse, etc, and it is my hope that he and I together will be able to identify eventually several centres in different parts of the UK, to provide a similar service for our members when the solution to their problems may be best attended to by a further relatively minor operation.

What we all need to say is, thank you to Tidings and all it does to bring together the wonderful people in the Colostomy Association office and the many colostomists who need help themselves or who want to help in various ways. They are all committed to further success in the future.

Kindest regards
Professor Bill Heald OBE



Message from our Chairman...

I am pleased to announce that the Colostomy Association continues to go from strength to strength! This year has seen great progress in patient liaison, support and financial stability.

I feel I must thank all our volunteers, who continue to wave our banner in support of patients up and down the UK. Volunteer feedback is enormously important to the Association as it helps give a clearer view of what is needed. Volunteers' tireless efforts

have not gone unnoticed. Indeed in 2011 we will launch a major initiative for volunteers. Two sponsored weekends are planned and details will be available shortly via head office. The concept being, to meet and get to know our volunteers and their partners, to learn from them and with their help further develop ways in which the Colostomy Association can deliver even better support to its members.

We are grateful to the stoma care product manufacturers/suppliers who have been extremely supportive of our efforts over the last year. We in turn have been able to offer them a service to extend the knowledge of stoma care products to ostomates via Tidings Magazine and by sending out invitations to their patient open days.

Our new website is in its final trials prior to its launch early in the New Year! Much hard work has gone into the fine-tuning to make it much more user friendly than at present. We have been very lucky to have the benefit of a volunteer experienced in IT who has provided technical support and liaison with the web designer. Other

volunteers and office staff have provided input and proof reading.

The Colostomy Association enters the New Year with great enthusiasm to dispel the myth of a colostomy being a problem and to ensure that patients about to undergo the procedure realise that in most cases it is not as bad as some would have them believe. As many of us 'living with a colostomy' are able to lead very positive and dare I say it 'normal' lives. However, for those who find themselves struggling or in difficulty the Colostomy Association will as ever be available to encourage, support and reassure at all times!

Finally, I would like to thank the Trustees for their continuing support and admirable work also head office staff for their efforts this year, I'm sure you know who they are!

Best wishes for 2011,
Monty Taylor - Chairman
Colostomy Association

Greetings from everyone at the CA office...

On behalf of the office we hope you had a great Christmas and would like to wish everyone a Happy New Year!

The office in Reading continues to be a hub of activity...answering callers queries and reassuring them with advice, support and an answer to their problems. Dealing with e-mails and requests for our literature from new colostomates, carers and stoma care nurses. Organising the helpline and liaising with volunteers to attend open days. Feedback from volunteers about open days lets Jo (who organises the diary) know what areas need more support.

Tidings continues to keep us busy! Articles that appear in the magazine always raise lots of questions with readers wanting to know more. It is so rewarding to receive calls congratulating everyone on the content of Tidings.

The interest shown, following the many articles that have appeared about irrigation, has been very gratifying. Members have been able to show their stoma care nurses the information and find out if they can irrigate. Stoma care nurses are calling the office to receive more information on the subject. A great step forward for a lot of our members.

Those members who are unable to irrigate are informed about how and where to obtain samples of pouches – to try and widen their knowledge of what is available. We suggest that all 0800 numbers of the manufacturers advertising in Tidings are called so that a wide range of pouches, flanges and accessories can be obtained.

We still find callers that have not heard of adhesive removers – so a quick call to manufacturers and samples are sent out to them immediately. A call to the office almost always is followed up by the words...if only. If only I had known about you when...

Manufacturer's representatives continue to visit, keeping us informed of new and improved products and services. We have a wall in the office with displays of the manufacturers products so everyone can look up to know what product they are talking about. We even have the special small pouches for babies on display. We have seen a large increase in mailings for company patient open day events, which has kept us busy.

As most of you know we had a very successful Open Day at the Heritage Motor Centre, Gaydon in Warwickshire last October. We would like to thank everyone who attended for making it such a success and to say thank you to all those who helped on the day. The CA Open Day steering group will meet in January to start work on the next event. The details of the event will be confirmed in the Spring Issue of Tidings published in April.

So what else have we been working on...well by the time you read this we will have gone live with our new and improved website. A big thank you to Gill and our new office volunteer Sarah for all the work they have put in to make this happen. Your comments, contributions and feedback about the new website would be greatly appreciated.

Other projects include...

- A new volunteers database that will improve our services to you and to new patients. This will enable the CA to match new patients to an appropriate volunteer.
- Work continues on the Volunteers Handbook, and Volunteer training will resume shortly.

A BIG thank you to the volunteers who covered the Helpline over the Christmas period without your support the CA would not be able to offer this invaluable service.

Well until the next time we report have a great New Year!

**Warm regards,
Richard, Gill and Jo**

Other News... BBC Radio Berkshire

Through a friend of one of our local volunteers in Reading the Colostomy Association was invited to appear on the Anne Diamond show on BBC Radio Berkshire on 21st November at 11.00am.

Prior to the day we were asked by the producer to submit background information to enable the programme to be compiled. Richard Bray and I were asked to be at the BBC Reading Offices at 10.30am for the broadcast.

The producer met us at reception, introduced himself, got us both a cup of coffee and told us that Anne Diamond could not be there but that Phil Gayle would do the interview instead. The next thing we knew we were being ushered into the broadcasting studio at 11.03 whilst the news was being read from elsewhere. We had a brief chat with Phil, then the flashing red light stayed on, and we were on air!

Phil put us completely at our ease and after a few minutes of chat there was a music break and a short discussion about questions he wanted to explore. The broadcast lasted about 45 minutes the time flew by and was an interesting experience.

However, the scariest thing when driving back through Reading with the radio tuned to BBC Berkshire and listening to the tail end of Phil's programme I heard him say, "earlier this morning we were talking about colostomies with Monty Taylor, Chairman of the Colostomy Association who summed up having a colostomy like this..."I was hearing my voice on the car radio – a very weird experience but a very worthwhile one for the Association!"

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...



Kind thanks to everyone who wrote in with donations...

Sainsburys donate...

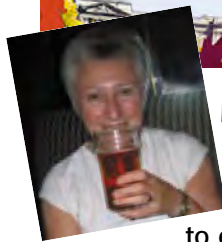
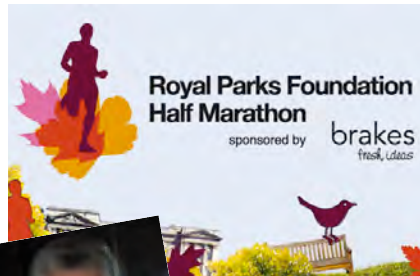
Sainsburys donated £100 because the husband of a staff member recently had a colostomy.

Rockwell Collins UK Ltd...

donated £200 as a thank you for the advice and help CA gave to an employee.

Runner Ian raises funds as a thank you to CA for support...

Many thanks to Ian McIntosh who ran the Glasgow half marathon and Scottish kilomathon. He raised the fantastic amount of £710, which will be split between us and Dr Grays. Ian's mum Margaret had a colostomy a couple of years ago, and Ian wanted to say thank you for all the support received.



Marathon Effort...

On October 10th last year, I decided to embark on a 13 mile quest to raise money for the Colostomy Association, a charity that brought significant help to my Aunt Gwen (pictured above) as she battled against cancer.

This charity is often an unsung hero in the fight against the emotional impact an illness can have on a person. The work that the charity accomplishes brings enormous relief and support to individuals who are suffering as well as their families.

I decided to run the Royal Parks Half Marathon in honour of my aunt who sadly passed away in the summer.

To date I have raised almost £1,150 from the kind donations of family, friends and colleagues, which I hope will help the charity in continuing its valuable work.

**Best wishes,
Amanda Geller**

500 Club - Sept Draw

| | |
|-----------------|---------|
| Mrs B R Hatton | £362.00 |
| Mrs A Wilde | £181.00 |
| Mrs E M Butcher | £ 90.50 |
| Mrs A Campbell | £ 90.50 |
| Dr H C Fowlie | £ 90.50 |
| Mr L W Fincham | £ 45.25 |
| Mrs M R Green | £ 45.25 |
| Mrs E Payne | £ 45.25 |
| Mr D Oakey | £ 22.63 |
| Mr P Martin | £ 22.63 |
| Anon | £ 22.63 |



Charity Flowers...

Did you know if you order from Charity Flowers the CA receives 15% of your order. The bouquets are stunning and come from Guernsey Flowers. Send for your FREE catalogue today or visit: www.charityflowers.co.uk or simply telephone 0870 5300600

In Memory...

| | |
|------------------|----------|
| Mr K V Gregory | £1898.00 |
| Doreen M Braxton | £ 302.51 |
| Mr G W Dawe | £ 165.82 |
| Beryl S | £ 100.00 |
| Mr J B Pritchard | £ 63.20 |

Thank you

Don't forget our Recycling project...

We continue to recycle old mobile phones. If you, or anyone you know, received a new mobile phone this Christmas please ask them for the old one! For a freepost envelope contact: www.recyclingappeal.com or Tel: 08451 30 20 10 quoting the Colostomy Association as your charity.



The Colostomy Association would like to say... A big **THANK YOU** to everyone who donated and raised funds on our behalf during 2010. We try to publish as many letters as possible - to those of you not mentioned here... you are not forgotten - we would not be here without your help - So, **PLEASE keep up the GOOD WORK in 2011!**

Softima® Closed and Softima® Convex



Experience Quality. The new Softima® Closed and Convex range from B. Braun.

Experience Choice. Either the gentle convexity flange for retracted stomas or the security of flat flange for extra comfort.

Experience Freedom. The Softima® range is so soft and discrete that you will forget you are wearing a pouch.

Why not experience Softima® today? Either call 0800 163 007 or fill in the coupon below and return using Freepost.

B. Braun Medical Ltd | OPM | Thorncliffe Park | Sheffield | S35 2PW
Tel. 0800 163 007 | Fax (0114) 225 9111 | www.bbraun.co.uk

08/2011-11

B | BRAUN
SHARING EXPERTISE

To sample the better degree of comfort offered by Softima® Closed or Convex Closed simply fill in the form below and return using the FREEPOST address.

Please send me a sample of:

Convex Flat

Beige Transparent

Stoma size _____

Name: _____

Address: _____

Postcode: _____

Telephone: _____

Email: _____

B. Braun Medical Ltd | FREEPOST SF10771 | Sheffield | S35 2FZ

Tom Reid...Our Lone Volunteer in Scotland

The Colostomy Association has volunteers all over the country. However, at present, only one of them lives up in Scotland. Tom Reid has been a colostomate for more than eight years. He told Tidings about how he first found out he had bowel cancer, and how he came to have a colostomy.

During the first six months of 2010 Tom attended thirty-six stoma open days. He also represents the CA on the Scottish Stoma Forum whose aim is to ensure high quality stoma appliances and a wide range of choice for ostomates.



As a CA Volunteer and colostomate...Tom feels his role is to provide those in authority with a better understanding of the needs of people with a stoma. He says, 'Even when my days are eight to ten hours long, if I can help just one ostomate and answer their questions then to me it's all worth it.'

You could say Tom was lucky. If it wasn't for bowel screening he wouldn't have known he had bowel cancer... At the time he was fifty-eight, working as an engineering manager in Dundee. The screening kit arrived through the post and his wife, Isabel, persuaded him he should do the test because 'you never know...' Tom followed the instructions, sent it off and thought no more about it.

Then the letter arrived. 'Unusual cells needing further investigation,' it said. A colonoscopy revealed a polyp the size of a five pence piece; at the same time the polyp was removed and measurements taken to aid the surgeon during the operation – the

simple operation to take away two inches of bowel either side of the polyp and rejoining the ends. But five days later Tom's luck ran out: for four days he had a very high temperature and stomach pains. Then he started to vomit and felt very ill indeed. It was a Saturday night and the 2002 World Cup was on TV. He didn't know it at the time, but the join in his bowel had leaked and he'd developed peritonitis.

At midnight the duty surgeon was called and at one o'clock in the morning Tom was taken down to theatre for emergency surgery. The operation lasted four and a half hours and afterwards he was taken to Intensive Care. His wife knew nothing

of this until she got the phone call from ICU telling her to come at once and bring someone with her. When Isabel arrived she was told that her husband had less than a 5% chance of survival.

Tom spent eighteen days in ICU. He remembers nothing about the first ten, apart from the "futuristic hallucinations" which always seemed to involve boats and the sea. Later he discovered that he had been lying on a water bed. He was then transferred to the High Dependency Unit and from there to the ward. At first Tom was just glad to be alive. It was only later, when he realised that he had a stoma and what this meant, did he think: 'Why me?'

When he left hospital Tom believed his stoma would only be temporary, and was looking forward to his six month appointment when he thought he would be given a date for the reversal. So it was frustrating to still be waiting a year later and then a shock to be told that, although there was a possibility of a reversal, he may not have complete control of his bowels, especially when he got older.

Tom had been living with a stoma for two years when he developed a parastomal hernia. He was admitted to hospital for an operation to repair it, but as he waited to go down to theatre, feeling rather light-headed from his pre-med, the surgeon came to tell him that his operation had been cancelled, because another patient required emergency surgery. However, the operation was rescheduled as soon as possible and took place a fortnight later. The site of the hernia was reinforced using mesh and the stoma re-sited on the other side. It was after this operation that Tom was told that it would never be possible for him to have a reversal as his bowel was now too short. At first this news left Tom feeling "gutted", but as time passed he came to accept it.

The first Stoma Open Day that Tom ever attended sticks in his mind. There he met an eighty year old lady who'd had a stoma for many years. She was still using the original black rubber bags and cried with relief when she discovered "disposables". He spoke to Sandy Wood, our CA volunteer in Perth at the time, and it was then that Tom decided he would like to be a volunteer too.



Tom...CA volunteer and our man on the ground in Scotland...travels north of the border, and covers the whole of Scotland travelling as far afield as Inverness in the north, Stranraer in the south, Kilmarnock to the west and Edinburgh to the east. Tom says, 'If I can help just one ostomate and answer their questions then to me it's all worth it!'

Since becoming a volunteer in 2008 Tom has lost count of the number of colostomates he's visited or spoken to at Open Days or over the phone. Nurses in Perth and Stirling ask him to talk to patients before or after their operations. Tom is very aware that there are many more new ostomates who would benefit from meeting someone else with a stoma, and feels it is a shame that not everyone who goes into hospital for stoma surgery is told about the CA and the support that our organisation can offer.

Along with representatives of the other patient associations (Ileostomy Association & Urostomy Association), Tom represents the Colostomy Association on the Scottish Stoma Forum. This is a committee which also includes the stoma care industry and healthcare professionals. Their aim is to ensure high quality stoma appliances and a wide range of choice to help ostomates achieve the best quality of life. Tom joined the forum in May 2009 and has been involved in discussions about the cost to the government of stoma care products and services, and the issue of sponsorship of stoma care nurses (in Scotland NHS posts are no longer sponsored by appliance manufacturers and suppliers). As a colostomate Tom

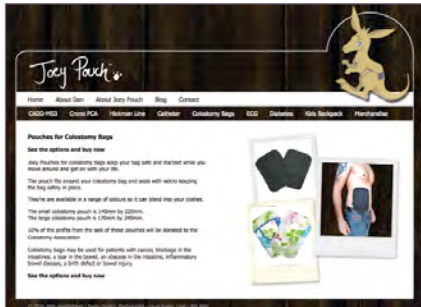
feels his role is to provide those in authority with a better understanding of the needs of people with a stoma and to persuade the government to take these needs into account before making decisions which affect the lives of ostomates.

Tom is always very busy attending Open Days organised by hospital stoma care nurses as well as appliance manufacturers and suppliers: during the first six months of 2010 he attended thirty-six. At present he is our only volunteer north of the border and covers the whole of Scotland travelling as far afield as Inverness in the north, Stranraer in the south, Kilmarnock to the west and Edinburgh to the east. On these, sometimes long, journeys Isabel often goes with him and they listen to CDs of Tina Turner and Abba as they travel the highways of Scotland. When you ask Tom why he does it he says, 'Even when my days are eight to ten hours long, if I can help just one ostomate and answer their questions then to me it's all worth it.'

Tom's message to all ostomates: 'One day at a time and enjoy every one of them.'

Update on new stoma care products and services

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



All about Joey Pouch...

Joey Pouch is the creation of Daniel Male. Daniel, now 29, was diagnosed with the terminal heart and lung disease (Primary Pulmonary Hypertension or PPH) at the young age of 20. After years of problems experienced when wearing a pump and Hickman line - Daniel designed the Joey Pouch to hold and conceal the pump rather than having it constantly falling out of his pockets!

Joey Pouches for colostomy bags keep your bag safe and discreet while you move around and get on with your life. Available in a range of colours. The small colostomy pouch is 140mm x 220mm. The large colostomy pouch is 170mm x 240mm.

How to get in touch...
Phone: 01872 575382
or 07500 338 480
Email: joeypouch@live.co.uk
Web: www.joeypouch.co.uk

Note: 10% of the profits from the sale of pouches will be donated to the Colostomy Association.

The Esteem synergy® Flat Mouldable stoma system from ConvaTec...

The Esteem synergy® Flat Mouldable stoma system from ConvaTec is an evolution in the design of stoma care solutions. The device is able to be moulded to the exact shape of your stoma, and actively adapts to your stomas movements throughout the day. As opposed to standard traditional cut to fit stoma systems, Esteem synergy® Flat Mouldable gives your stoma the gentle hug that it deserves, and minimises your need for any additional seals or pastes.

For further information
Contact: 0800 282 254 (UK)



STEALTH BELT

Stealth Belt Pro... is our newest ostomy support belt designed provide extra strong security and a full range of size adjustability. This belt makes a great starter belt. The Pro is ideal for people whose weight varies and for people who are active. Features include:

- Durable, high tech light weight stretchy fabric that is washable and flexible.
- Extra strong double closure system.
- The Pro Belt is fully adjustable. It may be tightened or loosened for a full sliding range of sizes.
- For more security during water sports or extreme sports the Pro belt may be clinched up to extra tight settings.
- May be worn for intimacy or sleeping, twenty four hours a day.

To learn more visit...
Web: www.stealthbelt.com
or Email: sales@stealthbelt.com

New models of Overkill Alarms available now...

The STOMALERT product which senses stoma activity was first shown at the Gaydon Open Day and received a lot of interest and helpful comments. Based on this feedback, two new variations to the original product are now available. The first of the new developments is a



vibrating alarm, for those with hearing difficulties or for those who do not want to disturb others. The second variation dispenses with the cable and uses a radio link to the alarm. This is invaluable for parents and carers who do not share the same room.

