WINTER 2011 | Issue 24

colostomy association

Tidings

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

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

OstoMART
Limited

RESPONDER

FREE HOME DELIVERY SERVICE

PROVIDING A FAST, TRULY PERSONAL AND DISCREET SERVICE SINCE 1991

✓ FREE DELIVERY
✓ DISCREET SERVICE
✓ QUALITY ASSURED
✓ ON-HAND ADVICE
✓ AWARD WINNING CUSTOMER CARE
✓ FREE GIFT

Try the **RESPONDER** delivery service NOW

Call **0800 220 300**

www.ostomart.co.uk

You'll be glad you did!

Our high levels of customer service are recognised internationally, so security and peace of mind is assured

QUALITY ASSURED BS EN ISO 9001

ASCB (E)

BHTA British Healthcare Trades Association

Why choose the **RESPONDER** service?

- Free home delivery of all your stoma or continence prescription requirements. All manufacturers' products stocked and supplied
- Electronic Prescription Service (EPS)
- Online ordering facility
- Impartial product advice and complimentary sampling service
- Quick, discreet and reliable overnight delivery
- Deliveries can be made to any chosen address (without a signature if required)
- Open on Saturdays
- Extended midweek opening hours
- Ultrasonic, computerised cutting of all appliances to your exact stoma size/shape
- ISO Quality assured service
- Free gift and MRSA resistant flannel with first order
- Complimentary wet or dry wipes & perfumed disposal bags with each order.
- Award winning personalised service
- BTEC qualified stoma & continence customer support staff
- Access to stoma care nurses for unbiased product advice and support
- Prescription collection from your GP if required

welcome to WINTER

Happy New Year and welcome to the winter issue of Tidings...

As another year begins it's easy to focus on what's ahead as the past year fades but before we all get excited about what's noted on our calendars and on mine it's the Olympics! I would like to take a look back at 2011.

The last four issues of Tidings have been incredible, packed with stories, education articles, hints and tips, product information, practical advice and with YOUR help...OK! Let's just stop right there shall we, who do I mean? Well, that's easy YOU of course – Tidings readers – for without YOUR letters, emails, stories, fundraising efforts, educational articles, product information...Tidings simply wouldn't have the same appeal! When I say – Tidings readers – whom do I mean? Well, the list is growing but in essence its...colostomates, their families living here in the UK or in sunnier climes abroad, those involved in stoma care – clinical nurse specialists – around the UK and overseas, new patients, surgeons, GPs, stoma care product manufacturers and suppliers, carers, support groups, pharmacists and more! Tidings readership continues to expand, long may it continue, as it raises awareness for the work of the Colostomy Association.

During 2011 I have had the privilege to attend several healthcare/stoma care related conferences and CA volunteer training events as Editor of Tidings and the enthusiasm and appreciation of Tidings has brought a tear to my eye on several occasions but I must stress it is a Team effort which includes you! I cannot impress on you enough how well Tidings is received by healthcare professionals and in particular stoma care nurses who regularly give Tidings to their patients – a BIG thank you to them!

Over the past year Tidings has continued to clarify, inform and support ostomates 'living with a colostomy'. It's the Editors task together with the Editorial team, to keep the colostomate in our 'mind's eye', to deliver support, reassurance and provide practical advice within the pages of the magazine, as well as examine the negatives and report on the positives so that when Tidings drops through the letterbox it brings a plethora of information relevant to colostomates, their families and carers.

I would like to take this opportunity to thank EVERYONE for their fantastic contributions and if there is anyone amongst you toying with the idea of writing something for Tidings please don't hold back, be brave, you never know your story or article could help someone!

I would also like to thank my Editorial team for their on going support and in particular Associate-Editor Rosemary Brierley who keeps me focussed and keeps a beady eye on the detail. The teams passion, ideas, observations and articles shine out from the pages of Tidings. A sad farewell to team member Gill Herbert who with eyes and ears peeled on behalf of colostomates contributed much to Tidings. A warm welcome to new team member Duncan Wells – I'm sure many of you will enjoy his contributions and warm welcome back to Jo McKenzie long time CA office administrator.

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

A big THANK YOU to the advertisers who without their continued support, Tidings magazine in its current form would not be possible! And last but definitely not least, kind thanks go to the unsung heroes who continue to ensure the highest quality of production and print that this publication truly deserves!

Tidings magazine extends a warm hand to YOU and to everyone in 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.

I usually finish by giving a run down on the contents of Tidings but this time I'm going leave you in peace to find out for yourselves! Happy reading!

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!

Jane

Email:
editor@colostomyassociation.org.uk

PS.If you would like to get in touch with the Colostomy Association or Tidings please take a look at Page 6.

inside..........

all your regulars

cover story

Cover picture © Edward Byrne Photography

Reaching out...
Northern Ireland
featured on page 56

...this issue

& special features

update...

real lives...

health...

travel...

Don't forget your travel certificate this winter...
Contact CA office on 0118 939 1537 to get yours today

support...

interest...

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

About...the Colostomy Association

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

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

Simply contact us by post:
Colostomy Association
2 London Court,
East Street, Reading RG1 4QL

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

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

Find us on Facebook:

Find us on Facebook

Simply visit our **website** and **register** at:
www.colostomyassociation.org.uk

Don't delay... Donate Online today!

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

1

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

JustGiving

2

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

Tidings is YOUR Magazine...

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

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

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

Feedback... We are always trying to improve your Magazine and welcome your feedback. Enjoy this 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	2012
Summer	July	2012
Autumn	October	2012
Winter	January	2013

EDITORIAL TEAM

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

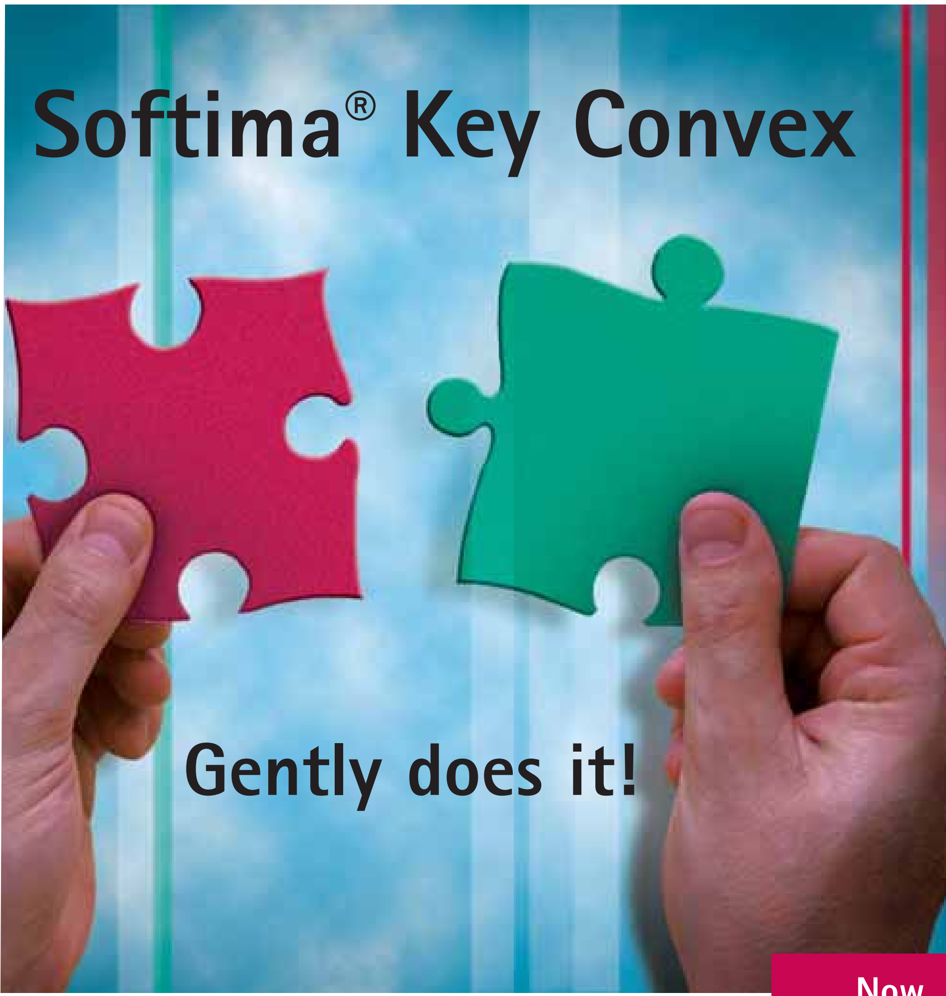
or e-mail the editor direct:
editor@colostomyassociation.org.uk

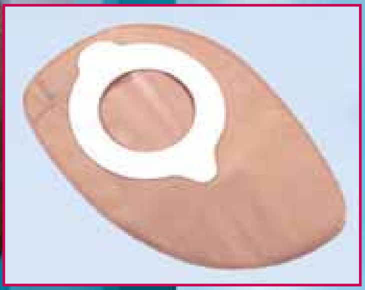
or e-mail:
cass@colostomyassociation.org.uk

colostomy association

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

Softima® Key Convex





Now On Prescription

Softima® Key - The world's first truly guided two piece ostomy system is now available with convexity.

Convexity with comfort - Gentle, smooth and comfortable convex to fit closely for extra security with minimum pressure.

Secure and simple - The "key, guide and lock" system ensures precise, secure and easy connection every time.

B|BRAUN
SHARING EXPERTISE

B. Braun Medical Ltd I OPM I Thorncliffe Park I Sheffield I S35 2PW
Tel. (0114) 225 9000 I Fax (0114) 225 9111 I www.bbraun.co.uk

XX-SKCA4T-11-11

For a free sample, simply fill in the form below and return using the FREEPOST address or freephone: 0800 163 007

Please send me a sample of:

Convex ☐ Flat ☐

Closed ☐

Stoma size...mm

Name:
Hospital Name:
Address:

Postcode:
Telephone:
Email:

XX-SKCA4T-11-11

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

Message from our President...

We all enjoyed another stimulating and exciting open day - this year held in Leeds. Without straying into the field of politics, I could not help feeling impressed that we were indeed creating our own colostomy “big society”.

The willingness of colostomists to learn and to help each other is, through the medium of our Association, very special.
I hope for better lives and greater enjoyment for the increasing number of survivors from better cancer surgery in the future.

I continue to visit and operate in many countries throughout the world. Visits this year have included South Africa, Brazil, Australia, Germany, France, Italy and once again to Russia and Hungary. Indeed the list never seems to stop. I am however, increasingly convinced that better lives for colostomists depends upon organisations such as our own, and indeed upon the willingness of our members to come forward and support the various initiatives that the Association puts forward.

I hope I can be forgiven for repeating my enthusiasm for seeing that every colostomist is made aware of the potential advantages of the irrigation management method for his or her stoma. We are in the New Year, about to start production on a friendly, watchable and practical DVD that we hope every colostomist in the country will be able to see for themselves. We are also working hard on plans to accommodate the teaching of ‘irrigation’ to those who wish to learn for themselves.

During last year I have approached the Association of Coloproctology of Great Britain and Ireland with a request to help us identify units around the country that will promise to take a special interest in the revision and improvement of anyone whose colostomy is less than optimal, and can be made better by surgical revision. This is a highly specialised aspect of surgical training, and requires particularly fastidious and careful surgeons with a special interest in the practicalities of stoma management.

This year parastomal hernia has been a regular topic in the colorectal surgical meetings around the world and surgeons are becoming increasingly aware of how common it really is. Our members may need to be reminded that they do not have to put up with less than optimal stomas and that the National Health Service is committed to seeing these revised appropriately, if it should become necessary.

Our new Vice Present, Mr Ian Daniels FRCS of the Peninsular Medical School in Exeter, has already expressed his willingness to help. He is an established international expert in the repair of all forms of incisional and stomal hernias and the unit that he is building up in Exeter is a perfect example of what we hope to be able to replicate in various parts of the country. I am hopeful for real progress during the coming year.

Finally, I think we all need to express our Christmas good wishes and thanks to the people who work in the Colostomy Association office and who commit themselves to the running of the Association in many different ways. Tidings is a marvellous magazine, and I look forward to seeing what you have to contribute to it during 2012.

Seasons greetings and a very Happy New Year to everyone!

Professor Bill Heald OBE
President
Colostomy Association

Message from our Chairman...

This past year has, in many ways, been very exciting for the Colostomy Association and 2012 promises to be even more so. At the end of 2010 the Trustees decided that our main priority for the forthcoming year would be to pay more attention to volunteers and prospective volunteers and with that in mind a small team set about the task of arranging two "volunteer weekends away" the first in Chester and the second in Huntingdon. Both events were very kindly sponsored one by ConvaTec and one by Dansac.

The reasoning behind these two "volunteer weekends away" was to reaffirm the Colostomy Association's relationship with established volunteers and bring together prospective volunteers. We felt it important to invite partners as well as the volunteers themselves as, on many occasions, it is a "team effort" between the two of them.

There were presentations and much discussion on various subjects – Trustees were able to interact with volunteers and explore their main interests and skill sets to ensure volunteers matched the present and future strategic requirements of the Colostomy Association going forward.

The second stage of the process was to train the volunteers and this part of the programme unfortunately came to a halt as Bob Buckley our training team leader was taken ill. Sadly Bob died at the end of November but the Trustees felt, as a tribute to his untiring efforts, that he would have wanted the training scheduled for December to go ahead. On 13th and 14th of December 18 volunteers booked into the Premier Inn, Reading. The course was dedicated to Bob's memory. I and my other Trustees shall be eternally grateful to him for his untiring efforts to make our training programmes a success. He will be an extremely difficult act to follow.

However, Mary Thomas, Sue Hatton, Duncan Wells, Jane Wood together with Gill Herbert and Jo McKenzie (our head office administrators) worked very hard indeed to ensure that the two courses – Volunteer Induction and Volunteer Helpline Training went as smoothly as possible.

Northern Ireland has not been well supported in the past but the stoma nurses at the Belfast Hospitals together with two extremely keen prospective volunteers asked if the Colostomy Association would help them to set up a CA volunteer group in Northern Ireland. Two of our Trustees flew to Northern Ireland and attended an Open Day with prospective CA volunteer Chris Wright. The day was very well attended and colostomy support in Northern Ireland is now a reality.

The forthcoming year will now give us the opportunity to put all this hard work into effect by ensuring that the Colostomy Association is represented at most stoma events taking place throughout the UK.

May I take this opportunity to thank all the manufacturers and suppliers for all the support and sponsorship we have received throughout this year without whom we would be unable to provide colostomists with the help they need and deserve.

Seasons greeting to you all and Best Wishes for 2012

Monty Taylor
Chairman of Trustees

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 literature from new colostomates, carers and stoma care nurses.

Open Day...As some of you may know we had another very successful Open Day at Weetwood Hall, Leeds 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.

Several people have expressed an interest to attend a future CA open day event. If you would like to attend please register your interest by emailing Jo McKenzie at CA head office, details can be found on page 6. Due to venue constraints the cut off for attendee numbers will be approx. 200. Details of this year's event will be confirmed via our website or in the Spring Issue of Tidings published in April.

Moving on...It is with regret that we say farewell to Gill Herbert CA head office administrator who left us last November. Gill worked hard for the Association and showed real enthusiasm and drive to get things done on behalf of all the many ostomates that require our help and support. Gill came to the Association, six years ago, when it was the British Colostomy Association. It was not long after that we learnt that we were to lose the backing of Macmillan Cancer and that the BCA would cease to exist. When the decision was made to form the new Colostomy Association, in 2005, it was all "hands to the pumps" with new Trustees and the most willing office staff of Gill, Jo and Beryl. Gill worked tirelessly to ensure the continuation of the Association, she will be greatly missed.

Volunteers are needed...for Open days as there are more each year. Feedback from volunteers about open days lets Jo (who organises the diary) know what areas need more support, so keep in contact.

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

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 is almost always followed up by the words…if only I had known about the CA before…

Organising the helpline rota is quite a task and requires peace and quiet to sort it all out. Volunteers confirm the days they can take calls and Jo then sorts the rota into a coherent structure. Well done Jo!

Our Facebook group is growing fast, we now have over 400 members so why not join. It's simple and there's no cost involved. You will receive a very warm welcome from those already on board!

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 and Jo
and office volunteers
Margaret and Colin

A huge loss to the Colostomy Association...

Bob Buckley CA Volunteer and Volunteer trainer passed away last November. Bob was such a special person – through his voluntary work with the Colostomy Association he touched people's lives and helped change perceptions of 'living with a colostomy'.

A positive person, Bob was kind and understanding with a little humour attached and a sparkling smile. He loved running and fishing and was a very proud family man. He had many special skills which made him an excellent CA volunteer and trainer.

