

Tidings

Dedicated to Colostomates their Families and their Carers

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ste port.



inside...Open Door visits Manchester Airport

NEW

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welcome to SPRING



Introducing our NEW One to One Leaflet - this leaflet explains the work of the CA and provides information about our support services. You can even fill in the form inside and join us! A comprehensive list of our literature can be found on the back cover.

5,000 of these leaflets have been included in patient supplies sent out by Fittleworth - so please look out for them!

We thank Fittleworth for agreeing to the mail out and for kindly sponsoring the production of the leaflet.



Putting the FUN into fundraising...

The Colostomy Association now has its own page on the JustGiving website. Simply visit: www.justgiving.com/colostomyassociation

JustGiving have made it **FUN to Fundraise** - you can set up your own page it's really easy and only takes a few minutes. You can personalise it with your own colours, photos and messages. Then email it to your friends and family, to encourage them to donate online. JustGiving sends donations straight to Colostomy Association and adds Gift Aid to every eligible donation.

To learn more about JustGiving visit: www.justgiving.com



At last spring is truly here! Spring is definitely the best season of all. It's strange isn't it because as soon as the clocks change you begin to feel better, wake up earlier and seemingly have more energy...I just want to throw off those winter blues and get on...with what, everything! We can stop thinking about keeping warm and get out and about - enjoy a walk in the countryside...a run in the park, or a spot of gardening, or heaven forbid some decorating!

I know from the letters and emails to the editorial team how much you enjoy reading Tidings. I expect many of you have been waiting for this issue of Tidings to fall on your doormat. The Colostomy Association has been reviewing Tidings production costs and a tender document was written with a view to ensuring good value for money for the charity. I am pleased to say that the outcome of the tender has reduced costs and not affected the quality of the publication, although you may have received it a little later than usual. We now have a new supplier for the print and mailing of Tidings based in Melksham, Wiltshire.

Speaking of your letters we received a great deal of feedback from the last article on irrigation, thanks to all who wrote in. A stoma care nurse also emailed to say how enthusiastic she is about irrigation and would like to hear from other stoma care nurses who promote irrigation.

The staff at head office received several calls relating to travel and the introduction of body scanners to UK airports. With this in mind I visited Manchester Airport with a group of ostomates to find out more. I hope this article will allay any concerns you may have had.

I have two pieces of 'sad news' to report - Ann Leppington-Clarke, stoma liaison nurse and CA trustee passed away in early March, Ann had been ill for sometime. The CA and Pelican Cancer Foundation recognise her professionalism, dedication to patients and her championing of irrigation. The CA also bids a sad farewell to a staunch supporter - Philip Allmark, Managing Director of CliniMed Ltd and SecuriCare (Medical) Ltd, who sadly passed away in February. Philip did much to ensure the survival of the charity.

On a lighter note, I have a great deal of news to tell you about - changes at trustee level, training, a new direction for our Open Day plus our new One to One leaflet, (see opposite) available from CA head office.

Tidings contributors and volunteers never cease to amaze the Editorial Team. Your stories, endeavours and triumphs are a joy to read, and as we know overcoming what seems to others to be a small victory can make all the difference to you day to day. One recent intrepid colostomate - Vanessa Denvir, came forward bravely to answer a request sent out by Gill Herbert to our volunteers. Maverick TV had approached the Colostomy Association, because they wanted a 'colostomate' to appear on their 'Embarrassing Bodies' programme, which goes out currently on Channel 4 on Friday evenings. Vanessa writes passionately about her experience.

I hope you enjoy this issue - please let us know what you think - your feedback and ideas really help the Editorial Team to plan the next issue of Tidings - as I always say YOU make Tidings what it is...YOUR magazine! So, get some paper and a pen or your fingers on that keyboard today and let us know what you want to see and read about in Tidings!

Email: editor@colostomyassociation.org.uk

PS. I try to answer all your letters and emails but should you slip through the net please don't hesitate to remind me!



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EDITORIAL TEAM

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Amanda Gunning

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**Tidings is
YOUR Magazine...**

Editorial Submissions:

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

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

Tidings Magazine:

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

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

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

Please include any relevant photos or illustrations as these

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

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

- Images should be in RGB mode
- Images should not be less than 2480 pixels x 1772 pixels at 300 pixels per inch



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SUPPORT GROUPS in your region support groups strengthen and empower people

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**.



2

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

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

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

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

About... the Colostomy Association

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

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

How to get to in touch...

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

By telephone:
General Enquires: 0118 939 1537

Stoma care queries only:
Helpline: 0800 328 4257

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

Find us on Facebook:



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

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

Tidings Magazine Summer Edition advert booking by 7th May copy by 4th June publication July 2010

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

Advertising Enquiries
For advertising enquiries and media pack
Tel: 0118 983 6226

The Colostomy Association is five this year...Yes! It's five years since we became an independent charity



First birthday celebrations in 2005

We have come along way since 2005 when we celebrated our very first CA birthday! " At the time those of us who volunteered to be Trustees never imagined we would be so successful a year later." commented Sue Hatton at the first birthday celebrations.

Well, the CA has certainly moved forward since those heady celebrations. We have accomplished much and laid good foundations for the future of the new charity.

To celebrate our fifth birthday we would like to invite you, members of your family, carers, stoma care nurses, stoma care suppliers to write in with a short message to commemorate five years of the CA...we will post your messages on the website and include them in future issues of Tidings this year.

Telephone Helpline Training...



Coloplast once again played host to another Telephone Helpline Training session at Peterborough on the 22nd and 23rd of February. The attendees were Vanessa Denvir, Sharon O'Steen, Muriel Findlay and Douglas Haywood. They are shown in the photo together with trainers, Jean Scott and Bob Buckley, CA volunteers and Wendy Osborne, stoma nurse specialist with Coloplast. Thanks to all attending and thank you Coloplast for sponsoring the event!

Uppermost on our agenda has been raising awareness for those 'living with a colostomy' and the 'pathways that lead people to a colostomy'. In fact with your help and that of our volunteers and the staff at head office we see and hear in the media the word 'colostomy' being mentioned more and more. Whether it is in a positive light or not doesn't really matter - it is being talked about and that's important. Just recently one of our volunteers, Vanessa Denvir, appeared on the Channel 4 programme 'Embarrassing Bodies'. Programmes like this do much to change perceptions and enlighten public opinion, often having a beneficial effect on those that watch and the health of the nation. With this in mind we hope it is only a matter of time before the wider world comes to understand what 'living with a colostomy' entails.

CA will continue to work hard on behalf of all colostomates, their families and carers to reassure, support and encourage all who are 'living with a colostomy'



The ROYAL SOCIETY of MEDICINE

'Medicine and Me: Living with colostomy' is a joint venture organised by the Royal Society of Medicine and the Colostomy Association - 14th April 2010

'Medicine and me' meetings aim to provide a forum in which patients' concerns about their illness are given top priority. The meetings provide an opportunity for patients and their families to share their experiences, to hear about the latest research and to question the experts. We will be reporting on this event in our Summer edition.

It is with regret that we say goodbye to two stalwart members of the original Board of Trustees...Marilyn Beynon and Robin Mills who gave their time and energies to the formation of the new charity back in 2005 and since.



Marilyn Beynon has decided to step down as Trustee. Marilyn did much to support the work of the Colostomy Association culminating in the success of the CA's first Patient Open Day event in her hometown of Swansea last September. The CA wishes her and her family all the best for the future and thank her for her efforts over the past years.

We also would like to thank Robin Mills for his sterling support of the Colostomy Association and his poignant comments and observations. Robin had little idea of what a colostomy was until he came out of hospital with his own 'model' in 1984. Robin's wife found out about the Colostomy Welfare Group and contacted the Hertfordshire Organiser who came to see Robin with sample bags and a wealth of advice. Robin became a patient visitor for CWG then later BCA. Robin stepped up to the mark when he found out the BCA was being threatened with closure, and became a CA Trustee. We wish Robin and his family well.

NEW



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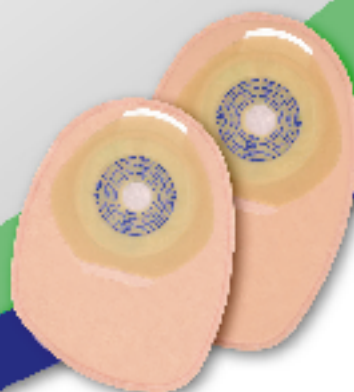
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CA welcomes aboard Mary Thomas as a new Trustee...Mary gives us a little background history...

Hello, my name is Mary Thomas, a Welsh expat living very happily in Buckinghamshire.

In October 2008, after spending the majority of my career in the Internal Auditing profession, I took the opportunity to retire. My last job was Head of Internal Audit of a major central government department. An accountant you may think, but no, my expertise lies in helping organisations put in place good governance and risk management arrangements to achieve their objectives. So, how did I become involved with the CA? I have long been aware of the work of the CA from a friend from my Army days, Sue Hatton, Executive Trustee.

Coincidentally in the 1970s, my father had a stoma formed after a bowel cancer operation. It was suggested that my experience might be of value to the CA's development and initially I was invited to observe Trustees meetings and help with strategic planning. I was also invited to help at the CA Open Day in Swansea, which just happened to be on my home turf. This proved to be a fantastic event and an excellent opportunity for me to learn about the CA, meet and talk to colostomates, nurses and suppliers and listen to various presentations.

Little further persuasion was needed to 'sign me up' when at the end of the day I got to join in the singing of the Swansea Male Choir!

I was delighted to be asked to become a Trustee. I look forward to contributing to the excellent work of the Association and hope to meet many of you in due course.

Change of direction for CA Open Day Peninsular Gathering...

- Reaching out • Building awareness
- Moving forward • Joining forces



We had such a positive response to the article in the winter edition of Tidings about the proposed Open Day to be held at the China Fleet Country Club in May 2010.

Unfortunately, we are not going ahead with our own proposed Open Day at the present time although we will keep you updated on future events. Instead we are joining with the other Patient Associations - IA, UA and Ostomy Lifestyle at an Open Day event to be held in May.

The event is being organised by Salts Healthcare and will take place on Monday 24th May at Buckfast Abbey. Salts have put together an excellent agenda and each Patient Association has been allocated their own room and presentation facilities.

Invitations will be sent out in April - the area focus being Devon and Cornwall. If you live in these counties and would like to attend, pre-booking is essential, all will be made clear when you receive your invite. If you intend to go to the event and can offer transportation to others please get in touch with CA head office on 0118 939 1537.

Back in the fold...In the last couple of issues of Tidings you may have recognised a familiar name. Rosemary Brierley, who was editor of Tidings issues 3 to 9, has agreed to come back on board as associate editor. Her role will be to ensure Tidings has stories from readers of all age ranges and with a variety of conditions that lead to a stoma. She will also be compiling the Readers' Writes pages and continuing to write her regular column "A Colostomate Comments..."

So, if you would like Rosemary to focus on a particular topic or issue that affects you day to day or have a story to tell, please write to:

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

or simply e-mail: associate-editor@colostomyassociation.co.uk

Manchester Airport opens its doors to Tidings...



Back row left-right: Jane Wood Editor, Barbara Orlans, Vanessa Denvir, Joan Hodgkinson, Maureen Kelly-Smith, Ernie Hulme CA Vice-Chairman. Front row: Chris Ainsworth

Ostomates take a closer look at the body scanner recently introduced at UK airports by Jane Wood Editor

This Open Door focuses on body scanners - an addition to the new security measures recently introduced at our UK airports. Tidings has been prompted to investigate following a number of calls to the CA offices and concerns raised in the National Press.

Tidings approached Manchester Airport because they were already trialling a body scanner in Terminal 2; previous tests had been conducted at Heathrow Airport 2004 to 2008. Contacting the Press Office at Manchester Airport in January 2010 Tidings requested information on the use of body scanners and how they might impact on the travelling ostomate. The Press Office were only too pleased to help but were awaiting an announcement from the Department of Transport indicating that body scanners would go live shortly and suggested Tidings get back in touch after the announcement.