All three models are fully explained on their web site www.stomalert.co.uk with prices and order form.

OstoMART...

In response to many requests from nurses and patients alike we are pleased to announce the introduction of **OstoMIST Mint Spray** to compliment our wide range of Odour Neutralisers.

OstoMIST Mint Spray Odour Neutralising Spray - Highly effective odour neutralising drops and not a masking agent! The spray is effective with the worst odour problems. The 100ml and 50ml spray bottles compliment the rest of the OstoMIST range.

OstoMIST Mint Spray
Product Code:
SBL1 x 100ml Spray Bottle
SBL2 x 50ml Spray Bottle

Available on prescription from your usual supplier or direct from OstoMART: 0800220300

Samples are available now!
Call us FREE 0800 220 300 - OstoMART Ltd



OstoMART Ltd – Great News!...

The dedicated Customer Care Team at our Peterborough Service Centre have taken first place in the Peterborough Evening Telegraph Business Awards Customer Care Plus category beating off other local companies with their consistent and dedicated customer service. The photograph shows the team at Peterborough (l to r) Gillian, Helen, Louise, Kerry and Angela and in the background is Roger Black who presented the award.

kills 99.9%
of known bacteria

Two Thumbs Up!

The alcohol-free hand sanitiser
approved by the NHS.



EcoHydra

“Good enough
for nurses”

“Good enough
for me”

For your free sample call us on
freephone 0800 888 501



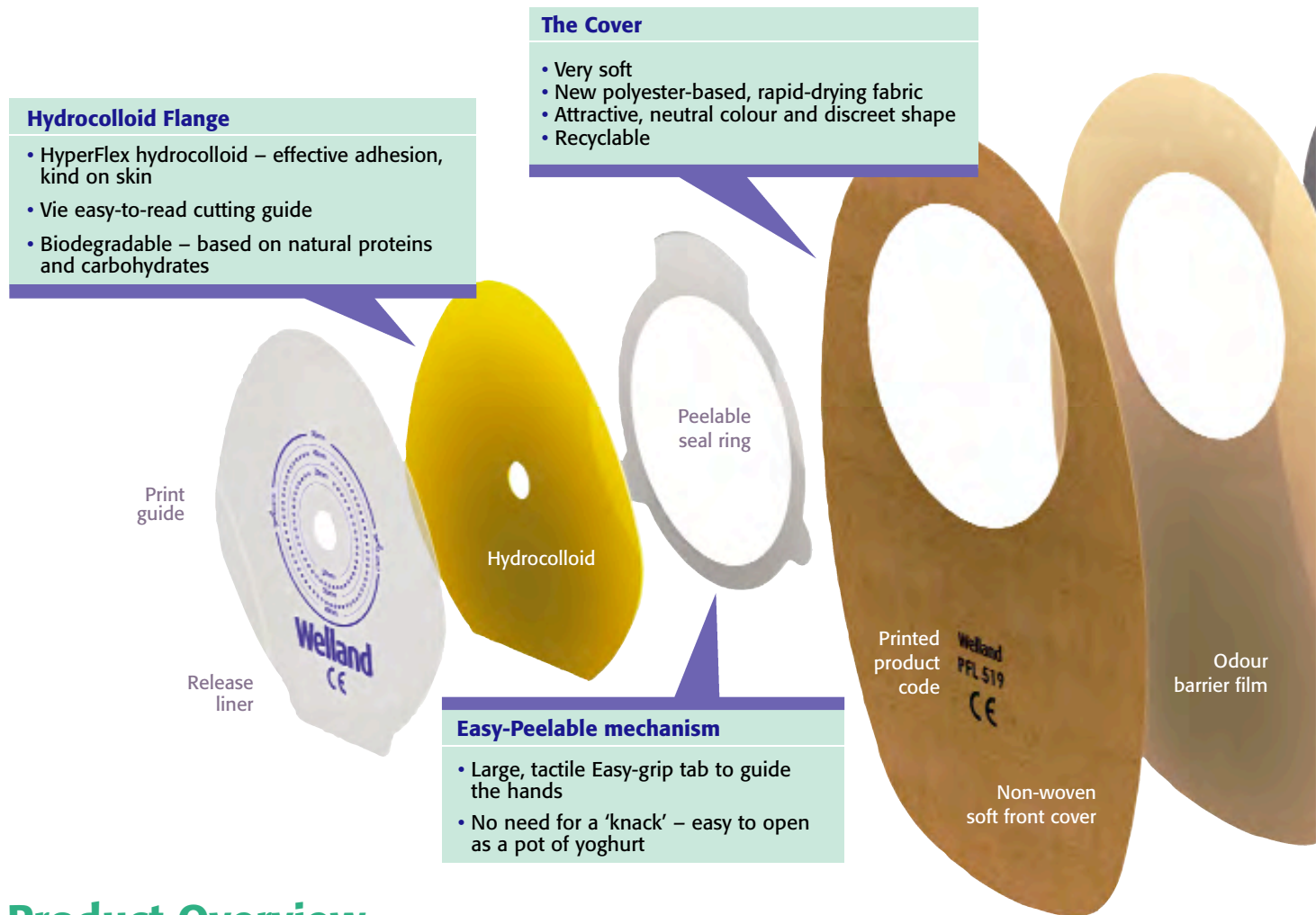
Use EcoHydra before and after pouch changes to reduce the risk of infection. EcoHydra sanitises hands instantly and repeated use throughout the day dramatically improves hand hygiene. It's also kind to your skin.

EcoHydra is available completely free of charge when receiving orders from Bullen Healthcare's fully customised home delivery service



In the first of a **NEW Series...Tidings** takes an **in-depth look at ostomy products...research and development, product trials and how a product finally comes to fruition.** We examine the finer detail of the product itself and learn about its key features and benefits...that can make a difference to ostomates and their 'quality of life'. In the spotlight this issue is...

FreeStyle Vie® Flushable...



Product Overview...

"Brilliant", "remarkable" and "20/20" are just a few of the numerous testimonials received for Welland's life-changing product, FreeStyle Vie Flushable. It's the most practical solution to pouch disposal there is, offering the security and comfort of a standard pouch combined with the convenience and green credentials of a toilet flushable liner.

You remove the outer cover as easily as a yoghurt pot lid, drop the biodegradable inner liner, flange and waste into the toilet bowl, and flush it away. The clean, recyclable outer cover can then be popped in your pocket or handbag, and into the most convenient bin or recycling unit. It's as easy as that!



Step One...It's easy...

But how did we come up with such a significant product, incorporating the world's first biodegradable flushable liner, and the only one-piece flushable on the market? And what actually goes on behind the cover? Lots of elements work together to create a

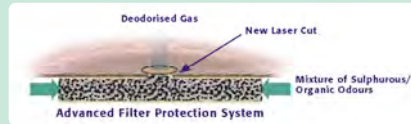
stoma bag, but in the finished product they are 'under wraps' so to speak! Here the designers of FreeStyle Vie Flushable have created an 'exploded' diagram of our product to show you how all the different parts fit together, and to help you decide if it will work for you.

The Journey...

The "Flushable" range was launched sixteen years ago, after 3 years of research and development. CliniMed and Welland had been listening keenly to patients' concerns and feedback. They realised there were some key issues which needed addressing urgently – issues which were affecting quality of life. One in particular was disposal of used

The Filter

- Vie laser-cut Dual-Carb filter
- Cleans gas of organic and complex odours
- Reduces ballooning
- Won't get blocked



The filter

Inner bag

Odour barrier film

Non-woven soft back cover

Unique Biodegradable Liner

- Liner in two parts: outer fabric and inner film
- Strong outer fabric maintains shape during wear, then dissolves on contact with water in toilet bowl
- Inner film collapses round faeces, 'shrink wrapping' them, allowing them to be flushed away
- Degraded by bacteria in the sewage system in the same time as normal waste

pouches. We heard too many stories about the embarrassment and distress caused by inadequate facilities, and clinical reports backed this up (e.g. White 2002).

Unfortunately there was no consistent guidance for ostomates, who were told in hospital either to cut the bottom off, empty and wash the pouch (often a messy business) and then dispose of it, or to place pouch and contents in a plastic bag and put it in the rubbish. Ostomates told us they found changing their pouch inconvenient, time consuming, unpleasantly odorous and indiscreet; in short, they found the whole process 'abnormal', and saw the ease of just flushing the lavatory as a thing

of the past. It was decided that we would develop a new product to deal with the problem of disposal..... and take a significant step towards life as it was before the stoma.

Our first flushable product was named Impact®, because it had just that: a life-changing, positive impact on users' freedom and peace of mind. And since then we have continued to develop and refine our flushable technology – the next big step being the introduction of the first of the FreeStyle® ranges, with its new, attractive shape, and more comfortable fabric on both sides. (And where appropriate, all the FreeStyle innovations were applied across our other ranges - so that the research

into our flushable bag benefited closed, drainable and urostomy pouch users as well).

And we didn't stop there. Our commitment to development means we are constantly improving our offerings to our customers – after all, satisfying users' needs is the sole purpose of our research. We know our customers are the experts, and we hold "focus group" meetings of users, run by our clinical research team, to understand and implement their suggestions. And of course we ultimately trial any new product with a large group of users to be sure we are fulfilling their needs. So in developing our "third generation" flushable technology we consulted groups of Stoma Care Nurses, our existing flushable users and closed pouch users of all brands, and with the information gathered we were able to move on to our latest biodegradable flushable range...FreeStyle Vie Flushable!

Unique Liner

The biodegradable inner liner is the really crucial part of FreeStyle Vie Flushable. It is the result of extensive experimentation alongside research and feedback – strength during wear versus solubility on disposal is quite a balancing act! – and it is completely unique to our products. Biodegradability was an important feature to develop: it has been estimated that approximately 36.5 million used ostomy appliances are sent to landfill sites in the UK each year (Black, 2000), so environmental responsibility was a priority.



Step Two...It's simple...

Separation

FreeStyle Vie Flushable's new Easy-Peel™ liner and Easy-Grip tab make changing much simpler for those with dexterity problems or impaired vision. Research showed that, in the past, more than 25% of people motivated to use a flushable bag could not continue due to difficulty with removal of the liner, maybe through poor grip or eyesight, or because they couldn't learn the 'knack'. Stoma



nurses were sometimes put off recommending flushable products because of the necessity of learning this knack – so we found a much simpler way to remove the inner liner when we designed FreeStyle Vie Flushable. Now, pouch changes can be completed far more easily and in much less time, making the whole process more discreet.

The Cover

The water-shedding properties of FreeStyle Vie Flushable's new cover means it really is like water off a duck's back! This helps prevent perspiration build up, and you can shower, bathe and swim without worrying about wet patches and discomfort: just pat down gently with a towel. The thin flange and neutral colour combine to create a discreet shape that's the perfect cover under clothing, and flushability means you don't have to carry so many accessories.

Flange

FreeStyle Vie Flushable is available in pre-cut sizes for you or your home delivery service to customise from your template, using the easy-to-read guide. A breathable film flange backing makes for a mouldable fit, improving comfort and avoiding leakage, and tabs make the flange easy to apply and remove. "A joy to wear" comments one happy customer.

The Filter

The FreeStyle Vie Flushable laser-cut Dual-Carb® filter removes organic and sulphurous odours and reduces the likelihood of ballooning by maintaining a steady flow rate. The filter won't get blocked – which is one of the root causes of ballooning – because the inner liner holds waste away from it. We knew odour was a big concern for ostomates, so we spent a long time finding out which carbons cleaned which types of gas – namely the sulphur containing odours (eggy smells) and the organic containing odours (rotten cabbage smells). We've mixed these carbons in the right proportions in the filter, so you can eat what you like without worrying. And changing is less odorous as well, as the waste is completely contained in the inner liner until you flush it away.

Tried and Tested

In tests based on the UK and European standard for domestic waste, 100% of liners flushed away first time. Independent evaluation at the Landesgewerbeanstalt Bayern (LGA) concluded that the pouch met or exceeded all European standards for toilet disposability. Meeting these standards means that the pouch can be flushed down any toilet which can

accept toilet paper; so as well as in your everyday toilet you can use FreeStyle Vie Flushable in portaloos, in the air and, with care, at sea.



Step Three...It's flushable...

Results from a study of 86 colostomates show that 37% would avoid going abroad, 33% would avoid air travel and 23% were reluctant to stay with friends (White, 2002). These findings are worrying – but we hope that anyone in this situation will feel encouraged to try FreeStyle Vie Flushable and the freedom it brings. Disposability makes it ideal for a wide range of situations, including visiting family and friends, holidays, travel, restaurants, cinemas and theatres ... and you can probably think of many more!

User and Industry Awards

When a pre-launch evaluation by a group of 120 patients endorsed all FreeStyle Vie Flushable's new features – we knew we had made a big leap forward in the journey towards the ideal flushable pouch. And since the launch in March 2009, praise for the product keeps on coming; it really has been changing people's lives!

One such person is Andrew McQuillan. As the Managing Director of a multinational manufacturing company, Andrew is always travelling and meeting new businesses and people. The problem of disposal used to be a constant one. Andrew notes that male toilets in particular are often very poorly equipped, without a shelf or a bin – so what are you supposed to do with used pouches? Carry them into your meeting?



Andrew in Rome on business

Andrew decided to give our flushable pouches a try, and hasn't looked back since. He says he can change quickly, change anywhere, and live more confidently. When he moved onto

FreeStyle Vie Flushable, the benefits were even better.

"Simple...easy...more secure", there's now "no smell, no fuss, no embarrassment" associated with changing. "[I] feel more normal", he declares – which is exactly what we're aiming for.

We have been proud to receive several awards along the journey to develop FreeStyle Vie Flushable. We won Millennium Product status (awarded to products which demonstrate innovation, creativity and are pioneering in their field), an Independent Living Design Award, and the Sussex Business Award for Innovation. We are also grateful to the Department of Trade and Industry for their grant of Stage I and Stage II SMART awards to support development of the product.

Now all we need is to spread the word as far as possible: that FreeStyle Vie Flushable can make a huge difference to everyday life and not-so-everyday life as well. It is CliniMed's aim to make a colostomate's life as 'close to normal' as it was before surgery, and being able to flush waste down the toilet without worrying about disposal is a big part of this. As one customer writes "I am a normal person. I can go away without thinking [of toilet arrangements]. I am confident, unembarrassed and that means a lot". And of course we'll keep working on improvements by listening to users' suggestions and ideas, as part of our ongoing research and development.

Our pouches with flushable liners have been listed on the Drug Tariff for the past 16 years, and ostomates have used nearly 18 million to date (including 2.4 million of the very latest FreeStyle Vie range). They are readily available on prescription alongside our standard colostomy bags. For a sample, or for more information about FreeStyle Vie Flushable or any of our products and accessories, please call our Careline on: 0800 036 0100. To see an example of Flushable in action go to <http://www.freestylevieflushable.co.uk/index.html>

FreeStyle[®] Vie
FLUSHABLE

References:

Black, PK (2000) Holistic Stoma Care, London: Balliere Tindall. White, Craig A. (2002) Pouch Change and Disposal Study – Final Report

NEW



v.secure

v.discreet

v.comfortable

and with an Easy-Peel™ flushable liner,

v.LIBERATING

FreeStyle Vie® Flushable is a new flushable pouch that's designed to make pouch wear and disposal simpler and more comfortable. As well as a soft outer layer and improved Dual-Carb® filter, FreeStyle Vie® Flushable has an Easy-Peel™, biodegradable inner liner that can be disposed of down the toilet. Imagine how convenient that could be!

CliniMed®



FreeStyle Vie®
FLUSHABLE

Manufactured by Welland® a CliniMed® Group company

For a free sample of FreeStyle Vie® Flushable, please complete the coupon and return it to: **CliniMed Ltd., FREEPOST HY241, High Wycombe, Bucks. HP10 8BR** (NO STAMP REQUIRED), call our free confidential Careline **0800 036 0100** or visit **www.freestylevieflushable.com**

Mr/Mrs/Ms: _____ Initials: _____ Surname: _____ Address: _____
Postcode: _____

Tel. No.: _____ E-mail: _____

I understand that this request will be handled by CliniMed Limited or SecuriCare (Medical) Limited. I would like my details to be kept on file, so that I can be kept up to date with information about relevant new products and services.

Manufactured by Welland® a CliniMed® Group company. Welland products are distributed in the UK by CliniMed Ltd. Tel: 01628 891100 Fax: 01628 623579 Email: inquiries@clinimed.co.uk or visit www.clinimed.co.uk. Fannins N.Ireland: 028 907 31581. Fannins Ctr: 0035 312 90 047. CliniMed Ltd, a company registered in England number 01648927. Registered office: Cavell House, Knowles Beech Way, Loudwater, High Wycombe, Bucks HP10 9QY. CliniMed®, FreeStyle Vie® and Dual-Carb® are trademarks of CliniMed Holdings Ltd. ©2009 CliniMed Ltd. 1048/0209

Pathways to a colostomy

Accidental Injury...leading to an emergency colostomy

For about one in a hundred colostomates their stoma is the result of an accident. Helen McTurk, now twenty-seven, tells us about what happened after she was involved in a severe car accident in August 1990, when she was only six years old.

Readers'
PANEL
contributor

The after effects of that day still have a huge impact on my life twenty years later. When I arrived at the hospital I was given an emergency colostomy, along with other life saving procedures and care. Things might have changed over the years, but back then emergency operations were just that!

The doctors and nurses had no time to try and make my body look as natural and 'normal' as possible. I was therefore left with a cobweb-like network of scars, and a huge stoma protruding from the right side of my abdomen. It was quite high up, sitting about 5cm (2 inches) below my last rib, and was about the size and shape of a golf ball. I know some of you out there might be thinking that it doesn't sound so bad, and there may even be some of you with stomas of similar dimensions. But I can tell you that on my small, fragile six year old frame, it was totally out of proportion. And as if things couldn't get any worse, I had the bags to deal with.

Back then there were only a handful of companies who produced stoma bags, and they were all pretty much the same. Big, bulky and made with only basic plastic, they would look very crude when compared to today's equivalent. I think it's easy looking back to understand why I took to the stoma like a brick in water, sinking with a feeling of confusion, immaturity along with the normal innocent questions about the body, that most children have. It is no surprise that it didn't take too long for the childish act of rebellion to rear its evil head. This ended up with me totally neglecting my stoma, resulting in my parents and stoma nurses providing 100% responsibility in making sure my bag was emptied and changed when needed. With time I did learn



My stoma was one year old on the 11th of November, and it's been an amazing year! My diary has been full most weeks with outings, meals and parties that would not have been possible before having my stoma.

and understand the need to take care of my own hygiene requirements, and eventually became more independent.