Bob was always available to talk to ostomates that called our Helpline – he was an advocate of irrigation. Never too busy to stop what he was doing, Bob would talk to, advise and encourage those who were just beginning to learn how to live with their colostomies.

The greatest tribute to Bob will be the CA volunteer training programme which is now dedicated to his memory. He was an inspiration – and let's hope that via this programme he will continue to inspire volunteers of the present and future!

He will be greatly missed by everyone that knew him.

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

Donations
When sending your donation/s **please mark your letter/cheque** with **Tidings Issue 24**....
Thank you!

Dear CA,
Re: Collection Box...
I celebrated my 80th birthday in the summer and collected £30 with my CA donation box.

Yours
P D

Thank you everyone for your kind donations

Dear Tidings,
Marathon Effort!

My name's Chris and I ran the Chester Marathon last October and raised £162. This year I will have had my colostomy for 27 years! I enjoy sport, especially running. I decided to run the marathon to raise funds for CA, to let people know that you can still enjoy sports even with a colostomy!

Best regards,
C D

Mini raffle raises £25...Kind thanks go to **J M**

In Memory...

Herbert Stott	£200

Thank you

Dear Sir/Madam,
Wedding Anniversary celebrations....
Please accept a donation of £150 on behalf of Amanda Williams. The collection was taken at my daughter's 25th Wedding Anniversary celebrations. (She was diagnosed with chronic Crohn's at the age of 18). Your organisation so helpful over the years - many thanks.

Kind Regards
G S

Dear CA,
Bring n' Buy for CA!
We are a group of ladies called Woodlands Park Adult School and we give to various charities during the year. I suggested at our next bring and buy we give to you. I have had my colostomy 9 years now, and I know money is always needed. Please accept a donation of £82.65.

Yours sincerely
I W

Dear CA,
Please accept a donation of £22.40. This donation is made up of the many 20p's that we collected by holding and selling paperback books. The sum raised was over a period of time as you can see we are a group that reads a great deal! £10 was donated by one member...Gerry, who was thrilled to read the latest Tidings and found on page 22 the answer to most, if not all, of his dietary problems!

Best wishes
J

Celebrations all round... Charity Hog Roast raises over £1000 for CA...

I shall always remember my 62nd birthday, September 2007 as I celebrated it in hospital, having been aroused from an induced coma in intensive care. I had been rushed to hospital some two weeks earlier with what turned out to be a perforated bowel, requiring serious emergency surgery! A day or so before my birthday, it was decided I was fit enough to come back to the world.

After a total of 10 weeks in hospital I was discharged, under supervision, and over the last four years I have lived a full and normal life – including a new husband, but that's another story which I may tell on different occasion!

I thought, earlier this year, that I would like to give support to new colostomates and become a CA volunteer – I am delighted to say that I have recently completed two CA Volunteer Training courses, which I thoroughly enjoyed! >

The **Colostomy Association** would like to say... A big **THANK YOU** to **everyone who donated and raised funds on our behalf during 2011.** 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 2012!**

Apart from that, other than my annual donation to the Colostomy Association and attendance at my local quarterly get together with the stoma care nurses, I have done little to show my appreciation for the care and support I received. So, last Summer I decided to hold a charity hog roast at home to raise funds for CA!

Fortunately my future son in law is a butcher with both the equipment and experience needed to supply and cook the hog! My husband and I have a wide circle of friends, including the local Lions Club, scouts and former colleagues. An email to our contacts resulted in over 80 people wishing to attend and those, who couldn't be with us offered to donate.

We were really lucky with the weather and with the support of friends and family assisting with gazebos, catering and serving everyone had a great day! A friend also sold raffle tickets and the end result was a donation of £1020.65 including Gift Aid for the Colostomy Association!

Did I mention that all this took place on my birthday? Most people get taken out on their special day this was something very different. Phew! Ah! Well! All for a great cause...will it be an annual event? We'll just have to wait and see?

Best Wishes
S P

Dear Tidings, Bowling for funds...

My husband is, this year's President of the Crystal Bowling Club in Stourbridge. The holder of the office nominates a charity of his choice to be the recipient of funds generated from their annual charity day. He thought it appropriate to name the Colostomy Association as this year's beneficiary. Although a national charity, the Colostomy Association is not so well known and he was a bit apprehensive as to what the response would be from members. He therefore provided each member with a short description of the work you do and the services you provide. It was well worth the effort as club members raised a total of £318.00 some 40% higher than our previous best! We also took the opportunity of involving family and friends in our fundraising efforts and raised £440. We hope this donation will help benefit the many thousands who are in need of your services.

Yours sincerely
P P

colostomy association

Please note: Change of bank account details for the 500 Club!

The **500 Club bank account details changed in June 2010.** It has come to our attention that some standing orders have not been amended and are still being paid into the old bank account. Unfortunately from **1st June 2011 these payments will no longer be included in the draw.**

Please check with your bank that they have amended your standing order to take into account the new details - many thanks. **Because as they say...you have to be in it to win it!** If you have any queries about the changes, please contact the office on 0118 939 1537.

The **new bank details** are...

Bank:	**NATWEST**
Account number:	**89252314**
Sort code:	**60-17-21**

About the 500 Club...

We are pleased to announce the **Colostomy Association '500 Club'** giving you the **chance to win cash prizes ranging from £25 to £1000**. For the **sum of £24 per year,** you will be entered into **a quarterly draw for cash prizes of £500, £250, 3 x £100, 3 x £50 and 3 x £25.** At the end of each year **a further prize of £1000 will be awarded.** Draws take place at the **end of March, June, September and December** and winners will be notified shortly thereafter. **Membership is restricted to the first 500 applicants so don't delay...**

Simply complete and cut out the **standing order mandate below** and return it to: Colostomy Association, 2 London Court, East Street, Reading RG1 4QL as soon as possible.

Note: If, at the time of any draw, the club is not fully subscribed, the Colostomy Association reserves the right to distribute prizes in the proportion of the subscriptions received.

My Details:

Title: Name: Surname:

Address:

Postcode:

Telephone number: Email:

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: **500 Club** Account No: **89252314** Sort code: **60-17-21**

the sum of **£24.00** amount in words: **Twenty four pounds**

Date of first payment: and thereafter on the same day every year until further notice

Name: (IN CAPITALS)

Signature: **Date:** / / 2012

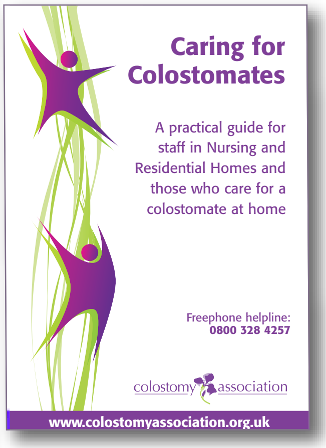
Registered Office: 2 London Court, East Street, Reading RG1 4QL Registered Charity No: 1113471

NEW for 2012...Two patient information leaflets

CA is updating the leaflet on rectal discharge...We are hoping to include the experiences of how people with a stoma cope with this problem. If you have suffered from a discharge of mucus from the rectum, please contact the Associate Editor by writing to CA Head Office or e-mail...
associate-editor
@colostomyassociation.org.uk

Caring for Colostomates

A practical guide for staff in Nursing and Residential Homes and those who care for a colostomate at home



Caring for Colostomates

A practical guide for staff in Nursing and Residential Homes and those who care for a colostomate at home

Freephone helpline:
0800 328 4257

colostomy association

www.colostomyassociation.org.uk

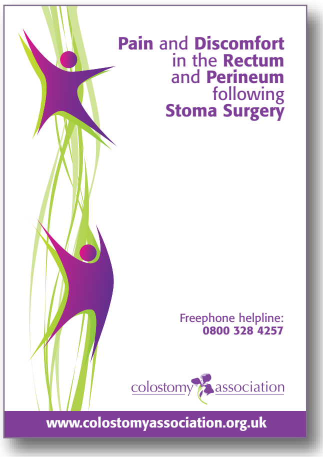
Not all the calls and e-mails we receive at CA head office are from people who have a colostomy themselves. Nurses and care assistants in residential homes will contact us for advice and information.
Sometimes it will be a partner or other family member who will be caring for a colostomate when they come home from hospital. Perhaps it is someone who has a relative or friend with a stoma coming to stay and they want to know how they can make their visitor feel more comfortable and relaxed.

The sort of questions they ask are: When in the bath or shower should the bag be left on or taken off? How do we dispose of the used pouch? What should we be giving him/her to eat?

Our new carer's leaflet answers all these questions and more:
There is a patient profile for recording the type of stoma appliance currently used and the name and the contact details of the current supplier – useful for those living in a nursing or residential home - as well as other important information and telephone numbers.

Diagrams show the different types of bag available and how to change it. The leaflet also considers common concerns that a carer may have e.g. bleeding when cleaning around the stoma, mucus discharge from the rectum, ballooning, pancaking etc. It explains why these problems sometimes occur, how to deal with them and when to seek medical advice.

Pain and Discomfort in the Rectum and Perineum following Stoma Surgery



Pain and Discomfort
in the Rectum
and Perineum
following
Stoma Surgery

Freephone helpline:
0800 328 4257

colostomy association

www.colostomyassociation.org.uk

Regular readers of Tidings may remember that in Issue 20 we asked for ostomates to contact CA if they had experienced pain in the rectum or perineum following stoma surgery. Some of the replies we received were published in issues 22 and 23.
Now, with the help of Penny Fitzgerald, Lead Colorectal Specialist Nurse, Tina Lightfoot, Lead Nurse for Surgical GI Services, and Julie Clements, Stoma Care Nurse from the Countess of Chester Hospital NHS Foundation Trust, we have published a leaflet on this subject.

The causes of this type of pain and discomfort are not fully understood and will depend on whether the rectum and anus are still intact, or if the rectum has been removed and the anus closed. Various treatments and coping strategies are discussed. Nine colostomates share their experience of how they suffered from pain in the past or how they live with the discomfort today.

Medi

Ostomy Accessory Range

Available on prescription through all leading Home Delivery Appliance Contractors and Pharmacies

CERTIFIED HEALTHCARE GRADE FORMULATION

- Healthcare grade certified ingredients
- Suitable for the care of Ostomy, Continence and Wound care patients
- Sting free Lifteez Adhesive Remover and Derma-S Barrier Film
- Excellent Quality and Value

If you would like FREE samples of any of these products, please complete this coupon and return it to:
Wilkinson Healthcare, **FREEPOST** NG203/1, Unit 9 Glaisdale Business Centre, Glaisdale Parkway, Bilborough, Nottingham, NG8 4GA

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

Address: ....

.... Postcode: ....

Tel No: .... E-mail: ....

Alternatively, call us on Freephone:

0800 626 524

or email us at mediownlabel@aah.co.uk

Please send me samples of the following products (Please tick):

Derma-S Barrier Film - Non Sting	Wipes ☐	Aerosol ☐
Lifteez Adhesive Remover - Non Sting	Wipes ☐	Aerosol ☐
Derma-S Barrier Cream	Sachets ☐	
Gelsorb Solidifying Agent	Sachets ☐	

☐ I agree that this request will be handled by Wilkinson Healthcare or AAH Pharmaceuticals Limited and that my details can be kept on file, so that I can be kept updated regarding any information about relevant products and services.

AAH

Distributed by:
AAH Pharmaceuticals Limited,
Coventry, CV2 2TX.

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

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

Comfizz New Product 'Level 2 and Level 3 Support wear'

Level 2 Medium Support Wear

Level 2 support wear (boxer or brief style) provide all the same benefits as level 1 but with that little bit more support. The garments are firmer & can support a hernia or support the muscles during physical activity without restricting the stoma. They are also ideal for discretely holding incontinence pads in place. Soft breathable fabric with two way stretch for an ultra comfortable fit. Available on prescription.

Level 3 Firm Support Belt

Premium firm support belt, ideal for holding hernias, protecting hernia repairs and giving extra protection and support during strenuous activity or supporting prolapsed stomas.
Built in stabilising ribs prevent wrinkling ensuring stable support. Velcro fastening for easy fit. Integrated prolapse cover provides total support without restricting the stoma. Different apertures available, to fit most bag flanges, maintaining a secure fit for maximum comfort.
Available on prescription

Stoma Protector

The protector offers additional rigid protection against pressures or unwanted forces onto the stoma for example from seat belts or physical sports. This is a useful optional extra with the level 3 belt, it simply velcros on.
NOTE: The protector can only be used in conjunction with the level 3 belt.
Available on prescription

To order or for further information visit www.comfizz.com or tel the Comfizz team: 01757 229 531 or email charlie@comfizz.com

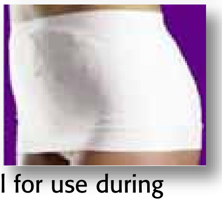
From Pelican Healthcare... Pelican Protect Plus Non Sting Barrier Film with added Vitamin E

Pelican Protect Plus provides the optimum in skin protection with the benefit of Vitamin E to nourish and moisturise the skin.

Pelican Protect Plus will safeguard the skin against adhesives, solid and liquid waste and enzymes.

Pelican Protect Plus is supplied in a single sachet for discretion and convenience.

Pelican Support Stoma Waistband...



Pelican Healthcare is delighted to introduce the Pelican Support Stoma Waistband, a seamless unisex support garment in a soft and breathable fabric providing the ultimate in comfort, confidence and discretion.

Pelican Support provides lighter support for small hernias, and is ideal for use during physical activities to provide extra security, support and confidence. Pelican Support provides a smoother body shape and is ideal for swimming and intimacy.

Pelican Support is available in 3 sizes, and there is a choice of white or beige to suit all preferences.

For further information please call the Freephone Sample Helpline on 0800 052 7471, visit www.pelicanhealthcare.co.uk or e-mail contactus@pelicanhealthcare.co.uk

New Amcare website launched...

Amcare are pleased to announce that following on from the launch of the ConvaTec Stomacare patient website earlier this year, we have now launched a new Amcare website.

This site aims to provide information and support to existing and potential Amcare clients, with guidance on the services that Amcare offers and how to order products, along with links to support groups and associations. With a fresh look and feel, this site has been designed to be user-friendly and clear for our customers, to ensure that users have full and comprehensive information about Amcare and the services we provide.

The new website can be visited at www.amcaredelivery.co.uk

OstoMART Ltd are pleased to announce that we are one of the first Dispensing Appliance Contractors to be fully operational for the Electronic Prescription Service (EPS) in England.

This means that patients using our Responder Home Delivery Service will be able to benefit from an even faster service, no need to collect your prescriptions in person and post them, more choice and an overall easier process from the comfort of your home. You can ask your GP practise if they are set up for EPS and if not when this will happen.

To register for the Responder Service or to find out more about EPS and how it can benefit you call us on Freephone 0800 220300 or visit www.ostomart.co.uk

Suportx Easy Peel Hernia/Abdominal support belts

Suportx Easy Peel Hernia/Abdominal support belts are made from a dynamic material that allows the stoma to function regularly whilst providing comfort and support. The unique twin attachment system allows the garment to be worn and adjusted easily. The Easy Peel system allows the stoma pouch to be accessed whilst the belt is still being worn, ideal for when emptying or changing the pouch whilst out and about.

NEW Suportx Tube belts, available with or without lace, are ideal for support and offer ultimate discretion. The tube belts can be worn under fitted clothing and are ideal for use when exercising, playing sports and even swimming (tube with no lace only). A wide variety of sizes, depths and bespoke options are available on prescription.

Please see our main advert on page 19 and Call Free - 0800 9179584 for further information.

What Mary Did Next ....

Mary Le Coyte

I was stopped in the street the other day by a complete stranger, who'd read about me in Tidings...quite a shock, but a pleasant one, when I learned that my story had helped someone feel better about their own experience. One of the good things about Tidings is that through its pages we can all share experiences, and so help each other on what can be a difficult journey.

So I'm here again to share a bit more of my story and to explain what happened after my abrupt departure from the Clipper Race (rather than from the port it was leaving). The rightness of my retirement was borne out a few days later, when all the symptoms came back with a vengeance and I returned to hospital at high speed. Hernia surgery became a matter or urgency, just as the boats were battling stormy conditions in the Bay of Biscay. I was definitely in the right place!