On the 1st February 2010 the Government directed airports with available scanning technology, to begin using it as part of their normal aviation security procedures.

In a written ministerial statement, Lord Adonis, Secretary of State for Transport said: "Given the current security threat level, the government believes it is essential to start introducing scanners immediately. However, the Department is aware of potential concerns involving privacy, health and safety, data protection and

equality issues. We have therefore issued an interim Code of Practice to ensure airports undertake scanning sensitively, having regard for the rights of passengers. I wish to consult widely on the long-term regime for their use, taking full account of the experience of the initial deployment. The department will therefore, shortly be launching a full public consultation on the requirements relating to the use of scanners as set out in the interim code of practice, and will consider all representations carefully before preparing a final code of practice later in the year. I am grateful for the representations already received from the Equality and Human Rights Commission."

Tidings contacted Manchester Airport again and spoke to Paul Hadfield Press Officer and then to John Greenway, Press Office Manager. John suggested a visit may be beneficial to ostomates as they could take a look at the body scanner in action and ask questions that they felt needed answering.

Taking the initiative Tidings contacted Patient Associations, IA and UA and invited representatives to join CA volunteers on a visit to Manchester Airport. Those in the group were Ernie Hulme - Vice Chairman, Barbara Orlans and Vanessa Denvir from the CA, Chris Ainsworth - Chairman of the Manchester IA and Joan and Bob Hodgkinson from the UA. Also included were Maureen Kelly-Smith

from CliniMed/SecuriCare and Tidings Editor, Jane Wood. The visit was set for the 12th March and the group met in reception at 1pm at Olympic House, Manchester Airport. John Greenway – Press Office Manager, Sara Gilmore – Operational Training Manager and Alan Kemp from the Security Development Team greeted all attending.

After collecting the necessary security passes the group set off for Terminal 2 accompanied by the three staff members who were bombarded with questions on the way. All in the group entered the staff security check zone (airport staff and visitors going 'airside' are always security checked) coats, shoes, belts, keys and walking sticks etc all had to be removed for screening and handbags were searched, each member of the group were also patted down before going 'airside'.

After quite a trek across the Airport we reached Terminal 2 and the body scanner.

The following is an in depth view of the technology, procedures and training...

Advanced Imaging Technology (AIT) or Body Scanners: There are two types of body scanner currently in use at UK airports. They use either backscatter X-ray or active millimetre wave technologies. The body scanner in use at Manchester Airport is a Rapiscan Systems Secure 1000 Single Pose. The system rapidly and comprehensively scans passengers requiring only one pose. Arms and hands can either be lifted in an easy salute position or held slightly away from the body with no other movement required. The technology simultaneously scans front and back thereby eliminating blind



spots and potential opportunities for concealment; a full scan is completed in seconds. The system uses backscatter

technology – low-level x-ray beams are passed over the person being scanned - the amount of x-ray energy generated is very small, in fact much less than the naturally occurring background radiation people are exposed to daily. For example: A person would have to be inspected 1,000 times by the Secure 1000 to receive the equivalent of one typical chest medical x-ray.

The scanner is able to detect concealed small objects, organic and inorganic materials, metals and non-metallic objects - liquids, ceramics, weapons, plastic explosives, narcotics, metals, contraband and currency.

Scanning Procedures: At present passengers are randomly selected for scanning, as stated to the House of Commons by Lord Adonis: "In the immediate future, only a small proportion of airline passengers will be selected for scanning".

Security personnel manage the scanning procedure. Staff are sited at the body scanner and also remotely in a secure room away from passengers. A passenger is approached in a respectful manner and asked to enter the scanner. The on-scene security officer activates the scanner and data is transmitted to the remote security officer. The remote officer is responsible for operating the computer and its imaging software. Reviewing and analysing received data, which is deleted immediately after the scan is declared 'complete'.

There are two monitor screens used during the procedure, each serves a different purpose, they are positioned as follows:-

Scanner communication monitor:

The first monitor is mounted on the outside of the body scanner and is purely for communication between the attending security officer and the remote security officer. No recognisable image of any individual appears on this monitor. Messages 'scan in progress' or 'clear' appear on this screen. If the scan is 'clear' the passenger can continue their journey. If however, something conspicuous is detected, a 3-dimensional representation of a human figure will appear, with the suspect area outlined in red. The security officer sited at the body scanner will ask the passenger to step out of the scanner and reveal and remove the item/s. A further scan will be done. If this second scan is still not 'clear' the passenger will be accompanied to a discreet curtained area nearby for further discussion.

The body scanner highlights anomalies and security officers are trained to deal with issues of this nature, in a sensitive manner similar to those employed when undertaking hand searches. (It is unlikely that stomas or empty ostomy appliances will appear on the scan, however, appliances that contain some matter may show up as a faint grey area). If a passenger refuses to enter the scanner then they will not be permitted to fly.

How much X-ray radiation exposure is generated by the Secure 1000?



A person would have to be inspected 1,000 times by the Secure 1000 to receive the equivalent of one typical chest medical x-ray.



In one day on Earth, a person is exposed to 60 times more radiation than in one inspection by the Secure 1000.



In two minutes of a typical commercial aviation flight, a person receives the same amount of radiation exposure that they would from one inspection by the Secure 1000.

Note: All the technologies deployed have been assessed by government health and safety regulators. The dose received from being scanned is far below the allowed levels in the UK and does not constitute an unacceptable risk to health.

Reviewing Procedure



Secure room showing second monitor and review in progress



Communication monitor highlighting suspect areas



Body Scanner showing communication monitor

Remote secure room containing imaging software and computer:

The second monitor screen is located remotely together with the computer running the imaging software. The remote operator is security checked before entry and again on exit. Data received from the body scanner goes directly into the imaging software where it is processed. An algorithm is applied which, lessens image definition, resulting in a blurred chalky white representation of a human figure with no recognisable personal features. It is this image that is reviewed and analysed. All images are deleted immediately after review is complete and no data is retained or saved on any computer or on any other media. At no time will you or any other member of the public be able to see the scanned image and the remote operator has no contact with the passenger being scanned.

Security Personnel Training: Security officers who are to be screeners have to obtain appropriate security clearances before receiving training. They receive training in accordance with an approved package. Training is sensitive to the diversity of the travelling public and takes into account - mobility, hearing and visual impairment, and hidden conditions such as a 'colostomy'.

Security Officers are also trained to screen and be empathetic towards the travelling public in respect of:- wheelchairs; crutches; canes; walkers; prosthetic devices; casts; support appliances; service animals; orthopaedic shoes; exterior medical devices; assistive/adaptive equipment; augmentation devices; ostomy supplies; medications and associated supplies; hearing aids; cochlear implants; tools for wheelchair disassembly/reassembly.

Sara Gilmore – Operational Training Manager at Manchester Airport revealed to the group that she had recently become an ileostomate. Sara who is responsible for training procedures commented...

"I fully understand how an ostomate might feel about having their body scanned. But, please let me reassure you that all our security officers are put through detailed training programmes and are fully aware of hidden conditions such as a 'colostomy or ileostomy' as well as the different ostomy appliances and other medical or augmentation devices that may present."

Questions raised by the Group...

Q: How many countries use body scanners?

A: United Kingdom, Holland and United States of America – although other countries are interested in the use of Body Scanners and have visited Manchester Airport to enquire about them.

Q: How many are in use at Manchester Airport?

A: There are three installed at each of the three terminals. Although only one is currently operational at Terminal 2.

Q: Do all passengers have to pass through the body scanner?

A: No, it is done on a completely random basis once passengers have passed through the regular security checks.

Q: If I am asked to pass through the Body Scanner and refuse, what will happen?

A: Security staff will chat to you to find out why you might choose not to enter the body scanner. If you have any concerns, especially regarding the wearing of an appliance of any description, they will discuss this with you to help alleviate any concerns. If you still refuse to pass through the Scanner you will be unable to fly

Q: I'm concerned about the level of radiation emitted from the Scanner – is it safe?

A: The amount of radiation emitted from the Scanner is very small, in fact much less than naturally occurring background radiation. You would have to pass through the Body Scanner 1,000 times to receive radiation equivalent to one typical medical x-ray.

Q: What image of me is seen by security personnel?

A: No recognisable image of any person is seen by any security officer. Details that might identify a person are automatically blurred by the imaging software.

Q: Can my stoma/medical appliance be viewed through the scanner?

A: It is unlikely that stomas or empty medical appliances can be seen on the scanned image. Appliances that contain some matter may show up as a faint grey area.

Q: If I have a stoma or am wearing a medical appliance, will security personnel treat my circumstances sensitively?

A: Security personnel are thoroughly trained to recognise ostomy appliances and are also aware of hidden medical conditions. If you are concerned, you are advised to mention to the security officer that you are wearing a medical or ostomy appliance so you can be seen in a private area – they will respond positively to your request.

Q: What happens to the scanned image – are they retained on the computer?

A: Images are NEVER retained or saved onto any hard disk or external disk of any kind, they are deleted after the review and security check is complete. Staff working in the secure room using the imaging software and computer are security checked before and after their shift. They work alone and are not allowed to bring any items into the room – so that NO images can be recorded in any other way. The computer is locked to the floor and has no internal storage, the USB ports have been removed.

Q: What about children, pregnant women or disabled wheelchair users?

A: Children and Pregnant women are not excluded from passing through a body scanner. Wheelchair users who can stand are also not excluded but those unable to stand (for whatever reason) will be excluded. It might be advisable to have a letter from a medical practitioner if you fall into this category.

Q: Should I always carry a letter from a medical practitioner when passing through Airport security?

A: It is not always necessary to carry a medical letter from your GP but it does depend on your circumstances. If you are an ostomate wearing a medical appliance then the Patient Associations – CA, IA and UA can provide you with a Travel Certificate in multiple languages which you may find helpful when passing through security.

Colostomy Association Statement...



The Colostomy Association strongly recommends that you carry a travel certificate with you at all times so that you have a document to present to security staff to describe your condition should this be required. It may also be helpful to have a letter from your GP. If you do not already have a travel certificate, we will be pleased to send you one by post (please contact CA Head Office on 0118 939 1537).

The CA have been in correspondence with the Department for Transport to highlight awareness of the concerns of travellers with stomas and have provided information that will be useful to security staff dealing with these issues.

DfT Consultation: A full public consultation will start soon with responses being used to help produce a final code of practice to be published later this year. You will be able to contribute via the DfT website.

CA will keep you updated on body scanners and will report back on the outcome of the public consultation.

For further information about body scanners - a comprehensive list of Q&A's are available online at:

www.dft.gov.uk/pgr/security/aviation/airport/body-scanners/information

The interim Code of Practice is available online at:

<http://www.dft.gov.uk/pgr/security/aviation/airport/body-scanners/codeofpractice>

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Update on new stoma care products and services



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



NEW from Pelican Healthcare

Pelican Healthcare is pleased to announce that the cutting range of our Pelican Select Convex standard size pouch has been extended to 60mm, so ostomists with larger stomas may now also benefit from the unique Select Convex Skin Protector.

We have also introduced a brand new accessory product:

Pelican Release Non Sting Adhesive Remover with added Vitamin E is an effective non sting adhesive remover with a refreshing spearmint fragrance and added Vitamin E to nourish and moisturise the skin. Pelican Release is easy to use, dries quickly and will not compromise adhesion. Pelican Release is available as a sachet or aerosol to suit all occasions and preferences.

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



SureCalm Healthcare... has been formed by the coming together

of three Home Delivery Companies - AlphaMed, BCA Direct and Homestyle Positive

All three businesses have been established in excess of 15 years and have grown serving many thousands of patients in a discreet, confidential and reliable manner. Our combination creates the largest independent home delivery service in the U.K., managed by a very experienced team with a long track record in supporting the NHS and patients at home. We have no bias to any appliance manufacturer, giving you what you want when you need it. Our friendly, knowledgeable and enthusiastic regional teams take time to understand your needs and know the importance of every request right from picking the order, to customising your products and delivering it to your door. For further information please call 0800 854 753 or email info@surecalm.com

OakMed launch new stoma paste...