As time progressed, and I was entering my mid teenage years, I heard the news I had been waiting for. After ten years of living with the stoma, the doctors were now talking about the possibility of a reversal. They were not sure what the outcome would be, or if it would work at all. I was more than willing to give it a try.

It didn't all go to plan, but I did manage to live a relatively "normal" life for ten years. However, my bowel was so unpredictable; I suffered with incontinence on a daily basis. I missed more meals than I would like to remember, I left hundred's of parties and social events early, then I just couldn't take anymore.

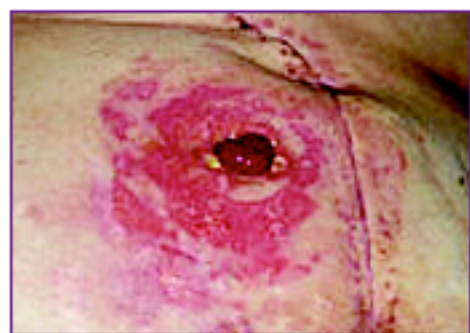
So the time came to talk to my partner of four years, about my plan of rehabilitation in to society. I'm incredibly fortunate to have a very supportive package of family and friends that made it a relatively easy transition.

My stoma was one year old on the 11th of November, and it's been an amazing year! My diary has been full most weeks with outings, meals and parties that would not have been possible before having my stoma. This has ended up with me gaining some much needed weight, which is a first for me. I am now in my second year of training to be a nurse and my confidence has grown so much; I sometimes forget I even have a stoma. I'm not going to lie and say that I don't have bad days, but those days are now few and far between.

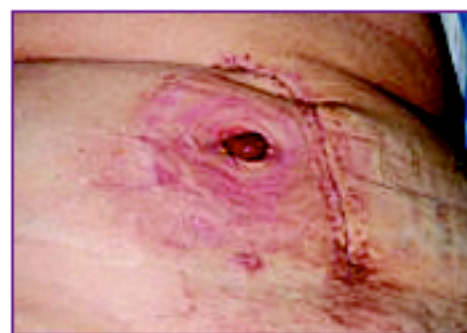
Does the skin around your stoma sometimes become **RED or IRRITATED?**



Pelican Healthcare are now the sole UK Distributor of **Eakin Cohesive® Seals . . .**



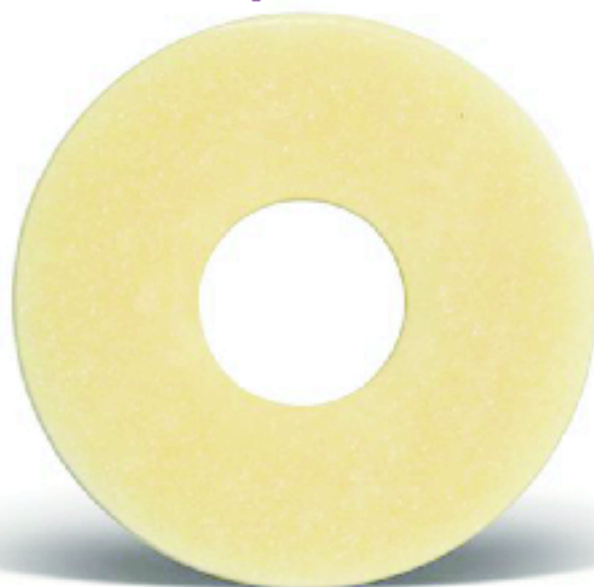
Day 1



Day 4

Eakin Cohesive® Seals will provide a complete seal around your stoma and prevent leakage and skin irritation.

Eakin Cohesive® Seals will help repair sore and red skin.



To obtain your complimentary samples of Eakin Cohesive® Seals, please complete and return this coupon to:-

Pelican Healthcare Ltd Freepost Licence No. CF1933 Cardiff CF14 5GX
call: **FREEPHONE 0800 052 7471** or e-mail: contactus@pelicanhealthcare.co.uk

Name (Mr/Mrs/Miss/Ms):

Address:

Post Code:

Cohesive SLIMS® (48mm diameter)

Use for frequent pouch changes and everyday skin protection

For further information on the Pelican Home Delivery Service please tick

pelican
HEALTHCARE
an eakin company 

Sophie Medlin BSc RD Colorectal and Nutrition Support Specialist Dietitian at Torbay Hospital, South Devon Healthcare NHS Foundation Trust writes for Tidings on aspects of diet and your stoma...



Courtesy of South Devon Healthcare Foundation Trust

In her second article for Tidings - Sophie provides advice on how to lose weight. She considers why some ostomates may find this difficult and suggests solutions.

New Year... New You!

Losing those extra pounds after Christmas can be difficult when you have a stoma. Many people gain unwanted weight following stoma surgery due to changes made to their diet in an effort to control their output.

A good way of assessing whether you need to lose weight is to calculate your Body Mass Index (BMI). Your BMI measures how heavy you are in relation to your height and can be calculated using the equation; Divide the weight by the height squared. For example, you might be 1.6m tall and weigh 65kg. The calculation would then be: $1.6 \times 1.6 = 2.56$. Then divide 65kg by $2.56 = 25.39$.

- If your BMI is below 18.5 you are underweight and should not be looking to lose weight. If you are under weight and are struggling with your appetite speak to your stoma nurse or GP who can support you and may refer you to a dietitian.
- If your BMI is between 18.5 and 24.5 you are within the healthy range, which shows that you're a healthy weight for your height. However, it's still important to eat a healthy, balanced diet and include physical activity in your daily life.
- If your BMI is 25.0 or more this is above the ideal range, which means

that you're heavier than is healthy for someone of your height. Excess weight can put you at increased risk of heart disease, stroke and type 2 diabetes, so losing your excess weight is advisable.

You may be interested to know what your weight was prior to your stoma formation; your stoma nurse or consultant should have a record of this. Gaining excessive weight following stoma formation can lead to stomal retraction (where the stoma sinks into a skin fold or dip in the abdomen) and hernias which can cause complications fitting devices and may require further surgery.

Unfortunately there isn't an easy solution to losing weight. Despite what you may read in magazines or on the Internet, the only way of successfully managing your weight for good is making small changes to your lifestyle. Try to accommodate more physical activity and make healthier food choices. While fad diets may reduce your weight quicker, keeping it off is another matter. Sometimes it seems that all 'healthy' foods are high in fibre and can cause unwanted side effects. While high fibre foods are good for keeping you fuller longer, they are not the be all and end all of reducing your weight and, therefore, people with stomas should still be able to reduce their weight successfully without adverse consequences.

A balanced approach - Your overall diet should be well balanced and include a wide variety of foods from all food groups. Making small changes

to all the food groups can help you to reduce your weight gradually and keep the weight off.

Starchy foods such as bread, rice, pasta and potatoes: These foods should make up roughly a third of your overall diet. You should have a starchy food with each meal, as they are filling and low in fat. But beware of adding butter or spread, creamy sauces or oils to starchy foods, as this will increase their calories. Remember, starchy foods which have been cooked, chilled and are then heated for eating, i.e. ready meals, pasta and rice salads or reheated food from previous meals, become 'resistant starches' making them difficult to digest and liable to cause bloating and increase stoma output.

Milk and dairy foods: Try to eat calcium rich foods such as dairy produce every day. However, dairy foods can be high in fat, which promotes weight gain. Choose low fat dairy produce such as skimmed milk and lower fat cheeses and yoghurts to help reduce fat and calories in your diet to aid weight loss.

Foods and drinks high in fat and/or sugar: These should only be consumed in small quantities or as a treat as they promote weight gain and generally have little nutritional benefit. Included in this section are fats, oils and spreads which should be limited. You may find that avoiding buying cakes and biscuits reduces the temptation to have them so often.

Meat, fish, eggs, beans: These are excellent sources of protein, which are

essential for good health. Women should have two portions of protein rich foods per day, and men three. Again, choose low fat options. Lean meat with all visible fat trimmed off will also help to control your weight.

Fruit and vegetables: These are excellent sources of vitamins and minerals and the vast majority are very low in calories and fat. Unfortunately the high fibre content of fruit and vegetables can affect stoma losses and make these foods more difficult to tolerate. Peeling fruit and vegetables and cooking them well can help with these problems.

If fruit and vegetables do cause you a problem, you may find it difficult to choose healthy snacks. Here are some low fibre, low calorie snack ideas to keep you going in the afternoon:

- Cracker breads or rice cakes with bovril/marmite or extra light cream cheese
- Low fat yogurts
- Cup-a-soups (slimming variety)
- 2-3 rich tea fingers
- Sugar free jelly

Fats - There is much written about healthy and unhealthy fats and their pros and cons. While it is important to be aware of the types of fats you consume, from a weight loss perspective it is good to remember that all fats gram for gram have the same amount of calories. This means that butter has the same amount of calories as olive oil. Therefore all fats should be consumed in lower quantities if you want to lose weight.

Portion size: Perhaps your diet and stoma output are in delicate balance and, although you do want to lose weight, you are worried about making any changes due to the risk of unwanted side effects. Or maybe you feel you are eating the right things and still not losing weight. Reducing your portion size is a fool proof way of reducing your calorie and fat intake, promoting weight loss. Here are some tips to getting portion in perspective:

- A portion of cheese is a small matchbox sized piece – around 30g.
- A portion of meat should be roughly the size of the palm of your hand – between 60-90g depending on your size and build.
- Check food labels, the calories and fat may be listed as per 100g, not per portion.
- Try a smaller plate – a side plate may help you to control your portions.
- Measure out fat and oil to keep the amount you use under control.
- Eat your food slowly and chew every mouthful for longer, this helps you feel fuller quicker.

| All per 100g | Low: a healthier choice | Medium: fine in moderation | High: only have occasionally |
|--------------|-------------------------|----------------------------|------------------------------|
| Sugars | 5g or less | 5.1-15g | More than 15g |
| Fat | 3g or less | 3.1-20g | More than 20g |
| Saturates | 1.5g or less | 1.6-5g | More than 5g |
| Salt | 0.30g or less | 0.31-1.5g | More than 1.5g |

Traffic light system applied to food labels makes it easier to choose healthy options

(Information courtesy of the British Heart Foundation)

Calorie Counting and Food Labels -

Keeping an eye on your calorie intake can also help you lose weight. Women should aim for around 1200-1500 kilocalories (Kcals) per day and Men 1500-1800kilocalories. Checking food labels will give you more information about the nutritional composition of your food.

Alcohol - Alcohol is very high in calories, which have no nutritional benefit. Be aware of the extra calories you could be consuming from alcoholic beverages.

Average calorie content of alcoholic drinks:

| | |
|-------------------------|-----------|
| Bitter: | |
| 1 pint | = 170kcal |
| Cider: | |
| 1 pint dry | = 204kcal |
| 1 pint sweet | = 238kcal |
| Premium Lager: | |
| 1 pint | = 482kcal |
| Red Wine: | |
| 125ml (small) glass | = 85kcal |
| Dry White Wine: | |
| 125ml (small) glass | = 82kcal |
| Medium White Wine: | |
| 125ml (small) glass | = 92kcal |
| Sweet White Wine: | |
| 125ml (small) glass | = 117kcal |
| Spirits: | |
| per 35ml measure | = 66kcal |
| (not including a mixer) | |

Physical activity - Physical activity is very helpful in weight management and will burn calories and promote weight loss. It also has many other health benefits. If you are considering taking up a new exercise regime you should first discuss this with a member of your healthcare team. Many GP surgeries now offer 'exercise on prescription' schemes, which give you the opportunity to increase your physical activity levels in a safe and controlled way.

Excellent sources of further information include:

- NHS: www.nhs.uk
- The British Heart Foundation:
Tel: 020 7554 0000
Web: www.bhf.org.uk/
- The Food Standards Agency:
General enquiries - Helpline
Tel: 020 7276 8829
Email: helpline@foodstandards.gsi.gov.uk
Web: www.eatwell.gov.uk/

Your diet questions answered...

Q: *In Diet and Your Stoma (Tidings Issue 19) it states that: 'the last part of the small bowel (terminal ileum) absorbs vitamin B12 so if you have had your terminal ileum removed you may require three monthly vitamin B12 injections.' In April 1998 I had my rectum and part of the large bowel removed due to cancer. A month later I had adhesions and had an operation to remove part of the bowel (and other affected parts) to clear obstructions. I am not sure if any of the small bowel was removed. However, I now have a stoma. I visited my doctor to discuss my feelings of tiredness and low mood. He suggested various diet changes, rest etc. but nothing was said about B12. Do you think this could be a cause? I have been feeling very, very tired and listless for a long time but hesitate to visit the doctor again, unless lack of B12 might be the cause.*

A: Without your full surgical history it is difficult to know if B12 deficiency is the cause, your description of the surgery certainly suggests this may be the culprit of your symptoms. Your GP can check your B12 levels with a simple blood test and can commence treatment if needed. Other symptoms of vitamin B12 deficiency include problems with concentration so if you still feel this may be the problem I would suggest you make another appointment.

Insurance and the Ostomate...

Taking on Travel Insurance...Duncan Wells UK voice over artist and ostomate - tracks down insurance providers...examines the small print and provides us with a factual account based on his research...



Insurance companies are not very imaginative and if you present them with something they have not come across before they will either refuse you insurance or charge you an enormous premium. However, having got off to a bad start, insurance companies are being much more sensible in their dealings with ostomates...

The first point to remember when asking for insurance is to declare everything. Declare the stoma and the medical condition that resulted in your stoma. And don't forget to declare any other pre-existing medical conditions. If you fail to do this it may invalidate the insurance.

The second point is to shop around.

Now let's get a couple of insurances out of the way to start with. Being an ostomate will not affect your household insurance (contents or fabric) or your car insurance, assuming you are declared medically fit to drive.

However, because a stoma is the result of some other medical condition, being an ostomate may affect a number of other insurance areas including; Life Insurance, Medical Insurance (BUPA etc.), Critical Illness Insurance, Mortgage Insurance, Travel and Medical Insurance and Key Person Insurance.

Leaving Life Insurance, Mortgage Insurance, Medical Insurance (BUPA etc), Critical Illness Insurance and Key Person Insurance on one side, because clearly any illness or medical condition will have a significant impact on these, we are left with Travel Insurance.

The more recent your surgery and the longer your stay in hospital the higher the premium loading is likely to be. In insurance terms 1 year is a good milestone. If you have been out of hospital and treatment free for a year then this will help to keep the loading of the premium down. If you decide to travel 11 months after your treatment it might be worth delaying this until 12 months have passed as you may well benefit from a better premium. It is worth speaking to the specialist insurance companies who understand medical conditions. There may well be a loading on the premium but this is likely to be a great deal less than you would pay

with a mainstream insurance company. There have been instances when mainstream insurance companies have charged cancer patients 10 times the normal premium. And recently someone was quoted travel insurance at £1000 for a 2 week stay in the USA which a specialist company arranged for just £180.

If you have had a stoma for a number of years and do not need medical attention for this or the condition that caused it you will be very unlikely to have to pay a loading on the premium. And you may get the best rates by approaching the mainstream insurance companies because you and your condition may well fall outside their area of concern.

You may also be asked about certain types of medication such as anti depressants. Anyone who has experienced long term hospitalisation or a reasonable stay in ITU will have been given anti depressants by the hospital. Always declare exactly what you are taking. Generally as long as you have not been admitted to hospital with a mental illness within the last 12 months, the taking of anti depressants should not affect the premium.

It is also possible with insurance companies to elect not to insure the pre-existing medical condition or stoma, if you don't think anything will go wrong or you feel that you can handle it. Mind you, if you opt for this and the pre-existing medical condition results in hospitalisation during the period of insurance and repatriation, you will be in for a big bill. Repatriation by air from Europe costs in excess of £25,000 and then there will have been the medical costs in the country where you were staying.

If you do have a complicated pre-existing condition that requires treatment it may be better to speak to the specialist medical insurance

companies because their staff are likely to be more understanding and informed about your condition. There have been comments from people in the past that mainstream travel insurance company call centre staff have been insensitive and have asked whether callers had a "terminal diagnosis". On occasion they did not know what a mastectomy was. On that basis, describing your ostomy is likely to go way above their heads.

So who are these 'enlightened' specialist insurers?

• **InsuranceWith.com**

(www.insurancewith.com) was set up by Fiona Macrae who saw a gap in the market. She says she was moved to start the business after being diagnosed with breast cancer in her thirties and found it difficult to get cover afterwards. "I had worked in the insurance industry and felt a better service could be offered." Another advantage of dealing with a specialist insurer is that their medical help line staff may well be able to understand your needs better, in the event that you have to claim. For example all the medical help line staff at Insurancewith.com are doctors.

Here are some other specialist insurers.

• **Free Spirit (www.free-spirit.co.uk)**
Considered to be good.

• **All Clear Insurance**
(www.allclearinsurance.com or www.allcleartravel.co.uk) – their approach is rather broad brush and their screening process is not that deep so they may well quote high premiums for minor conditions and low premiums for conditions that should command a higher premium.

• **Freedom Insurance**
(www.freedominsure.co.uk) – You can't deal with them online, only over the phone. Again they don't delve too deep.

Many mainstream insurers will refer customers to specialists. Axa (www.axa.co.uk), for example, refers customers to Freedom Insurance, while Aviva (www.aviva.co.uk) puts clients in touch with All Clear Insurance. Other mainstream insurance companies that take an enlightened approach to insuring people with pre-existing medical conditions are; Royal Bank of Scotland (www.rbs.co.uk),

City Bond Sure Travel
(www.citybond.co.uk or www.suretravel.co.uk),
Saga (www.saga.co.uk),

Don't just ring one specialist, as ever it pays to shop around as quotes can vary substantially. A recent 'mystery shopping' exercise showed that Insurancewith would charge a 63-year-old woman with a history of breast cancer £30 for a two-week holiday in Cyprus. All Clear Insurance, on the other hand, quoted £85 for the same insurance.

And if you need further advice, you can always contact the Association of British Insurers, at:-

Association of British Insurers
51 Gresham Street,
London,
EC2V 7HQ
Phone: 020 7600 3333
Email: info@abi.org.uk

Very Important...If you are travelling in the European Economic Area EEA you should always carry a European Health Insurance Card (EHIC replaces the old E111) as well of course as your travel insurance.



This allows you to benefit from reciprocal health agreements in EEA countries and will entitle you to free or reduced cost medical care in the country you are visiting, although you may have to pay for certain things at the time and then claim the money back later.

The EHIC doesn't cover you for any medical treatment you have planned in advance, only for medical emergencies, although it will cover you for continued treatment for an ongoing illness while you are abroad, such as regular injections.