Before my initial surgery, the importance of not doing anything strenuous during the recovery period had been drummed into me, and I didn't fancy a hernia, so I was a very obedient patient. Nonetheless, a hernia developed within a few months and, as is the way of such things, grew. I leant to live with it, but it was not so much a love-hate relationship as a hate-hate relationship. My surgeon looked at it and suggested it was best to do nothing unless it became really troublesome, and we should watch and wait. Then we moved house, and all my post-cancer care was transferred to Exeter, where I came under the care of the CA's Vice-President, Mr. Ian Daniels. He asked me how I felt about the hernia. I took a deep breath and, trying to remain calm and matter-of-fact, gave a reply something like "well, it causes me a lot of discomfort, and it's very large and prominent, which makes it difficult to find any clothes that fit, let alone something that camouflages it, and every morning I have to strap myself up with heavy-duty lycra first thing and wear it until last thing at night, and I've banned mirrors, and do I have to live with this for the rest of my life?"

Mr Daniels gave me a bit of a look before saying, equally calmly, "Not necessarily. I need to look at your scans. And you need to be at the bottom of your weight curve before any surgery."

An elegant turn of phrase, I thought, and went home to start losing the two stone or so which had piled on as I ate my way through inactive convalescence, fighting depression with food. In the spring of 2011 I met Mr Daniels again, and he confirmed that surgery was not only possible, but could and should go ahead in October, after I had completed my ocean racing adventure.

So much for planned surgery! When I turned up yet again as an emergency, Mr Daniels' response was "let's get the job done and get you sailing again as soon as possible". Now call me old-fashioned, but I always thought surgeons were creatures of genius who perform miracles with bodies but sometimes fail to see the bigger picture of the patient before them; suddenly, I was being treated as someone with a life which was a matter of importance to medical staff as well as to the patient herself. The value of this approach to anyone who has to live with a long-term physical condition is inestimable.

The surgery itself was less troublesome to me than I had expected, with little post-operative pain, very well controlled in hospital. I did, of course, have to observe a strict recovery programme of nothing strenuous for a full six weeks, but we're all used to that after stoma surgery anyway! My new stoma (I lost a bit more of my colon) worked erratically, just like the original in the weeks after surgery, and needed time to settle down and behave properly, and, at the time of writing, may still need some minor adjustment. But, whilst I shall never have the tummy of a supermodel, I no longer have a droopy mass like half a watermelon on one side, and I can now wear the same sort of clothes as any other woman. Above all, I am grateful that I now get the lycra out only for strenuous activities, and supermarket shopping, and can live a normal life free of discomfort. I am very careful to avoid activity which would encourage a recurrence of my hernia!

The best news is that I have now had official confirmation of a place on *Visit Finland* for Leg 8 of the Clipper Race! I shall sail from New York early next June (wearing the lycra as a safety measure!) feeling comfortable and confident about my body, and hopefully demonstrate that adventure is open to ostomates as much as to anyone else. And maybe I'll get the chance to tell you all about it when I get back...

Mary Le Coyte

NEW

AMI

Call 0800 9179584

SUPORTX™

Tube Belt

Available with or without lace

After the successful launch of their highly popular Easy Peel Belts, Suportx are now offering tube belts with or without lace. The tube belt offers smooth lines and is discrete under clothing, whilst still offering maximum support. The tube belt with no lace is ideal for sports, exercise and even swimming. Choose from a wide variety of size and depth options. Available in 3 colours - white, black and skintone.

Available on NHS prescription

Easy Peel Belt

Suportx Easy Peel Hernia/Abdominal Support Belts are easy to wear and adjust. They are also the most comfortable hernia support belt on the market today. Suportx also offer a wide variety of hernia support girdles/briefs for ladies and men. Choose from a wide variety of size and depth options. Available in 3 colours - white, black and skintone.

www.suportx.co.uk

Hernia/Abdominal Girdles & Briefs

High Waisted Underwear with internal pockets

AVAILABLE ON NHS PRESCRIPTION • AVAILABLE ON NHS PRESCRIPTION • AVAILABLE ON NHS PRESCRIPTION • 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

> "A stoma doesn't mean it's the end of your life: it's the start of another life."

Edith Brighton, 67 years old, from Ormskirk, Lancashire has enjoyed the beach holiday that, since major bowel surgery, she never dreamed possible.

It was on her last holiday in Crete three years ago that she became unwell. She thought she was suffering badly from haemorrhoids. But she was in for a shock on arriving home: Edith was referred urgently to Southport Hospital where a sigmoidoscopy revealed a seven inch tumour in her anal canal.

The operation opened up her stomach from the naval down, removing lots of muscle and she was fitted with a non-reversible stoma. She was then admitted to the specialist cancer unit for 3 months' of intensive radiotherapy and chemotherapy.

But after that unexpected and traumatic experience, Edith declares she's never looked back.

Taking control

Edith tried a variety of colostomy bags, doing lots of research herself and taking advice from her stoma nurses. Six months ago she was introduced to Vitala™ Continence Control Device (CCD) from ConvaTec. She adapted to it well and built up the wear time gradually. "The Vitala™ has been fine," she says. "You can have mishaps with it, but you can have mishaps with colostomy bags too."

With the confidence that Vitala™ CCD has given her, Edith has been able to take the beach holiday she didn't dare think possible.

Vitala™ can be worn for up to 12 hours, so it was perfect for a long day travelling from home to the hotel. "I coped fine on the aeroplane – no problems at all," she says.

> “The stoma has extended my life, it’s part of me now. It doesn’t make you an invalid.”

The confidence to swim

“I even went swimming in the sea wearing my bikini and Vitala™!” she says. “I was a little bit nervous at first,” she laughs, “but it was absolutely brilliant!” This was the first time she’d been allowed to swim since the operation. “I used to go once or twice a week and take my granddaughter too, so it was a blow not to be able to,” she says. “Because of where the cancer was, my oncologist advised me against swimming in pools because of the risk of infection. But the sea is OK.”

Edith said it felt strange, not having swum for three years and being a little unsure which muscles had been removed, but by the time she got up to her chest in the sea she thought: right, I’m going for it! And Vitala™ even held up when big waves were breaking over her. “It felt wonderful!” she says.

At first she was anxious about Vitala™ staying in place, so checked it as she came out of the sea. She also worried in case her swimsuit clung to the device, drawing attention to it. But her mind was put to rest when she struck up a conversation with a retired couple on the beach. “It turned out the man had worked in the medical profession,” she says. “He asked very politely whether I had a stoma and how long I’d had it. He was amazed to see me confidently splashing in the sea and looking so well enjoying my holiday! He couldn’t believe how discrete it was.”

The benefits of wearing Vitala™ far outweighed Edith’s concerns. “I thought I would never go on holiday again. I was very apprehensive at first, wondering how my stoma would take to the heat, but they were unnecessary worries, even though it was 45 degrees C!”

Keeping life as normal as possible

“The stoma has extended my life, it’s part of me now. It doesn’t make you an invalid,” she says. The surgery meant Edith has had to learn to modify her level of activity. She used to be a keen walker and now can’t carry heavy shopping or push a loaded trolley. She looks after her two grandchildren during the week and was worried about taking them to the park. But she is resourceful and determined to keep her life as normal as possible. “You do get anxious, but you’ve just got to stay positive,” she says. “A stoma doesn’t mean it’s the end of your life.”

Edith is highly independent but knows her stoma nurse is at the end of the phone if she has any questions. “With a stoma, it’s all about learning what is ‘normal’ now.” Edith has a hernia as well as her stoma, so has learnt how to apply Vitala™ to suit her particular needs. Everyone’s surgery is different and it is important that a stoma nurse ensures that Vitala™ is the right device for you.

“With Vitala™ I can do my gardening again,” she says. “It doesn’t prevent you kneeling down or stretching. I can climb up my step-ladder and cut the top of my hedge!”

Edith is now planning to go abroad to see her son this year and another beach holiday. “My family think I’m doing absolutely brilliantly,” she says.

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

For further information on Vitala™ Continence Control Device, please call 0800 467866, email vitala.webcare@convatec.com or visit www.vitala.com

AP-011576-GB
VIT010
September 2011

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

Sophie explains what can cause constipation and how alterations in diet and lifestyle can help to prevent this problem...

About Constipation...

Constipation is a problem which is thought to affect up to 30% of the population. It is generally described as passing stools less frequently than usual or passing stools which are dry, hard and lumpy. It can cause many unpleasant symptoms such as bloating, pain, feeling sick and loss of appetite. In ostomates, constipation can also cause the stool to build up at the top of the bag leading to what is referred to as 'pancaking', which can cause leakages and sore skin.

In general, only patients with colostomies are at risk of constipation. This is because it is the large bowel that absorbs most of the fluid we drink. People with ileostomies should pass looser stools. If your ileostomy stops working for six hours or more, you must seek medical advice. If you have ever been told you have adhesions or strictures, or have been put on a 'low residue' diet by your doctor or consultant the following advice is not suitable for you.

Constipation can be caused by several factors.

Diet

One of the key things which can cause constipation is diet. This may be because the diet does not provide enough fibre, the amount of food is not adequate or not enough fluid is taken.

There are **two different** types of fibre:

Insoluble fibre resists digestion in the small bowel and adds bulk to the stool, increasing stool volume and increasing the transit time of food through the bowel. Generally, it is high fibre cereals and the skin, pips and peel of fruit and vegetables which provide us with a good source of insoluble fibre.

Soluble fibre acts like a sponge, absorbing water and helping the stool to remain soft and easy to pass. Soluble fibre is found in the flesh of fruit and vegetables, oats and barley.

In general, people should try to achieve a balance of the two fibres in their diet for good digestive health. However, ostomates may find it more convenient to have more soluble than insoluble fibre to reduce the volume of stool passed but keep the stools soft.

When introducing more fibre into the diet, do it slowly and change one thing at a time. It is important that you increase your fluid intake alongside taking additional fibre.

Higher fibre foods

Peas, beans, Brussels sprouts, parsnips, spring greens, wholemeal, rye and granary bread, wholemeal pasta, bran-based breakfast cereals, muesli.

Foods with a medium fibre content

Most fruit and vegetables, nuts, brown and white bread, brown rice, other pasta, baked goods containing wholemeal flour or dried fruits, wholewheat breakfast cereals, porridge.

(Above taken from The Manual of Dietetic Practice, edited by Briony Thomas, Third edition, 2001).

Good ways of adding fibre include:

- Baking cakes with wholemeal flour
- Having fruit cake or foods containing dried fruit
- Drinking juice with the pulp, or having prune juice
- Trying smoothies
- Adding dried fruit to breakfast cereal

Fluid

Fluid also plays an important role in preventing and treating constipation. It stands to reason that if there is not enough fluid going in by mouth, the stool will not contain enough fluid and will be too hard. Most adults need between 1.5-2 litres (3-4 pints) of fluid per day. This includes all fluid except for alcoholic drinks. Some tips to help you get enough fluid are:

- Keep a jug or bottle of water in the fridge so you can measure how much fluid you are having
- Keep a range of cordials, flavoured waters and other drinks to tempt you to drink more
- Use ice and nice glasses to make drinks more appealing. Some people also find a straw helpful
- Ensure you drink more in hot weather and after exercise to replace what you lose through sweat

If you feel you are getting enough fibre but are still constipated it is most likely that it is inadequate fluid intake that is causing the problem. This is because the fibre acts as a sponge in the bowel, absorbing water and softening the stools. This process however, relies upon plenty of fluid being taken by mouth. Adding extra fibre and not adding extra fluid could actually make you more constipated.

Exercise

Being inactive as a result of illness or a chronic condition can add to problems with constipation. If you feel that reduced activity has affected your bowel motions speak to your GP who may consider some medication to help to relieve your discomfort. However, buying laxatives from a chemist and using them long term can make the problem worse, so it is important to speak to your doctor. Take more exercise if you are able. Gentle exercise such as walking every day can increase the movement in your bowel and help to relieve constipation.

Medication

Many medications can cause constipation, particularly painkillers, indigestion medication, calcium supplements, water tablets and iron supplements. However, it is very important that you do not stop taking medications without first discussing it with your GP. It is likely that they will be able to alter your medications to improve the problem.

When is Constipation not Constipation?

Sometimes when people have had a lot of surgery, have hernias or have stricturing disease, for example Crohn's disease, they can develop intermittent or total bowel obstruction. A bowel obstruction is defined as:
Blockage of the intestines (bowel) producing symptoms of vomiting, distension and abdominal pain, failure to pass flatus (wind) or faeces (complete constipation) is usual.
(Oxford Concise medical dictionary, Seventh Edition, 2007, Oxford university press).

Some people find that they fluctuate between constipation and very loose stools. This is a common problem, but if coupled with abdominal distension and pain it is important that you speak to your stoma nurse, consultant or GP to rule out partial or intermittent obstruction.

Your Questions Answered...

Q: *Just wondering if you can offer some advice. I've had a colostomy for three months and haven't been able to get a proper night's sleep as my bag fills up with wind during the night to almost bursting point. I have to get up every two hours or so to empty it. I've read all the lists of good/bad foods and stick pretty closely to them. Is there anything else I can do to prevent this?*

A: Wind can be a difficult thing to control. (I wonder if this was a problem for you before you had your stoma formed) As you are already following the lists of foods to avoid and include, here is some more in depth information we give to our patients with Irritable Bowel Syndrome who suffer with wind:

- Drink at least 8 glasses of water per day
- Include plenty of low fibre foods
- Include oats
- Try probiotic yogurts/drinks for at least 4 weeks
- Reduce alcohol intake and have at least 2 alcohol free days per week
- Avoid fizzy drinks
- Be cautious with the amount of fruit and fruit juice you include. Try not to have more than three portions per day
- Avoid foods containing resistant starch. These include wholegrains, seeds, sweetcorn, muesli, green bananas, garlic and onions
- Resistant starch can also be formed during the cooking process so you might find that reducing your intake of pre-cooked or ready-made meals containing, potato, pasta or rice, oven chips and other preheated potato products may help
- Foods which typically cause wind include beans, green leafy vegetables, onions, garlic, leeks, asparagus, Jerusalem artichokes and chicory so try to reduce your intake of these

Hopefully there will be something here that you can pick out as the possible cause of your problem. Remember to cut out one thing at a time so you can be clear about which food is causing your problem. I hope this helps.

Note: As always this advice is very general and will not be suitable for everyone reading this article. If you are unsure please speak to your consultant , dietitian or stoma care nurse.

Pathways to a colostomy

When I was two days old I was rushed to Alder Hey Children's Hospital, because doctors were concerned because I hadn't had a bowel movement. Tests diagnosed Hirschsprung's disease, a condition where there are no nerve endings in the bowel.

Before I was two months old, I underwent an operation called a "pull-through" where they took away the "diseased" part of the bowel and re-joined the ends. While the bowel was healing I had a temporary colostomy. However, doctors soon discovered this procedure had not worked, so they tried again at nine months old, but this didn't work either.

During my school days I needed a one-to-one carer as I was continuously incontinent. Every couple of months there were visits to Alder Hey Hospital for check-ups, clinic visits and more tests. When I was nine years old I underwent another "pull through" procedure. I remember waking up on the ward in the middle of the night in pain and wanting my mum. Thankfully Mum was able to stay on the Alder Hey site at the "Ronald McDonald House" run by a charity, to allow parents to stay in a comfortable room and be close to their sick children.

Unfortunately this "pull-through" was unsuccessful too. As I was reaching my teenage years and still needed to wear nappy-like pads, my consultant suggested a colostomy. I remember the clinic where he told my parents. I didn't have any idea what was being said, but I could sense there was not a nice atmosphere and we were being told of more surgery.

The operation took place when I was thirteen years old, in my third year of secondary school. I said goodbye to my friends as I would be off school for a long time. On April 6th 2003 I went in to Alder Hey Hospital. My consultant and anaesthetist came to see me on the ward. The position of the stoma was marked on my stomach: I didn't know the importance of where the colostomy was sited until I was older. In my teens I realized it affected the type of jeans and tops I could wear. When I went down to theatre I was actually excited at the thought of a new me, with no incontinence. I was naive about the extent of pain and the long road I was facing.

My operation lasted twelve hours. The nurses kept my mum and dad informed about what was going on and why it was taking so long; the operation should have only lasted around four hours. I had cysts on my ovary which they drained, and also there were lots of adhesions, scar tissue from previous operations, which were tangled together around the bowel. The surgeons had to cut through all these adhesions before they could even begin on the colostomy.

For the first few days I just slept, only waking up while nurses made me comfortable and checked my catheter, drip and other medications. I slowly started to recover. After about a week I started dreaming of McDonald's and KFC, I felt hungry, which was a good sign. The first things I ate were yoghurt, then toast. I took one day at a time: getting out of bed and sitting in a chair for a bit longer each day, watching TV or doing some arts and crafts with my mum. One day I had a surprise when three friends from school came to see me. The nurses disconnected the drip, we went outside, had an ice lolly and sat in the sun. I'll never forget the green ice lolly coming through my naso-gastric tube, which was there to stop me feeling nauseous and went up my nose and down into my stomach.