Oakmed are pleased to announce the launch of their new stoma paste. It's resistant to the aggressive output from stomas. It also has a very minimal alcohol content resulting in an easy to use paste that doesn't dry out, helping to prevent stinging. It is available on prescription now. Please see our main advert for more details or call our freephone number 0800 592786 for samples.



Fulcionel® by CUI

CUI is pleased to announce an increase in functionality of the

Fulcionel® hernia support belt. Quite a few ostomists have limited dexterity in their hands and fingers. The new product has a patented pouch that makes it extremely easy to fasten and unfasten. The breathable fabrics used in the belt allow a wearer to keep the belt on for extended periods of time. In fact many trial users have commented that their quality of life has greatly improved as a result of this innovative belt. The reaction from nurses who have helped trial the belts has been extremely positive. CUI Fulcionel® have recently developed a new range of hernia girdles that are extremely comfortable and supportive for ostomists with perineal and large hernias. For further information please see our main advert or call Freephone 0800 279 2050.

NEW from Peak Medical



Peak Medical is pleased to announce the launch of the new EuroTec 1 and 2 piece drainable pouches with SoftSafe closure and Finger Pocket, now available on FP10 prescription. The Ileomate 1 piece and Combimate 2 piece drainable pouches incorporate a unique Finger Pocket for the insertion of one or two fingers to enable easy drainage and hygienic cleaning of the pouch. A 24-hour high capacity bar filter with a Gore-Tex membrane protects the filter from 'strike through' caused by liquid stool. An additional safeguard is a layer of film, the 'raincoat' which separates the filter from the stoma.

For more information please see Peak Medical's main advert. To be one of the first to try the new Ileomate and Combimate range of drainable pouches simply call the Peak Medical Freephone number 0800 652 0424.

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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...



Special thanks goes to... the Donald Forrester Trust who recently donated £5,000 to CA

Thank you
everyone
for your kind
donations

About the Donald Forrester Trust... In 1934 the late Donald Forrester set up Films & Equipments Limited as a manufacturing company supplying the film industry. After the sale of the business in 1960, the company became, and remains, an investment company. Mr Forrester died on 25th February 1985 and his widow decided to set up the Donald Forrester Trust in his memory.

The **Colostomy Association** would like to take this opportunity to thank the **Donald Forrester Trust** for their kind donation of **£5,000**.

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

A BIG thank you to fellow support groups...

The Guernsey Ostomates - for people with Colostomies, Ileostomies, Urostomies and Carers...

Dear Sir/Madam
I am writing to you to thank you for supplying our support group with copies of your Tidings Magazine which I have circulated to all our 65 members in our newsletters. They are greatly received and are very interesting and helpful. It was decided at our last meeting to make a donation of £ 300.00 to the Colostomy Association by way of thanks.
Regards SDLM

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

Epsom & District Stoma Support Group

Dear Sir/Madam
At a recent meeting our group decided to make a donation of £25 to the Association and I have pleasure in enclosing a cheque for this amount.
Yours Truly
A M

Trafford Bowel Care Support Group

Wish to thank CA and staff by making donation £250. For your generous support towards all our endeavours.
Mrs JC

New Colostomate...writes

Dear Sirs
Please accept my donation of £500 to your Colostomy Association Fund. I am a relatively new 'Colostomate' (April 2009). Living on the Isle of Man we have a very good 'stoma nurse' attached to Nobles Hospital.
Best wishes
JM

Donations - In memory

Dear CA
My mother-in-law who unfortunately had a colostomy many years ago, sadly passed away recently. Her carer thoughtfully suggested that instead of flowers donations be made to your charity. As such, I am very happy to donate £225.00. Thank you for all you do. I'm sure CA is not a very high profile charity but my goodness my mother-in-law got great support!
Yours sincerely
CR

Dear Sir or Madam
Donation in Memory of Dave Cox
Please accept £106.50 as a donation in memory of Dave Cox from his Parts Department colleagues at Haynes Ford in Maidstone. Dave started his career here in 1968 and was a real joy to work with. He is sadly missed.
Yours faithfully
BW

Dear CA
My husband passed away last November. Your Tidings magazine helped a great deal in so many ways. Please accept this donation of £30.00. Thank you
Sincerely
MB

Terry Skydives for the CA...



Please accept this donation of £177 representing the remaining funds raised from my charity sky dive in September. I will now have to think up something else to do!!
Thank you Terry

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

What an amazing lady...and what spirit!

Dear CA

In memory of Miss Ruth Lilian Finbow

Please accept these donations of £40 and £10 in memory of Miss Ruth Lilian Finbow who passed away in February on her 97th birthday.

The following may be of interest to the Colostomy Association and to Tidings readers...Ruth had a colostomy about 50 years ago and until 3 years ago aged 94 managed it herself. I hope this may be of comfort to those who have just had a colostomy or are about to have a colostomy - life really does go on.

Ruth had her operation in St Mark's Hospital, London and I know that at times she was asked to go and talk to new patients.

When she was getting on in years she told the specialist at St Mark's that she was getting too old to travel to the hospital so would not be coming back for any more checkups! What spirit!

Yours sincerely
R W Finbow
Ruth's nephew

Your Donations...

| | |
|------------------|----------|
| Mrs M Bowker | £ 100.00 |
| Edwina | £ 125.00 |
| Mr M H Craddock | £ 100.00 |
| Mr & Mrs White | £ 340.00 |
| Mr S Howrany | £ 20.00 |
| Mrs M L Marshall | £ 50.00 |

Thank you

Leaving a Legacy...

We are always thankful for the donations we receive - but have you ever thought about leaving a legacy to the CA in your will?

Why leave a legacy to charity?

Leaving a legacy in your Will is the only certain way you can be sure that your wishes are carried out. Yet only around 30% of adults have made a Will. Leaving a gift to your favourite charity (or charities) also means they can continue the work you supported during your lifetime.

There are several different ways to leave a legacy - here are a few well known ones...

- **Residuary legacy** - This allocates a set share or percentage of your whole estate after all of your debts and funeral expenses have been paid, and any other legacies have been made. It is called a "residuary legacy". This type of gift in your Will means that however much your financial circumstances change, the proportion of your estate, by share or percentage, that each beneficiary receives will stay the same.

- **Pecuniary legacy** - A legacy of a fixed sum of money is called a "pecuniary legacy". This is most appropriate where you wish to leave a definite cash sum. Because of the effects of inflation a legacy like this may have lost real value by the time of your death. You should always review your Will from time to time to ensure that it still reflects your wishes.

- **Specific legacy** - It is possible to leave a specific item as a legacy in your Will. This is known as a specific legacy - for example, a piece of jewellery, or a painting. The item is usually sold and the proceeds of the sale are used to continue the charity's work.

There are some other types of legacies which can be included in Wills if your affairs are more complex or if the examples above do not cover the wishes you have in mind.

What if I already have a Will?

If you already have a will you can add what is known as a 'codicil'. This is a clause drawn up and witnessed in the same way as a Will but adds a further

instruction to it. A codicil can be used to add a charitable bequest to an existing Will without the need for rewriting the whole document. Your solicitor will be able to advise you.

Did you know...you can also make gifts to certain people and organisations without having to pay any Inheritance Tax. (a legacy to a charity is Inheritance Tax-Free; even if the estate is large enough to be subject to Inheritance Tax, this is not payable on any charitable bequests). If your estate is worth more than the Inheritance Tax threshold - £325,000 for the 2009 -10 tax year - there are some important Inheritance Tax exemptions that allow you to make gifts to others and not have to pay tax on them when you die. (These gifts are exempt whether you make them during your lifetime or as part of your will.)

Who you can make exempt gifts to:

- your husband, wife or civil partner, as long as they have a permanent home in the UK
- UK charities
- some national institutions such as museums, universities and the National Trust
- any UK political party that has at least two members elected to the House of Commons or has one elected member but the party received at least 150,000 votes

Are you considering leaving something to the Colostomy Association?

If you are considering leaving something to the Colostomy Association in your Will - here are the details you will require:-

1. **Charity name:**
Colostomy Association
2. **Charity Address:**
2 London Court, East Street,
Reading, Berkshire RG1 4QL
3. **Our Registered Charity Number:**
1113471

Note: It is important to seek independent professional advice from a Solicitor preferably specialising in making or updating a Will.

For more information about Inheritance Tax visit:-

www.hmrc.gov.uk/inheritancetax/

Me and my Bag

by Virginia Ironside

Some of you may be familiar with Virginia Ironside as she bravely agreed to talk about her Ileostomy at our National Conference in Reading some time back. For those of you who may not know much about her here is a little light reading...

Virginia started her career as a journalist – after her first book, *Chelsea Bird*, was published.

During the sixties' she wrote a rock column for the *Daily Mail*. But after suffering from long bouts of depression, Virginia decided to apply for the job of agony aunt at *Woman* magazine. "Anna Raeburn had just left – and I got the job," says Virginia.

Since then Virginia has worked as problem page editor for the *Sunday Mirror* and *Today* newspapers.

Virginia now writes the *Dilemmas* column for the *Independent* every Monday, and a monthly column for the *Oldie* magazine.



Picture courtesy of Catherine Shakespeare Lane

Virginia writes candidly... 'all kinds of people were supposed to have a bag but none would ever "come out" about it - everyone clams up as if it's the Worst Thing in the World. Well, as I and plenty of the other 100,000 bag-wearers in the UK have found, it isn't.'

When I was told that I had to have a bag or I would die, there wasn't much option. I'd been battling with Ulcerative Colitis for years and had taken every drug imaginable to avoid having a bag – what I thought would be the end of the world. I'd been high as a kite on steroids, lain for hours on end having immuno-

suppressant drugs dripped into me, used enemas, foam in every orifice it seemed, and still nothing worked. Clearly my colon was in tatters. Finally, racked by pain, I gave in. ("It's usually the pain that gets patients to take the decision in the end," muttered my gastro-enterologist darkly).

Anyway, I ended up with a bag. Like the Queen mum was supposed to have. Like Cliff Richard was supposed to have. Like all kinds of people were supposed to have but none would ever "come out" about it. It's amazing. Stars are quite happy to reveal all about themselves and those around them, but when it comes to a bag, everyone clams up as if it's the Worst Thing in the World.

Well, as I and plenty of the other 100,000 bag-wearers in the UK have found, it isn't.

Even the operation wasn't as bad as I'd thought. I was out of hospital within four days and apart from a moment when the wound split open when I was on my own at home in the middle of the night (that did prompt a few tears, I can tell you, and desperate calls to a doctor neighbour who came down and bandaged me up with sellotape until the morning) and with the help of an amazing stoma nurse, I did pretty well. Indeed, I was even driving my car (rather nervously) within a few weeks. When I got the hang of the whole thing I found the day-to-day procedure to be dead simple.

Now I change my bag every couple of days – I take it off, clean the stoma, jump into a bath and loll around a bit, leap out, and slap the new one on and Bob's your uncle. Of course I've had the odd accident - two to be precise. Once when I opened it rather too vigorously all over someone's bathroom carpet, and once when it just came apart in the middle of someone else's guest bed – but having experienced far worse with Ulcerative Colitis I didn't, embarrassed as I was, feel I actually had to crawl away and commit hara-kiri. And my friends were terribly understanding. Then there was the time when I was half-way to A&E in the middle of the night thinking I was bleeding to death, when I suddenly remembered what I'd eaten the night before – beetroot which is notorious for causing your output to turn red!

But the first thing that amazed me was that though I thought I'd have to be wearing flouncy baggy things for ever it wasn't so. I could wear tight skirts and trousers and swimming costumes and no one would know. Then, thanks entirely to Tidings; I found that there were different kinds

of bags on offer. I tried them all and found one that suited me best. And then I found these brilliant panties, from Cui Wear (through an ad in Tidings, too), which I could get for free on prescription. And then I discovered these great little sachets (yes, thanks to Tidings) – Trio Diamonds – which, if you put them into your bag before you go to sleep, you can have a whole night's sleep without getting up to go to the loo once!