The European Economic Area EEA Countries included are...Austria, Belgium, Bulgaria, Czech Republic, Cyprus, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland*, Ireland, Italy, Latvia, Liechtenstein*, Lithuania, Luxembourg, Malta, Netherlands, Norway*, Poland, Portugal, Romania, Slovakia, Slovenia, Sweden and United Kingdom.
*Part of the EEA but not part of the European Union (EU)

You can apply for a card by phone on 0845 606 2030 or on line at www.ehic.org.uk or by post – pick up an EHIC form from the Post Office.

Please be aware that: reciprocal health service agreements do not always cover the full cost of treatment. They do not cover the cost of getting you home in an emergency, for instance. It is always advisable to have travel insurance even when travelling around the EU. But you'll still need a European Health Insurance Card because your insurance company may not cover the cost of treatment that the card covers.

If you try to claim in full, they may say you should have had a card! Always read the small print. You can find out about these health agreements in the 'Health Advice for Travellers' booklet available from your Post Office. And of course the level of the premium is also governed by where you are travelling. In the USA medical costs are very high and premiums reflect this. Next comes the rest of the world and then we have Europe where medical costs tend to be the lowest and attract lower premiums.

Happy holidays and I hope this information will help you get affordable travel insurance premiums. Me? I happen to be with Saga because that's who Sally got reasonably priced travel insurance from when I came out of hospital. But as soon as it comes up for renewal I'll be giving Insurancewith a chance to quote!

The following page provides a list of Travel Insurers extracted from the Colostomy Association Fact sheet...

Insurance and the Ostomate...

Following is a list of insurance companies that specialise in providing cover for ostomates:

• **CATIP (CA travel insurance policy)**

A policy designed for ostomates by an Ostomate.

Contact details:

Tel: 01202 512161

E-mail:

peter.martin@bournemouthinsurance.com

Web:

www.bournemouthinsurance.com

• **Leisure & Lifestyle Insurance**

Specialist insurance for people who have a stoma, No age limit for single trips 75 for annual and then Assessed.

Contact details:

Tel: 08445 763029

Web:

www.leisureandlifestyleinsurance.co.uk/
specialist-travel-insurance

The insurance companies listed below will cover ostomates. We recommend that you contact at least four companies as quotes can vary:

• **Age Concern**

Will insure pre-existing medical conditions and cancer with medical screening. No age limit.

Contact details:

Tel: 0845 6012234

Web: www.ageconcern.org.uk

• **All Clear Travel Insurance**

Will insure pre-existing medical conditions with screening. Annual policy age limit 70years. Single policy, no age limit.

Contact details:

Tel: 0845 2505250

Web: www.allcleartravel.co.uk

• **Chartwell Insurance**

Will insure pre-existing medical conditions with screening. Annual policy age limit 64. Single trip 79

Contact details:

Tel: 0800 6524652

Web: www.chartwellinsurance.co.uk

• **Columbus Direct**

Please ring for medical condition/s cover. Various offers, can be aged up to 99.

Contact details:

Tel: 0800 0680060

Web: www.columbusdirect.com

• **Free Spirit**

Will insure terminal conditions. Ring for quote. No age limit.

Contact details:

Tel: 0845 2305000

Web: www.free-spirit.com

• **Insurance With**

Created specifically to help those suffering from medical conditions to get travel insurance.

Contact details:

Tel: 0845 2307159

Web: www.insurancewith.com

• **JD Consultants**

Will insure pre-existing conditions with screening. No age limit.

Contact details:

Tel: 01689 859102

Web: www.jdtravelinsurance.co.uk

• **Leisurecare**

Covers cancer related conditions, phone for personal service during office hours.

Contact details:

Tel: 01793 750150

Web: www.leisurecare.co.uk

• **Marks and Spencers Ltd**

20% cheaper if booked online.

Tel: 0800 731 2424

Contact details:

Web: www.marks&spencer.com/
travelinsurance

• **Travelbilty**

Travel insurance company especially created for people who are disabled and those with pre-existing medical conditions. Subject to screening. Annual 69, single trip 79.

Contact details:

Tel: 0845 3381638

Web: www.travelbilty.co.uk

• **Worldwide Travel**

Will insure pre-existing conditions with screening. Age 74 for annual and single trips.

Contact details:

Tel: 01892 833338

Web: www.worldwideinsure.com

Note: It is crucial to let your insurance company know of any pre-existing medical conditions. If not, the claim will be deemed invalid and rejected on the grounds of non-disclosure.



Planning a trip or holiday this year?

The Colostomy Association has a Travel Advice leaflet that could really help you plan your journey. There are also two types of Travel Certificates available in European languages and Arabic, Hindi, Mandarin, Thai and Vietnamese.



Contact: 0118 939 1537 for your FREE copies today...

Editors Comment

Kind thanks to Duncan Wells for his time collating and writing this article. If you have Travel Insurance tips and experiences to pass on please

write to:

The Editor, Tidings Magazine
Colostomy Association
2 London Court East Street
Reading RG1 4 QL

e-mail:

editor@colostomy association.org.uk

e-mail:

cass@colostomy association.org.uk

Tel:

0118 939 1537

Live life **to the full**



Life is rich, exciting and diverse ...and we think it should be enjoyed!

Life doesn't have to be limited when you need to use a medical appliance.

Have your supplies delivered straight to your door, freeing up your time to live life to the full.

- Delivery to any UK address
- Quick, discreet and reliable service
- Complimentary accessories with each order
- Comprehensive sample service
- Overseas Emergency Cover – World Assist Alliance
- Helpful, friendly and knowledgeable staff

We are open 6 days a week:

8am to 8pm Monday to Friday

9am to 1pm on Saturday



SPECIALISTS IN HOME DELIVERY OF MEDICAL APPLIANCES

www.fittleworth.com

email: caring@fittleworth.com

Freephone National **0800 378 846**

Scotland **0800 783 7148**

Birthday celebrations

Colostomy Association Open Day 2010

A great birthday present gradually revealing its generous content and hidden surprises!



'I really enjoyed it... What a great day...great speakers! It was my first experience of a CA Open Day I will definitely come to the next one'...

These were just a few of the many comments from ostomates attending the recent Colostomy Association Open Day 2010 last October.

And what a day it was too packed full of information and inspiration!

A little background...prior to Saturday 16th October, in fact early May, several venues were considered to host the CA Open Day. The winner hands down was the Heritage Motor Centre, Warwickshire; it really did tick all the boxes! Kindly sourced and sponsored by CliniMed/SecuriCare Medical.

A small steering group began planning the open day. The group included Sue Hatton Executive Trustee, Mary Thomas Trustee, Richard Bray General Manager and CA staff member Jo McKenzie. Jane Wood donned a different hat and brought her many years of experience in event and exhibition management to the table. Maureen Kelly-Smith PR Manager CliniMed/SecuriCare Medical sat in to give the exhibitor's viewpoint.

As you can imagine all kinds of ideas and suggestions come up for consideration when organising any event some are adopted whilst others are discarded. The weeks leading up to the event came and went. Other sponsors came on board, Salts Healthcare, Coloplast, ConvaTec and OstoMart, kind thanks to them all.

Discussions continued...queries, emails, telephone calls, written documents, visits to the venue, requests for speakers, meetings and much more. The event required constant monitoring. Nothing could be left to chance!

Finally the message in the diary read...CA Open Day Saturday 16th October, venue, the Heritage Motor Centre near Gaydon, Warwickshire, start time 10:00am. It was CA Day!

Members of the steering group arrived at the venue the day before. On entering the Conference suite they found several early exhibitors were already fitting out their stands. The sound desk, lights, and PA system were also being installed and tested. CA had three areas to set up: specialist discussion, volunteer and CA main stand. While some work finished around 5pm, the venue's event coordinator and team carried on with their preparations into the evening.

Saturday dawned...the response to the Open Day invitation had been good but as with any organised event you never really know how many people will come, until the day, you can only hope they will! Everyone waited filled with nervous anticipation and excitement! As the clock ticked towards 10:00 am, ostomates, their partners and family members arrived. In amongst them CA Trustees past and present, CA volunteers, VIP guests, and presenting speakers.

Gathering was an eclectic mix of people, a mini snapshot of individuals involved in and representing the world of stoma care. Ostomates, Healthcare professionals, National patient support groups, Online patient support groups, Manufacturers and suppliers of stoma care products, all brought together in an atmosphere that promoted the positive aspects of 'living with a colostomy'.

A murmuring buzz built as people drifted into the Conference suite. Two large illuminated projection screens emitted warm messages of welcome to the gathering audience. The 34 round



tables with 8 chairs around each were virtually hidden by some 270 attendees sitting chatting ready for the off. Guests were grouped around the six or so exhibitor's tables whilst others were still in the gallery amidst the displays of stoma care products.

By 10:45am it was time to 'mic up' the speakers. As everyone began to settle, Sue Hatton made her way onto the stage and up to the lectern to welcome everyone in her inimitable style and wearing a specially designed CA polo shirt! Sue's welcoming address discussed the importance of open days, outlined the day's agenda and mentioned the inevitable housekeeping. Sue then handed over to CA's indefatigable President, Professor Bill Heald OBE.

Professor Heald took to the stage, generously congratulating the CA on its achievements to date. Professor Heald outlined his hopes and aspirations for the Colostomy Association. He talked about the potential for surgeons to discuss irrigation with patients prior to surgery. He suggested surgeons leave more bowel in place where possible to give patients choice offering the opportunity for irrigation. He also hinted that surgical practice methods at the close of a patient's operation could be improved leading to better stoma formation and with it an increase in patients' quality of life. Professor Heald delighted in taking questions from the audience on a variety of stoma related topics, passing some queries by CA stoma care nurse Amanda Gunning RGN for comment. On occasion Professor Heald became very animated and excited by the content of the

queries and conversations, which highlighted the importance of open days and the enormous benefit of open discussion.

Next to speak should have been Mr. Ian Daniels FRCS. However, Ian had been delayed due to performing emergency surgery and was on the Motorway making his way up country from Devon. That's real dedication and commitment for you! We'll catch up with Ian later.

So with the agenda slightly changed and a request to speak earlier than was anticipated accepted! The indomitable Siobhan Crowther Manager of Lynn's Bowel Cancer Campaign stepped forward! Siobhan walked onto the stage wearing an attractive spotty dress! What's so unusual about that you ask? Well as you may or may not know in November the charity organises a "Dress Spotty Day" or "Spot the Symptoms Day" to raise awareness of the need to spot the symptoms of bowel cancer. Everyone is encouraged to dress "spotty". Hence the spotty dress!

Siobhan outlined the need for bowel screening especially if bowel cancer is already in your family and explained about the screening programme and the simplicity of the test kit. In conclusion, Siobhan said, "Bowel cancer is preventable, treatable and curable". Siobhan took several questions, one in particular a query on screening and the age of a family member - Siobhan's answer, "If you are concerned about a loved one and know your family history, and think there is a risk of them developing bowel cancer, ask them to go and see their GP".

Completing the morning session, taking to the stage to tell their stories and raise awareness for their much beloved charity Breakaway, came its Founder Julie Bastin, together with her brave daughter Hannah! They were followed by several other courageous youngsters with members of their families and Gail Fitzpatrick, Paediatric Stoma Care Nurse and Breakaway Trustee. Here are a few words from Julie...

"We arrived at the venue and, as usual, my nerves kicked in as our time arrived to speak! Gail Fitzpatrick, Paediatric Stoma Care Nurse and Breakaway Trustee, Carol and her son Fergus (15) Ainsley (18) Joshi (17) and his Mum Karin, Tara (17) and my Hannah, nervously walked onto the stage and sat in a group together.

After a few minutes, the adults could have left the stage and left the 'kids' to it. They took over and spoke so openly about their stomas, about growing up with one, about living life as a teenager with one and about what Breakaway means to them. Fergus summed up Breakaway, 'I was 12 hours old when I had my colostomy, but was 12 years old before I met anyone like me, that's the difference Breakaway makes!' It was truly humbling to listen to them speak. I have known some of them for three years now and to see how they have flourished is amazing. I am so proud of them all!

A huge thank you to the Colostomy Association for inviting us to their Open Day and very special thanks to Sue Hatton, who made a request to raise funds for Breakaway right after our presentation! Open Day attendees and

guests raised an amazing £421.30. Reena Patel Product Marketing Manager for Convatec matched the amount bringing it to £842.60! This money will go directly to families who without financial support would be unable to attend a Breakaway event".

Time for refreshments! For the attendees a chance to stretch their legs, chat and visit more than twenty exhibitors' stands to catch up on the latest stoma care products or visit the Museum. For the CA, an opportunity to sell raffle tickets to raise funds for the Association and to explain some of the fantastic prizes on offer. For others, a little breather and quick coffee, then off to seek out the missing afternoon speakers - Mr Ian Daniels and now also...Mr Glyn Davies MP! Coming towards the Conference suite doors was...Yes! You've guessed it! Mr. Ian Daniels FRCS trailing a large laptop bag behind him, arrived! Yeah! He'd made it! To give Ian sometime to relax, load, and test his presentation the lunch period was extended slightly.

At just gone 1:30pm people were still arriving. It was great! Buzzing! But how to get everyone back into their seats, a tricky task I hear you say! Especially when they could be anywhere within the venue! How was it done? Well by the public address system of course! 'Ladies and Gentlemen would you please take your seats the next session is about to begin - thank you'.

Taking the lectern for the afternoon session was Mr Ian Daniels FRCS Consultant General & Colorectal Surgeon at the Royal Devon & Exeter Hospital. Mr Daniels treated the audience to an excellent and fascinating overview of Parastomal Hernias – Cause and Treatment (an often common complication of stoma formation). He discussed the reasons why a patient may be more susceptible to herniation and talked about the new thinking on stoma siting. Placing the stoma through the belly (front) of the rectus muscle to reduce the rate of herniation using the muscle to provide more support.

In what can only be described as a great atmosphere, ostomates were encouraged to ask questions. Two roving mikes were made available and although it was a tight squeeze at times to get round to people most of the queries asked were answered! Several ostomates standing to give their thoughts and thanks for the day!

Worryingly there was still no sign of Mr Glyn Davies MP. So, the lovely deep

voiced Duncan Wells, one of the UK's top radio and television voice over artists who had previously agreed to be a stand in speaker got ready! Some of you may remember reading Duncan's remarkable story in 'Pathways to a Colostomy' in Tidings Issue 12 called 'Blown Up'. Just as Duncan headed towards the stage Mr Glyn Davies MP appeared, he'd made it too! Great! But needed a breather! Duncan went on stage, his voice quickly had the audience transfixed as he entertained with his incredible story of his own medical trials and experiences, traumatic though they were. Conjuring visual pictures interspersed with notable quips he had the audience laughing and clapping! Thank you Duncan – great job!

As time was running short and the presenters were so good it was decided to run with the rest of the original agenda. Up next came Vanessa Denvir gorgeous CA volunteer of "Embarrassing Bodies" fame! Vanessa wove a spellbinding story talking about her surgery for Crohn's related cancer. Plus experiences that led her to want to volunteer for CA and other notable charities namely IA and NACC. These life-changing events revealed her to be the creative and talented young woman that she is today! Vanessa really is someone who through her own positivity continues to dispel the stigmas and myths that surround ostomates bringing to others a better understanding of what life is like 'living with a colostomy'.

At last...Glyn Davies MP for Montgomeryshire followed – Glyn had spoken at the very first Colostomy Association anniversary celebrations at Station Road, Reading back in September 2005. Glyn delighted to be asked to speak again, reinforced the work of the charity, and gave his congratulations to all involved. He pointed out how important patient associations were giving members the opportunity to come together at events such as these. Here are a few of Glyn's comments about the CA Open Day from his online blog...

"I was late arriving at the Colostomy Association's 'Open Day' today. It was held in the Conference Suite at the Heritage Motor Centre at Gaydon, off the M40, and it took a bit longer than I anticipated. It's 112 miles away! Lucky for me that I was late. The organisers had to move my slot from immediately after lunch until last slot of the day. Meant I heard presentations of 'My Story' from Duncan Wells and Vanessa

Denvir. One of the pluses of my involvement in campaigns and charities to do with various 'illness and diseases' is that I get to meet the most amazing people!

The C A has been going as a self-funding charity for five years now. I went to its first birthday party in Reading and did the cake and ribbon cutting honours. Pleased to be invited back today! Anyway, this blog wishes a Happy Birthday to Sue, Ernie and all the good people at the Colostomy Association".

Thank you Glyn your effort and time was much appreciated as always!

Rounding up the day Monty Taylor – Chairman of the Colostomy Association took to the stage but just before Monty's final words, the winners of the raffle prizes were drawn.

CA had been gifted some fantastic raffle prizes, they came from private individuals and the attending stoma care companies for which we must say a massive thank you.

The main prize donated by Duncan Wells was a sailing weekend on his fantastic boat 'Dorothy Lee'. It's true to say sometimes things are just meant to happen as this prize went to the courageous children of Breakaway!

Monty ended the day by saying... 'Events such as this really make a difference and give those who attend a real sense of belonging to a charity that exists to encourage, support and reassure all who are living with a colostomy'.

The CA would like to say a BIG thank you to everyone who attended, presented, supported, exhibited and sponsored the Open Day - we hope to see you all again this year!

Editors Comment
The Colostomy Association is planning another Open Day event this year. To be a part of it simply contact:

Richard Bray – General Manager
on 0118 939 1537

or email:
richard.bray@colostomyassociation.org.uk

Shhh...

Listen
up



QuietWear™
Material

virtually eliminates
embarrassing
pouch noise

QuietWear
Pouch Material

To receive a **FREE** sample of our new ostomy pouch incorporating QuietWear call customer services on **0800 521 377** or fill in the form below.



To receive **FREE** samples of our new QuietWear Pouch, simply fill in the form below and return to: Customer Services, FREEPOST, Hollister Ltd, 42 Broad Street, Wokingham, Berkshire RG40 1GZ.

Name: _____

Telephone: _____

Address: _____

Email: _____

Postcode: _____

Stoma size: _____

Hollister Ostomy. Details Matter.



Attention to Detail. Attention to Life.

Ten Months Later...

Several readers have written to say how much they enjoyed the article “Ten Weeks Later” which we published in Tidings issue 18. Back then Susan Fifer described how she felt as a new ostomate and passed on some tips which were helping her to come to terms with her changed body. As promised, we are now including a follow-on article in which Susan tells us what she has learnt since she last wrote to us and how she feels now...ten months later.



I've just reread the original article I wrote ten weeks after I had my colostomy. Like looking at a diary from your teenage years, it all seems a long time ago and, fortunately, things have moved on.

It's now ten months since my operation and I'm amazed and delighted at how well I feel and how much I can now take my bag for granted - well not too much but enough to let me live a normal life and do all the things I want to do.