Then a few days later my mum and dad took me to Knowsley Safari Park. As I was still quite poorly I slept through most of it; the slightest bit of effort to get up out of bed made me exhausted. I still had a long way to go to get better.

The time came for me to have my colostomy bag changed for the first time. I had to soak it off in the bath. I think that was the most painful part of the whole procedure. The nurses were so patient with an impatient patient. Then I was discharged from hospital. I could go home and try to lead a normal life without being incontinent and without having to wear pads. I still felt exhausted: like I had been put in a boxing ring!

I started going back to school, at first just for a few hours a week and then I slowly built it up for longer, but often I would get jostled in the corridors and have to go home early. After several months I was so much better and was going out with my friends a lot more, I was going swimming and becoming a more confident me. My parents couldn't keep me in!

>


QuietWear™
Material
virtually eliminates embarrassing pouch noise

Faye on her recent trip to Snowdonia to raise funds for Alder Hay Children's Hospital

I have now had my colostomy for nine years and would never look back. I do have blockages and my doctor has prescribed Lactulose and Buscopan, but, touch wood, in recent years things have much improved. I am now slowly recognizing the signs of a blockage and I can mostly manage it at home without being rushed into hospital to be put on a drip.

However, my colostomy doesn't stop me from doing anything. I go to the gym at least every other day. I love swimming. I just wear my usual closed bag. At first I wore a one-piece swimming costume, but now I have a lot more confidence and wear a tankini.

When it comes to boyfriends, there are some out there that are genuine and caring, and will understand what a colostomy is. I have had previous relationships – as serious as can be at this age. I try and tell the person I'm meeting about my colostomy almost straight away, but not too soon - after a couple of weeks, maybe. They need to get to know you first, but as soon as you are ready, just literally blurt it out at the soonest opportunity. I have the attitude that if they can't accept me with a colostomy – as I do come as a package – then it's really not worth wasting my time or their time.

As regards work, I have my own Dog Grooming business and have also done supply work as a teaching assistant at a school for autistic children. Then last September I began a four year training course to become a nurse. My ambition is to work with children as I spent so much of my own childhood in hospital.

Since having my stoma I have travelled abroad, to Spain, Cyprus, Mexico and Florida. I make sure I have twice as many bags as I normally use and pack half in one suitcase and the other half in another, in case one gets lost. I also pack four day's supply in my hand luggage. The best thing about being on holiday is that it's your time to enjoy. Don't worry about problems with your colostomy, the more your worry the more likely they are to happen.

I recently climbed Snowdon to raise funds for Alder Hey Children's Hospital. There were twelve of us in the group and it took us four hours to reach the top then have a cup of tea and go back down to the bottom. I had no problems with my stoma. We raised £5,000 for the"Ronald McDonald House". I am planning on doing a sky dive for the hospital next year.

I am now twenty-two years old and would like to meet new people of a similar age with colostomies, but nine years on I still haven't met anyone in my age bracket. ■

Faye Jones

What is... Hirschsprung's disease

Hirschsprung's disease occurs in 1 out of every 5000 live births and is much more common in boys than girls.

Ganglion cells are formed in the baby's intestine soon after development begins in the womb. These nerve cells are needed for intestinal muscles to move food and digested matter onward by a series of wave-like contractions called peristalsis.

In Hirschsprung's disease these ganglion cells are formed in the upper bowel but do not spread to the lower bowel, thus normal peristaltic movement cannot occur, resulting in constipation and blockage.

In infants, symptoms include failure to pass meconium (the sticky black substance that lines a developing baby's bowel during pregnancy) within the first 24-48 hours, bile vomiting, a distended abdomen and poor feeding.

Hirschsprung's disease is diagnosed by using a number of techniques. The most vital diagnostic tool is the rectal biopsy whereby a tissue sample is taken from the rectum and studied under a microscope to see if ganglion cells are present.

Treatment involves surgery where the affected part of the bowel is removed. This may be performed in stages with a temporary colostomy (or ileostomy) formed to allow time for the colon to recover. In some cases the stoma may be permanent.

For more information about Hirschsprung's disease a leaflet is available from Core, a charity that funds research into gut, liver, intestinal and bowel illnesses.

Available by post from...

Core
Freepost LON4268
London NW1 0YT

Phone: 020 7486 0341
Email: info@corecharity.org.uk
or to download on line at
www.corecharity.org.uk

Need a helping hand?

Have your supplies delivered direct to your door

- A dispensing centre local to you
- Opening hours 8am to 8pm
  Monday to Friday,
  9am to 1pm Saturday
- Quick, discreet and reliable service
- Complimentary accessories with each order
- Comprehensive sample service
- Overseas Emergency Cover -
  World Assist Alliance

World Assist Alliance programme for our customers abroad on holiday or business

National Service, Locally Based

SPECIALISTS IN HOME DELIVERY OF MEDICAL APPLIANCES

We have a range of information sheets available, please tick the relevant boxes for those that you require.

Stoma Cutting Template ☐ Living with a Stoma - Hints and Tips ☐ Common Stoma Problems ☐
Dietary Advice ☐ Travel Passport ☐ World Assist Alliance ☐

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

Address: ....

.... Postcode: ....

Telephone No: .... E-mail: ....

Alternatively, you can send a text. Please text **HANDS** (capital letters) plus your **name, phone** and/or **email** address with your request to **88802**

TID-01/2012

Fittleworth
FREEPOST, Hawthorn Road, Littlehampton, West Sussex BN17 7LT
National: 0800 378 846 Scotland: 0800 783 7148
www.fittleworth.com caring@fittleworth.com

fittleworth

Hernia Support Belts & Girdles

(Bespoke Available)


Fulcionel Easy Wear Belt


Unisex Bespoke Belt with "darted cup"


Unisex Bespoke Belt with "seamed cup"


Ladies Bespoke "seamed cup" girdle

CUI High Waisted Underwear with inbuilt Patented Pouch cover (on NHS Prescription)


Full Brief


Shortie


Boxer


Fitted Trunk

FREEPHONE: 0800 279 2050

www.cuiwear.com

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

Wilkinson Healthcare,
Delivering Better Care!

As one of the UK's leading independent Dispensing Appliance Contractors we can offer you:

- The ability to choose from a wide range of appliances from many different manufacturers
- No product bias or pressure to choose one brand over another
- Free appliance customisation using state-of-the-art cutting technology, to ensure the perfect fit for you
- Free and discreet next day delivery to the address of your choice
- Free and caring support delivered through specialist Nursing and Care Centre teams

Call our Freephone Care Centre to find out more: 0800 626 524

www.wilkinsonhealthcare.com

Irrigation and you...

Sue Hatton Executive Trustee writes...at the CA Open Day 2011 in Leeds last October we were joined by Lucy Russell CNS/Stoma Care - Norfolk and Norwich University Hospitals NHS Foundation Trust. Lucy is passionate about 'irrigation' and has written into Tidings previously. Lucy kindly agreed to explain the equipment and procedures involved in 'irrigation' to CA attendees. Here are some of the Q&A's from the day...

Lucy writes...I had several interesting conversations while 'manning' the irrigation stand at the last CA Open Day in Leeds.

The general thread of the conversations were in regard to individual suitability, how soon to start after surgery and about the irrigation procedure itself.

Some of the questions were as follows:

It had been mentioned, within one of the presentations, that colostomy irrigation is for: **a left sided stoma**

Q: My colostomy is on the right side, can I still learn to irrigate?

A: The term 'left sided colostomy/stoma' is used to indicate that the stoma is formed from the sigmoid or descending colon. In other words, enough large bowel remains for the body to produce fairly formed waste. There would be poor results and little point irrigating a colostomy formed much higher in the bowel, or near the Ileum, as ileostomies and obviously urostomies cannot be irrigated. Your colostomy may have been repositioned to the right side but as long as your colon has not been foreshortened, the position doesn't preclude irrigation.

Q: I had my surgery a month ago, when can I start to irrigate?

A: There is no hard and fast rule about when to start irrigating, but three months post-surgery gives time for recovery and the strength to start learning the process.

Of course, individual circumstances always need addressing, such as wound healing, chemotherapy and bowel pattern. Additionally, some people with a colostomy will be unable to irrigate due to other medical problems. It is very important to request an appointment with your stoma nurse to find out if it's appropriate for you to learn to irrigate.

Q: I am a keen traveller – how would I manage when on a busy tour schedule? (I'm thinking of a train journey through India!)

A: If a holiday schedule necessitates very early starts or long journey times, such that an irrigation session has to be missed – don't worry about it! Wear a drainable pouch (if disposal is a problem) and catch up on your routine again when you can. Generally it's helpful to keep to a regular habit, but sometimes 'life intervenes'! Some people don't irrigate when away and others go with hooks, string/cord, jugs, kettles, sterilizing tablets and so on.

Irrigation is about gaining control of bowel habits, attaining more freedom and confidence in activities – so there's a trade off with the organisation and time required to achieve this. Each individual will have different priorities, so it's a matter of doing what is right for you.

Q: How long does the procedure take?

A: I usually advise people who are new to irrigation to allow an hour for the whole process. But it's not an exact science and everyone will differ somewhat.

Initially, it takes 5-10 minutes to run the 500 – 750mls of warm water into the bowel. Once it has run in, the cone is removed and there is often a return of some irrigation fluid within a few minutes. Most of the return is usually within the first 20 minutes, but I usually advise to keep the sleeve on for a full hour for the first few times (secure the end of the sleeve and carry on with washing/reading/little jobs) and then wear a full size pouch. It's wise to be cautious during the early days of irrigation while you find out how your body is going to adapt to the new routine. New irrigators need to be patient in allowing time for the procedure - seasoned irrigators may complete the procedure in 15-20 mins!

Other questions relating to individual suitability were answered in the following way:

The potential irrigator needs to have reasonable hand/eye coordination, the ability to learn and perform a sequence of steps and the motivation to give time to learn the procedure and give discipline to a daily or near daily routine.

Irrigation would not be suitable for those with active cardiac or renal disease or ongoing bowel disease. The individual will need to have a colostomy that is visible and without complication, such as prolapse or large parastomal hernia.

It is important to discuss individual suitability with your stoma care nurse so that the procedure can be started safely and with opportunity for success.

It may take several weeks for someone to achieve a predictable bowel pattern with irrigation, but once mastered it can afford the individual new freedoms and an enhanced quality of life.

Editors Comment

I would like to thank Lucy for giving up her free time to attend the CA Open Day - the 'irrigation' stand was very busy indeed!

Are you suffering in silence?

Living with a parastornal hernia

By Caroline Cowin and Caroline Redmond

There are around 102,000 people in the UK living with a stoma. The latest research suggests that half could go on to develop a parastomal hernia, a bulge around the stoma.

Parastornal hernias are caused because stoma surgery disturbs the muscle structure, making a potential weak point. Over time, the muscles stretch and lose strength. Violent coughing, heavy lifting, vigorous exercise or poor muscle tone can force the abdominal contents, usually the intestine, through the weak spot.

Last year, Salts Healthcare conducted a study to find out more about what people living with a parastomal hernia had to cope with. Salts asked over 300 patients with a hernia to tell them about their clinical diagnosis, the type and severity of problems they encountered, how they managed their hernia, what sort of appliances they used, how they rated them and how they fell about it. Their findings follow...

Diagnosis

The first thing we established was that over half of the hernia cases in colostomists developed within a year of the original sloma surgery. Interestingly enough, another piece of research published last year found that although a lot of people had hernias, only a quarter of them knew they had one. Our study also found that the vast majority of hernias are diagnosed by either a hospital consultant or stoma care nurse. GPs only diagnose around 10% of cases. So we have a common complication of stoma surgery which patients are failing to spot but stoma care specialists can diagnose on review. That could mean that around half the people who don't have a regular review with a stoma care specialist may have an undiagnosed hernia.

Signs and Symptoms

So what are the signs of a parastomal hernia? As we already said, the most obvious sign is a bulging round the stoma. The study also found that the stoma can change size by as much as 8 millimetres, or the width of a pencil. Just over a third of colostomists said their stoma was uncomfortable and a third experienced odour problems.

Over half get a dragging or pulling sensation and about half said they felt heaviness around their stoma. Another main issue raised in our study was an increase in problems with the skin around the stoma. The majority of colostomy patients rarely, if ever, reported problems with their skin before developing a hernia. After developing a hernia, people said their skin became more sore and itchy. Hernias tend to distort the skin around the stoma, so it's harder to get a good seal around Ihe pouch. We also found that developing a hernia also seems to affect the size of a stoma and just under half of colostomy cases reported their stoma had grown the width of a pencil.

Obviously, changes in skin flatness and stoma size can have an effect on how well a pouch fits. If the pouch doesn't fit properly, you run an increased risk of having a leak. We know from other researchers that the main cause of skin problems is the corrosive output from the stoma coming into contact with the skin and damaging it.

However, the biggest change people told us about was that the skin around the stoma became thinner. If the skin is thinner, it's more likely to be damaged if there's a leak, or if people are rough when they change their pouch.

Leaks also had an impact on peoples' mental wellbeing. The majority of stomas leak at some time during the day and night, and there is a significant minority who have bad leaks, even though the majority of colostomisls feel that leaks during the day are not very bad. Leaks during the day also seem more likely to happen on a weekly basis or less often. Night time leaks are different though. The majority tend to be happening monthly or less often and people are more likely to rate them as bad ones. We can only speculate on why that is. Is it because they are generally less frequent and so more upsetting when they happen? Or is the physical amount leaked more?

Management

When we asked whether having a hernia made it more difficult to put on a pouch, nearly half of the colostomists agreed. Strangely enough, almost half of them said that having a hernia made no difference to how they managed their stoma. This seems to be backed up by the fact that 68% of people continued using the same type of appliance. Of those who changed their appliance, the majority had switched to a convex adhesive.

Accessories

Although almost half the study used support belts or girdles to manage their hernia, only a quarter thought it was the best way to manage a hernia. Despite that, support belts were still the most popular way to manage a hernia.

The second most popular management technique was, 'Forget about it and get on with life'. Finding a mental attitude being classed as a good management technique might be surprising until you delve a little deeper. Although nearty two thirds of colostomists agreed that having a hernia had made them more self-conscious, only a third said they worried about it. We don't know whether this is because people think a hernia as part of having a stoma, or they don't want to appear concerned. Certainly, this may be something to do with the fact that over half of hernia sufferers rarely, if ever, sought help from a trained stoma specialist once their hernia was diagnosed.

Conclusions

This study has given us information about the diagnosis, effects, and management of parastomal hernias, We know that people generally start developing a parastomal hernia within a year of surgery, many without realising it. We know reviewing patients regularly for the signs and symptoms of a hernia can help reduce management problems. However we don't understand enough about management techniques, and may be wasting time and money on things that don't work. It's clear we need better understanding of the needs of the patient. It's also important that we develop more appropriate individual management techniques to look after the physical and mental effects of a hernia.

One way is to try and focus on the individual rather than get lost in the statistics. We have created 'Mary', a 'typical colostomist' suffering with a parastornal hernia. Mary is a fictional character, but her story is based on the experiences shared by real colostomists diagnosed with a parastornal hernia. We use Mary as a thumbnail sketch to remind us about what she has to deal with and how she copes. With her help, Mary will keep us on track to deliver better results for her and others who need help and support with a parastomal hernia. Read Mary's story now to see what you have in common and where your story differs (see opposite).

Mary's story

A Colostomy patient living with a parastomal hernia

Age: 65 years
Gender: Female
Weight: "About right"
Stoma type: Colostomy
Stoma age: 6 years
Appliance type: One piece
Adhesive type: Flat
Change frequency: Once or twice a day
Hernia diagnosis: Stoma Care Nurse

"I was diagnosed with bowel cancer in 2004 and I've had my stoma since 2005. My hernia was diagnosed about a year after surgery.

I get discomfort around the stoma. It feels like there's something dragging or pulling on it. I also have problems with odour. I ordered a support garment to try and stop the heavy, dragging feeling but I don't always find it comfortable.

Before I had the hernia, I seldom had any problems with my skin. Even when I did, they weren't usually bad. Now I get problems more frequently and they seem to be a bit worse than before. The biggest change I've noticed is that the skin seems to be getting thinner. Il also feels more sore and itchy now, but the skin doesn't seem to be as red or irritated.

I also get leaks, both during the day and at night. It may happen about once a week in the daytime, and the leak is not so bad. It leaks less often at night, but it's worse when it happens. I've also noticed that my stoma seems to be slightly bigger. It's grown about the width of a pencil, which is noticeable.

I also have more trouble putting on my pouch now as well. I haven't had to change my appliance but a nunber of people I know have started using a convex adhesive.