I was doing so well I wondered whether I really wanted the operation for the internal pouch that I'd been booked in for this January. I'd been wary of this op. My surgeon, who was really keen to do it, insisted I talk to other patients who'd had it done. "Go for it!" said one. "It's brilliant! I've only had pouchitis once since I had it!" Pouchitis? No thanks, whatever that was. Another crowed: "Go for it! I only have to get up a couple of times every night to go to the loo!" A couple? I'd rather not get up at all, thanks. "Go for it!" screamed another. "You can eat nearly everything you want!" Did I hear her use the word "nearly"? At the moment I can eat exactly what I want, thank you. And finally, another old lady of eighty, who'd had an internal pouch, said she regretted it. "My muscles just aren't what they used to be," she said. "I have to wear a pad all day."

Then, finally, I had an adhesion. Or was it a blockage? Or a twist? The result was that nothing came out into my bag and I had an excruciating pain in my side. Luckily, just as I was wheeled into an emergency room for a hernia op, the whole thing righted itself. And as I lay, mightily relieved, and waiting to be discharged, the registrar, who had to sign me out, asked me what were my future plans. "I was going to have an internal pouch," I said. "But after talking to lots of patients, I've decided just to have the rectal stump removed in January, because of the risk of cancer. And stick with the bag."

And to my amazement he replied: "Good idea. I see surgeons all the time, and these internal pouches can be devils to get right. If I were in your position and happy with the bag, I'd..." "Go for it?" I suggested. "Exactly," he said. Now I realise that the internal pouch is ideal for some people. And successful. And quite

honestly, if I weren't sixty five, single, and not looking for a bloke, then I probably would have been thrilled to find an alternative to the bag. But at my age, I'm not prepared to work out yet another way of going to the loo, and my motto is: "If it ain't broke, don't fix it."

So here I am. Resigned and happy. The 'bag and me.' It may not be exactly a fashion accessory. But at least it does give a new meaning to word "bag-lady."

Virginia adds...

I have now had my operation but found it very difficult to get any information about this particular procedure. Some people told me I'd not be able to sit comfortably for months afterwards; others said I'd get over it quickly without pain. As it happened, the surgeon was able to remove the rectal stump without having to go in through the rectum (which could have been a bit ouchy later) but even so, it was a major operation and it took me six weeks to recover. Now there's no going back. But it's a relief to know that although I may one day get cancer, I know it won't be cancer of the bowel or the rectum.

Editors Comment

Thank you Virginia for taking time out of your busy schedule to write for Tidings. We hope you come back soon with another article or better still find someone else willing to 'come out' and talk as candidly as you.

If you would like to comment on Virginia's article please get in touch e-mail: editor@colostomyassociation.org.uk or write to: Colostomy Association 2 London Court East Street Reading RG1 4QL or telephone: 0118 939 1537

Irrigation and you...

Sue Hatton Executive Trustee writes...There has again been an extraordinary response to my request to Irrigators to share their experiences. It has been fascinating to read how others irrigate. In this issue Bob Buckley CA volunteer and fellow Irrigator and CA stoma care nurse Amanda Gunning review your feedback and answer your queries...

Tidings received excellent feedback following on from the last Tidings article on irrigation. Thank you all for your valuable contributions please keep them coming. We would especially like to hear from Stoma Care nurses who promote irrigation to their patients.

Tidings focus on irrigation is certainly having an affect. Although irrigation is not for everyone, by raising awareness of this procedure we hope to introduce irrigation as an alternative method of bowel management.

The last issue of Tidings featured a comment from Mrs Anne Carruthers. Anne mentioned that when irrigating she uses six litres of water. This struck a chord with several Irrigators and became a cause for concern. Tidings contacted Anne for further clarification. It is important to mention at this point that we are all different. Anne explained that she does use 6 litres of water overall but that it is infused in 2 litre quantities. She lets her bowel work and then introduces a further 2 litres at a time and so on. Anne says she is doing this with the blessing of her stoma nurse.

CA stoma nurse Amanda gives the following advice:- It is recommended that someone planning to irrigate for the first time should use 0.5 litres (500mls). Then only on the advice of the stoma care nurse the amount may be increased depending on the effect the initial amount of water has in clearing the bowel. The amount of water people use to irrigate the bowel varies, just as our bowel habits vary, but generally speaking up to 1.5 litres (1500mls) may be used. Any more than this must only be used with medical consent.

Roger Ashford comments on irrigation, "The period of enforced sitting down every morning has also allowed me to re-discover a childhood passion for reading. I actually look forward to a peaceful half-hour or so with a cup of tea and a good book!"

Bob's comments - and why not Roger, enjoy!

George Bradbury is disappointed because irrigation doesn't seem to work for him, "I attempted irrigation every morning for almost a year, but was disappointed to fail at it. My problem was never being able to retain all the water for any length of time, as most of the water would run straight out immediately. It was as though my remaining intestine went upwards directly after the stoma, so that the water could not flow right through. It worked to some extent, but the bowel was not evacuated entirely, so my stoma would still activate and I never could go without my usual pre-irrigation pouch."

Bob and Amanda's joint response - Well, George first of all you don't give up! The water may not be flowing into your bowel but running straight out for a number of reasons. The water may be flowing too quickly through the irrigating set and into the bowel, so you could try running it more slowly through the irrigating set. Sometimes the cone pushes up against the bowel wall which may prevent the water from flowing through the bowel. Try gently moving the cone while it is still positioned in your stoma to allow a free flow of water or try repositioning yourself e.g. standing up then sitting back down again, leaning backwards a little to ensure you are not crouching forward too much. Once the water is instilled some people find that massaging the tummy helps.

Some other tips to help make irrigation successful include:-

Relaxing – this is key and colostomates will tell you that it is essential to relax. Try deep breathing exercises prior to irrigation.



The above publication is available from head office on 0118 939 1537 or, alternatively, you can register online at: www.colostomyassociation.org.uk and download a PDF version to your PC.

Some people need a chair next to the loo so that they can either sit up straight or lean back, which is difficult to do on the loo.

Sometimes water will come out; this may be due to wind or a small stool impeding the flow, just pull the cone out and try again.

Make sure the irrigation bag is high enough to ensure the water is gravity fed into the stoma.

Dave Gordon tells us he has been irrigating for 15 years and despite contacting suppliers with suggestions for equipment improvements, he hasn't received much joy.

Bob comments - Why not explain your improvement suggestions in Tidings, Dave, and see if we can raise interest?

Pat Willo could write a page about the disadvantages of irrigating including having only one family bathroom, despite this Pat has been irrigating for 21 years.

Bob and Amanda's response - This is often cited as a problem by would be irrigators. If you only have one loo it can be tricky if you occupy it for a long period. Perhaps irrigating when the toilet is less busy could be a solution, e.g. at night rather than in the morning. It is advantageous to irrigate at the same time daily but it doesn't really matter what time.

Carol Whitmore was pleased to see Dorothy May's fold up music stand, which can be transported and used to hang your irrigation bag from.

Other suggestions for hanging your irrigation bag when away from home include. Plastic suction hooks (make sure you use 2!) which can be used on tiles and mirrors, bent coat hangers, elastic cords with hooks on each end etc.

Carol also explained she had been irrigating for 8 years and despite initial misgivings she now felt; "My self-confidence and body image improved dramatically and I felt emotionally stronger. I firmly believe that this contributed to my being able to pick up the pieces and achieve my ambition of starting and running my own small business."

After an email to the editor from Lucy Russell SCN an enthusiastic exponent of Irrigation at Norfolk and Norwich University Hospital NHS. Tidings contacted Lucy to learn more... Lucy writes

I am a SCN and feel very enthusiastic about the focus on irrigation by the CA. I have had the privilege of helping several people with colostomy irrigation and each has been delighted with the boost to self-confidence, self-esteem and freedom following this method of colostomy management.

However, Specialist Nurses with large case loads and low team numbers struggle to keep up with the demands of their multi-faceted role. The SCN will not only be responsible for initial assessment to ensure that irrigation is appropriate, but will also be providing information, help and guidance as regards the procedure and lifestyle implications. Once suitability is established, time is required for a teaching schedule. We have adopted a method of assigning three consecutive days for two-hour sessions. We negotiate facilities within the hospital on an individual basis, as we have no dedicated clinical area for our specialty.

Unfortunately, despite the efficacy of colostomy irrigation, resources are unlikely to be in place to facilitate high "up take".

Lucy finishes by saying...

A national survey might serve to highlight how many areas already offer help with this procedure and what the uptake is. If there's a positive response, could this be an area for the CA to support their professional counterparts in lobbying to promote facilities for this procedure?

**Lucy Russell SCN
(Colorectal/Stoma Care
Specialist Nursing Team
Norfolk and Norwich University
Hospitals NHS Foundation
Trust)**

Lucy would like to hear more from other Stoma Care Nurses, please contact the Editor for more information. Tidings will be visiting Lucy to learn more about Irrigation and the role of the stoma care nurse.

Please remember - To find out if Irrigation may suit you - always seek medical advice. If there is a possibility that you can irrigate, you will require an assessment from your stoma care nurse and agreement from your consultant. Once agreement has been obtained the stoma care nurse will be able to provide you with a teaching schedule, relevant information and the necessary equipment. Irrigation must only be attempted under medical supervision.

In terms of general advice those people most likely to be considered for irrigation would have a left sided end colostomy (if you are not sure what type of stoma you have please contact your stoma care nurse, consultant or GP).

Irrigation is not suitable for everyone. Those who cannot irrigate include people with an ileostomy, transverse colostomy or with complications such as a prolapse, stenosis, a large hernia or underlying bowel disorders.

Note: The Colostomy Association has a Facebook group online. Registration with Facebook is simple and FREE. You will find many colostomates only too willing to discuss irrigation or other topics with you, so why not sign up today...just visit www.facebook.com.

 Find us on Facebook

Editors Comment

If you would like a copy of our leaflet *An Introduction to Irrigation* or would like to share your Irrigation experiences or have any hints or tips please contact us e-mail: editor@colostomyassociation.org.uk or write to: Colostomy Association
2 London Court East Street
Reading RG1 4QL
or telephone:
0118 939 1537

A fond and sad farewell to a legend in colorectal nursing... Sister Ann Leppington-Clarke RGN CNS



It is with the greatest sadness that we report the passing of our friend, liaison stoma care nurse and Trustee.

It is with the greatest sadness that we report the passing of our friend, liaison stoma care nurse and Trustee.

Ann sadly passed away in early March leaving a loving family to whom we send our condolences. Colleagues, friends and patients from the Pelican Cancer Foundation, The Hampshire Clinic and the Colostomy Association will all sadly miss Ann.

Ann was a slight but quietly feisty and positive lady; she was the ultimate professional in every way. Ann was someone who listened, encouraged and stood by you when you needed a friend.

It was Ann who cared for and encouraged Sue Hatton when she most needed confidence, guidance and a gentle yet firm nudge to help her recover from her dangerous brush with cancer.

Indeed after the Colostomy Association Conference in 2008, Sue spoke with delight about how she was determined to secure Ann as the Colostomy Association Liaison Stoma Care Nurse, "Sister Ann cared

for me, she was a great no-nonsense person and gave me real confidence in myself. It was Sister Ann who, (before my operation to have stents removed) told me that I should have 'a nice clean bowel' and frog marched me off to a tiny loo and taught me to irrigate! I have never looked back since, I am indebted to her." Ann accepted Sue's request and became Liaison Stoma Nurse that year and later a CA Trustee.

Last September Ann accompanied the Colostomy Association to the Patient Open Day held at The Liberty Stadium, Swansea where she gave a fascinating and in-depth presentation about Irrigation. Ann concluded her presentation by saying that she knew a seventy-nine year old who had been irrigating for forty years. Ann made a plea to all surgeons and stoma care nurses to offer irrigation as an option to anyone about to undergo surgery, resulting in a permanent colostomy. The Colostomy Association hopes that Ann's plea does not fall on deaf ears and CA will endeavour to keep her wish alive.