It's difficult to decide at what point this happened. It wasn't overnight. In some cases there were other things competing for my attention - chemotherapy was one of them. A semi-permanent line in my arm for the chemo resulted in a blockage (Deep Vein Thrombosis DVT) and so I had to give myself daily injections of anti-coagulants for three months. There were some predictable results. I probably don't have to give too graphic a picture to this readership of the problems of trying to do a morning bag change while having a nose bleed at the same time. In such situations a sense of humour is helpful - though may be stretched to its limits.

The end of chemo was probably the turning point. The arrival of summer helped and I picked up old activities and started new ones. I was a bit wary of air travel - the volcanic ash delays sent my imagination into overdrive about airports and not having enough supplies. However, I decided that I would see how I'd cope with an overnight ferry to Ireland; we had a wonderful five days in Cork and Killarney. I was very pleased at managing a bag change with no problems in the tiny bathroom attached to our cabin. Mind you, the Irish Sea was, unusually, like the proverbial millpond. I'm not sure what it would have been like in a force six gale.

In terms of travelling, I think I prefer the impersonality of a hotel room where I can organise things the way I want them, to replicate the situation I have at home. I find this a bit more awkward when staying with friends, even though they are all aware of the situation and very understanding.

While I still haven't taken up potholing, I have joined a table tennis group at my local U3A and have just bought a ukulele. I've also lost some weight - nothing to do with my appetite or any illness but just as part of a reappraisal of my options and my situation.

So, are there any further things I've learned since the end of the ten week milestone?

One - It helps to be organised and have a routine. I do a daily bag change in the morning after I have had a shower. All my supplies are on a small trolley in my bedroom (the kind you buy to organise kids' toys) and I lay out everything I need plus my clothes before I go into the

bathroom. A bag change with no "interruptions" from the stoma can take place in about twelve minutes. I did try timing myself once but realised that this was never going to be an Olympic sport, so why rush.

Two - If you are invited to a local "stoma event" by one of the supply companies, then try to go. You get free samples and can find out about new products. In one case we were all given a box of chocolates which I'd take over a new stoma bag any day of the week. It also lets you chat to other ostomates and the local stoma nurses so it feels like a meeting of a fairly exclusive club. Sharing experiences is really valuable, something which you can also do via the ostomy websites on the Internet.

Three - I was surprised that many toilets for the disabled, particularly in hospitals, were often so poorly equipped and laid out. In a normal public toilet I expect at least a hook where I can hang my coat and my bag. In many places I was reduced to putting these on the floor - not very hygienic. I actually got my chemotherapy day unit to get a row of hooks put up for this purpose in their section. Never managed to do the same in the main reception area of the hospital, no matter how many customer service evaluation forms I filled in.

Four - I found a small shopping bag that had a zipped section at the bottom which was supposed to be for umbrellas. I put my supplies in there. I now carry an empty washing up liquid bottle which I fill up at the washbasin before going into the toilet stall so I am less reliant on using the disabled toilets. This works because I drain rather than change my bag during the day. There are toilets in some places

where each toilet has its own wash basin – if you're in central London, check out the toilets at the Wallace Collection gallery. Generally, museums and art galleries are good; (traditional) theatres are awful.

Five - The Sengenic nappy bin recommended in an earlier edition of Tidings was a great idea. There is no smell whatsoever from a week's worth of bags. I live in a house and so could put the bags in the outside bin on a daily basis if necessary but, if you live in a flat and/or have mobility problems, the nappy bin solution is a much better idea.

A reversal is now on the cards. While this was always a known possibility, I spent the first few months after my initial operations saying that there was no way that I wanted more abdominal surgery if it wasn't absolutely necessary. If I could manage the colostomy and get on with my life then why go for elective surgery?

It was when my surgeon called me in for a chat that he raised the question of a reversal. He understood my concerns about more surgery and recovery times, the possibility that I might need a temporary ileostomy or that there could be a repeat of the leak to the join in the colon which had resulted in my original colostomy. We discussed all this and I then realised that, since there was a good chance of success, it would make sense for me to try.

He could have done the surgery quite quickly but we agreed to fix a date for four months later to give me time to get friendly with the idea. Surgery will now be in a month's time. I've decided not to get worried about it - well, not too much anyway. I recovered well last year and then had the prospect of chemo to think about. This is going to be a different ball game and, whatever the outcome, I have a better understanding of what can happen. Whether I'll be this sanguine the day before the operation is anyone's guess but it's a good way of coping at the moment.

Susan Fifer

We will be asking Susan to write for a future issue of Tidings to tell us how she feels once she has had her reversal.

The Good Digestion Show 2011
 Incorporating
IBD Expo 2011
 & **Stoma Central**
 24-25 June 2011
 at EXEC, Peterborough

As how like no other,
 The Good Digestion Show is a
 hub of resilience for anyone
 with a digestive disorder or
 food intolerance, and those
 with a permanent or
 temporary stoma.

Do certain types of food
 aggravate your system?
 Do you have to be careful of what
 you eat due to allergy or a
 digestive disorder?

**The Good Digestion
 Show has the answers!**

- Meet stoma manufacturers face-to-face and find new products and accessories that can make your life more comfortable
- Sit in on one of the informative seminar presentations
- See celebrity chef Lesley Waters and Antony Worrall Thompson showing you how to spice up your meals whilst avoiding those 'no go' products
- Find lactose free and gluten free alternatives to everyday foods
- Explore the different therapies that can improve your quality of life, reduce anxieties and ease IBS

Book early on line at
www.thegooddigestionshow.co.uk
 for discounted tickets, or call
01271 375393

UC inspires Show...

On Friday 24th and Saturday 25th June 2011, the doors will open to a new national exhibition called The Good Digestion Show, incorporating IBD Expo Stoma Central, bringing together all matters relating to living with a permanent or temporary stoma, digestive disorders, IBD and IBS, and food intolerances.

Being held at EXEC at the East of England Showground, Peterborough, this exciting exhibition is the brainchild of husband and wife team, Craig and Caroline Bramwell. Whilst Caroline lived through years of suffering Ulcerative Colitis, Craig spent hours and hours researching about the condition, how to improve it through diet and lifestyle changes, and the ultimate choices of surgery.

The exhibition is the culmination of pulling all that research and knowledge into one interactive event. Not only can you meet all the stoma manufacturers face to face, but there will there be great food to sample and new exciting recipes to try out, with celebrity chefs Antony Worrall Thompson and Lesley Waters giving cooking demonstrations in the Theatre Kitchen. The Seminar Theatre will also host a programme of interesting and informative seminars and workshops.

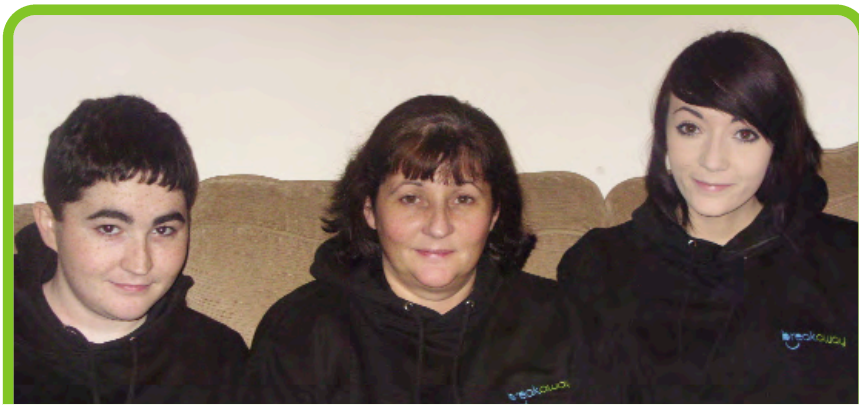
Said Caroline: "Having lived with UC for many years and now having a permanent stoma myself, I have found that it is possible to have a quality of life, but it is important to see all the choices that are out there. I know I am not alone in this, which is why I felt so passionate about it and why I have brought this event to life."

Since her surgery in March 2009, Caroline has already taken on a big challenge to prove that you can overcome conditions like UC – she cycled from London to Paris in under 24 hours for charity in July!

To find out more about...
 The Good Digestion Show visit:
www.thegooddigestionshow.co.uk



Breakaway...bringing families and children together building confidence for the future...



From L to R: Joe pictured with Mum and sister Tara

A Family Affair...

It was with some trepidation that I agreed to attend and support Breakaway at the Colostomy Association Open Day.

My daughter, Tara aged 17, had been asked to speak about her brother who had an ileostomy aged 17. I must say I had reservations and bad nightmares about this on her behalf!

My son had been ill for three years with Ulcerative Colitis before having an ileostomy and as many families will know, one child's illness in the family affects everybody.

I didn't realise until the CA Open Day how much it had affected Tara. She got up with her 'new friends' ostomates themselves and spoke about her brother's illness and how much it had affected her. She emphasised how wonderful it was to be able to talk to other siblings like herself with a poorly brother or sister.

My family feel Breakaway have given us a new lease of life. We love the atmosphere, the friendliness, and how 'we have all been in the same boat' at some point - how fantastic it is to talk to people who really do understand and can empathise with you.

Breakaway is a fantastic charity, some of the teenagers keep in touch via their mobile phones and facebook and can't wait for the next Breakaway weekend to happen. We as a family now help out as volunteers as we love it so much and to see how everyone benefits really is amazing.

Vickie Connelly (Mum)
Breakaway Volunteer

Joe's story...

It was January 2009 and half way through my IT course at college and I was struggling to cope with my colitis so me and my mum went to see our GP. 'It's not good is it Joe?' 'No,' I replied. That day I was referred to Leicester Royal Infirmary and I didn't know what to think because steroids usually helped to calm down my colitis. My Mum was crying in the doctors and I had to stay strong for her although I could have quite easily joined her.

We arrived at the hospital and I was given a side room. Over the next few days my colitis was getting worse and I was told that the surgeons would be in to see me soon to talk about having a stoma. My mind was all over the place! I didn't want to have an

operation. After a few visits from the stoma care nurse I was getting prepared for what would change my life forever.

The inevitable happened and I woke up in intensive care. I didn't want to even look at my scar. I was soon off to another side room and a few days later I started to feel unwell. It came to the point where I couldn't even move. After getting more tests they came to conclusion that I had peritonitis. Emergency surgery! I was rushed down to the operating theatre. I could see all the surgical equipment that they were about to use on me; I wasn't scared this time I just wanted to be well!

A month or so passed and I came home. Within a few months I had fully recovered. I thought about doing college again and starting over. I began my college course and within a few of weeks things weren't going well; I was struggling, and finding it difficult to talk to the others on my course. Me and my mum went to the GP again to see if there was something wrong. After talking to him and filling in a questionnaire I was told that I was depressed. He put me on some anti-depressants and I decided it was best if I stopped college for a while.

Within a couple of months I felt a bit better but was really bored at home so I started to do some volunteer work at a special needs school. I really enjoyed helping the disabled children learn. I stayed at the school for the rest of the year.

After an appointment with my Stoma care nurse she told me about Breakaway and that I could talk to other people with stomas and my family could talk to other families. I wasn't sure at first, as I am a very shy person.

As a family we decided to go to a Breakaway weekend not knowing what to expect. Everybody was so

friendly it was such a relief to know that I wasn't alone. I had so much fun too! There was canoeing, wall climbing, zip wire, a huge obstacle course, and a small petting farm.

Just to talk to other teenagers really helped me, and I have made some friends too which I was struggling to do at college. For me Breakaway has really helped me be more confident. I love Breakaway and simply can't wait for the next one!



CA Open day... Tara speaks out

I like to think of myself as quite a confident and outgoing person. But when I found myself standing in front of an audience of about 300 people at the CA Open Day preparing to read my speech I found it a little intimidating! But because Breakaway means so much to me I never felt more comfortable!

What made it easy was being surrounded by my friends. The special friends I've made at Breakaway! Having them with me on stage made me feel more confident especially as I know I'm not the only sibling who has faced worries about their brother or sister.

My brother was 17 when he had to have an ileostomy; it was a big shock for all of us. What made it a bigger shock was he didn't even have 24 hours to come to terms with what was happening. Everything was such a head rush but if it meant saving his life then the choice was taken away from us.

I never thought anything would be the same again, I knew things would be different but never different in the

good way, and Breakaway is who I need to thank for that. I really don't know where we would be right now if it wasn't for Breakaway. The support and all the fun we have, as a family mixing with other families who have faced similar difficulties is amazing. It has changed our lives for the better and our weekends away with Breakaway are something we relish!



Join us for our
next Breakaway
Weekend!

We're going back
to the forest!

YHA
National Forest
East Midlands

29 April 2011
for 3 nights

Put some smiles on young faces, chat and share your experiences in a relaxed friendly environment, but more importantly come and have fun!

The cost of three nights full board accommodation is just £165 per person. All rooms are 2-4 beds and en-suite. There is also a bar, bistro and coffee shop.

For further information on this and future events.

Call us on 07903220040
Email us on
break.away@tiscali.co.uk
Visit our website on
www.breakaway-visit.co.uk

Call us on: 07903220040 or email us on: break.away@tiscali.co.uk
or visit our website on: www.breakaway-visit.co.uk

If you would like to make a donation to Breakaway...
visit: www.justgiving.com/breakawayvisits



Hannah chats about Breakaway...

Breakaway has been really busy and very popular this year! At the Colostomy Association Open Day Sue Hatton organised a collection for Breakaway. It was very kind! Now Breakaway can pay for some more kids to come along... I even went up on stage for the presentation!

It was so nice to see some of my Breakaway friends at the Open Day, even if Fergus played knock a door and run on our hotel room door the night before!

When my Nanna was in hospital recently, in the next bed to her was a lady called Dot. Dot has a Colostomy and was quite poorly. Nanna told her all about Breakaway and she gave me £10 to put towards the Christmas party. Dot told me that she has always wanted to be famous she is really good fun. So I promised that I would mention her in this article. Hope you get better soon Dot!!!

I am very busy at the moment because I am now the editor of my school newspaper and I am adding something about Breakaway!

I hope everyone has had a nice Christmas time and wish you all a Happy New Year!

Hannah
Aged 9



Gutless Kayaking...

Enjoying the challenge and pushing the boundaries...

Justin Hansen and friends successfully paddle the 240 miles of canal between Manchester and London!

Justin was diagnosed with Crohn's disease in 2003...here Justin follows up on his previous article and tells us about his experiences whilst on his remarkable adventure...

In the autumn edition of Tidings I talked about my forthcoming kayaking trip. My plan was to kayak from Manchester to London, symbolically linking the UK's two specialist intestinal failure hospitals, Hope Hospital in Salford and my hospital, St Mark's, in Harrow. Canals run fairly close to both hospitals and I thought it made sense to simply paddle from the one to the other. Once that was all decided the name for the trip seemed fairly obvious: Gutless Kayaking.

I have Crohn's disease and have lost a lot of intestine over the last seven years. So much so, that I now have short bowel syndrome. This means that in addition to having a stoma I also need intravenous nutrition (TPN) to survive. Most food and drink makes a rapid trip through what's left of my system so I have a very high volume, and liquid, output. Leakages are a constant threat and I haven't had 100% faith in any of the stoma products that I've used to date. I knew that there would be a lot of unknowns on this trip especially in terms of when and where I would be needing to change my stoma bag. For this reason I decided that it would be best to use a bag that I could change or empty as quickly as possible. Ordinarily I tend to use a Dansac Nova, one-piece, drainable bag. But for the kayaking trip I swapped to the two-piece Convatec Natura bag. The flange on this has a mouldable flexible hydrocolloid collar, which one just needs to pull into shape before securing around the stoma. To this I attached a urinary night bag. Under normal circumstances a urinary night bag would not be appropriate since the diameter of the output valve is very small and tends to get blocked easily. But, thanks to my short bowel syndrome and relying entirely on



'It was amazing to meet so many people along the way who asked what the trip was all about, and to find myself talking to total strangers about the pros and cons of varying stoma products. I was also staggered to discover how many others either were or knew an ostomate'.

intravenous nutrition, I was able to survive easily for the twenty days of paddling without eating anything! This ensured that my output was of a liquid consistency and the bag didn't block. Another benefit of not eating was that the volume of output was greatly decreased, which in turn meant less leakages (only had one) and less emptying.

The trip was organised as a fundraising event for St. Mark's Foundation. This is the charitable arm of the hospital and carries out cutting edge research and educational programmes in bowel disease. I've spent a lot of time there as an in-patient and am always impressed by the team ethos and knowledge of the staff. Before setting off, I needed to



talk to with my doctor, pharmacist, nutritionist and dietician about how to make this trip possible. TPN is a life-support system for me - I have to be attached to a machine for 12 hours a day. Whilst I was kayaking I needed to be attached to it for 24 hours a day, for 20 days. The team at St. Mark's altered the nutritional content of the TPN in order to give me the best chance of completing this challenge. I needed to be provided with a lot of medical supplies en route, so BUPA Home Healthcare delivered these products to me on the canals every three days. They also installed a fridge on our support vessel since the intravenous nutrition needs to be kept between 2 and 8 degrees.

As a further sign of support from St. Mark's, my consultant gastroenterologist, Dr. Simon Gabe, and consultant radiologist Dr. Michele Marshall, met us in Manchester at the start and cycled the whole route back to Harrow. It only took them a couple of days. A few of the doctors from Hope Hospital also came along to wave us off.

After the very long build up (it took me and my sister, Victoria, about 6 months to organise) and a great send off we finally got the boats into the Bridgewater canal and paddled away. I was accompanied at the start by three friends and we quickly found out who's clothing wasn't waterproof. It rained on 15 days out of the full 20. We saw some beautiful countryside, lots of nature (dead and alive), 166 locks, a fine selection of floating fruit

and veg, and of course a couple of abandoned shopping trolleys. I think our thorough preparation paid off because there were no calamities, just a few scrapes and aching muscles. The roll of duck tape was the most popular accessory in the kit bag: used as bandaging for cuts; to make an impromptu rudder; repairing torn clothing; securing bags of intravenous nutrition to the inside of my rucksack; to protect blisters etc. It was amazing to meet so many people along the way who asked what the trip was all about, and to find myself talking to total strangers about the pros and cons of varying stoma products. I was also staggered to discover how many others either were or knew an ostomate. We managed to collect over £400 from these little chats.