I do worry about having a hernia, it's made me more self-conscious. I normally ask the stoma care nurse at the hospital, if I need advice".

(Mary is a composite persona based on research conducted by Salts Healthcare Ltd.)

Editors comment:
If you have a story to tell about your parastomal hernia we'd love to hear from you...see page six 'How to get in touch'.

Readers' Replies about Pouch Disposal...

The article on disposing of used appliances on page 34 of the last issue of Tidings prompted three of our readers to write in with their own views and experiences on this issue.

Dear Editor

I read with some interest Rosemary's article regarding how to dispose of used appliances. My stoma is almost a "contemporary" of hers having been operated on in August 1991. Initially I used a drainable pouch and as things began to get back to normal it was suggested that I used a closed bag, which I did, but soon reverted to the drainable ones, and have not changed since.

Firstly, it is easier to empty a drainable pouch than to change a closed one, no matter where you are.

Secondly, if you are having to carry out this procedure even once daily, and probably more frequently, it is doing your skin no good at all.

Thirdly, at a time when waste is very topical would it not prevent the waste of plastic if everybody used drainable pouches? It wouldn't do the manufactures a lot of good, I suspect, but does that matter.

To a degree she answers my question when she states:-"The drainable bags I take with me...are designed to be emptied and so don't present a problem."

Is it necessary to use a closed bag at all?

Yours
Arthur

Dear Rosemary

I read with interest your article on the disposal of used appliances in the Autumn 2011 issue of Tidings.

Like you, I do as I was first taught by my stoma care nurse. Her method is rather simpler than yours - perhaps an opportunity to make your life easier? She advised simply emptying the majority of the contents of the used pouch into the toilet using the same hole it came in through. Thicker contents can be encouraged out like toothpaste from a tube! The flange is then folded over on itself - for a one piece appliance this then seals it, for a two piece it simply leaves a clean outer surface to hold on to. The folded pouch is then placed in a disposal bag which is tied up and dropped in the household waste. The same process is applied to used irrigation tubes. No cutting, no rinsing, no fuss!

I find I can do a change in less than a couple of minutes, in any toilet as no extra space or equipment is needed. When in a public toilet I hold the tied disposal bag and put a coat or other top over my arm, then discretely drop the bag in the nearest bin.

The suggestion of rinsing used appliances, double wrapping or using clinical waste collection seems to be making life unnecessarily difficult. Disposable nappies are put in a nappy sack then into the bin. Dog poo is bagged and dropped in any litter bin (in our village the dedicated dog bins have been removed and we are encouraged to use any litter bin). I think a used appliance in a disposal bag is less of an environmental health issue than either of these items and I have no qualms about my disposal method.

Best regards,
A.B. (Mr)

Disposal of Used Appliances – a reply

Rosemary Brierley's article in the last Tidings about Disposal of Used Appliances got me thinking. Should I look at the way I go about disposing of my used appliances? Rosemary seems to have it well worked out. Perhaps I have become set in my ways. I have maintained that disposal of used appliances is harder for men because there is never a bin for


AbsorbaGel
Odour Neutralising Absorbent Sachets
for Ostomy Pouches
Contents: 150 sachets
Order Code: 9000
CE

Readers' Replies about Pouch Disposal...

clinical waste in the Gents loo, whereas there is in the Ladies, usually. However, all of us are different and there is often a considerable difference in what we have to deal with. Those with a colostomy and a reasonable length of large bowel which will remove a lot of the liquid find that their output is fairly well formed. Those with an ileostomy and no large bowel or those with a right sided colostomy and very little large bowel find that their output is more or less totally liquid. And these are two very different things to deal with. I have a right sided colostomy and liquid output. A lot of the ileostomy and right sided colostomy patients will use a drainable pouch. This is not something that I have ever been able to face up to. I use a two part system, flange and pouch with sealed pouches. And I have always laid a small plastic bag – as provided by the distributor – into the sink and placed the used pouch into this. Now I need to get rid of the plastic bag and the clinical waste contents so I need an appropriate bin which is why I will invariably be in the disabled loo.

However, what if I were to adopt Rosemary's method of emptying the pouch down the loo, I suspect I would still have to use a plastic bag because with a liquid output the pouch will not sit in the sink or on a flat surface, it will collapse and the contents will run out, as has happened many times when I have had to balance everything precariously on the loo seat in the Gent's lavatory – the clearing up being time consuming and requiring miles and miles of loo paper, tough if it's dispensed sheet by sheet, rather than on a roll. But assuming I used a plastic bag in the sink for this, made my change to the new pouch and then took the used pouch to the loo, emptied the contents (cutting a pouch containing liquid is asking for trouble, so we would just empty the contents out of the hole at the top) and rinsed it through by holding it under the flush, I would have a good deal less of a problem disposing of a slightly soiled plastic bag and the used pouch. The pouch would go into the plastic bag and I could find a bin at leisure. There wouldn't be the pressure to dispose of the used pouch and contents in its plastic bag as in the past. True it would be a good deal messier than my current system and there would be more 'involvement' from me, something I have always tried to keep to a minimum – pouch off, into plastic bag, a few wipes and new pouch on again - is about as close to disposable waste as I want to get, but doing things the Rosemary way I would end up with less of a disposal problem. At one time I had considered a flushable pouch, until a nurse pointed out that this might not be a good idea given that the flushable pouches dissolve in water and my output being liquid might well dissolve the pouch. The consequences of that don't bear thinking about.

Using Rosemary's method for me would involve a good deal more faff at the point of changing but a good deal less worry about the disposal. So I will give it a try. You might wonder why I haven't just got on with it. Well it's like anything in this stoma business, change is always a bit of a worry. We are all resistant to change, after all our tried and trusted system works. So I will build up to it. I will let you know how it goes.

Duncan Wells
CA Trustee

Helpful Ostomy Support Groups & Organisations...

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

RADAR
the disability network

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

Colostomates are entitled to a key which will open 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+VAT
Contact head office: 0118 939 1537
for an application form.

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

From RADAR
National Key Scheme Guide 2011
Price: £16.99 incl. delivery

SenSura® Mio

98% AGREE*
“Fits my body’s contours”

*Source: Product evaluation results DK, UK, FI, NL, CH. Total respondents: 218

“It has given me the best confidence I could ever ask for”

Vanessa, SenSura Mio user, UK

The colostomy appliance that follows every body movement

SenSura Mio fits individual body contours and follows your body movements. Whether you are bending down, stretching or twisting, this colostomy appliance maintains a secure fit thanks to the elastic adhesive. So you can feel secure.

Sign up for free samples of SenSura Mio on telephone **0800 917 8641**

Watch a video with users’ reactions to trying SenSura Mio.

www.sensuramio.coloplast.co.uk

The information you provide to us will be used to process your orders and for general administrative and record-keeping purposes. We will only disclose your personal information (including details of the products you have purchased from us) to carefully selected third parties who provide services to us and/or if required by law. By submitting your information to us, you consent to Coloplast using your information in the manner described above and to us contacting you by email and/or telephone and/or post in order to keep you informed of Coloplast products and services that we think may be of interest to you. If you would prefer that we do not contact you in these ways, please let us know by calling us on 0800 220 622.

Coloplast Limited. First Floor Nene Hall, Peterborough Business Park, Peterborough. PE2 6FX
The Coloplast logo is a registered trademark of Coloplast A/S. © 2011-09 All rights reserved Coloplast A/S, 3050 Humlebæk, Denmark.

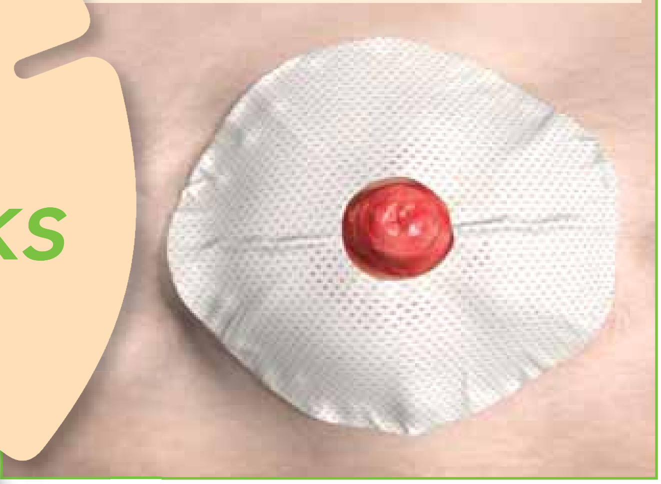
Coloplast

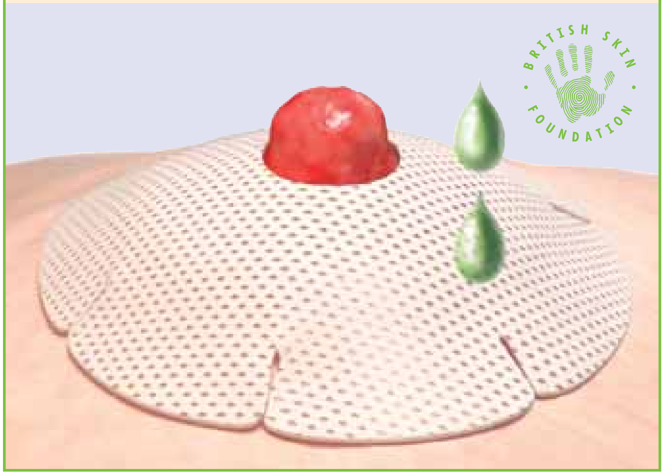
Disabled Lavatories

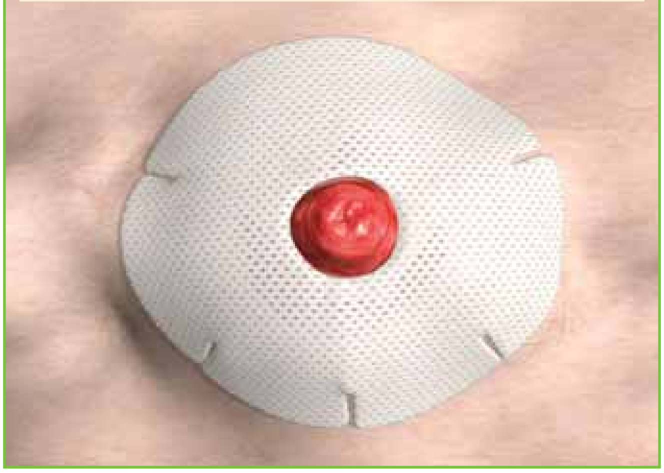
Ostomates represent just 1% of the disabled population in this country so perhaps it is not surprising that we have been designed out of 100% of the disabled lavatories! That's if we can actually get into one in the first place, given that councils (and RADAR even) hand out the keys to drug takers, wastrels and vagrants. Do you have to prove that you are disabled to get a RADAR key from the council? Do you have to have a note from your doctor? Does the disabled person have to be the one applying for the RADAR key? No. No. And No. Most councils will accept the word of any citizen who says they need a RADAR key for a relative or friend who is disabled. Hand over your two quid and now that's another fraudster preventing a legitimate user of the disabled lavatory from gaining access.

And when you do gain access, what do you find? Is there anywhere to hang your coat? No. Is the basin a reasonable size? No. In fact our breakfast bowls at home are larger. Are there any flat surfaces to lay out your pouch, wipes and so forth? No. Is there a place to leave clinical waste? Yes. Thank goodness. Because as a man that is why I have to go to the disabled loo.

There is nowhere in the men's lavatories to leave one's waste bag and you can't in all conscience leave it on the floor in the cubicle. That's not the only problem with the ordinary lavatory of course. It is very difficult to lean over the lavatory with the seat closed and effect the process of a change. And then there is always the possibility of disaster. My stoma invariably decides that exposure to the fresh air is a call to action. With a sink the consequences are not so bad. In a cubicle and using the closed lavatory seat on which to place pouch, plastic bag and wipes, the consequences are catastrophic. >




BRITISH SKIN FOUNDATION



So that’s why we are in the disabled lavatory, with the new pouch balanced precariously on top of the sloping top of the hot air hand dryer, the wipes stuffed behind the tap in the sink and the plastic bag in the sink itself. One’s jacket? Ah, well that’s lying on the floor, inches away from some rather suspicious looking liquid which appears to be creeping slowly towards it.

Things could be worse though. Have you come across the new disabled lavatories on the trains, the ones with this enormous semi circular door? You press the button and it opens to reveal a cavernous interior. And they open in full view of the other passengers in the carriage, all 36 of them. I was faced with one of these the other day. I am standing up straight, no wheelchair, holding an overnight bag in one hand and my laptop in the other and the passengers watch this apparently able person enter the disabled loo. You have to remember that having an ostomy, qualifies you as officially disabled according to the Disability Discrimination Act, only the passengers don’t know that. I pressed the button to shut the door but it didn’t move. There I am standing in the disabled lavatory in the full glare of the critical passengers. So I put down my bags and shut the door manually. It was a big heavy door and I am sure they thought I was taking a dreadful liberty. Then I noticed that the sink was slightly recessed under a counter. I placed a bag in the sink and as I withdrew my hand so a blast of hot air blew the bag out of the sink onto the floor. Not a very good start.

With the bag back in the sink I removed my hand and set off a great gush of water. I put my hand back into the sink to remove the bag from its wetting and received a splat of something liquid. Soap I discovered when I pulled my hand back. Great that’s all that ostomists need, an automatic hand wash basin. By keeping my hands down low as though playing the piano in a very flat manner I managed to get by without setting off the sensors. Then of course you exit the disabled loo and find that there is someone in a wheelchair with their helper waiting to go in. And they are incandescent with rage that you who are apparently able bodied should have held them up.

And this business of having automatic water is becoming more and more popular. I have discovered this at several airports. Oh yes they have the automatic taps but do they have anywhere for you to hang your jacket? No. Any flat surfaces? No. It’s not asking much. All we want is coat hooks, flat surfaces, larger sinks and no automatic, water, soap and hot air. Or at least the ability to turn the automatic to manual to using a cabin crew expression. Oh and that’s another thing, have you ever tried changing in an airplane loo? It’s interesting to say the least.

But all this is to suggest that life for the ostomate is difficult out in the big wide world. It isn’t really because we are a resourceful lot and we manage. It would just be nice if facilities like disabled loos which are supposed to cater for us, actually did cater for us.

To this end, design researcher Jo-Anne Bichard has been investigating the design of publicly accessed toilets which includes disabled toilets and she has completed a number of studies recently into what ostomates require from disabled loos.

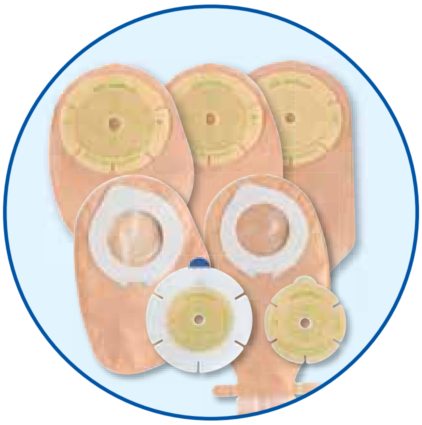
It has been established that;
A clean shelf to lay out supplies
Appropriate bins for disposal of pouches
Full length mirror to check self after changing
Paper towels to dry stoma
Coat hook to hang coats and bags
were key design requirements. Added to this management issues that needed to be considered included;
Good cleaning and well-maintained supply of toilet roll and paper towels
Hot water
Toilets well signed and located in easy to find places to be accessed in an emergency.

At this stage these appear to be just proposals but the aim is to make them part of the British Standards and Building Regulations. At the same time local authorities are being encouraged to make service provision information more transparent and readily available and this is being realised through an initiative called Open Data, to which the public has access. So we can now see what provision local councils are making for public toilets. And there is a website – ‘Google’, The Great British Public Toilet Map - where you can look up your nearest public toilet, although at present it only covers London and I found the site rather creaky.

In time there may be greater provision for the ostomate in disabled loos. There’s only one stumbling block though. Many providers of disabled loos do not include a shelf due to fears that it will be used for illegal substance abuse. So the very thing we require, is the very thing that the providers are reluctant to provide. And that’s where this article started, if local councils and RADAR actually had a proper vetting process for those requiring RADAR keys, such as a doctor’s certificate, they wouldn’t be handing keys out willy nilly to the recreationally drug dependant and we could have our shelf.