From Pelican Cancer Foundation: Ann, affectionately known to many as "Annie" established both an endoscopy service and a stoma care department in Basingstoke and was instrumental in helping to build Basingstoke into a world-class centre for rectal cancer surgery. Much of our achievements would never have happened were it not for her skill, determination and ability to surmount the many difficult intestinal problems we created down through the years. Many grateful patients whose lives were maintained and restored to normality by her attention to detail and her good-natured efficient approach bear testament to her skill.

Professor Bill Heald OBE and Mr Brendan Moran write...two of the surgeons with whom she worked for the last 25 years. It is difficult to find words, which come near to doing Annie justice. A few that come to mind to describe the warm, friendly, caring person that she was would include "inspirational", "dynamic", "legendary" "leader", "teacher", "can-

do person" and a "true friend to so many in so many ways" She truly ranks as a person whose life was selflessly dedicated to the needs of her patients.

She inspired numerous students and young nurses, medical students and both young and old doctors in her "can do" "no-nonsense" approach in caring for her patients with whom she had a uniquely personal and lasting relationship. Her recent dedication to the care of her beloved husband Terry, who died last year after a two-year battle with cancer, was further proof, if any were needed, of her immeasurable and untiring ability to care. Against all the odds she managed to care for Terry while still "dancing" in the corridors of the hospital long before dawn. She missed Terry terribly and it was very few months before her own illness was diagnosed. Terry and Annie had survived the IRA bomb blast at the Conservative conference in 1984 and perhaps that created a very special bond.

The world is a better place because Annie lived and her achievements will live on and propagate. We hope to establish a Stoma therapy centre in her memory in Basingstoke, The Ann Leppington-Clarke Unit so that what she has achieved will be remembered and will grow.

An Irish phrase summarises our thanks to this wonderful lady "Go raibh mile mile maith agut" which translated means "A thousand, thousand thanks" from so many of us.

In writing this eulogy we would encourage readers of Tidings to put pen to paper to explain to others what Ann meant to them personally. We hope that a collection of such letters would be of lasting value as a tribute to her memory and as a lasting testament to the unique role of the Stoma Therapy Sister and the Colorectal Nurse Specialist.

So readers, please think hard about her and write in to the CA about what she meant to you.

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Pathways to a colostomy

Bowel Cancer - a readers' experience



Two thirds of people with a colostomy have it formed as a result of bowel cancer.

Bev Scott, a CA volunteer in Cambridgeshire, talks about his feelings when he was diagnosed and was awaiting surgery.

He goes on to talk about the nine years he has lived with a colostomy.



Before my illness I hated seeing or reading anything about cancer. I did not even like saying the word. I was very frightened of it.

I cannot remember when I first had symptoms, but I kept putting off going to the doctor. Some years earlier I'd had bleeding piles so I put it down to that. Eventually in 2000 things got so bad I was forced to visit the surgery. The doctor knew immediately there was something wrong and referred me to Addenbrookes Hospital in Cambridge. From then on I was a complete wreck and could not face work.

My wife, Sue, and I hardly spoke on the way to my outpatients' appointment. Mr Miller, the surgeon, examined me and warned me that it was probably something serious. He did a biopsy and I was to go back in two weeks time for the results; the appointment was the day of our wedding anniversary. Life went on in a daze. I did not know it then, but I was to have almost four months without any proper sleep.

June 12th arrived - a lovely sunny day. Anyway I thought I knew what was to come and yes, I had bowel cancer. I was just fifty years old. I remember walking along the corridor to fetch Sue with one shoe on and one shoe off. I said, 'Hey mate we are in trouble here.' My operation was arranged for July 20th - almost five weeks away. My surgeon explained what was going to happen, but it was a complete blur to both of us.

Sue drove us home - what a journey. How was I going to tell my family? I told my teenage sons and we had a fantastic group hug moment I shall never forget. Then down to see my Mum: to put it mildly she was almost hysterical, understandably so, as I am her only child. We decided from the beginning to be up front about what was going on and told the rest of the family, friends and work colleagues

the truth. Looking back I think it was the right decision.

Slowly we began to accept what was to come; there was a lot of praying and a lot of tears from me. Sue, my wife, was the strong one. Thinking back we had some wonderful times in the weeks leading up to the operation. Family and friends visited all the time showing their love; sometimes we had nearly twenty people in our lounge.

I had a week's radiotherapy before my operation to help shrink the tumour. Lots of tests followed including one for my heart. I lay on the bed and sticky probes were attached to my chest. The nurse could not get a reading so I asked her if I was dead. 'No,' she said laughing - she had forgotten to plug in the machine - whoops!

Waiting for the operation was extremely hard. Sue and I had a couple of short breaks away, although I was in a lot of pain, losing blood and finding it very difficult to sit down. We stayed in Daventry visiting Leamington Spa, Warwick and Stratford-upon-Avon. Neither of us had much of an appetite although the food in the hotel was splendid. The second break was at Searle's Park in Hunstanton and, not being too far from home, we had lots of visitors.

I can remember one particular day when my stoma nurse, Marie Waller, visited me at home for the first time. I really had no idea at that point what a stoma or colostomy was. Marie showed me pictures and some different appliances that I would have to wear for the rest of my life. When Marie had gone I had the most almighty job of picking myself up off the floor. What was I going to do?

The day of my operation arrived. Sue drove to Addenbrookes as I was completely numb. We'd had a scare the night before, the hospital phoned to say we had to call back in the morning to make sure they had a

bed! I got this lovely room all to myself. Why do hospital staff always think I am a woman? The name Beverley is now classed as unisex. Three hours later I was in the main ward with other men.

When I had settled in, the stoma care nurses came round. While I sat up, stood and bent down they marked where my stoma would be. That night with the laxative you have to take I felt really ill - no sleep as usual. The morning comes, I wash, shave, phone Sue - pretty cool that's me. At 8.30am, I'm off, not feeling too bad: they must have given me something to calm me down.

Then nothing. Eight hours later, 'Mr Scott, Mr Scott, Mr Scott are you awake?' Oh Yes - I have survived. I'm still here.

It is impossible to say how much I appreciated what Addenbrookes did for me: the surgeon, Mr Miller, the stoma care nurses, Vanessa Coleman and Marie Waller, and all who looked after me. I had to be able to walk up and down stairs and change my bag myself before they would let me go home.

I had only been home from hospital for half an hour before a local nurse was there to see me. Later an infection developed where my bottom had been stitched up and it had to be dressed for about six weeks, which was rather uncomfortable. However, life went on with visitors coming and going a lot of the time.

We got the biopsy result from the operation after about two weeks. Unfortunately, I had to have six months of chemotherapy - a week every month: all in all I had twenty-nine doses. I would sit in an easy chair with the nurse on a stool in front of me whilst the chemo was given - feeling very sorry for myself. One day, I sat opposite a very pretty young girl who I had seen in oncology sometime before. She did not have any hair on her young head, but was laughing with the nurses - I thought: come on Scott pull yourself together!

The chemo did not make me lose my hair, but it affected me for about two weeks after it had been administered, in the guise of a painful tummy, diarrhoea and lack of energy. Between doses we would try to do different things like going away to



Bournemouth for a few days. On my monthly visits to oncology my specialist nurse was Kim Bennett and we are very grateful to her for her care and concern in looking after me. After my last dose of chemo I felt very emotional, going round saying goodbye to all the nurses. Knowing it was over was like winning the lottery.

Not long after my treatment was complete I arranged a sponsored walk of six miles around Littleport. The proceeds of £3000 were donated to the Oncology Department. When we took the cheque into Addenbrookes I felt like royalty. It was nice being kissed by nurses rather than having them stick a needle in me.

In all I had eight months off work before I went back to my job in the Flood Defence Department of the Environment Agency. I now have a colonoscopy every three years.

A few years ago I noticed a swelling around my stoma. On Christmas Day I was in such severe pain I had to go to bed and was very frightened. All sorts of things were going round in my head. I thought I was going to have to go to hospital, but by Boxing Day I was OK again. I made a hospital appointment with the surgeon and it was diagnosed as a parastomal hernia. I now have to wear a support belt, but if it gets worse I will have to have it seen to.

This is my account of my illness. We are all different and I can't speak for others. However, as a volunteer for the Colostomy Association I do hope I can help others through the hard times cancer can cause. I do have some bad days still but life goes on. Cancer has made me appreciate life more: it has made me think more

about others. It may sound daft but many good things came about because of my cancer. I do not think we would have had our dream holiday in Australia if I had not been ill and hopefully we are off to Mexico very soon.

Don't forget...April 2010 is Bowel Cancer Awareness Month...

Lynn's Bowel Cancer Campaign

"Spot...Check!!" - SPOT the symptoms of bowel cancer and CHECK with screening a new campaign to boost the NHS Bowel Cancer Screening Programme

Visit: www.bowelcancer.tv



Bowel Cancer:

The Facts - Bowel cancer is the third most common cancer in the UK after breast and lung cancer. Almost 100 people in this country are diagnosed with the disease every day. Bowel cancer affects similar numbers of men and women.

The Symptoms - When bowel cancer is found early more than eight out of ten people will survive. Bowel cancer can have recognisable symptoms. If you notice any of the following changes and they last longer than four to six weeks you should report them to your GP. These symptoms are unlikely to be caused by cancer, but it's better to play safe.

- Bleeding from the bottom without any obvious reason
- A persistent change in bowel habit to looser or more frequent bowel motions
- Tummy pain, especially if severe
- A lump in your tummy

The NHS Bowel Cancer Screening Programme

- offers screening every two years to all men and women aged 60 to 69.

To find out more contact the freephone helpline: 0800 707 60 60. (You can ring this number to request a screening kit if you are over 70.)

or visit:
www.cancerscreening.nhs.uk
or write to
NHS Cancer Screening Programmes
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You could
be our next
**Weekend
WINNER**

Well our first winner's weekend looks like it could have taken place on the French Riviera but this was actually Torbay on a cold February weekend. What a view!



Our lucky winner Alison picked Torbay as the location of choice for a special weekend away with her 19 year old daughter. Alison, who is a psychologist by profession, entered the prize draw after receiving a mailing from ConvaTec. She has had a stoma for about 10 years and is a member of the Ilcostomy Association and the National Association for Colitis and Crohn's Disease as she is always keen to keep up to date with the latest thinking and developments.

Alison and her daughter arrived at the hotel on Friday afternoon to an afternoon tea overlooking the spectacular scenery. Following a relaxing evening and dinner at the hotel they were both whisked off the next day to Image Consultant - Jo Smallbones, Look Your Best, for a day of pampering and beauty hints and tips.



Alison and her daughter enjoyed a morning of learning about what colours to wear and a make-up masterclass followed by lunch at the studio. The afternoon consultation then focused on style and bodyline analysis which really means advice on what clothes suit what body shapes and so on.



Alison thoroughly enjoyed the day and told us that she had chosen this activity so that she could share it with her daughter and have some 'quality girl time'!

ConvaTec is delighted to have provided this weekend for Alison and is fully committed to supporting people with a stoma.



A Colostomate Comments...

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

"Irrigation can be the answer... but not for everyone"...

Irrigation can give a colostomate a new sense of freedom and control. It can restore self-esteem. With all this I would totally agree. However...some of us with a colostomy choose not to irrigate and I would like to speak out for all those who, like myself, are quite happy with the "status quo" and will continue to use a bag.

'You won't believe how much better you'll feel. You must try it.' I hear all you irrigators shout.' Well, I have,' I reply. 'And yes it was good to go out wearing just a stoma cap and to be confident that my stoma wouldn't work for the rest of the day and probably the following day as well.' 'So why don't you still irrigate?' you ask.

Well for three months I did. With teenage children at home, taking over the bathroom for half an hour or more wasn't easy but I did it. Then came the holidays, helping out at a children's summer camp – a month under canvas in a field miles from anywhere, the only facilities chemical toilets in a wooden hut the size of a telephone box! I decided a bag would be simpler.