For me it was a fantastic feeling to be taking part in an endurance trip like this, having spent so many years recently in hospital. My consultant gastroenterologist suggests that I may have performed a world record, since he's not aware of anyone else on artificial nutrition completing this type of endurance event before! A couple of years ago I never would have imagined that I'd be doing this. Not just because I was in such a poor state but also because of my life long aversion to organising things. I would prefer to be able to simply head off and deal with problems as they arise. I constantly need reminding that things are different now, and I have to somehow accept the changes. Trying to achieve a decent quality of life is a never-ending battle and sometimes it

seems as if the effort, frustration, documentation, exhaustion, setbacks, embarrassment and indignity is all too much. However, in some perverse way there's a part of me that enjoys the challenge of trying to push the boundaries of what we're led to believe is our lot.

I don't think I'll ever be able to thank everyone who made this possible for me. But my sister, Victoria, and girlfriend Jane need a special mention, as does Richard Carpenter from the National Association of Boat Owners.



Last week I went up to St. Mark's for the handing-over-of-the-cheque ceremony. To date Gutless Kayaking has raised over £20,000 for research into bowel disease, and the figure is still rising.

For more information about Justin and his adventure...Gutless Kayaking, visit his website: www.gutlesskayaking.com



A Colostomate Comments...

written by Rosemary Brierley - Associate Editor

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

To tell or not to tell?

There was a time when no one mentioned breast cancer, but today everyone is quite open about it. Maybe, sometime in the future, bowels will also not be a taboo subject and no one will raise an eyebrow when we mention the word colostomy. For that to happen, ostomates probably need to make the first move. There are those who are quite happy to speak out: Glyn Davies, MP for Montgomeryshire, and Vanessa Denvir, CA volunteer, both spoke at the CA Open Day. Vanessa has also appeared on the Channel 4 programme "Embarrassing bodies". But what about the rest of us: do we tell people we have a colostomy, or do we prefer to keep it a secret?

To answer this question I asked the ostomates who attend our local support group. This resulted in a lively discussion.

'I want people to know me, not my stoma,' said a member who has been attending the group for many years. She never mentions her colostomy in social situations: she fears that when she tells people their eyes will drift down below her belt to search for signs of her bag: she doesn't want to have to explain what a colostomy means, she doesn't want people's pity.

A relatively new colostomate told us how he makes no secret of his stoma. For him the last few years have been a struggle but he is proud of what he has gone through. When he explains, people are full of admiration; they look at him and say, 'I just can't

believe what you are telling me.' In his experience when people know they are incredibly supportive and when problems occur they can be very understanding. By telling people he has built upon a fantastic network of friends and this was part of the healing process. Another reason to be open and discuss things is that we never know when we might need support in the future if we develop any problems associated with the stoma.

'Yes, but you need to be selective and choose the right moment to tell people,' another man added. He too doesn't believe a stoma is a stigma, but he doesn't tell everyone. His immediate family and close friends all know. He has played tennis with the same group for many years, in fact before his operation, and they all know about his stoma. Recently he and his wife joined a badminton club and he would be quite happy to tell anyone there about his stoma - should the need arise. 'That's right,' agreed another colostomate. 'I would only mention it if the subject comes up. I tell people on a need-to-know basis.'

'But perhaps we all worry too much about what people think,' someone pointed out, 'when, in reality, other people are far more preoccupied with getting on with their own lives.' 'That's right,' agreed someone else and went on to tell us how when he first had his colostomy he felt he needed to tell everyone, but now they've all forgotten that he has a stoma. For years he and his wife have visited a Greek island for their annual holiday, and spent time on a nudist beach; after he had his stoma he continued just as before and no one took a bit of notice of his pouch.

After the meeting a female ostomate told me how she doesn't try to hide her ileostomy when she is in the communal changing rooms at the gym - just turns her back on the other people present, which, for the sake of modesty, even a non-ostomate would do. When trying on new clothes she has always sought a sales assistant's opinion; now she points to her right hand side and says, 'Well of course now I have this. Can you see it?' Most of them understand what she's talking about and will reassure her that if she hadn't told them they would never have known.

So to get back to the original question: To tell or not to tell?

It seems that we all have our different ways of coping with a stoma. Some of us will just tell our nearest and dearest - friends and acquaintances only on a need-to-know basis. Others are quite open about it, and keen to tell everyone how grateful they are that a stoma has saved, or improved the quality of, their life. It is these people who will spread the word and maybe in the future no one will consider bowel problems and stomas embarrassing.

Editors Comment

If you have any issues you would like raised in this column

please email:
associate-editor
@colostomyassociation.org.uk

or write to:
Associate-Editor
Tidings
Colostomy Association
2 London Court, East Street
Reading RG1 4QL

Readers' writes

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

Dear CA

Tidings magazine has been a life saver to me. I had my colostomy for cancer of the rectum in 2008 just after retiring from thirty years in the NHS. Ernie Hulme gave me my first copy as I left the surgical ward for the last time. I was then looked after at home by the dedicated Julie Rust.

From the start I was having leakage problems and spent a while in my shed with a hacksaw and file attempting to make a plastic clamp to fit around the bag for more support. While having a breather from this I had a good read of Tidings and saw the Sash belt advertised. I could not believe my luck. This has given me confidence to carry on as normal and I sometimes forget I have a stoma.

When you look at the ticks on the Readers' Feedback Questionnaire you will see that I read Tidings from cover to cover. I've learnt a lot from your contributors and the fortitude of some people has to be read to be believed.

Since reading of how others have coped with their problems with the aim of living a normal life - not forgetting the children who have the rest of their lives to do the same - I have decided not to moan about anything ever again. It is now quite some time since my wife called me Victor Meldrew!

All the very best
Yours sincerely
P. C. (Mr)

Dear Editor

At home and on holiday while changing my stoma bag I burn incense sticks. I simply stick one in a tablet of soap. The ash falls into the wash basin and is simply rinsed away. I find the incense sticks give off a gentle perfume, not as obvious as an aerosol spray. The sticks are quite cheap - approx £1 for 60 - and so peace of mind.

Hope this tip may help my fellow ostomates.

With thanks
S.J. (Ms)

Dear Tidings

I am a very young sixty-three year old; I love clothes, dancing, music and travel. To me, image is very important: make-up hair and clothes have to be right before I will venture out. In 2005 I had to make the decision to have a colostomy - the reason being acute diverticulitis. I had suffered quite a few years but it had got to the stage where the pain was unbearable and then I became incontinent, but it was my decision to make.

It was going to be a simple keyhole operation, but things did not go to plan. I had to have a large incision as they could not get the bowel to the surface. After a few months this caused a parastomal hernia which was operated on in December 2006. Within a few months the hernia was back and in June 2008 the hernia strangulated and I had to have the stoma moved to my right side leaving a small hole where the old stoma had been. This caused

problems for months and then they found there was mesh left in from the hernia repair. Again the hernia came back on the new stoma site. My consultant has offered to operate but at the moment I am trying to live with it and I am coping.

Over the time I have had my colostomy I have found a lot of comfort from Tidings. It always seems to answer my questions as well as giving useful information. I would love information about starting a support group as there does not seem to be one in our area. I have spoken to my doctor and he thinks this would be a good idea.

My operation was done at the Royal Shrewsbury Hospital and their help and support has been second to none. They are always there if you have any problems or need help.

Yours sincerely
C. O. (Ms)

Rosemary replies: A factsheet for ostomates who are considering setting up a local support group is available from CA head office.

Dear Editor

I was diagnosed with bowel cancer in 2008. Before I went for the operation I had chemotherapy and radium treatment to shrink the tumour. I had my operation which removed part of my bowel and the muscles in the lower part of my body and closed my back passage. Then this had to be reopened due to an infection and a bad discharge. I was in hospital for five weeks after the operation, then home for three

Readers' writes

weeks, back in for two weeks, home for a short time, then back for more treatment. In all I was in the operating theatre five times.

Eventually I was fitted with a VAX machine which drained the fluid through tubes into a canister. I was sent home with this machine and district nurses came in every day. Eventually it cleared up.

I feel great now and I would like to tell others not to give up even if it is a hard struggle. I had a lot of help from my wife and family. We have been on cruises and look forward to the next one. From reading your letters and articles I feel that I am not alone and can understand a lot more from your information. I would also like to say there is always light at the end of the tunnel.

Yours faithfully
B. A. (Mr.)

Dear Editor

Thought you might like to hear my story. I had an abdomino-perineal resection, removing anus and rectum, for a non malignant growth resulting in a permanent colostomy. I just wanted to say that all colostomies are not the result of cancer. Fortunately, I feel better now than I have for years. My colostomy causes me no trouble usually.

I have been on a cruise to Iceland alone and am setting off for another cruise around Britain in August. I feel this is the best way to travel with this condition. However, do not eat too much. It is very tempting but can have a rather ghastly outcome.

Thanks for your magazine.
I look forward to the next.
C.L. (Ms)

Dear Editor

I have received Tidings for about four years. I haven't often read it cover to cover as it all seems a little daunting, but one thing has stood out: colostomates seem to have a huge sense of humour, which I, suppose, can be a big help - one certainly needs it.

I was born seventy-six years ago with an imperforate anus. There was not a lot that could be done in those days and my mother didn't realise something was wrong; she just thought I was a grizzly baby! These days it would have been put right straight away. My grandmother who was changing me noticed something badly wrong. This was four weeks after I was born. I had lots of things done to try and rectify the problem. By the time I was eight years old I'd had thirteen operations and a colostomy.

I did have it reversed. I owe a great debt to the surgeon, a pioneer in plastic surgery at the time. I was in hospital during the early years of the war. Other patients were airmen being treated for burns - trying to make them faces where they had none. So that put things in perspective, even for me as an eight year old child.

I've experienced all the problems of trying to control my bowels - always having accidents. Four years ago it was suggested I should have a colostomy, but since then I have had many health problems and, quite honestly, couldn't face another operation. I've lost count of how many I've had - at least forty. I just felt I had to write to say that I'm so very glad people can get the support they need these days.

I still live a full and happy life. I'm told I have a wonderful sense of humour too. As I said at the beginning, we need it.

Yours faithfully
M.D.R. (Mrs)

Dear Tidings Editor

I am a fifty-one year old woman who suffers from a medical condition called Fowler's Syndrome. 'What is that?' I hear everyone saying, just as everyone does! Well it is a condition that affects only females aged between twenty and fifty years old and is basically a total failure of the bladder's sphincter muscle.

In 2005 I underwent surgery for a Neurostimulator Implant which is a device that sends electrical pulses directly to the bladder stimulating the sphincter and in return promoting normal voiding. I was like a new woman after almost three years of catheterisation and infections.

Then in October 2007 my bowel also stopped working. I found myself in hospital with impacted constipation. No one at the hospital had ever heard of, or knew anything about, Fowlers Syndrome. So I spent the next twenty-eight days being tried with laxatives after undergoing test after test: endosonography, muscle biopsies, scans, X-rays - examination after examination all with no diagnosis, only slow transit. After twenty eight days I was referred to St Marks Hospital, still suffering from impacted constipation and vomiting.

It was agreed that Fowlers Syndrome was the cause of my problems and I was introduced to the Peristeen irrigation system - A five inch rectal catheter is inserted into the rectum which is held in place by the catheter balloon, water is then pumped into the bowel. I received the machine in January 2008 and used it at home for over a year. Then in May 2009, whilst using the irrigation system, the catheter balloon burst while inserted in my rectum. I was readmitted to hospital; again no one knew or understood my problems or medical condition. After twenty-two days I finally underwent surgery for a colostomy and within two days was back at home recovering.

Readers' writes

Within days I started to get problems with liquid faeces from the stoma: everything I ate seemed to pour through me. Also I still had faeces in my rectum. My own GP has always tried to be helpful and understanding of my problems but he is not a bowel specialist.

Fortunately I have since found a wonderful area stoma nurse called Marie Culleton; she has been so supportive and tried so hard clearing the impacted faeces from my rectum. We did try the stoma irrigation system which unfortunately was unsuccessful. I also have a very large parastomal hernia. Maria talked to me about the problem and ordered some supportive underwear which has been a great help. I and my family wish to thank her for her continuing care.

B.G. (Mrs)

**To Sue Hatton,
Executive Trustee
Re: CA Open Day, Gaydon**

Dear Sue

I must congratulate you on the Open Day. It was the first time I had been to anything like it and came away very impressed. I met so many people, saw so many products and ideas, as well as listening to some really good speakers. Then to top it all had a humbling conversation with a young man from the Breakaway group. Altogether a very rewarding day.

Yours sincerely
B. K. (Mr)

Dear Madam

Your article "Irrigation can be the answer...but not for everyone" in the Spring issue of Tidings is very encouraging for people like us. I had a colostomy operation three years ago. Since then I have been using a

two piece system with a flange and drainable pouch. I have also slight hernia.

I feel very apprehensive about travelling alone due to my anxiety about how to cope if the bag is full and needs changing. This is particularly problematic especially if there is loose motion. Would you please provide some practical advice on this matter.

It would be helpful to know what I should carry with me or what I should do when I travel long distances by train or aeroplane. How shall I dispose of the pouch and other material? I shall be much obliged for your help.

Yours faithfully
P.K.M. (Mr)

Rosemary replies: Many people who have a colostomy find it easier to empty or change their pouches in a disabled toilet where there is a washbasin and a bin for disposing of used pouches. Some of these toilets are kept locked but you can obtain a key from CA head office (see details on Page 48) CA also produce a leaflet, Travel Advice, which contains many tips for travellers including a list of what to carry with you. Used pouches and wipes etc. can be sealed inside a disposal bag and placed in the waste bin in a train or aeroplane toilet.

**Editors Note:
Do you suffer from rectal pain?**

If the answer is Yes...please get in touch. The CA is producing a leaflet about rectal pain following stoma surgery. We would like to include patient experiences... please contact the Associate Editor details opposite. Many thanks!

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:
associate-editor@colostomyassociation.org.uk
or write to:
**Associate Editor
Colostomy Association
2 London Court,
East Street,
Reading RG1 4QL**

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



Yours
**Rosemary Brierley
Associate Editor**



Tidings magazine is available in PDF format. Simply visit: www.colostomyassociation.org.uk and register to download or email the editor direct at: editor@colostomyassociation.org.uk to organise a PDF to be sent to you.

Irrigation and you...

Sue Hatton Executive Trustee writes... I feel I must reiterate that those of us who are able to irrigate do not feel superior to those who choose not to or cannot for what ever reason. We just feel lucky that we were given the option and we want more stoma care nurses to recognise 'the efficient management of a colostomy is a matter of profound importance to those patients who need to spend the rest of their lives with one'. (Anon quote 1958). Thank you all for your valuable contributions please do keep them coming.

We had such an amazing CA Open Day! Janet Bradley, who wrote in the last issue, was inundated with enquiries as she discussed irrigation with attendees at the designated specialist area.

Janet writes: "What a successful Open Day it was at the Heritage Motor Centre, Gaydon on the 16th October. So many people must have worked extremely hard to set it all up. The venue was so spacious and welcoming!

I manned the CA specialist area stand and spoke to many interested colostomates about irrigation explaining how it works. I had equipment kindly provided by three different companies - Coloplast, Dansac and B.Braun. I demonstrated the equipment and explained that my irrigation method takes me 30 to 50 minutes a day.

The response was overwhelming! At one time I had four people listening to my mini-talk and several others trying to get nearer. Fortunately, Steve Bonham a CA volunteer came to my aid and together we were busy the whole day. Both Steve and I enjoyed getting the message out to everyone especially as irrigation can take away some of the problems and stress involved in having a colostomy. I am sure the interest was as a result of the talk given by our President Mr. Bill Heald OBE who is fully in favour of irrigation".

Helen Johnson writes: At first I was very apprehensive; I just couldn't imagine putting the cone into the stoma as well as dealing with all the other apparatus! So I procrastinated and found excuses until my daughter pushed me into seeing my stoma care nurse. I have arthritic hands but found that I could manage the equipment very well. Like many others I irrigated every day to start with. The more I irrigated the more confident I became. I was learning quickly! I found that there didn't have to be a regular pool

of water on the floor and I didn't have to stay on the loo for the whole session. I could walk around my bathroom, with the sleeve rolled and secured after inserting the water. I could clean my teeth and give them a good flossing; I even had time to put on my makeup!

My next challenge is a cruise. I would like some advice about the water supply on ships, especially as one contributor to the last Tidings referred to using bottled water abroad. I thought you had to use tepid water? So how do you warm bottled water if travelling? I hope my enthusiasm for irrigation is coming through in this article. It has changed my life, my teeth are much cleaner, my dentist is so impressed and the bathroom sparkles as I emerge from my special hour.

Many thanks to Sue Hatton and the Colostomy Association for bringing to the fore such an inspired campaign... Helen Johnson, Falmouth Cornwall.

Sue writes: Have we got any tips from "Cruising Irrigators!"

Bob Buckley comments: I use bottled water on cruises and warm it using a travel kettle.

Nelson Swinney writes: In late 1987 I had a colostomy and in early 1988 started to irrigate; unlike some, I irrigate daily, which means that each morning I can catch up with some reading! My purpose for writing is to answer queries in the autumn issue of Tidings several readers expressed their concern about the cleanliness of their irrigating equipment. From the beginning this caused me concern and once they became available, I regularly used Tristel surface cleaners to ensure that all surfaces that might come into contact with my hands or equipment were disinfected on a regular basis. Fortunately "Tristel at home" is now available not only for those who irrigate but for bag users too. Details can be found at www.tristel.com

Janet Bradley requests someone's help to sort out her confusion over hot water.

Janet writes: "In one of the manufacturer's instructions for irrigation, they illustrate filling the water container with water from the hot tap. I am concerned because I always thought water from the hot tap was not potable (suitable for drinking). I therefore always boil water from the cold tap. At Gaydon, I met another irrigator whose surgeon had told him that it was not dangerous to use water from the hot tank because bacteria are not absorbed by the large intestine. When I lived abroad I was told to clean my teeth with boiled water, even if I didn't swallow it because bacteria could be absorbed through the mucous membrane in the mouth. When travelling overseas I use bottled water. I immerse a small bottle in a washbasin of hot water until it is body temperature.

Sue writes: I believe that most irrigators use water from the hot tap. Many of us have done this for years, without even considering whether it was safe or not. Again it is a matter of choice. Do write in and tell us your experiences!



Editors Comment

You can learn more about irrigation from our leaflet - 'An Introduction to Irrigation' to obtain your copy

telephone:
0118 939 1537

contact:
Colostomy Association
2 London Court East Street
Reading RG1 4QL

e-mail:
cass@colostomyassociation.org.uk

OstoGuard

No Sting Barrier Film
With **LAVENDER**



- **Non Sting**
- **Rapid Dry Formula**
- **Quick & Easy to use**
- **Protects Skin from faecal & urinary effluent, digestive juices & adhesives**
- **Aids in flange / pouch / dressing adhesion & removal**

OstoGuard No sting Barrier Film is a rapid Dry Film specialty created from the latest silicone technology and incorporating Lavender Essential oil, the oldest of nature's remedies for soothing painful sore skin!