Duncan Wells
CA Trustee

CHOICE OF 24-HOUR HELPLINE
OR CUSTOMER CARE CENTRES



CHOICE OF ANY MAKE OR MODEL
OF STOMA PRODUCTS

CHOOSE PRESCRIPTION
DELIVERY SERVICE OR EPS*

SALTS
medilink
Your link to better care

CHOICE OF WIPES,
HAND GEL AND DISPOSAPACS

CHOOSE OPTIONAL POUCH
PRE-CUTTING SERVICE

CHOOSE TO ORDER BY POST,
EMAIL OR PHONE

CHOOSE FREE NEXT-DAY DELIVERY
AT TIMES TO SUIT YOU

CHOOSE FREE VISITS FROM
STOMA NURSES AT HOME

MEDILINK IS FIRST FOR PATIENT CHOICE

Anyone can offer free, next-day delivery. It's our commitment to patient choice that makes Medilink so popular. You can choose any make or model of products; choose how to receive your care – over the phone, face-to-face in our customer care centres or at home with our stoma care nurses; and even choose how to order – our new Electronic Prescription Service means you can get the products you need, when you need them.

Find out more on 0800 626388 or visit www.salts.co.uk/medilink

*When your GP is able to transmit prescriptions electronically breakaway

putting smiles on young faces

Julie Bastin - Founder and Trustee writes...

"Breakaway five years on...has now completed 11 residential weekend activity breaks, with many more in the pipeline for 2012. Breakaway is able to link families together on a local level. To see the impact that we've made on the children's and parents' lives is humbling. Breakaway will continue to grow, we have lots of exciting plans in place for next year…we may be five years old but this is really just the very beginning."

Meet the breakaway buddies – young ambassadors for the charity...

Breakaway Buddies – Are there to support, befriend and mentor children who attend breakaway events..

From Left to right: Joshi aged 18, Ainsley aged 18 and Fergus aged 16... support Hannah aged 10.

Ainsley writes... Hi, my name is Ainsley and I'm 18 years old. I was diagnosed with Ulcerative Colitis when I was 15 and had to have surgery to form an Ileostomy around six months after diagnosis.

After my surgery getting used to the stoma was very difficult however Breakaway helped with different aspects of coming to terms with it. Now I am a Ski Technician and a Snowboarding Instructor at my local dry ski slope, I have been rock climbing, jumped off a 30ft waterfall, went on holiday with my friends this summer and much more, the point is I don't let having a stoma stop me doing anything!

I enjoy being involved with Breakaway, helping out at the events, going to conferences and doing presentations to raise awareness of the charity.

Joshi writes... My name is Joshi and I am 18. At the age of 11 I was diagnosed with UC and when I was 13 I had surgery to form an Ileostomy. Life was quite daunting for a while.

Finding Breakaway and the support that was offered really changed my perception on life with a Stoma. I felt better able to cope with growing up – amongst others that understood. I believe that peer to peer support is invaluable for young children and teenagers dealing with the challenges thrown at you by this sort of surgery! In my role as Breakaway Buddy, I represent Breakaway at open days to raise awareness. I have delivered presentations to patients, surgeons, and paediatric nurses about my life growing up with a stoma, and the benefits of Breakaway. I attend all the Breakaway events that I can to help out and to help the teenagers with any questions that they may have, and show them that you can do everything that your friends do, I have!

I have recently just moved away to University in Bath, to study computer science, but I will continue to support Breakaway in any way that I can around my studies. This charity is amazing and I am proud to be a Breakaway Buddy!

Hannah writes... Hi, my job is being a Breakaway Buddy. I like being a Breakaway Buddy because I get to help and be involved.

I know what it is like for those who have a Colostomy, Ace or a Mitrofanoff as that is what I have had and still have two.

As a new born baby I had a Colostomy. That was until I was one. For the next four years I didn't have anything. When I was five I had an Ace. Two years ago I had a Mitrofanoff.

After all that I am fine, and know that I can do everything that my friends do. Being a Breakaway Buddy means that I can ensure people who are scared or upset have someone to talk to that knows how it feels.

More information about Breakaway...

Write to us or send a donation to:

Breakaway
PO BOX 7982
Swadlincote
DE11 1FB

Telephone:
07903220040

Email:
info@breakaway-visits.co.uk

Web:
www.breakaway-visits.co.uk

Donate online via:

JustGiving

http://www.justgiving.com/breakawayvisits

Readers’ writes

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

Dear Editor

My bag is about ten years old. In that time I have visited China, New Zealand, America, Canada and several European countries. I check-in on line and get the exit row whenever I can. Failing that I go for the two seats at the back of the plane.

I have had no problems at airport security though I was patted down in Warsaw and asked, 'What is that? ' I was cross and tired and I just answered, 'A bag of s..t!' and that was that. Naughty I know.

As far as insurance is concerned, AA will give annual travel and holiday insurance up to age eighty at a very reasonable price. Last year Worldwide was around £250 and this year Europe Only around £150. (But do note it also covered me for the many holidays I have had in this country too. Since retirement, we have been going to a cottage in Cornwall, for three weeks four times most years.) However, for the first five years it did not cover anything to do with cancer but that was no problem. This is my last year as I am reaching that eightieth milestone so after next August I will have to search elsewhere.

Best wishes
M.D. (Ms)

Dear Editor

Reading through the article Parastomal Hernias in the Autumn issue of Tidings, I was somewhat intrigued by the letter included from M Hemadri .

In that letter he advocates situating the stoma at the “belly button” (my wording). I can understand his reasoning and the statistics that he quotes for such a procedure. However, I wonder if he has performed any research into the subsequent comfort, etc of ostomates for whom this technique has been employed.

My stoma is located rather high up but not quite as high as this would require. I am quite happy with my stoma but there are occasions when its position can cause a little discomfort. Fortunately (?) my days of serious gardening are now over, so prolonged bending is no longer a problem. More importantly, however, is the fact that I am unable to wear a belt or anything tight fitting around my waist. I imagine that this could be something to be experienced by those treated in such a way.

I would be interested in other views on this aspect.

Thank you for producing such an informative magazine with such a varied selection of articles.

Best wishes
B.W. (Mr)

Dear Editor

My emergency colostomy operation, a Hartmann’s Procedure, was performed in May 1998, the result of an undiagnosed hole in my bowel following gynaecology laser treatment for adhesions. I developed septicaemia and peritonitis and was admitted to I.T.U. My husband was told I had a 50/50 chance of survival – a unique gift for his 51st birthday. But I did survive, even though I stayed another ten weeks in hospital, suffered a second bout of septicaemia and spent a couple of months further, confined to home with district nurses calling.

I have Behcet’s Disease, (www.behcets.org.uk) which affected my healing. My wound became so badly infected that it wouldn’t heal despite every treatment the doctors tried. Eventually I was sent home with all stitches removed and told that in time, the gaping wound would somehow draw together. This apparently had been the case with many soldiers who were wounded during the First World War. God bless Mother Nature – it did eventually heal!

Thirteen years on and I am not a pretty sight. I have developed a large parastomal hernia and several others. I have virtually little or no muscle wall between my hip bones. There is no possibility of repair or reversal as I have been told by specialists that I am unable to have any tummy operations unless it’s to save my life.

I became aware very early on in hospital, that my rectum was quite full and I felt the need to use the bed pan. The desire to strain was accompanied by pain and profuse sweating. But despite all my effort I was unable to clear my rectum.

As the weeks wore on, the attacks of pain and spasm eventually cleared the solid matter but I was by then passing mucus discharge and suffering continual infections. I saw several doctors and specialists who diagnosed it as some kind of proctitis. I have tried suppositories, enemas and pills, none of which have had any effect on the problem. I now accept this as part of my life.

I did, however, get referred to my current specialist who has helped considerably. He admits me to Day Surgery every few months for a rectal flush out, which, although it hasn’t stopped the discharge, has stopped

Readers’ writes

the recurrent infections and blockings I was experiencing in the early days. The spasms are far less frequent and intense but the odd one still stops me in my tracks. The discharge is now constant but fortunately my anal muscles currently work quite well so accidents are few and far between.

Yours truly,
J.H. (Mrs)

Dear Editor

I have been receiving the Tidings magazine for just over two years following my Colostomy in February 2009. I have found the content informative, inspiring and to be honest at times a little, shall I say, concerning, when I read about the traumas and difficulties that some colostomates experience following their operations and what they have to endure when living with their colostomy. I count myself very fortunate in many respects both because my colostomy and subsequent ileostomy gave me very few problems, with the exception of the dreaded “Pancaking”, and now because I have recently had a very successful, albeit rather prolonged and at times traumatic, reversal.

The main point of my e mail is of course to advise you that I no longer require the services and support of the magazine and the wonderful CA. I also have to say that on my research in to the reversal on the internet and also on your own website I found a lot of very negative opinions/reports. When the time came for what was the first of two operations I nearly backed out and coming round following that first operation wished I had. But I had a brilliant surgeon and today I have to say I feel as good as new and count myself amazingly fortunate.

I would like to thank you all at the CA for your support and keeping me so well informed over the past two years.

With very best wishes for the future
Kindest Regards
L. P. (Mr)

Dear Editor

I am writing about Dale Kennett's letter in the last Tidings concerning rectal pain.

I have spoken with my surgeon about the same thing, and he told me that the rectal stump still secretes mucus even when no longer “in use” and this mucus sets like rock causing the pain. He advised me to empty the rectum regularly with suppositories which is the conclusion Dale came to on his own. My problem is that I used to manually evacuate due to my MS and was causing damage, hence the colostomy, and even with the help of a suppository I need to manually evacuate which is still a problem.

Regards
D.A. (Mr)

Dear Editor

I am a colostomate of twelve years and had numerous balloonings and leaks, so a scientific approach was required. After a lot of experimentation I discovered the best method that suited me was as follows:

Place your new bag next to your skin (under a vest or shirt) and leave for approx 3 – 5 minutes whilst preparing your stuff. Next take the warm bag and mould to shape, either concave or convex. Then place back against warm skin.

Remove old bag, clean the site with baby wipes. The lanolin type stops the skin from going red and chafing. Dry thoroughly with toilet tissue. Wipe the stoma site with a silicone-based wipe, which not only coats the skin but also assists in adhesion. Allow a few seconds to dry.

Bend new bag in half and fit bottom half first, followed by the top half. Now smooth down in circular motion starting from the middle, working outwards. Tidy up. Job done.

Best regards
P.H.M. (Mr)

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

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

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

If you want to be involved in the next issue of Tidings magazine **simply drop us a line**

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

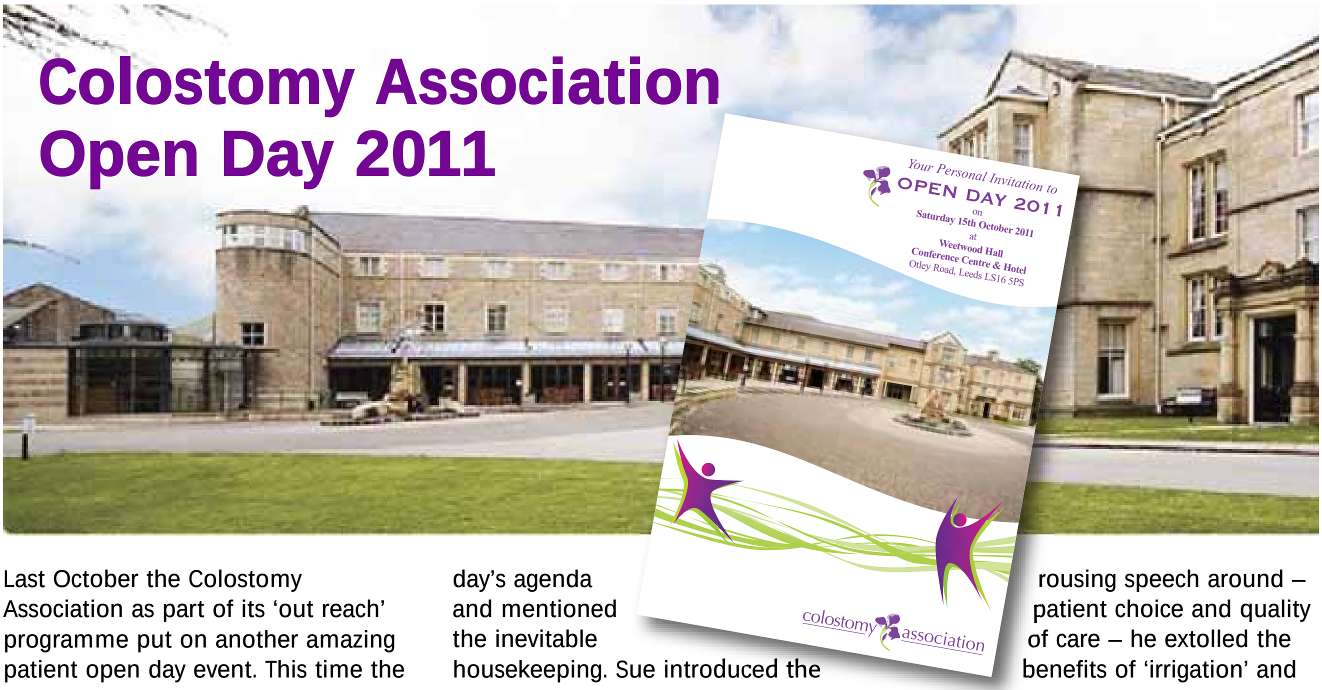
or write to:
Associate Editor
Colostomy Association
2 London Court,
East Street,
Reading RG1 4QL

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

Readers’
PANEL
contributor

Yours
Rosemary Brierley
Associate Editor

Colostomy Association Open Day 2011



Your Personal Invitation to
OPEN DAY 2011
on
Saturday 15th October 2011
at
Weetwood Hall
Conference Centre & Hotel
Otley Road, Leeds LS16 5PS

Last October the Colostomy Association as part of its 'out reach' programme put on another amazing patient open day event. This time the focus was the North of England. Leeds had been identified as a central location and Weetwood Hall ticked all the boxes as a suitable venue. The event's agenda similar to last year's featured aspects of 'Living with a colostomy at home and abroad'

The response to the open day invitation was excellent 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 in their places waited in nervous anticipation and excitement as the clock ticked away to the start time, the doors opened and attendees began arriving, some had stayed the night before at the venue. They were greeted by Vice Chairman Ernie Hulme, Richard Bray General Manager, Gill Herbert and Jo McKenzie CA office administrators. As at last year's event it was 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 brought together in an atmosphere that promoted the positive aspects of 'living with a colostomy'.

Sue Hatton, Executive Trustee – the hostess with the mostest – opened the day in her inimitable style! Sue's welcoming address discussed the importance of open days, outlined the day's agenda and mentioned the inevitable housekeeping. Sue introduced the first of the day's presentations, 'trouble shooting – post operative skin complications' presented by Jo Sica SCN/CNS. Jo is an experienced stoma care nurse specialist of some standing, she has travelled globally in her work with Hollister, written articles on stoma care, held a post on the WCET UK committee and lobbied MPs in support of her colleagues and patient care. Jo has kindly provided an excerpt from her presentation - 'Post operative skin complications' which you can read opposite.

Jo's presentation gave an insight into skin care around the stoma with a new colostomy. Jo finished her presentation and took questions from the audience. Sue thanked Jo and suggested that colostomates chat with Jo over the lunchtime break.

Entering the meeting room in haste came the President of the Colostomy Association, Professor Bill Heald OBE hotfoot from Leeds railway station! A little background, Professor Bill Heald OBE highly respected in his field is involved in advancing surgical techniques around the world. He is also part of the Pelican Cancer Foundation, which is based just outside Basingstoke in Hampshire. Pelican has become a `centre of excellence` for sharing life-saving, life-enhancing knowledge and skills with future generations of surgeons and cancer teams. Sue introduced Professor Heald who delivered a rousing speech around – patient choice and quality of care – he extolled the benefits of 'irrigation' and rallied the audience calling on them to be pro-active and get involved in supporting the CA, their own healthcare professionals and the NHS.

Sue thanked Professor Heald for making it up to Leeds and explained to the audience that Prof Bill had been her surgeon, and that along with Anne Leppington-Clarke SCN/CNS, they had between them got her through her surgery, introduced her to 'irrigation' and gave her a positive way forward! Sue also drew the audience's attention to the poster on 'irrigation', which had been accepted and exhibited at the WCET UK Conference in Liverpool, entitled 'Improving quality of life through choice – Colostomy Irrigation'.

After a full morning...lunch was announced, a buffet of hot and cold snacks and an opportunity for interaction between attendees, guests, CA Trustees and staff, presenters and exhibitors. It had been decided at the planning stage that the open day would offer two extended time periods one in the morning prior to presentations and one over lunchtime to give people time to view the exhibits, chat and perhaps make new friends!