It was, and do you know when I came home four weeks later I decided a bag wasn't that bad after all. So that is how I've managed my colostomy for the last twenty years. And in all that time has anyone realised I have a colostomy? Not unless I've chosen to tell them. Has wearing a bag stopped me from doing anything I wanted to do? No, I go swimming. I have

travelled to all five of the world's continents and have changed my bag in toilets on trains and on aeroplanes - even in a Portaloos at the top of Table Mountain!

My stoma was formed because my bowel didn't work, so I'm happy having a colostomy that does work. For the moment irrigation is an option I'll keep in reserve in case, sometime in the future, my bowel stops working again.

Please don't get me wrong; I'm really happy to see Tidings devote two pages of each issue to irrigation. I fully support the Colostomy Association's initiative to make sure that everyone who has a stoma, which is suitable for irrigation, is aware of this option. The fact that in this country less than 5% of people who have a colostomy manage it by irrigation is not because they don't want to but because they don't know about it or have never been offered the opportunity to try it out.

However...Let's not forget that there are those who cannot manage their stoma by irrigation: Maybe it is not appropriate for their type of stoma or they do not have sufficient colon still intact to make it feasible. Perhaps they have an ongoing medical condition e.g. Crohn's disease or a heart or kidney condition which make it inadvisable... or it could be that, like me, they know all about irrigation, may even have tried it, but after careful consideration have decided it's not for them. So please, all you enthusiastic irrigators, respect our decision and refrain from telling us how it reduces the problems of having a stoma. These are minor inconveniences we accept and have learnt to deal with, so that no one would know we have a colostomy... and for most of the time we, ourselves, can completely forget we are wearing a bag.

"Pouch Disposal"...

In issue 15 we posed the question of whether the inner liner of toilet disposable colostomy bags could be flushed down the loo on a cruise ship. We asked readers to let us know of their experiences. So far we have had three replies, but one of them we are unable to follow up, as there were no contact details.

All the comments we have received so far refer to the CliniMed product. We would particularly like to hear from anyone who has tried the Dansac Novalife Flushable, which is a two-piece where only the liner, and not the flange, is flushed down the toilet.

Written by
Rosemary Brierley
Associate Editor

Editors comment

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

Embarrassing Bodies – Who’s Embarrassed?



Having been a volunteer with the Colostomy Association since my surgery for Crohn’s related cancer in 2005, I’ve done all the usual things volunteers might consider doing (open days, hospital visits, telephone listening, etc) but looking in my email inbox on a December afternoon was the most unusual request yet.

You can still catch Vanessa on Embarrassing Bodies (Series 3 Programme 1 - 3rd Feb 2010 9.02pm) at Watch4oD simply visit: www.channel4.com/programmes/4od

Maverick TV approached the Colostomy Association looking for a willing candidate to appear on Channel 4’s ‘Embarrassing Bodies’ programme – preferably in their 20’s or 30’s (I just scraped through at a youthful 39!). Maverick wanted someone who could help “dispel the stigmas and myths surrounding ostomates ultimately leading to a better understanding of what life is like ‘living with a colostomy.’”

All manner of thoughts passed through my mind as I considered what was being asked of me. I had joined CA to help ostomates pre and post surgery, to offer information and support – was I now prepared to take that huge leap forward and announce my condition on national television no less to the general populace?

I am not shy about having had surgery for a colostomy. I am open and willing to discuss it with those who are genuinely curious. I have modelled for Vanilla Blush (an ostomy lingerie and swimwear company), appearing in a Scottish Sunday newspaper supplement. It wasn’t that I was embarrassed, just a little concerned about how I would be received by those who knew me but didn’t know about my condition.

I spoke with friends and the general reply was “If anyone could pull it off, you could...I couldn’t do it but it’d be for a worthwhile cause...it’s brave of you to consider it”. However, a couple of people said I might regret it and on challenging them on this response I found their answer was more about their fears and concerns rather than my own. Fellow ostomates were generally positive about the programme and I asked their advice about things to consider discussing.

Agreeing to take part a couple of days later, I then had a telephone conversation with their researcher and

we agreed she would send me a list of background questions. The researcher acknowledged that there were some quite personal questions on the list along with the obvious questions relating to why and when I had surgery and how it affects me on a day-to-day basis? Below are some of the questions and the answers I gave. I understand that some ostomates might choose not to be so open with their personal information but if the general public (and potentially new patients) were to get some understanding of what life is like with some form of stoma, then being as honest and open as possible was the only way to go.

- Q: Do you find it easy to tell people that you have a colostomy?**
- A:** Depends on the individual and why I feel I might have to tell them – one gauges the person you are dealing with and the situation.
- Q: If you start a new relationship (work/friends) with a person when do you tell them about your colostomy?**
- A:** Again, it depends – every situation is different – it’s like telling someone you have any condition that isn’t well known or discussed.
- Q: How do people react when you tell them you have a colostomy?**
- A:** It really depends on the individual concerned – mostly people feel some admiration that you cope.
- Q: What do you think embarrasses other people most about your colostomy?**
- A:** Their own issues.
- Q: What do you think people are too embarrassed to ask?**
- A:** How your bowels function and how appliances work.
- Q: What do you fear people are thinking?**
- A:** I don’t!

embarrassing bodies

Q: What is the most embarrassing thing that's happened to you because of your colostomy?

A: I've had leaks, which obviously whiff a bit, but I usually realise this pretty quickly and deal with it.

Q: What is the worst thing that people have done or said to you because of your colostomy?

A: That they couldn't cope with a colostomy and are glad they haven't had to have one – you don't know what you can cope with until you have to.

Q: What is the best thing that people have done or said because of your colostomy?

A: As before, admiration for getting on with my life and not letting it hold me back.

Q: Does your colostomy affect your sex life?

A: Not really, if my stoma is playing up I don't indulge.

Q: What are the common misconceptions about stomas/colostomies?

A: The dated ideas of black rubber bags – no one really has an idea of how the medical appliances function or are applied or exactly how the bowel functions.

Q: What do you wish people knew?

A: The above.

Q: What situations do you find hard when living with a colostomy?

A: The looks from people when you leave a disabled toilet – just because I don't have a wheelchair doesn't mean I don't have a need to use a disabled toilet.

I thought of the many things ostomates and non-ostomates thought were difficult to do and one of those was enjoying a swim at their local swimming baths, which is why I chose to do the pool feature (wearing one of Vanilla Blush's latest swimwear creations!).

During filming I got flustered a couple of times and then realised why it was and discussed it with the producer. I notice a change in me when I talk about ostomy stuff to ostomates and non-ostomates. Have you ever noticed how you can be more open when at your local hospital or medical suppliers open day? It's because everyone in the room understands and empathises with your situation – here I was speaking about intimate issues relating to my health and life with two complete strangers and then airing it all to the nation!

Once the team had left it was then that I started to think about how the final piece might be portrayed. I had no idea what would be shown from a full days filming, or what would be voiced, I was at the mercy of the editing process.

Watching the programme I was very happy at the way the feature was edited, although it was brief, it was to the point. The next day there were even a couple of positive reviews in the newspapers.

What made the whole process worthwhile were the emails that the Colostomy Association received in response to the programme which were especially touching.

'It was a very good slot - each 'piece' on the program had but a short time and I think they did an excellent one on colostomies, especially considering it's hardly been mentioned before in such a way on TV - probably never on a prime-time channel mid-evening. Vanessa must have gone a long way towards better awareness.'

The feedback made me realise – that there is still much to do in raising awareness for those of us 'living with a colostomy'. I felt that this is an area that I can work on so – watch this space! By the way, those who said I'd regret took it all back!



Editors Comment

Thank you Vanessa for writing this article and for your brave appearance on 'embarrassing bodies'.

If you would like share your experiences with the editor please e-mail: editor@colostomyassociation.org.uk or write to:
Colostomy Association
2 London Court East Street
Reading RG1 4QL
or email: cass@colostomyassociation.org.uk
or telephone: 0118 939 1537



Breakaway Visits is the only England & 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. Breakaway offers the chance for families and young people to meet, talk about and share their experiences in a relaxed and friendly environment. The main aim of Breakaway though, is to have fun!

Join us for one of our 2010 weekends...May 28th or August 27th 2010 for 3 nights at YHA National Forest, East Midlands

We're going back to the forest! YHA National Forest is a modern and eco-friendly building, in Central England. Activities may include climbing, high ropes, zip wire, canoeing and much much more! There will be stoma nurses on hand to offer support, as well as people who have first hand experience of living with a bowel and/or bladder diversion/dysfunction. Dietary requirements can be catered for. The cost of 3 nights full board accommodation and activities is just £155 per person. Funding may be available to those of limited means, just ask for a bursary application form.

The main aim of Breakaway... is to have fun!

Christmas Party 3rd & 4th December 2010 In partnership with CliniMed and SecuriCare



Breakaway is very pleased to announce that the 3rd Christmas Party will be over 2 nights and include seasonal activities, at YHA Ilam Hall in the Peak District.

Thanks to the generous support of CliniMed & SecuriCare - this 2 night stay costs just £41.95 per person! The price includes all food and accommodation in private rooms (mostly ensuite), plus loads of seasonal fun and activities. Booking forms are available now. Book soon to avoid disappointment!

How to contact us...
telephone: 07903220040
email: break.away @tiscali.co.uk
website: www.breakaway-visit.co.uk

CliniMed... Breakaway is our nominated charity during 2010. Breakaway is the UK's only charity that runs weekend breaks for people aged 4-18 with bowel or bladder diversions. We are proud to support their great work!

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| Extra Large | <input type="checkbox"/> | <input type="checkbox"/> |

Stoma Size: _____ mm

Ostomates share their top hints and tips...

Odour - Most stoma appliances have a filter which incorporates a deodorizer, so odour shouldn't be a problem. However, if you are not happy with the filter on the bag you are currently using there are other bags made by different manufacturers that you could try.

Several manufacturers and suppliers of stoma care appliances produce drops or granules designed to neutralize any odour. These can be introduced into a clean bag before you put it on.

Odour could mean leakage or the filter may have come into contact with the contents of the bag making the deodorizer ineffective. If so change your appliance as soon as possible.

Some ostomates find that drinking tomato juice or buttermilk or eating natural yoghurt or parsley helps to control odour. Others take peppermint capsules.

Wind - Drinking peppermint tea or peppermint oil in hot water can help to reduce wind. Eating fennel or drinking fennel tea is another remedy.

Pancaking - This is when the output collects around the stoma and sometimes squeezes between the flange and the skin instead of going into your bag. One of the reasons this happens is because there isn't enough air in the bag and so the output doesn't take a downwards turn.

Lubricating your bags with baby oil or one of the many products available from the various supply companies will help the motion to fall to the bottom of the bag. Squirt a little oil or gel into your bag and give it a good rub around before you stick it on. Take care not to get any on the adhesive as this can reduce the effectiveness of the seal.

Covering the filter with one of the sticky patches that are supplied in each box of stoma bags will prevent a vacuum forming inside the bag.

Leakage - Ask your stoma nurse about rings and washers which can help to give a really good seal around the stoma.

Remember - Some medications may change the colour and/or odour of your output.

- Antibiotics may cause diarrhoea.
- Painkillers may cause constipation.
- Enteric coated or modified release tablets are designed not to dissolve until they have reached the latter part of the intestine, so they may appear unaltered in the stoma bag without having any therapeutic effect.

Your doctor or pharmacist will be able to advise you if alternative medication without these side effects is available.

Editors Comment

If you have a top tip or hint you would like share please e-mail:

editor@colostomyassociation.org.uk

or write to:

Colostomy Association

2 London Court East Street

Reading RG1 4QL

or email:

cass@colostomyassociation.org.uk

or telephone: 0118 939 1537

Helpful Ostomy Support Groups & Medical 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

• Ostomy Lifestyle
Tel: 0118 3240069
www.ostomylifestyle.org

• Stomadata & Stomafr
www.stomadata.com
www.stoma.fr
These websites are maintained by Adrian March. Adrian had a

colostomy for thirteen years, as a consequence of ano-rectal cancer. Adrian is a consultant to the CA.