SAMPLE EVALUATION RESULTS

- **92%** said **OstoGuard** Barrier Film is very effective
- **81%** said **OstoGuard** Barrier Film improves perianal skin condition
- **75%** said **OstoGuard** Barrier Film is better than their current product

DON'T JUST TAKE OUR WORD FOR IT!

HERE'S WHAT USERS OF OstoGUARD BARRIER FILM THINK!

- "Fantastic - The best thing I have ever used!" "Great product"
- "Excellent - quick drying and provides a very good base for the adhesive"
- "The product has made a massive impact on my life I was shocked at the difference it made to me and my skin. Did not sting - very soothing"

All original information on file at OstoMart Ltd HT 482

Drug Tariff Listed

Product Code: RMCA Single Mult
use Dab on Bottle 30ml

Product Code: RMCS 50ml Spray Bottle



OstoMist

Odour Neutralising Spray



You may spray OstoMist into a stoma pouch when changing an appliance or spray into the room to neutralize any odour quickly and efficiently.

Available in a pump action spray it is user and environmentally friendly.

Need More? No guesswork needed with see through container!

Available on Prescription:

Product: OstoMIST MINT SPRAY
Qty: 100ml Bottle
Code: SBL1

Qty: 50ml Bottle
Code: SBL2



OstoMIST odour neutralising spray breaks through the worst odour problems. It is **NOT A MASKING AGENT!**

*Our products really work!
Why not try it for yourself!*

0800 220 300

OstoMART Ltd

Specialist STOMA...

SUPPORTX™

www.suportx.co.uk

...underwear...

...hernia support belts & briefs

High waisted with internal pockets.
Ladies Briefs and Shorts.
Mens Boxers and Trunks.



Hernia support Belts and Briefs for Ladies and Men



NEW



EASY PEEL
Hernia Support Belt
Patented® Suportx

AMI

AVAILABLE ON NHS PRESCRIPTION AVAILABLE ON NHS PRESCRIPTION

For further information or a prescription request form please call FREE

0800 9179584

Monday to Friday 9am-5pm, excluding Bank Holidays



ami
LONDON

©2010 AMI

SASH

- The Sash belts are available in prescription and non-prescription for ladies and men.
- All belts are made from 100% cotton, plus an inner Oxford fabric and a hole in the side for the belt to go to fit your personal needs.
- No fitting is required. Belts are measured and made to fit your own girths.
- Your doctor, pharmacist and local NHS Centre/Store/Dispensary: 0800 389 3111

Security and Leakage Belt



• The Security and Leakage Belt is made of a soft 25mm (1") wide fabric attached to a metal ring for support to hold up the bag and the adhesive section of the pouch.



"Showing of confidence"

• This lightweight abdominal belt is designed to help solve any leakage problem by holding the adhesive section of the pouch against the body during all activities.

• The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch.

See us 0800 389 3111

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

Stoma Support and Hernia Belt

- The Stoma Support and Hernia Belt is made of a soft 25mm (1") wide fabric with velcro attached to a metal ring. It 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 stoma surrounding the stoma.
- It reduces most leakage problems and gives added security and confidence. Ostomists report that their abdominal pain in the stoma region while wearing the belt.
- Ideal for ostomists with a peritoneal hernia (a bulge around the stoma) the belt will also help prevent undergarment enlargement of the hernia.
- Ideal for work, sports, gardening, housework, different stoma positions and stoma requires little support.
- With support from the Sash belt you will be able to continue with your stoma some Ostomists are using it to prevent the need for hernia surgery.

See us 0800 389 3111

Freephone 0800 389 3111

Website - www.sashstomabelts.com

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

For more information:

SASH Woodhouse Woodside Road Hockley Essex, SS5 4RU England

Telephone: 0044 (0) 1702 206502 Fax: 0044 (0) 1702 206502 Freephone: 0800 389 3111

E-mail address: info@sashstomabelts.com Website: www.sashstomabelts.com



Dear Nurse

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



Julie Rust became Tidings Nurse in December 2004. She has answered readers' letters and e-mails in all twenty-five issues which have been published since then. We look forward to many more years of publishing her very sound advice. Thank you, Julie, from the Editorial team and the CA Trustees.

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.

distress. The solid stool may not be able to pass through this narrowing and therefore she is only passing loose stool into the toilet. I would not suggest taking any medication to alter the bowel action without advice from the surgeon who did the operation. I hope that you are able to get some answers and relief for your mum soon. All the best.

Q: *I have had a colostomy for four years after contracting necrotising fasciitis following surgery for a*

hysterectomy. I have had many surgical procedures since to try to repair the damage and it is only this year that I have been fit enough to get back to exercise classes. I have been swimming and walking but I am not sure what I can and can't do without harming the colostomy. I have two stomas, one that deals with faeces whilst the other emits mucus only. I went to a salsa class this week and thoroughly enjoyed it. There is much wiggling of hips and stretching of arms. Great fun!! Next week the coach says we will do tummy crunches. I think that this might not be wise for me. What is your advice?

A: Well done, you are an inspiration to all ostomates who wish to get back to doing exercise. From what you describe you have a colostomy and a mucous fistula. After this length of time following surgery for stoma formation you should be able to undertake any activity as long as you start off slowly- the skies the limit as they say! Obviously if you undergo further surgery for anything you would need to follow the advice of the surgeon at the time as to when to recommence exercise. When trying something new I would suggest speaking to the trainer and explain that due to some abdominal surgery several years ago you would need to take things slowly and may not be able to reach the levels they may expect immediately. Start off slowly and gradually build up, ensuring you do not over stretch initially. However there is no reason why you should not be able to do any activity with a certain degree of caution to start with.

Q: *I had a reversal 7 years ago and ever since my stools have remained very loose and very offensive (smelly). This really is an embarrassing problem for me. Are there any medicines or alternatives I could take to help solve this problem? Also, could you send me a proper diet sheet as everything that I seem to like to eat are the things I am not supposed to have!! Please help me.*

Q: *My mum has recently had a stoma reversal on 30/10/10. She had Adenocarcinoma of the rectum in December 2009. She is in pain. Her anus is sore and she has piles. She feels like she needs to go to the toilet but each time she does there is only a small amount of liquid stool on the tissue and nothing in the toilet. She gets no sleep and is running to the loo every 10 minutes for a slight bit on the toilet paper. The surgeon told us that where the join was had narrowed and so they gave it a stretch in theatre. When mum gets the feeling she needs to pass wind or poo she says it's so painful. After she returns from the loo she is all sweaty and shaky. She also has a tear, fissure, for which she has Rectogesic. She is still on 10 ml Oramorph, Zomorph and Paracetamol. I don't know whether what mum is experiencing is constipation or diarrhoea. Since the op she has not done a poo with any real volume. It's only been the slightest amount on the toilet paper. Does she need Loperamide or Lactulose? I am sorry for troubling you but hope this scenario seems familiar to you so you could perhaps recommend something or reassure us.*

A: Obviously I am not aware of the full surgical history of your mum's case and therefore it is difficult to advise on this problem. It is obvious from what you are describing that your mum is really struggling and is in pain when she passes her stool. It also sounds like she is not emptying her bowel completely. I would suggest a review by the consultant again as it may be that the anastomosis (join) has narrowed again and this is what is causing the

A: You do not say what surgery you had. Dependent on the amount and type of bowel you had removed the stool may be loose and erratic. A change in your diet may help and for specific information it may be useful to ask your GP to refer you to a dietitian to discuss this. Also certain medication can be suitable for patients to take to regulate the bowel. The first one to try is called Fybogel. It is a powder, which you mix with a glass of water, stir well and drink. It needs to be taken regularly twice a day. It is also important to ensure you drink plenty whilst taking this. You could also speak to your local Stoma Care Nurse who will have access to your medical notes and will be able to give specific advice taking into account the actual surgery you underwent.

Q: *Dad is 90 yrs of age. With a number of issues he copes with the bag remarkably well. However we do have a number of occasions when the discharge cannot be held when he is changing the bag – leading to a very embarrassing situation because the faecal matter cannot be restrained. Recently we have the problem that he is changing the bag very frequently – everything that he eats or drinks quickly finds its way into the bag. He would normally have a diet that is not heavy – a little bread or toast or maybe cornflakes in the morning; sandwiches or light salad at lunch (which could be cheese or meat based plus greens); and more than likely fish for the evening meal. Today he has had only a piece of buttered bread this morning; was encouraged to have two pieces of toast for lunch and would only have cornflakes tonight. All of that and any drink that he had caused an almost immediate filling of a bag necessitating change of the bag. I would welcome any help. He has just had a rectal prolapse contained; the rectal discharge then went berserk for a while but has settled – he still has one and has had since having the colostomy operation. Any advice would be very welcome.*

A: It is not unusual for a stoma of any sort to work when changing the bag. Patients do not have the ability to control when the stoma acts and therefore on occasion the stoma may work when you do not want it to. Certain foods can cause a looser output but from what you describe

your dad has quite a bland diet. Certain fluids can also cause a loose motion, especially fruit juices. However it is important that he drinks plenty of fluids even when the output is loose to ensure he does not become dehydrated. Is your dad taking any sort of food supplements as these can also lead to a loose output? If there is no obvious dietary reason for this loose motion it may be that a sachet of Fybogel taken mixed with water twice a day may help to regulate the bowel. Reducing the amount of food he eats will only make the problem worse; it is the type of food he eats which will cause a problem not necessarily the amount. Keeping a food and fluid diary may help as it will identify any particular food, which could be related to a loose motion, and he can therefore reduce this particular culprit if he wishes.

Q: *The skin around my stoma bleeds quite a bit from time to time. I am using LaVera cream (excellent for normal day-to-day maintenance) and when I get bleeding I use the cream and then sprinkle on Orahesive. I am keen to know what more I can do to prevent instead of trying to cure!*

A: When you have washed and dried the skin surrounding the stoma I would try a skin barrier protector spray or wipe. This will put a waterproof layer onto the skin, which will then protect it against the output from the stoma. There are many different ones available on prescription including Cavilon (available as a spray, a wipe or a foam applicator). There is also a wide choice made by the ostomy companies and you can telephone them to get some free samples to try to see which you feel is best for you. If the soreness and bleeding is particularly bad then the use of Orahesive powder and possibly a seal such as SecuPlast (Salts), Cohesvie (Pelican) or Adapt (Hollister) can be useful. If the soreness does not settle then it may be due to an allergy and a review by your Stoma Care Nurse can confirm this and they would then be able to advise more specific treatment and a change of appliance to solve the problem.

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 about twice a day.

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 left 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:

Colostomy Association
2 London Court, East Street
Reading RG1 4QL

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

CA attends... The World Council of Enterostomal Therapists (WCET UK) Conference 27th - 29th September 2010

Once again the Colostomy Association attended this special conference. For those of you who may not know, WCET UK is an association of expert professional nurses who care for people with ostomy, wound or continence needs. The WCET UK conference is held annually and the venue for 2010 was the Bournemouth International Centre.

Entitled "Are U Ready?" WCET UK conference offered healthcare professionals an opportunity to share complex cases both physical and psychological. Keynote speakers covered topic areas such as:

- Inflammatory Bowel Disease
- Colorectal Cancer
- Advanced Practice

Mary Thomas, CA Trustee, and Gill Herbert, CA Office Administrator, attended as unfortunately Sue Hatton, Executive Trustee and Richard Bray, General Manager, were unable to attend due to ill health. Jane Wood, Tidings Editor attended as Marketing Consultant for the CA.

Attending WCET UK, gives the CA an opportunity to meet stoma care nursing professionals in an inspiring and motivational forum. The CA has much to gain from this conference. Valuable relationships are forged and patient's perspectives are voiced.

CA also gains a clearer insight into the work of these dedicated healthcare professionals, which leads to an increased awareness of nursing and medical developments in professional practice.

Face to face meetings build confidence and prevent an 'us and them' culture developing. Knowledge and understanding is advantageous for all patient associations as it can be used to address change where and if appropriate.

Our close association with both IA and UA continues. A joint initiative in the form of a poster outlining the work of each patient association was discussed and agreed. An abstract of the content was put forward to the WCET UK committee for acceptance.

We are delighted to inform you that it was accepted and appeared on Poster Board 11 - here is the result...



From L-R: Anne Demick National Secretary IA, Mary Thomas CA Trustee and Hazel Pixley National Secretary UA

If you would like to learn more about the topics discussed at WCET UK why not visit:

www.wcetuk.org.uk/2010/programme.html

The 2011 Conference will be held in Liverpool at ACC Liverpool 3rd-5th October.

Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group
Freephone: 0800 0184 724
www.iasupport.org
- UA Urostomy Association
Tel: 01889 563191
www.urostomyassociation.org.uk
- IOA International Ostomy Association
www.ostomyinternational.org
- Gay Ostomates
Email: brian@gayostomates.org
www.gayostomates.org
- Stomadata & Stomaftr
www.stomadata.com
www.stoma.fr
- Macmillan Cancer Support
Tel: 0808 808 00 00
Mon - Fri: 9am - 8pm
www.macmillan.org.uk
- National Association for Colitis and Crohn's disease
Tel: 0845 130 2233
www.nacc.org.uk
- The Gut Trust (Irritable bowel syndrome)
Tel: 0114 272 3253
www.theguttrust.org
- Bladder and Bowel Foundation (B&BF)
Formerly Incontact and Continence Foundation
General enquiries: 01536 533255
Web: www.bladderandbowelfoundation.org
- Bowel Cancer UK
Tel: 020 7381 9711
Email: admin@bowelcanceruk.org.uk
Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK
Tel: 08450 719300 (Lo Call rate)
Web: www.beatingbowelcancer.org



NATIONAL KEY SCHEME
How to obtain a key to gain access to toilets for the disabled

Colostomates are entitled to a key which will open 8,000+ locked toilets around the UK. Some local councils will provide this key free, or for a small charge.

Keys can be obtained from the Colostomy Association at cost of £3.50. Contact head office: 0118 939 1537 for an application form.

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

New from RADAR - coming soon...
National Key Scheme Guide 2010
Pre-order Price: £9.49

PS. Don't forget...World Ostomy Day - Saturday 6th October 2012

If you have any fundraising ideas or suggestions on how CA can celebrate World Ostomy Day...contact the Editor via CA head office: 0118 939 1537 or Email: editor@colostomyassociation.org.uk - thank you!

If you are a stoma care nurse...Get in touch...and tell us your News!



Tidings was delighted to be contacted recently by Janice King Personal Assistant to the Stoma Care Department at The Princess Alexandra Hospital, Harlow.

Janice had been requested to contact Tidings by Tracey Hart CNS to let everyone know about 'Connect'. So here is what 'Connect' is all about...

'Connect' Harlow & District Stoma Group is a new social network for ostomates - who have either a colostomy, ileostomy or urostomy. The group was set-up by Tracey Hart,

Stoma Care Nurse at The Princess Alexandra Hospital, Harlow, a year ago, and is organised by a pro-active Committee comprising Chairperson, Vice Chairperson, Secretary and Treasurer.

'Connect' currently has around sixty members and has been specially created to enable stoma patients and their families to meet informally to share experiences and offer each other practical advice on living with a stoma. For this purpose it has regular

coffee mornings and holds various social events.

Anyone wishing to obtain further information on membership contact:

Lin Hart - Secretary to Connect
Tel: 01279 505273. Or alternatively,
Janice King
Stoma Care P.A.
at The Princess Alexandra Hospital
Tel: 01279 827072.
Membership is open to all ages and both sexes.

Connect's programme for 2011 is as follows... (further social events still to be included):-

- **AGM (11.00 am – 1.00pm) Thursday 20th January**
- **Coffee Mornings (10.30 am – 12.00 noon)**
Thursday 31st March
Thursday 2nd June
Thursday 1st September
Thursday 1st December

All the above will be held in the Main Hall of the Social Club at The Princess Alexandra Hospital.

Adhesive Remover Spray and Wipe for extra easy removal

Coloplast Adhesive Remover Spray allows you to easily remove adhesives. Should the adhesive leave residues on your skin, you can simply use a Remover Wipe.

Both are sting free and silicone based. They dry within seconds leaving the skin ready for the next appliance.

To request free samples please call our **Customer Care Team** on **0800 132 787** or visit www.charterhealthcare.co.uk



Coloplast Care
 Urology & Continence Care
 Wound & Skin Care



Coloplast - Involves products and services that make life easier for people with very personal and often sensitive conditions. Working closely with the people who use our products, we create solutions that are suitable to their specific needs. We sell our products in 100 countries. Our business is the only one, in urology, colostomy or ostomy, from 1 to 100 years. We operate globally and employ more than 2,000 people.

The Coloplast logo is a registered trademark of Coloplast A/S. All other trademarks belong to their respective owners.
 © 2011 Coloplast A/S, www.coloplast.com

Coloplast Unit 1
 Pine Road, How Hill
 Pembrokeshire, Pembrokeshire Park
 Pembrokeshire, Pembrokeshire
 Tel: 0800 132 787
www.coloplast.co.uk

Marketplace

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

If you have anything to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20. So, why not get in touch...contact editor@colostomyassociation.org.uk and let Tidings promote your business.

SOMAerect
Penile Rehabilitation

erectile dysfunction?
Try **SOMAerect** *5a* systems - World's first fully customizable vacuum therapy systems: **92% successful** with up to 40% recovery rate when used regularly, and no restriction on frequency of use. On NHS prescription from your GP for Colostomates / Pelvic Surgery. (SOMACorrect Xtra - NHS order code 15111)

Restoring intimacy naturally

XL
L
M
S

Call **0208 207 5627** today for your **FREE GP and Patient Guide.**

www.iMEDicare.eu

- BED PROTECTION
- BRIEFS
- PADS
- ACCESSORIES

Arelle

CONTINENCE CARE

Arelle provides high quality products for men and women

For more information and your discreet mail order brochure call Arelle FREE on 0800 389 3597

or visit : www.arelle.com

FREEPOST SWB11096, Bridgwater Somerset, TA5 1ZA

CUI International is the UK's leading and most innovative supplier of **Ostomy & Hernia support products**

AVAILABLE ON PRESCRIPTION

STANDARD AS WELL AS BESPOKE PRODUCTS IN WHITE, BLACK & SKIN TONE

Unique features of Fulcionel Easywear belt make it the **ONLY** product for ostomates that can be worn and taken off so easily yet provide vital support for long periods of time without discomfort.