Over eighteen exhibitors attended the CA open day made up of stoma care product manufacturers/suppliers and clothing and support garment companies. Other exhibitors attending included sister organisations such as IA; unfortunately, UA could not attend this year. Children's charity Breakaway-Visits (the only England and Wales based charity offering residential adventure activity breaks for young people from 4-18 with bowel and/or bladder diversions and dysfunctions and their families) was represented by Julie Bastin - Founder and Trustee. Julie's daughter Hannah helped register CA attendees, Carol Hunt and son Fergus also attended. Ostomyland's Jason Dale came to promote his patient support group website aided by Sarah Squire (who appeared on the Spring cover of Tidings). Helen Bracey manned the Ostomy Lifestyle stand and Lucy Russell CNS/Stoma Care - Norfolk and Norwich University Hospitals NHS Foundation Trust - came to host the CA 'irrigation' stand and wave the banner for 'irrigation'.

After lunch we were treated to the dulcet tones of voice over artist turned CA Trustee and presenter, Duncan Wells who many of you may know from his articles in Tidings and from previous open days. Duncan kindly offered to write and present 'travelling with a stoma'. There is no doubt from the many calls and emails that come into head office; travel is a hot topic with colostomates and stoma care nurses. Duncan's presentation was highly informative and covered...taking enough supplies...travel certificates and doctor's letter, airline rules...on board hand luggage...useful medication...and travel insurance! Duncan delivered his presentation with style, passion and gusto! Sue thanked Duncan for his excellent presentation and asked if he would write it up for the CA website and Tidings.

The last presentation of the day came from the enthusiastic and extremely personable Mr. Ian Daniels FRCS, Vice President of the Colostomy Association. Mr Daniels like Professor Heald is a highly respected surgeon who specialises in abdominal surgery and the diagnosis of gastrointestinal disorders. He is Consultant Surgeon at the Royal Devon & Exeter Hospital and performs surgery at The Exeter Nuffield Hospital and is often invited to perform specialist procedures in the UK, Europe and South African Hospitals. Ian delivered a fascinating and inspiring presentation around Parastomal Hernias. It included patient approach...meeting people understanding their needs...planning... pre op...post op...surgical techniques and much more besides. At the end people were queuing in the aisles to speak to him!

Monty Taylor Chairman of the Colostomy Association closed the day by saying...'Events such as this really make a difference and give those who attend a firm 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!

Post operative skin complications

by Jo Sica SCN/CNS

This snapshot aims to give those not present at the CA Open Day a summary of the key points of this presentation...

Having a new colostomy often presents challenges, especially in the early days. The skin around the stoma can breakdown easily if exposed to faeces.

Early post operative odema

In the early days, the stoma can be quite oedematous (swollen) but as the bowel settles, the stoma will shrink.

It is important to remeasure the stoma regularly and a healthcare professional such as a stoma care nurse can show you how to do this. The stoma appliance should fit the stoma snugly; too large and the pouch will leak and too small, the stoma will be strangled, so that the faeces cannot exit into the pouch. There can be many reasons for excoriated skin and some of the most common reasons are listed below;

Measuring a stoma

- A poorly sited stoma
- Retracted or short spouted stoma
- Weight loss or gain
- A poorly fitting appliance
- A change in the stomal output.

This may be linked to a number of factors including diet or medications including chemotherapy and radiotherapy, and even depression and immobility

Any of these can result in leakage, which will cause the peristomal (the skin around the stoma) to break down.

Allergy from a skin barrier

Some people are allergic or sensitive to components in a stoma skin barrier and may require a Dermatological opinion and skin testing.

Leakages from a stoma appliance can result in a person not only experiencing painful sore skin but can also lead to social isolation. It is important that anyone experiencing any kind of skin complaint should not try and treat it themselves but contact their nearest healthcare professional, ideally their stoma care nurse so that a thorough assessment can be made and treatment commenced.

It is not unusual for people to move areas and no longer be in touch with their original stoma care nurse. However, when they move to a new area, it is wise to seek out the local stoma care nurse. The local G.P surgery or hospital are good starting points when trying to find out where the stoma care nurse is. As long as someone has a stoma, they should be known to their local stoma care nurse.

There were numerous questions and comments from the audience and it was a good forum to share experiences and knowledge. Many people approached me afterwards and asked me about issues such as parastomal hernias, bleeding from small nodules on their stoma known as granulomas and prolapsed stomas.

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 every issue which has been published since then. We look forward to many more years of publishing her very sound advice.

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

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

Q: *I have had my colostomy bag for a year back from last Easter. I was told that the reason for the colostomy op. was that part of my over-long "drainpipe" had died! So I had to have that bit chopped off. When I first came out of hospital my "drains" were working quite normally. But after a while, I started to have Irritable Bowel Syndrome. Now, as well as IBS I seem to have a weak immune system so that whenever there is a virus flying around it always affects my bowel and I get loose, having to change my bag about a dozen times a day.*

I had been controlling all this by taking Imodium or Diocalm and sometimes Iron with Vitamin C and eating white rice. This is usually fine for a while but then I get blocked too much, and, 3 or 4 times this year have had to go to casualty and get un-blocked. I have sometimes managed to do this with Movicol Solution – but not always.

My surgeon has told me to stop taking Imodium – to get me "even" but I find I cannot avoid this if I want to carry on with my activities. Also I like, and do, a lot of walking for pleasure. This weak immune system as regards viruses started in 1989 when I got Post Viral Syndrome. Before that I was hardly ever ill or unwell. I am coming up to 75, and have no other health problems and am pretty strong constitutionally.

The stoma nurses have been very good – but they just say 'take Imodium' while the surgeon says not to. So what should I do? The stoma nurses also tell me to eat jelly babies, marshmallows but this does not make any difference.

A: You do not say what dose of Imodium you are taking or how you are taking it. Imodium should be taken 20 minutes prior to food when you have a stoma and the maximum dose is 16mgs (8 x 2mg tablets in 24 hours). If you find this 'blocks' you up it may be worth trying Imodium syrup as you can take smaller doses each time. However if your surgeon has suggested you stop taking Imodium it may be worth trying something such as Fybogel. This is taken as a drink (1 sachet mixed with a glass of water) twice a day and will help to bulk the stool without constipating, as long as you drink plenty of fluids whilst taking it. You do need to take it regularly for it to work. I hope this helps and you are able to continue with your active lifestyle.

Q: *I was diagnosed with prostate cancer Christmas Eve 2009 and began treatment in January. I had seven and a half weeks radiotherapy. Then in 2011 I was admitted to hospital again with rectal bleeding. Part of my bowel had to be removed as it had been damaged by the radiotherapy and I had a temporary colostomy which has since been made permanent. I lost three stone in weight, but have regained some of this and I now weigh 11st 11lbs (my height is 5ft 8ins). I have accepted my colostomy and it doesn't restrict what I eat but I find I do not enjoy my food and have no sense of taste. Can you tell me why this is and have you any suggestions of what might help?*

A: Quite a few people report this symptom following surgery, with some people reporting that they do not enjoy, or cannot tolerate a food which, prior to their operation, they ate regularly and really enjoyed. It is not unusual for your sense of taste to alter immediately post surgery but most people find that over a period of a few months this comes back. Also your appetite may have been reduced after your operation but again this should return to normal within a few months. I'm glad to hear that you have regained your healthy weight and hope that you will soon be able to enjoy your food again.

Q: *I had an ileostomy in October 2009 and until now haven't had any problems. Recently I have been having radiotherapy for a Rectal Tumour and I have been suffering* *from burning and itching down below including the left side of my tummy but not under my stoma bag. This itching was agonizing.*

Two weeks after the last treatment, the adhesive on my stoma bag began to fail and during the last week I have had 4 leaks. My Stoma Nurse came today and has sorted me out with some new bags to try.
My question is, can radiotherapy affect the adhesion of the bags?

A: Some people do find that during radiotherapy or chemotherapy their skin integrity suffers and they need to seek advice from their Stoma Care Nurse. There are many different products available and as you have seen your local Stoma Care Nurse I would suggest trying what she has arranged and see her for a review if the problem does not improve. Hopefully now that you have completed your treatment the problem will settle quite quickly.

Q: *Having read in Tidings about irrigation I began to irrigate 6 months ago. I had bowel cancer in 2004 which lead to my colostomy. As I have an enlarged kidney due to a reflux action I had to obtain permission from the consultant urologist. He advised me to only use one litre of water. It has been quite successful but does not entirely clear my bowel. I would like some advice as a small hernia has developed and I have some difficulty with water flowing into my bowel as some escapes initially. I do not know if this is due to the hernia. I had lots of problems with pouches pancaking so would like to continue irrigating but do not want to cause any injury.*

A: Some patients find that once they have a parastomal hernia it is difficult to continue to irrigate as the water does not flow freely into the bowel, as you have mentioned. Obviously I cannot assess the size of the hernia so it may be worth asking for a review by your local Stoma Care Nurse to see if there is anything that can be done to help to prevent the hernia getting worse or if a surgical review is possible with regards to repair. Your nurse may also be able to offer some support about changing the technique for irrigating, such as a change of position to help.

Q: *I am having trouble with my rectal stump after an ileostomy. I am 2 years post op and am having a lot of pain. I have used suppositories to clear any mucus but with no luck. Any advice appreciated.*

A: You do not say why you had the surgery and if there are any plans to reverse the stoma with reconstructive surgery. If reconstructive surgery, such as Ileo Anal Pouch Formation (Restorative Proctocolectomy) is a possibility then you will need the anal canal but the rectum will be removed during this operation. If however there is not any possibility of this surgery being performed then it may be worth discussing the potential of having the rectal stump removed. This in itself can have implications but a review by your surgeon to discuss this can highlight all the positive and negative points.

Q: *I had a colostomy on 7 October 2011 for rectal cancer. The stoma side is going well however I am having problems with the wound for the closure of the anus. There is an opening of approximately 1cm and it is leaking and I have to go to the surgery every day to have the wound packed and dressed. After all this time I cannot sit for more than 5 - 10 minutes as it is extremely painful to sit. I am having no problems with walking about, just the sitting, so therefore find I am spending a lot of time in bed. I would be keen to know if you have heard from other people who have experienced this problem and how long it took before the wound healed completely and any suggestions they might have.*

A: You do not say if you had any chemotherapy or radiotherapy prior to your surgery. It is often this wound which causes the most problems for patients and these can be worse if you have had treatment prior to your operation as healing is slowed down. Continue with the treatment from the District Nurses and maybe ask for a review of your pain relief medication to see if something can be prescribed. You could also ask your District Nurses about some of the special cushions available to help you to get some relief when you sit. I have many patients who report the same problem to me but with time I am sure that you will find this problem settles.

What kind of stoma do you have?

When food leaves the stomach it enters the small intestine, a long coil 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

No Regrets...

At the CA Open Day in Leeds in October, Betty Rukin said she would like to tell Tidings her story, to make the point that not all colostomies are formed because of cancer. Betty had her operation to form a colostomy in 2002, but the pathway to her colostomy began almost thirty years before.

On Wednesday 23rd August 1966 Betty gave birth to a son. The pregnancy had been normal, but unexpected. Betty and her husband, Terence, had been hoping for a baby for more than five years. When it didn't happen they adopted a seven week old baby girl, Linda. That had been the previous September, but by Christmas Betty knew she was pregnant.

The baby was due on 5th August, but it wasn't until the afternoon of the 22nd that Betty's waters were broken, and she went into labour. However, by eleven o'clock the following morning it was evident that the baby was in distress so Betty was rushed down to theatre. The gynaecologist had to make a large incision and use forceps during the delivery. He explained later that the problem was that the umbilical cord was only twelve inches long. Andrew was born at noon and taken to the Special Care Baby Unit. Betty needed stitches – the doctors wouldn't tell her how many, but repairing the damage took over an hour.

For several months after the birth Betty needed to use a rubber ring when sitting down, but caring for two babies under fourteen months left her with little time to sit down. In the late seventies when the children were settled at school Betty went back to work as a clerk/cashier. It was about this time that the problem with her bowels began to get worse: she was always checking up that there was a toilet not far away. When she told her doctor about the pain she suffered, and how she often had an urgent need to open her bowels he referred her to the hospital. The gastroenterologist she saw said she had Irritable Bowel Syndrome.

Betty and Terence Rukin present a TV, DVD and games equipment to Michelle Surrell, Director of Development, at the Forget Me Not Children's Hospice.

There were days when Betty felt really "washed out" but she still went into work. Then she changed her job and her new employer wasn't as understanding as her previous boss, so eighteen months later she decided to retire. Sadly a year later in 1991 her son, Andrew, died from a heart condition called hypertrophic cardiomyopathy. He was twenty-five and his son, David, was only three at the time.

Over the years Betty's bowel problems continued and in the early nineties she was referred to an incontinence nurse and had to wear pads. In the late nineties she sought a second opinion. Her daughter, Linda, came with her and asked the surgeon if her mother would need a colostomy. He replied, 'Yes eventually.'

So Betty says, 'When in 2002 I had my colostomy it didn't come as a shock. I'd had time to get my head round it and in a way I felt relieved that they were finally going to do something about it.' In hospital when the nurse showed her how to change the bag, she told him she'd be able to manage herself the next time. She says, 'It is so much simpler than coping with incontinence. I feel more in control.' Three months later her family and friends were all saying how much better she looked.

Betty uses a clear, closed pouch. She has tried others over the years, but still returns to the one she was given when she first had her stoma. Sometimes she uses a drainable bag when going on long journeys. Betty laughs when she recalls how once on a coach trip the only available toilet at the bus station had a door that wouldn't shut and no light. She still managed to change her bag in the dark. >

Leaks have been a problem for Betty, and her stoma care nurse said this was because her stoma had a moat around it and suggested she try using a washer to fill in this depression before attaching her stoma bag. This seems to have worked.

The reason Betty's stoma is recessed is because she has a parastomal hernia so she was very interested in the talk on hernias given by Ian Daniels, consultant surgeon and CA vice president at our Open Day in Leeds in October. She wasn't surprised when he said that some people's biological make-up means they are more likely to develop hernias, because even before she had her stoma she'd already had two umbilical hernia repairs.

Betty has had two parastomal hernias repairs one in 2004 and another in 2008. In both cases it was a tissue repair at the site of the hernia, but with this relatively simple procedure there is a high risk of the hernia recurring as Betty knows to her cost. Her surgeon has told her that if he ever decides to do another repair he would have to re-site the stoma somewhere else on her abdomen.

Not only did Betty enjoy the CA Open Day she also won the prize draw organised by Amcare & Convatec. 'It's strange how things happen,' says Betty. 'The week of the Open Day I went to a talk at the Monday Club of our local church, where I am secretary. The talk was given by the head of fundraising for the Forget Me Not Children's Hospice in Huddersfield.'

Betty was determined to do something to help the charity but was unsure how to go about it. Then on the Saturday she won the first prize of a TV and DVD combo, a Nintendo Wii Fit and a Wii Sports Pack. Betty and her husband have donated their prize to the teenage room at the Hospice in memory of their son, as this Christmas it will be twenty years since Andrew died.'

Not long ago Andrew's son David, asked his grandmother if she had any regrets about having his father because of all the problems she'd had since the birth. Betty said 'Of course not.' David replied, 'I'm glad because if you hadn't had my dad I wouldn't be here!' David's wife is now expecting a baby so in March Betty will be a great grandmother.

Betty Rukin

Readers'
PANEL
contributor

NOTEBOOK UPDATES AND EVENTS

Stoma Care Open Days...

Open days give ostomates the opportunity to meet and share experiences with other ostomates. Many people attend with friends and family as they are very sociable events.

Date: 24th March 2012
Venue: M Shed, Princes Wharf Wapping Rd Bristol
Time: 10am-1pm
Organiser: Stoma Care Depts, Bristol Royal infirmary and North Bristol Trust

Date: 12th April 2012
Venue: upper Room, ST Paul's, Darwell Street, Walsall
Time: 1pm-4pm
Organiser: Walsall Healthcare NHS Trust

Date: 21st April 2012
Venue: Level 3, Academic Centre, John Radcliffe Hospital, Oxford
Time: 10am-2pm
Organiser: Stoma Care Dept, Oxford Radcliffe Hospitals

Open day events are posted on the Colostomy Association website throughout the year...

visit: **www.colostomyassociation.org.uk**

Help us to help you

Do you want to make a difference?

By becoming involved in Welland product development and evaluation, you could help improve the quality of life of other ostomates around the world. Your feedback will help us to continue to design, develop and manufacture innovative stoma care products and accessories.