• Macmillan Cancer Support
Freephone:
CancerLine: 0808 808 2020
YouthLine: 0808 808 0800
www.macmillan.org.uk

• Cancerbackup
Freephone: 0808 800 1234
www.cancerbackup.org.uk
Macmillan Cancer Support and Cancerbackup have merged all telephone numbers and websites remain the same at the present time.

• National Association for Colitis and Crohn's disease
Tel: 0845 130 2233
www.nacc.org.uk

• The Gut Trust
(Irritable bowel syndrome)
Tel: 0114 272 3253
www.theguttrust.org

• Bladder and Bowel Foundation (B&BF)
Formerly Incontact and Continence Foundation
General enquiries: 01536 533255
Web:
www.bladderandbowelfoundation.org

• Bowel Cancer UK
Tel: 020 7381 9711
Email: admin@bowelcanceruk.org.uk
Web: www.bowelcanceruk.org.uk

• Beating Bowel Cancer UK
Tel: 08450 719300 (Lo Call rate)
Web: www.beatingbowelcancer.org

Loving couple...Delores and Stuart Westfield describe their parallel personal journeys when in 2005 both their lives were turned upside down by rectal cancer.



Cancer undoubtedly rates among one of the most traumatic events a person can survive. The pathway to survival can be an arduous journey of invasive treatments, setbacks and unexpected outcomes resulting in changes to physical appearance and hidden mental anxiety. The accompanying parallel journey of the partner can equally be as traumatic...



Dolores writes...In September 2005, I started experiencing pain from my lower rectum. I didn't take much notice of it, at first, as I thought it would go away. It didn't. About three weeks later, while I was out with Rachel, my youngest daughter, I told her about my discomfort. "Don't you think you should go to the doctor?" she replied.

Reluctant at first, I was glad I did, as the pain became more severe and was accompanied by bleeding. On learning of this development, my G.P. referred me to the cancer clinic at Queen Alexandra Hospital in Portsmouth. I thought she was just being cautious. However, I went on to have a colonoscopy and biopsy under general anaesthetic. It was then that the surgeon told me I had a tumour. My reaction was to go numb with shock, this couldn't be happening to me.

I lived a healthy lifestyle; I did not smoke, drink too much or eat junk food. Before I had become ill, I was the fittest I had been in years, having trained hard to go trekking in Tanzania on Mount Meru and staying in the foothills of Kilimanjaro. Nothing about my illness seemed to add up or make sense.

It was decided that the next step should be chemotherapy to soften up the tumour prior to radiotherapy

breaking it down. Great, I thought, just what I need. For six months, I went through this tortuous treatment, getting weaker and weaker. My poor husband and family must have suffered so much, but they were incredibly loving and supportive, even when I was so bad tempered because I felt so helpless. When I think back to those times and the shadow of the person I was after the chemo, it was like it had happened to someone else.

It came as a terrible blow when I was told that the treatment had not worked. I was referred to a surgeon named, Mr. Thompson, who was kindness personified. After examining me, he gently broke the news that I would need major surgery and a bag on my side for the rest of my life. I admit that at this point, I went into complete denial and didn't want to know anything more than the date and time I needed to turn up at the hospital.

I had the operation on 18th August 2006, my daughter's birthday, poor girl. The next day, I awoke in the intensive care unit because my blood pressure had not stabilised properly. I gingerly felt my side and found the bag there. It was then I knew it was for real and my next thought was that I had a choice: I could either let having a colostomy stifle me in a negative way, or I could get on with it and enjoy this second chance at life.

I had many visitors but one who meant a lot to me was Derek, my friend Hazel's husband. He'd had a colostomy for thirty years after being diagnosed with bowel cancer. Since his operation, he has run marathons, competed in athletics tournaments and travelled the world in his camper van. He is still an inspiration to me and is an amazing example to anyone who has had a colostomy. Derek entered the ward wearing a funny hat, which made me laugh. "Welcome to the club." were his first words. "Thanks," I said. "But, its not one I really wanted to join." "You'll be fine," he reassured me.

I was in hospital for over five weeks because everything that could go wrong did. While in hospital, I had the help and support of several stoma nurses who showed me what to do and answered all of my questions. Although, at this point I still did not know about the work done by the Colostomy Association. Which, in hindsight, would have made such a difference.

After I was discharged, the district nurses came to see me twice a day to pack my surgery wound. They were wonderful and I can't praise them enough. It was through their encouragement that I started to eat properly again which was the catalyst for regaining my strength. It was only at this point, six weeks after my

operation, that I felt like I had really started to make progress on my road to recovery.

I was effectively house bound during the four months my wound took to heal. As I couldn't make it to hospital, the stoma nurses from the Queen Alexandra Hospital visited me twice. Considering the low point at which I started, they were amazed at my physical recuperation and very pleased with my general progress.

The next time I saw them was when I was well enough to attend a regular hospital check up. But still, no one had mentioned the CA or Tidings to me. It was several months later when, by chance, I came across the CA on the Internet. It was so reassuring, there was an organisation to assist people like me 'living with a colostomy'.

I telephoned the CA head office and after chatting with Beryl Goddard (a CA volunteer at the time), I joined the CA at once, receiving my first copy of Tidings magazine soon after, which I found to be very interesting and helpful. The magazine also had an appeal for more volunteers. I had done a counselling course and had been a bereavement counsellor at a rehab hospital so I decided I would like to help people try to come to terms with their colostomy. I attended an induction day in Reading during which I learnt more about the reluctance of the media to address the issues surrounding colostomy. Since this time I have been successfully raising the profile of the CA via my local media: Angel radio, the Hayling Islander and Portsmouth Newspapers. Recently, Womans Weekly published a feature and Cancer Research has just done the same, in February.

I am now approaching the national media to raise awareness for those 'living with a colostomy.' After all, twenty years ago, other forms of cancer that are now in the public eye were once taboo subjects of conversation. I hope that whatever influence I bring, will help everyone who has or is about to have a colostomy. ■

Stuart writesDolores and I sat uneasily, silently holding hands. She looked pale after the investigation, which had been instigated after a deterioration in her health. The consultant doctor entered the room and pleasantly introduced himself to

us. His tone was contrasted by a serious expression. I thought something's not right. Then came the words that nobody ever wants to hear. "I'm sorry to say, Dolores, that you have a tumour."

Dolores immediately began her chemo and soon afterwards radiotherapy followed. Seeing her in constant pain was difficult to accept. No life experience could ever have prepared me for the months that lay ahead. I was acutely aware that, no matter how well I looked after Dolores, nothing I did made a difference, I could not take her tumour away. All I could offer was to be her rock, giving her my love and moral support.

Dolores had to take her chemo tablets regularly, everyday. She lined them up and kissed each tablet before popping them in her mouth saying, "Please make me better." The first time Dolores did this, she saw me watching her. "You think I'm mad, don't you?" "No, I don't," I replied honestly. "You do whatever you need to do to get through this." It was so upsetting for me to see her go through this daily ritual.

Four months later we found that both the chemo and radiotherapy treatments had failed. The chemicals had wasted Dolores to a near skeletal state. She was literally fading away before my eyes. The cumulative effect of the radiation had also left her with full thickness burns. I dressed these for her with antiseptic gel and as I did so large patches of skin began to slough off her upper thighs leaving raw flesh, which wept profusely. Her facial expression became noticeably set and sometimes, when I held her close, she cried in anguish. Although she seldom complained and never showed self pity.

The only course of action left was radical surgery, involving a resection to remove the tumour and the formation of a permanent stoma. During the twelve hour operation she needed six units of blood and a further emergency procedure to stabilise her crashed blood pressure. Her subsequent recovery was complicated by pneumonia and MRSA.

The constant, unrelenting stress began to exact its toll on my resilience. I no longer had the energy to feel angry. All that remained was a void of mental exhaustion and feelings of desolation. Early on, I had telephoned a well-known national cancer charity

for advice. My call was dismissed with a terse, "We don't deal with that sort of cancer." I told myself to be strong and suppressed my own emotional needs, because I thought that was what I was supposed to do.

Help came from Dolores son, Nick. He stood in for a few days, allowing me to join a group of friends on a weekend mountaineering trip. The tough physical challenge combined with lads banter and no mention of cancer, turned out to be just the tonic I needed.

Five weeks after her operation Dolores was allowed to return home. It was something I had encouraged her to look forwards to, as I feared the continual set backs had begun to make her depressed and withdrawn. I think the turmoil of the last few months coming so close to death and various setbacks had left Dolores traumatised. She seemed fragile and emotional.

The district nurses, who visited every day to dress her surgical wounds, were instrumental in helping Dolores feel as though there was a purpose in striving to be well again. We had lived a closeted existence, distanced from normality by the need to cope as best we could; cancer beset us with some difficult challenges. The immediacy of Dolores' illness had shown us what was important, but left us with little energy left to spare.

It took me several months to realise I had been suffering from what is known as 'burn out'. A debilitating condition brought on by constant elevated stress levels, which afflicts many carers. The problem with 'burn out' is that many people, including myself, don't recognise the signs and soldier on until it becomes so chronic as to render them ineffective and exhausted. I learnt rather late that, the most important steps in avoidance are to take regular breaks. Allow yourself time to properly rest and try to vary your routine with activities which bring happiness and enjoyment, all things I had largely neglected.

Knowledge of this has helped me make decisions about my future. It has not been easy and the transition is still in progress but, with Dolores' support, I am now enjoying a personal renaissance, working as a photographer and training to be a mountain leader. I can once again see a bright future for us both. ■

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In Memoriam Philip Allmark 1959 – 2010

It is with sadness I write to inform readers of Tidings of the passing of my colleague and friend, Philip Allmark, Managing Director of CliniMed Ltd and SecuriCare (Medical) Ltd, who died recently in February.



Philip Allmark 1959 – 2010

Philip had been welcoming current and former staff of CliniMed and SecuriCare - and their partners to a celebratory dinner in London. Feeling unwell during the evening, he was taken by ambulance to St. Thomas's Hospital, accompanied by his wife, Lida. He was admitted to the hospital's coronary care unit where, despite the best efforts of the medical staff to save him, he died in the early hours of the morning. He was 50 years old.

Philip joined CliniMed in February 1988 as a sales representative, and was promoted to Regional Manager in April 1990.

He was appointed National Sales Manager in January 1994, from which time I had the pleasure and privilege of working very closely with him. Subsequently he became a General Manager at CliniMed prior to joining the board of the company in October 1997.

In January 1999 Philip was appointed Managing Director of CliniMed, a post he held with distinction until October

2007, when he was given the additional responsibility of leading SecuriCare Medical. It is a testament to his skill that those businesses grew by over 20% in the twenty-four months that followed.

Philip was a gentleman, first class manager, director, loyal CliniMed Group associate and a friend to many of us. In the 16 years I worked with him I came to know him as a man of impeccable manners and great style. He had a ready laugh, and an endless enthusiasm for his work, which he always went about conscientiously and professionally.

He had a real understanding of the importance of the role played by everyone in a modern organisation. When bad weather hampered efforts to despatch the large volume of prescriptions in time for Christmas last year, Philip could be seen in the warehouse packing orders. Business results mattered to him; but so did the lives of those who worked alongside him. It's no coincidence, I believe, that we have had families from which three generations have worked simultaneously at CliniMed.

Following Philip's untimely death, warm tributes were paid to him by officials of the Colostomy Association, the IA, UA and Ostomy Lifestyle - all of who described him as a supporter and friend. He was quick to realise that the Ostomy Patient Associations, Stoma Care Nurses, and Industry have many interests in common. Interests that can be jointly pursued without compromising the integrity so necessary to all of those groups - so long as respect and courtesy remain the watchwords of the day.