Ladies Bespoke "Seamed cup" girle
*Patent Pending

Unisex Bespoke belt with "darted cup"
*Patent Pending

FREEPHONE: 0800 279 2050

www.cuiwear.com

GROUND FLOOR | 31 ST JOHN STREET | LEICESTER | LE1 3WL

Donation & Standing Order Form

Thank you for your support



Please use this form to make either a **Single donation** or a **Regular donation** by **Banker's Standing Order**. Simply **complete this form** and return by **post** to the **Colostomy Association 2 London Court, East Street, Reading, Berks RG1 4QL**. Telephone: **0118 939 1537** if you have any queries.

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

My Details:

Title: _____ Name: _____ Surname: _____

Address: _____

Postcode: _____

Telephone number: _____ Email: _____

1 Regular donation: I would like to make a **regular contribution** to the **Colostomy Association** every month/quarter/year in support of the charity. I have ticked the appropriate box below and filled in the amount. I have also completed the **Banker's Standing Order form** (Please tick.)

(Please tick.) Yes, I would like to make a **Monthly** donation of £ _____

(Please tick.) Yes, I would like to make a **Quarterly** donation of £ _____

(Please tick.) Yes, I would like to make a **Yearly** donation of £ _____

2 Single donation: (a donation of £15 or more covers production of four issues of Tidings per year)

(Please tick.) **Yes I would like to make an single donation**

I would like to make a donation of £ _____

I enclose a **cheque/postal order form** made **payable** to the **C.A. Ltd - Thank you!**

Please tick here if you require a receipt acknowledging your kind donation

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: _____

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**

the sum of £ _____ amount in words: _____

Date of first payment: _____ and thereafter on the same day every month/quarter/year)*

(*Delete as appropriate) until further notice. (Please cancel any previous standing order in favour of this beneficiary)

Name: (IN CAPITALS) _____

Signature: _____ **Date:** / / 2010

giftaid it

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 28p.** For example, a donation of **£15 becomes £19.23 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 28p for every £1 donated).

Signature: _____ **Date:** / / 2010 **Thank you for your gift**



The Colostomy Association is an independent charity financed solely by donations. Your **help and support** is **now 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 - we need to be here for them!

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

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

The Association provides:

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

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

• Regular Donation

Regular donations can be made via standing order (see Donation Form) Regular donations help us to plan ahead and like all donations are vital to our survival.

• Single Donation

Single donation from individuals and fundraising events are always welcome and greatly appreciated. So please keep them coming, no matter how small. Just £15.00 (or more) ensures we are able to continue to produce four issues of Tidings per year.

• Donate via Payroll Giving

Enables you to give direct to us straight from your gross salary (before tax is deducted), and to receive immediate tax relief of up to £4 for every £10 donated.

• Legacies - A gift in your will

If you are about to make a will, or are considering making a change to your current will, please consider leaving a legacy to the Colostomy Association to help us to continue to offer support to all those with a colostomy.



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**. **www.colostomyassociation.org.uk**
- 2 Visit the **Just Giving home page** you will see a search panel 'Find a Charity' type in **Colostomy Association**.



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



"For me the introduction to the Outlook Group was a very important event. My volunteer visitor came to see me in hospital in 2005 a few days after my surgery"...

Moira Hammond writes... about the **Outlook Support Group** based in North Staffordshire and Cheshire



Members of the Outlook Support Group with Moira (second from the left front row), Julie Rust (centre) and Ernie Hulme CA Vice Chairman (far right)

For me the introduction to the Outlook Group was a very important event. My volunteer visitor came to see me in hospital in 2005 a few days after my surgery.

Julie Rust, our nurse on the Bowel Care Team, had told me "You will meet Ernie, a fellow patient" so I was only slightly surprised when this large, bearded, smart gentleman said "Hello Moira" as I was gingerly walking down the corridor from the day room. It was Ernie who introduced me to the group and since then it has been a wonderful support to me and I have enjoyed every minute.



From L to R: Ernie Hulme, Moira, Julie Rust

About 12 years ago the Bowel Care Team at the University Hospital of North Staffordshire, along with some volunteers, decided to set up the Outlook Group for ostomists in North Staffordshire and Cheshire. Julie Rust was, and is, our local stoma nurse specialist, and along with Ernie Hulme and Val Moss (now retired) they were

the main driving forces from its start. The Inaugural AGM & Patient Open Day was at the Britannia Stadium home of Stoke City football club in 1999. Our first chairman was a very passionate and remarkable ostomist Barry Brailsford, who led the group for many years.

Another person that played a major role in the early days was Lee Findler who joined the bowel care team shortly after the formation of the group and was and still is, very supportive of the Outlook Group even though he is no longer on the Bowel Care Team.

Over the years the group have welcomed all Ostomy patients, whether they have a Colostomy, Ileostomy or Urostomy. Consultant Mrs Chris Hall, is our President while Julie Rust attends our meetings and committee meetings, keeping us up to date with any matters which we can help with within the hospital. Julie is also on hand during the evening group meetings in case anyone wants a private chat.

We have a meeting every quarter when we have a speaker and the opportunity to chat and have a good social time. Topics cover a wide area, including local interest, travel and voluntary groups to various medical subjects by staff from the University Hospital of North Staffordshire. We hope to introduce some daytime events and will be going out, either for a meal on February 23rd (enquire below for details) or on an outing. A very successful open day is held annually which many stoma

manufacturers attend, giving us a chance to see latest products and obtain samples. This year we had over 150 people attending.

Several of the members are trained volunteers and work under the supervision of the University Hospital North Staffs Bowel care team, providing support and advice to newly diagnosed Ostomy patients, their family and carers either at home or during their hospital stay and also with a friendly chat by telephone.

A newsletter goes out to our members in January outlining the events for the coming year. We regularly contribute to the Jacob's Well charity by donating surplus stoma items for overseas use. It is when one hears of the extremely difficult situations that patients overseas have to cope with, that we realise how well looked after we are in Great Britain.

On a personal note I really value the friendships I have made. There is always someone I know I could have a chat with if I needed to and it is strange to think I would not have so many new good friends but for my 'makeover'!!

However, new laparoscopy surgery techniques and shorter hospital stays now mean we are not always able to visit patients while they are in hospital. We would hope that this means we can contact them not only later on in the group, but ideally at any time as needed.

Any patients in the North Staffordshire and Cheshire area are welcome to come to our meetings so come along and join us. Our first meeting in 2011 will be on Wednesday March 16th at 7.30, when Andrea Green (Foundation Trust Director) from the University Hospital of North Staffordshire will be our speaker.

If you need further information or would like to be on our mailing list, please contact me on (01782 627551) or Ernie Hulme (01782 324441)

We look forward to seeing you soon.

Moira Hammond

SUPPORT GROUPS IN YOUR REGION

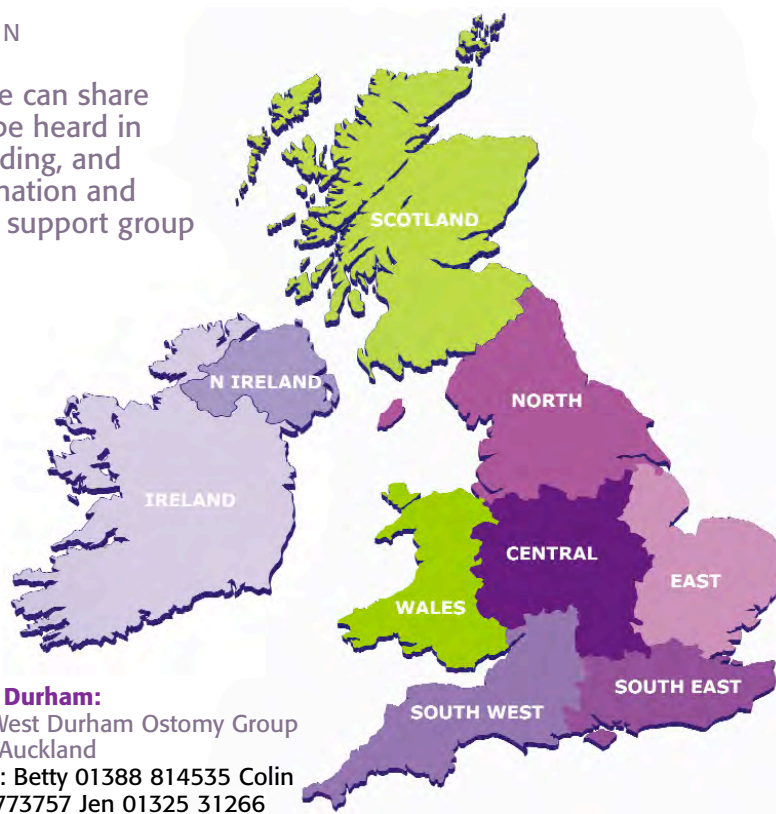
Support Groups are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding, and encouragement. Participants share information and resources. By helping others, people in a support group strengthen and empower themselves.

Stoma support groups in your region...

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

If you know of a **support group** not mentioned in our listings please get in touch...

e-mail: editor@colostomyassociation.org.uk



Scotland

Midlothian:

GOSH

Contact: Alex Topping 01501 772154

Maggie's Edinburgh Timetable

Contact: 0131 5373131

Glasgow:

Fittleworth Glasgow Stoma Support Group

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

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

Countess of Chester Hospital

Contact: Julie Clements 01244 366170

Drop in Clinic

Contact: Angela Perks/Deborah Singleton 01625 661598

Stockport Support Group

Contact: Angela Simpson 0161 419 5059

TOMAS (The Ostomates of

Macclesfield and Surrounding Areas)

Contact: Kath Wood 01625 875442

Warrington Ostomy Support Group

Contact: Jane Shaw 01925 662103

Cleveland:

Oops Group

Contact: Julie Morrisroe SCN/Carol Younger 01287 284113

County Durham:

South West Durham Ostomy Group
Bishop Auckland

Contact: Betty 01388 814535 Colin

01388 773757 Jen 01325 31266

Maureen 01388 818267

Derbyshire:

Stockport Support Group

Contact: Angela Simpson

0161 419 5059

Lancashire:

Oldham Stoma Support

Contact: June Wilde 0161 6787086

Trafford Bowel Care

Contact: Jackie Carey (Secretary) 0161

7489659 Doreen 0161 9627818 John

0161 7484655

Merseyside:

I.C.U.P.S

Contact: Stoma Care Nurse 0151

6047399

Liverpool Support Group Crosby

Contact: Barbara Percy 0151 5292842

(Afternoon)

Olivia Thomas Suite University

Hospital Aintree

Contact: Carmel/Pauline 0151

5292842 (Evening)

Northumberland:

Northumberland Cancer Support

Contact: Pat Fogg 0191 4102679

Teeside:

Bowel Cancer Support (Semi Colon)

Contact: Mr G Dickson 01642 563747

Pat Brydon 01642 897903

Tyneside:

Gateshead Health NHS Trust

(Stoma drop in clinic)

Contact: Sister Heather Wilson

0191 4878989 Ext 2221

NHS Molineaux Centre

Contact: Lesley Brown 0191 2195656

Royal Victoria Infirmary Support Group

Contact: Gordon Weatherburn

0191 2341109

Yorkshire:

Airedale Stoma Support

Contact: Jenny Shaw 01535 652516

or Sue Hall 01535 210483

Behind You (Calderdale & Huddersfield

Bowel Cancer Support Group)

Contact: Michelle Speight

01484 355062

CROPS (Colo-rectal ostomy & internal pouch support)

Contact: Gloria 0114 2879503

Dewsbury & District Ostomy

Contact: Janet/Eileen 0844 8118110

Rotherham Ostomates Caring Support

Contact: Contact CA for details

Scarborough Stoma Support Group

Contact: Sister Jean Campbell 01723

342388 Amanda Rowe 01723 342446

The Hull and East Riding Colostomy

Support Group

Contact: Pete Smith 07989 565335

and Claire Price 07805 978151

Isle of Man:

Optimistics

Contact: Stoma Nurse Lynne Webb

SCN 01983 534009

Stoma Support Group

Contact: Carole Cringle 01624 650212

England - Central

Buckinghamshire:

Milton Keynes Stoma Association

Contact: Bruce Pollard 01908 582563

Leicestershire:

Moving on (Leicester Royal Infirmary

Colorectal Support group)

Contact: Wilf Patterson (Secretary)

01455 220344

Nottinghamshire:

Nottingham Colostomy, Ileostomy &

Urostomy Support Group

Contact: Rosemary Brierley

0115 982 7868

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

Staffordshire:

Outlook
Contact: Ernie Hulme 01782 324441
Joan 01782 710828

Worcestershire:

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

West Midlands:

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

England - East

Bedfordshire:

Saturday Social Club
Contact: Karen Richards
01234 792278

Cambridgeshire:

Ostomistics
Contact: Heather Connor 01733
768332 Mob: 07757167422

Essex:

Connect
Contact: Lin Hart 01279505273
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 K Harvey (Chairman)
01206 271425
Brian Waller (Secretary)
01206 540449
Optimistic Ostomates
Contact: Janet 01702 385510 Angela
01702 385509
South Essex Young Ostomy Group
Contact: Paul Gray 01708 501268
STEPS
Contact: Jackie Coleman
01268 451937
Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa
0208 9708321

Hertfordshire:

Connect
Contact: Lin Hart 01279505273
Colonise
Contact: Gill 01727 851556
Connect
Contact: Lin Hart 01279505273
Stoma Fellowship
Contact: Andrea/Mandy 01438
781133

Lincolnshire:

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

Norfolk:

Ostomy Friendship Support Group
Contact: Contact CA

Stars
Contact: Anne Brown 01603 661751

Suffolk:

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

England - South East

Berkshire:

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

Hampshire:

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

Kent:

Ashford Stoma Support
Contact: Chairwoman - Mrs Ursula
Naish 01233 640863
Atoms Support Group
Contact: Maria Culleton SCN
01227 769679 or 07827997424
Canterbury & Coastal Stoma Support
Contact: Marie Culleton SCN
01227 769679 or 07827997424
Dover & District Stoma Support
Contact: Marie Culleton SCN
01227 769679
Maidstone Stoma Support Group
Contact: Judy/Kirsty
01622 224305

London:

Bowel Cancer Newham
Contact: Scyana 0208 5535366
Homerton Hospital Bowel & Stoma
Support Group
Contact: Toni Johnson 0208 510 7599
Angela Davy 0208 510 5318
Shepherd Bush Stoma Support Group
Contact: Roslyn 07984979728
or Mary 07773397234
Whipps Cross University Hospital
Contact: Christina 0208 5356563

Middlesex:

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

Oxfordshire:

Oxfordshire Ostomy Fellowship
Contact: Pat Longworth 01235 524163

Surrey:

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

Sussex:

(SAS) Brighton & District Stoma Care
support
Contact: Sylvia Bottomley 01273
554407
The Ostomy Friends Group
Contact: Jane Quigley 01323 417400
Ext 4552

West Sussex Princess Royal Stoma
Support
Contact: Tina Walker 01444 441881
Ext 8313

England - South West

Avon:

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

Cornwall:

Lanhydrock Ostomists Group
Contact: Christine Davey
01208 831471
Optimists
Contact: Sue Hatton 01326 340058

Devon:

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

Dorset:

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

Wiltshire:

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

Wales

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

Northern Ireland

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

Eire

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

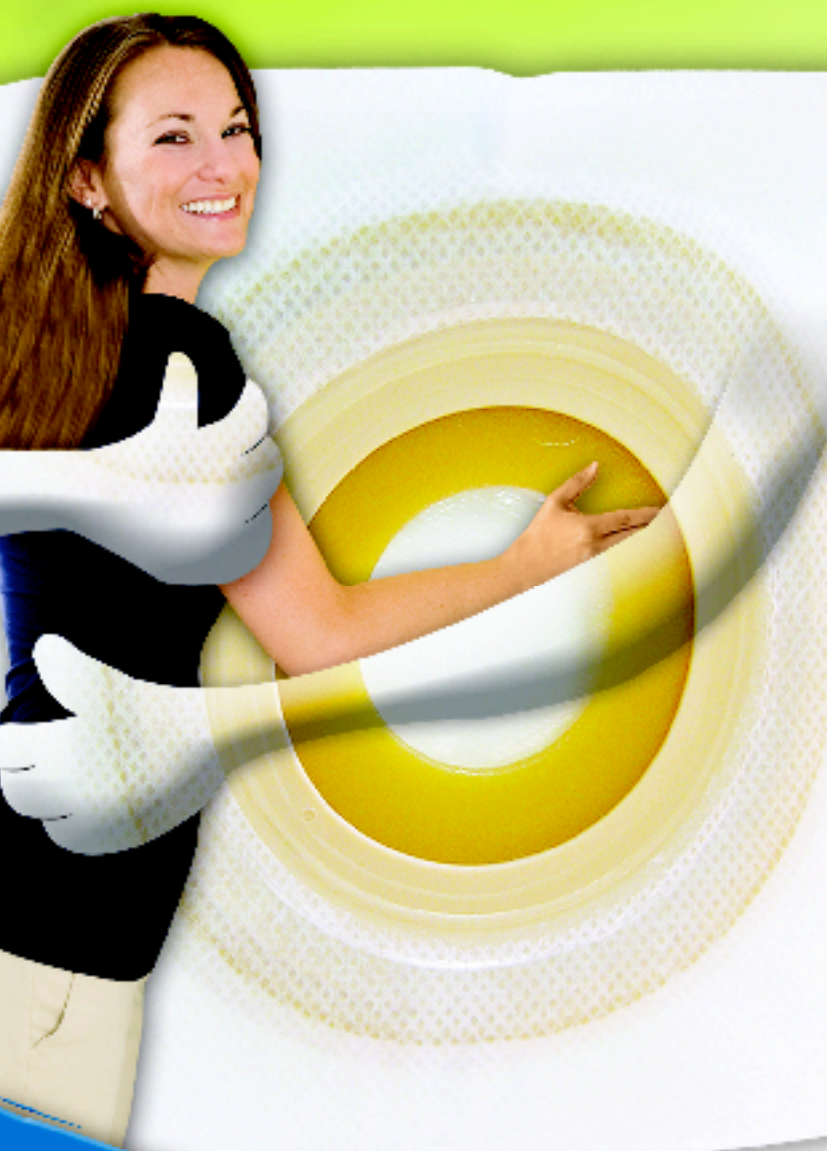


Convatec

Realize the possibilities™

Discover how to give your stoma the **hug** it deserves!

A new innovative stoma system unlike any other.



Traditional cut to fit flange

Gaps expose the skin to harmful output, which can lead to discomfort.



Convatec Mouldable Technology™ flange

Hugs the exact shape of your stoma, even while it moves.



Esteem synergy® Flat Mouldable

For further information Call 0800 282 254 UK

Email stoma.webcare@convatec.com or Visit www.convatec.com