For more information please contact our Stoma Nurse on:
Tel: **01293 848635**, email: **nurse@wellandmedical.com**
or visit our website: **www.wellandmedical.com**

Welland Medical Innovators in **Stomacare**

Welland Medical Ltd., Brunel Centre, Newton Road, Crawley, West Sussex RH10 9TU United Kingdom.
Tel: +44 (0) 1293 615455 Fax: +44 (0) 1293 615411 Email: info@wellandmedical.com Website: www.wellandmedical.com

Welland products are distributed in the UK by Clinimed Ltd. Welland and the Welland logo™ are trademarks of CliniMed (Holdings) Ltd.

CE INVESTORS IN PEOPLE Silver

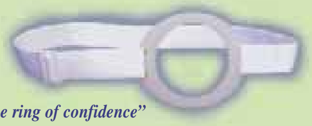
● ●

SASH

- The Sash belts are available on prescription and suitable for both male and female.
- All belts are custom made from information given on our Order Form and a hole is cut into the belt flange to fit your preferred pouch.
- No fittings are required. Belts are processed and mailed within two working days.
- For further information and to obtain an Order Form Freephone : 0800 389 3111

Security and Leakage Belt

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



"the ring of confidence"

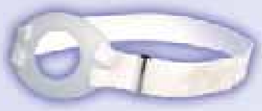
- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
- The belt also gives added security against the pouch becoming detached and will help to support the weight of a full pouch

Ref. no. SR103

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

Stoma Support and Hernia Belt

- The Stoma Support and Hernia Belt is made of a 50mm (2") non elasticized webbing attached to a restraining flange that fits between the bag and the adhesive section of the pouch.



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

Ref. no. S1

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

Marketplace

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

Ostomy Covers
Made by an Ostomate
for Ostomates

OSTOMY COVERS BY LINDA
Made to fit any stoma bag
•Most colours•
•Cotton or lace•
Phone 01205 723327

www.ostomycoversbylinda.co.uk

Annual Bowel Awareness and Stoma Care Open Day...

This is a health promotion event designed to raise public awareness of bowel disease which continues to be an increasing problem in the West Midlands and an update for Ostomists.

Date: Thursday 12th April 2012, 1-4.00pm.
Venue: Upper Room, St Paul's, Darwell Street, WS1 1DA

If you have a product to sell, an event to advertise or a message to communicate, you can place a small-ad for as little as £20.

Stoma care nurses... if you would like to promote your Stoma Care Department, its services and events... for FREE...

Then just get in touch... contact:
editor@colostomyassociation.org.uk

POUCH COVERS
Designed by Ursula Naish

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

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

For further information please contact:
Ursula Naish,
9 Oast Meadow, Willesborough, Ashford, Kent TN24 0AS
Tel: 01233 640 863
ursula.naish@ukonline.co.uk

- 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

colostomy association

Donation Form

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!

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

We provide:

- **An Outreach Programme** our own Open Day event for ostomates.
- **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 ostomates) these dedicated individuals bring a human touch.
- **Patient visiting** 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'. Display our literature and chat to ostomates.
- **A voice for your opinions at ongoing 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...here's how**

- **Regular Donation:** Regular donations can be made via standing order (see Donation Form overleaf). Regular donations help us to plan ahead and carry out our agenda. Every donation is vital to the charity's survival.
- **Single Donation:** Single donations from individuals, fundraising events are very welcome and greatly appreciated. So please keep them coming, no matter how small. Just £15.00 (or more) will help cover the cost of all our patient services.
- **Donate via Telephone or online via our Website:** These donations are easy to make...and are secure. Telephone donations are via RBS WorldPay simply call the Colostomy Association office during working hours to donate. To donate online visit: www.colostomyassociation.org.uk
- **Legacy donation - 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. Your legacy could secure the Association's future and provide continued support to all those 'living with a colostomy' present and in the future.

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

Your donation to the **Colostomy Association...**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**

Please turn this page to donate today Thank you...

To donate...Please fill in the form on the next page and return to the address overleaf - thank you

Donation & Standing Order Form

Thank you for your support

colostomy association

Please use this form to make either a **Regular donation** by **Banker's Standing Order** or **Single donation.** 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 correct details: full name, address and postal code thank you

My Details: Title: Name: Surname:

Address:

Postcode:

Telephone number: Email:

Optional Information: Date of Birth: Reason for your stoma:

Stoma Type: (Please tick) Colostomy ☐ Ileostomy ☐ Urostomy ☐

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

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.)

☐ Yes, I would like to make a regular donation of £ ☐ **Monthly** ☐ **Quarterly** ☐ **Yearly**

(Please tick.) **(Important: Please tick your preference above.)**

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:** / / 2012

2 Single donation:

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

☐ (Please tick.) **Yes** I would like to make **a single donation -** My donation is £

I enclose a **cheque/postal order form** made **payable** to the **C.A. Ltd - Thank you!** **Yes, I require a receipt** (Please tick.) ☐

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 25p.** For example, a donation of **£15 becomes £18.75 with gift aid,** at no extra cost to you.

☐ I would like the tax to be reclaimed on any eligible donations that I have ever made or will make to the Colostomy Association until further notice. I confirm that I pay an amount of income tax and/or capital gains tax at least equal to the tax that the Colostomy Association reclaims on my donation in the appropriate year (currently 25p for every £1 donated).

Thank you for your gift

Signature: **Date:** / / 2012

Registered Office: 2 London Court, East Street, Reading RG1 4QL

Registered Charity No: 1113471

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

Cohesive®

pelican
HEALTHCARE

Pelican Healthcare Limited
Sole UK Distributor of Eakin Cohesive® Products

- **Prevent leaks by forming a waterproof barrier around the stoma**
- **Completely mouldable to ensure a perfect fit every time**
- **Heal sore and irritated skin**

✂ -

To obtain your complimentary samples, 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) ☐
Ideal for frequent pouch changes and/or everyday skin protection

Large Cohesive® Seal (98mm diameter) ☐
Ideal for Urostomists, or to protect a large area of skin around the stoma

☐ Please tick here if you do not wish to hear about relevant new products and services available from Pelican Healthcare.

TIDINGS 11/11

Chris Wright writes...

about his patient journey and passion to become a Colostomy Association volunteer in Northern Ireland...

My patient journey....

For people of a certain age birthdays seem to have less and less significance than they did previously. However when I was diagnosed with bowel cancer two days before my 52nd birthday in 2007 and advised I was going to have a permanent colostomy. It certainly focussed my mind on my future. Here I was with a diagnosis that was totally unexpected I had to get through it. But how?

As I was focusing on the seemingly endless series of tests, scans and things being inserted into embarrassing places prior to the operation I didn't give much thought to anyone else who may have experienced this journey before me.

Having had time to mull over things I realised I did know one person who 'had a bag', a retired colleague I hadn't seen for some years who has an ileostomy and lived over 100 miles away in the Irish Republic.

I phoned him after my diagnosis and I was glad I did as he passed on one really useful tip that will stay with me forever, it was, "You'll make many mistakes, but you'll only make them once". How true.

Another gentleman, a friend of my mother's, visited me just days after my operation and as helpful and kind as he was, I wasn't having a good day and didn't hear much of what he was telling me. Apparently this is quite usual as there is so much to take in and learn.

Helping me to adapt to my stoma was stoma care nurse, Mary Jo. The advice and support she gave me helped me start living my life anew.

Giving back...

Fast forward to 2010. While attending my routine stoma review with Mary Jo I asked her if there was anything I could volunteer for. She suggested that I could try and set up a Colostomy Association group in Northern Ireland, as there was little or no support structure for colostomates here.

The seed was sown. I knew I couldn't commit myself to the task with any effect as I was working full time and my job involved regular travel throughout the UK. However, in June 2011 I accepted early retirement and contacted Mary Jo again to let her know I was now up for the job!

Mary Jo made the initial contacts for me. Among these were Anne Demick, National Secretary of IA (The ileostomy & internal pouch Support Group), who is based in Northern Ireland and Ernie Hulme, Vice Chairman of the Colostomy Association. At the recent Association of Coloproctology of Great Britain and Ireland Conference, Anne Demick spoke to Jane Wood - Editor of Tidings, to see if a meeting between CA and myself could be organised. I have to say Anne's advice from a local perspective has been extremely valuable.

Following a few weeks of e-mails and phone calls it was arranged for me to present the CA stand at a patient open day in Belfast. I had attended previous open days as a 'customer' and this was the first time I would be presenting the Colostomy Association to the colostomates of Northern Ireland, it was also an opportunity to canvass for volunteers. Prior to the event the CA had sent letters to those registered with them in Northern Ireland advising them that I, a local, would be there.

Ernie Hulme and Rosemary Brierley, both CA Trustees, flew over to Belfast to join me at the open day. They explained the literature and coached me on the 'dos and don'ts'. Adrian, a fellow colostomate who had received a letter and whom I didn't know beforehand, arrived unexpectedly to lend his support which was much appreciated.

This first open day was organised by the stoma care nurses of the Belfast Health Trust and took place in the

© Edward Byrne Photography

Local Colostomy Association Volunteers pictured at their meeting in Banbridge Civic Building Co. Down, from left: Sandra McAllister, Audrey Steele, Stoma Care Nurses Mary Jo Thompson and Lynn Berry, Adrian Ewing, Wilma Jackson, Mary Quinn, Sheila McQuaid and Chris Wright

Ramada Hotel in the city. I wasn't prepared for how busy it would be. Just meeting such a diverse range of people, ages, experience and attitude – and all in good humour, was both educational and inspiring. I also met the stoma care nurses from the Belfast Trust who were delighted to see the Colostomy Association represented at their open day.

I had my stoma in a different health trust area so I had not met them before, but their enthusiasm for establishing the CA in Northern Ireland reflected that of the nurses I already knew. The CA stand generated a tremendous amount of interest and from the many conversations I had, there was no doubt that the Colostomy Association's presence was much appreciated. During the course of the day our first five volunteers stepped forward!

Ernie and Rosemary invited these 'gallant pioneers' to an informal meeting when the open day closed to introduce them to the Colostomy Association and briefed them on the background of the organisation. You could feel the positive charge in the room as we talked about how we might go forward and how we could each support colostomates in Northern Ireland. There was no need to drum up any enthusiasm, it was already there bursting to get out!

Besides the obvious fact that we all have a colostomy the other significant common experience we had was that we had all travelled the journey alone. Our respective stoma care nurses had responded to the needs that we now know more experienced colostomates could potentially have provided. This was our inspiration to change the experience and to support, in whichever way we can, others new to living with a colostomy.

A second open day two weeks later at the Seagoe Hotel in Portadown was organised by the nurses in the Southern Health Trust. My operation took place at the Craigavon Area Hospital just up the road and I knew the stoma care nurses, Bernie, Mary Jo and Lynn (I mustn't forget Cheryl who keeps them organised and attends the open days too). This was my home territory I truly was 'local'. Ernie and Rosemary weren't there to supervise this time but Adrian volunteered to join me again. It was so good to have his company to support me on my first solo run!

Just as the good folk attending the Belfast Trust open day appreciated the presence of the Colostomy Association so too did the colostomates of the Southern Trust. I even met people I knew but had not realised they, their spouses or partners had a stoma. The day went just as successfully as the Belfast open day and another four volunteers stepped up to join the group. Their enthusiasm was amazing and so uplifting. We were now ten!

Sheila, a volunteer is a public representative on Banbridge District Council and was able to arrange a room in the council buildings for our first get together.

This happened in November a few volunteers were unable to make it due to prior commitments. Those attended were Mary, Sandra, Wilma, Sheila and Adrian, stoma care nurses, Mary Jo and Lynn, from the Southern Trust and Audrey, from the Belfast Trust.

I had made a prior round of visits to the local newspapers to promote our cause and to make any colostomates in the area aware of what we were trying to do. The local press were an 'open door' and they carried detailed articles about Sheila and myself with photos and contact details, they also dispatched photographers to our first gathering.

I wrote this article one week later and to date I have received e-mails from other colostomates seeking information on how to get involved. I was contacted by the local Tesco's Community Champion representative offering the use of their rooms for future get togethers and promotions. We are beginning to feel some firm ground.

As our first gathering was not fully attended a second one at my former employer's HQ, the Royal Mail Centre just outside Belfast will have a full turn out of volunteers and stoma care nurses.

A volunteer training package is now in the pipeline which can cater for up to 20 volunteers and I am hoping we can 'recruit' additional experienced colostomates from other trust areas which will give us a geographical spread of CA volunteers across half of Northern Ireland. A bit of a challenge but achievable. I now want to consolidate our first group of CA volunteers and begin to direct involvement with the charity. Eventually it would be terrific to see colostomate support groups established across Northern Ireland, all taking care of their own local issues, and if I can help them get started then I am happy to use whatever time and energy I have for that.

Mary Jo did a brilliant job helping me manage my stoma. I really understand and appreciate just how much she and other stoma care nurses give to their patients. I'm ready with my knowledge and practical experiences to give support to other colostomates.

The experience and enthusiasm of colostomates is out there, so let's reach out to find them and in doing so find volunteers who can join in and support those 'living with a colostomy'. ■

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

Stoma support groups
in your region...

Information about Support groups is regularly revised. 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:
Glasgow Stoma Support Group
Contact: Maureen O Donnel 01236 436479 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:
I.C.U.P.S
Contact: Stoma Care Nurse 0151 604 7399
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 311266 Maureen 01388 818267

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

Lancashire:
Oldham Stoma Support
Contact: June Wilde 0161 678 7086
Trafford Bowel Care
Contact: Jackie Carey (Secretary) 0161 7489 659 Doreen 0161 9627 818 John 0161 7484 655

Merseyside:
Crosby Support Group
Contact: Barbara Percy 0151 5292842 (Afternoon)
Aintree Stoma Support
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 487 8989 Ext 2221
NHS Molineaux Centre
Contact: Lesley Brown 0191 219 5656
Royal Victoria Infirmary Support Group
Contact: Gordon Weatherburn 0191 234 1109

Yorkshire:
Airedale Stoma Support
Contact: Jenny Shaw 01535 652516 or Sue Hall 01535 210483

Behind You (Calderdale& Huddersfield Bowel Cancer Support Group)
Contact: 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: CA for details 0800 328 4257
Scarborough Stoma Support
Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446
The Hull and East Riding Colostomy Support Group
Contact: Pete Smith 07989 565335 and Pete Rennard 01482 793966

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

England - Central

Buckinghamshire:
Milton Keynes Stoma Association
Contact: 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

Shropshire:
Oswestry Stoma Support group
Contact: Carole O'Ryan 01691 671624

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
Coventry Stoma Support
Contact: Martin Robbins 02476402616
Newhall Stoma Support Group
Contact: Sarah French 07773 396236 02476402616

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 01279 505273
M.E.S.S (Mid Essex Stoma Support)
Contact: Paul Foulger 01245 224374 Jeanette Johnson 01376 511862
N.E.S.S (North Essex Stoma Support)
Contact: Mr K Harvey (Chairman) 01206 271425
Brian Waller (Secretary) 01206 540449
Optimistic Ostomates
Contact: Janet 01702 385510 or 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 020 8970 8321

Hertfordshire:
Connect
Contact: Lin Hart 01279505273
Colonise
Contact: Gill 01727 851556
Hertford Stoma Support Group
Contact: Ralda 01992 535311
Stevenage Ostomistics
Contact: Alfred Levy 01767 316958

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

Norfolk:
Ostomy Friendship & Support Group
Contact: 01553 770288/768271/775698
Ostomy Friendship Group of King's Lynn
Contact: CA for details 0800 328 4257
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
WBOC (West Berkshire Ostomy Club) (Reading)
Contact: Jackie Dudley 01344 426652

Hampshire:
Solent Ostomates Support Group
Contact: Carole Summer 07527 707069
Wessex Urology Support Group
Contact: David Morris 02392 361048

Isle of Wight:
Optimistics
Contact: Stoma Nurse Lynne Webb SCN 01983 534009
Semi Colon Bowel Cancer Support Group
Contact: Tony Crowson Chairman 01983 244656

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
Dover Stoma Friends Group Support
Contact: Julie Bell & Ros Marshall 07771345701/01233616646
Maidstone Stoma Support Group
Contact: Judy or 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 & District Stoma Support Group
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 8318

England - South West

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

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

Devon:
Devon IA
Contact: Margaret Bond 01392 447374
Devon Stoma Support Group
Contact: Donna Ashbrook 01626 854862

Dorset:
CUPID (Colostomy Urostomy pouch Ileostomy of Dorset) Christchurch
Contact: CA for details 0800 328 4257
Cupid (Colostomy Urostomy pouch Ileostomy of Dorset) Poole
Contact: CA for details 0800 328 4257

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: Domenica Lear 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


CliniMed®
Confidence to flush, wherever you go
EXCEPTIONAL FLUSHABILITY
FreeStyle Vie®
FLUSHABLE