Because of the relative proximity of CliniMed and SecuriCare (which are based in Loudwater, Bucks) to the Colostomy Association, it has been easy to keep in touch over the years.

The respectful relationship that has developed has been particularly apparent in the recent past. When the British Colostomy Association was in transition to today's CA, Philip was a great supporter of Celia Waters efforts to effect as smooth a transition as possible. He was also an admirer and supporter of Ray Goddard, who worked so hard to represent the views of colostomates to the Department of Health during the recently concluded consultations on ostomy equipment and services. Most latterly, Philip was instrumental in making the services of stoma care nurse Mandy Gunning available to the CA, and letting Maureen Kelly - Smith, our Public Relations Manager, use her considerable imagination to help promote the Association.

Philip's funeral, attended by some 250 mourners - including CA Chairman, Monty Taylor and other current and former members of the Reading team - was held in bright sunshine on March 1st.

He is survived by Lida, his mother Mabel, and brother David to whom all friends, colleagues and well-wishers offer their sincere condolences.

Written by
Nigel Piercey
Chairman
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Ostomy covers designed and made by fellow ostomate...

Linda became an Ileostomate in 1990 following a year living with severe Ulcerative Colitis. After her operation Linda wanted to feel special so she decided to make her own ostomy pouch/bag covers...

My name is Linda Butler and I had an ileostomy in 1990 following a year of severe Ulcerative Colitis. I found that my main worries following my operation were body image and lack of self-confidence, especially during 'intimate moments'.

I wanted something to cover my pouch/ bag but just couldn't find any ostomy pouch/bag covers which fitted well or which I actually liked, so I decided to make my own. I now make them for other ostomates.

About my covers...my covers are made to fit every individual appliance which ensures a snug fit. There are so many different shapes and sizes that one size does not fit all. There is a flap on the reverse of the cover which unfolds to allow easy emptying.

The covers are made from cool polycotton and suit all ostomates; men, women and children. The covers

are soft, comfortable, long lasting and fully washable.

If you have a particular fabric in mind which you would like me to use to make your ostomy covers I am happy to discuss this with you.

Almost all of my customers come back to me for repeat orders with the most usual comment being 'How ever did I manage without them?' .

So, whether you have an Ileostomy, Colostomy or Urostomy, resulting in a Stoma, I'm sure that my covers will help you to regain your confidence and help you feel complete again.



Front

Back

Editors Comment

Linda Butler can be contacted on 01205 723327 or via e-mail: sales@ostomycoversbylinda.co.uk



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Readers' writes

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

Dear Editor

A year ago at the beginning of 2009, I was feeling under the weather and had begun to experience some colicky pains in my lower abdomen, so made an appointment to see my GP. That was the start of my journey. By mid February I had learned that I had severe diverticular disease and by the end of the month I was told that I would need an operation to remove a strictured portion of bowel.

As my husband and I had booked a lovely Caribbean cruise for the second half of March I foolishly asked if I could have my holiday first. My condition was worsening and it was quite obvious that we would have to cancel the holiday – just as well as it happened. The two weeks we should have been away I spent, instead, in hospital. The stricture had by then closed up completely. A Hartmann's procedure was performed on Friday 13th March - unlucky for some!

I was distressed to find that I had been given a colostomy as I believed that the bowel would be joined up and I would be as good as new. However, the surgeon assured me that he would be able to do a reversal after six months. This was a positive thought to hang on to, but when I saw the surgeon for the follow-up visit in May, he told me that he had decided to wait at least twelve months before attempting a reversal. He then began to list all the possible complications and difficulties –

more likely because of the considerable amount of bowel I had lost. Needless to say, I came away feeling deflated.

Before my next appointment due in October, I did some really deep thinking and some research. I must add that the Colostomy Association leaflet on reversal was a great help, together with articles and letters in Tidings magazine. A reversal would, I knew, entail two operations, with the formation of a temporary loop stoma and the inevitable lengthy recovery period. After all this there would be no guarantee of a successful outcome which, for me, would mean a return to normal function and regularity. This was the stumbling block. I knew I would hate it if I found myself having to find a loo four or five times a day.

In the meantime I was getting fitter and stronger. I returned to normal housework and shopping. By June I was out on the golf course and I added a weekly pilates class to gently strengthen the core muscles. I used this time, also, to assess my quality of life post colostomy. I became more accustomed to my daily bathroom routine which only takes about ten minutes longer than it used to. Once that is done and I am dressed, why, I am the same person I always was. Slowly I came to the conclusion that I didn't want to risk my current good health by undergoing operations with an uncertain result. This is what I told the surgeon in October. As he signed me off he commented that he felt this was a good outcome.

We have a wonderfully supportive Stoma Nurse Service here in Cornwall. I must also commend the suppliers of all my pouches and equipment for their helpfulness and efficiency. I am deeply grateful to the surgeon, medical staff and nurses, who brought me through a very difficult time (including three days in HDU) and most of all I must acknowledge my wonderful husband who looked after me so well, supported me unstintingly and never put any pressure on me over my decision - although he admits he is glad I won't be going back into hospital.

Now at the beginning of 2010 we start again in good health, gratitude and a very positive attitude. We shall be off to the travel agent very soon to see if we can book that long-delayed cruise!

Yours sincerely
J.L.B. (Mrs)

Dear Editor

I do enjoy Tidings magazine and the stories of various people and how they have coped with their situation. I am the recipient of an ileostomy as a consequence of a clot after my operation to have two heart valves replaced. This offending clot hit the bowel and kidneys and, to save my life, I had to have bowel surgery five days after my heart operation and then, at a later stage, kidney dialysis. I spent two months in intensive care and was then transferred to a ward until it was considered that I was

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Readers' writes

stronger and could be transferred to a Re-hab unit.

I had to learn to walk again as all my muscles were wasted and I had to be hoisted in and out of bed and into the wheelchair, but thanks to the wonderful nurses and physiotherapists, I can once again walk - with my stick in hand. When I first had my ileostomy it was on the right hand side, but due to a poor blood supply it had to be re-sited on the left hand side.

I am now back home with a care package arranged. I'm ecstatic and can hardly believe it. My thanks to all those who made it possible - especially my daughter, Ann.

Yours
M.A.M. (Mrs)

Dear Editor

I write to thank you for your wonderful magazine. This year it will be eight years since my operation for bowel cancer which resulted in a permanent colostomy, and five years since I heard of your magazine, which I would not be without.

I read quite often about people having difficulty with leakage, - the last person I read about was E. P. in the autumn 2009 issue of Tidings. I used to have this problem. I have had two parastomal hernias, one repaired. Due to leakage I ended up with sore skin. I changed my bag to Salts convex which is much more skin friendly and it has a large flange which is helpful.

At night time I use a Dansac ring and belt and during the day for support I use a Sash hernia belt. I have been doing this for the last twelve months and have not had one leakage, even when my bag balloons, and I feel very confident.

I hope this information will be helpful to E.P. and any other reader that has

leakage problems. Keep up the good work.

Yours faithfully
A.A.T. (Mr)

Ostomates who have persistent leakage and/or sore skin are advised to contact their stoma care nurse who will assess the problems and may suggest similar products to those mentioned in this letter. Appliance with a convex flange should only be used following advice from a stoma care nurse as long-term use can lead to problems. Ed.

Dear Editor

I would like to pass on my sister's tips for going through airport security. Having been told anyone can get a travel card, we now have a passport number and passport photo on the front of the card laminated in place, and keep it with our prescription and doctor's letter that has the same photo on.

I have an ileostomy, so for the flight I wear a see-through bag, but never put any solidifying agents into the bag until afterwards as I think this could be hard to explain.

I have to add that so far I have had no problems, except at our local airport where they seem to consider the "sixty somethings" off to warm weather to be persons of suspect. It must be the hearing aids, walking sticks, special shoes and medication that sets us apart.

Thank you for your great magazine
Mrs G

The CA is very aware of these problems and on pages 10 to 12 there is an account of a visit by Tidings Editor and a group of volunteers to investigate the situations an ostomate may encounter at airport security. Before travelling it is important to complete the form on the first page of

your CA Travel Certificate and get it signed and stamped at your GP surgery to prove it belongs to you. Ed.

Dear Editor

Thought you might like to pass this on to readers. I have found an alternative to Tommee Tippee (the bin designed for the disposal of babies' nappies which readers have told us they find useful for the disposal of used appliances).

It is a similar system but simpler and I found I can use cheap bin liners instead of replacing the cassette. The Angelcare Nappy Disposal System is available from Amazon: at present on offer at £7.49 post free. Normally £19.99. You can also see it at www.angelcare-uk.co.uk.

I got one. It took just three days to arrive and I found it to be as close to what I would ideally want as I was likely to find. I am not associated with the company that deals with it, just think it's useful.

Regards
Harry

Dear Editor

I am responding to M.A. (Ms) in Tidings Issue 16. She asked about other people who have a perineal hernia.

I had my operation in November 2007. I have very similar sensations and have several different cushions I use on different occasions (a more discreet one for travelling). It is uncomfortable from time to time and church pews and metal benches at railway stations demand use of my travel cushion. My consultant has advised against further surgery in my case.

I would be very happy to be in direct e-mail contact with M.A. if you can pass on my e-mail address to her.
Kind Regards,
H.B. (Mrs)

Do you struggle to put your Hernia/Abdominal support belt on?



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*Year Patent



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Readers' writes

Dear Editor

I write with reference to the letter from Ms D.F. in the last issue of Tidings. I emailed you some time ago on the same subject.

I have a non-reversible stoma, am blind in one eye and receiving injections in the other to arrest further deterioration, which happily is working well at present. I had rectal cancer four years ago and was overtaken with Age Related Macular Degeneration, of the wet type and treatable, two years ago.

I greatly believe that patients can help by communicating with each other, on practical and daily matters, and points of general interest. It is now two years since I first attempted to make such contacts and I have not progressed at all! It is almost beyond belief; these two conditions are very common and there must be other people out there similarly affected.

Total blindness is probably more than a remote possibility. I'm not yet compiling a contingency plan, more noting points for consideration and changing things to cope with the situation if that time comes.

A chat over the phone with anyone who is similarly affected would be welcome.

Yours sincerely,
P.B. (Mr)

Dear Editor

I have had a Colostomy for three years now and, like most people, was concerned when the only care for my extremely painful condition caused by twisted and knotted intestines was to have a colostomy pouch.

Thanks to my surgeon's very reassuring talk before the operation, the very helpful care and advice from the nurses at the William Harvey

hospital in Ashford and the continued wonderful support from my stoma nurse Julie Bell, I have managed very well ever since.

One of the most reassuring and helpful things has been the contribution of your publication Tidings, which I read from cover to cover every time I receive it. I believe that your magazine has aided my recovery and acceptance of my condition almost as much as any other help that I have received.

I shall never forget your wonderful Open Day at Reading University two years ago and meeting and talking to some of your staff and other colostomates.

Continue your good work and keep spreading the word in Tidings.

Yours with many thanks.
A.R.D. (Mr)

Dear Editor

As a new reader of the Tidings magazine, I was very pleased to see the article on irrigation. After having my stoma for a year, through cancer, I could never really accept it. I started irrigating in January, and it has transformed my life, sometimes I even forget I have one.

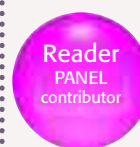
The stoma nurses at the Norfolk and Norwich University Hospital were brilliant and it only took me three mornings to learn. I advise any one who can to "go for it" as the freedom is lovely. I do feel very strongly there should be more information on this procedure.

Yours sincerely
W.K.A. (Mrs)

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 Reader Button to see where readers have contributed to Tidings

**Yours
Rosemary Brierley
Associate Editor**



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

The Conseal Plug – Is it an option for you?

The aim of this article is to give an overview of the Conseal Plug and to answer any questions on how, when and why it would be used.

Written by

Claire Lowther CNS – Stoma Care, Charter Healthcare

Wendy Osborne CNS – Stoma Care, Charter Healthcare Nurse Manager
Coloplast Ltd

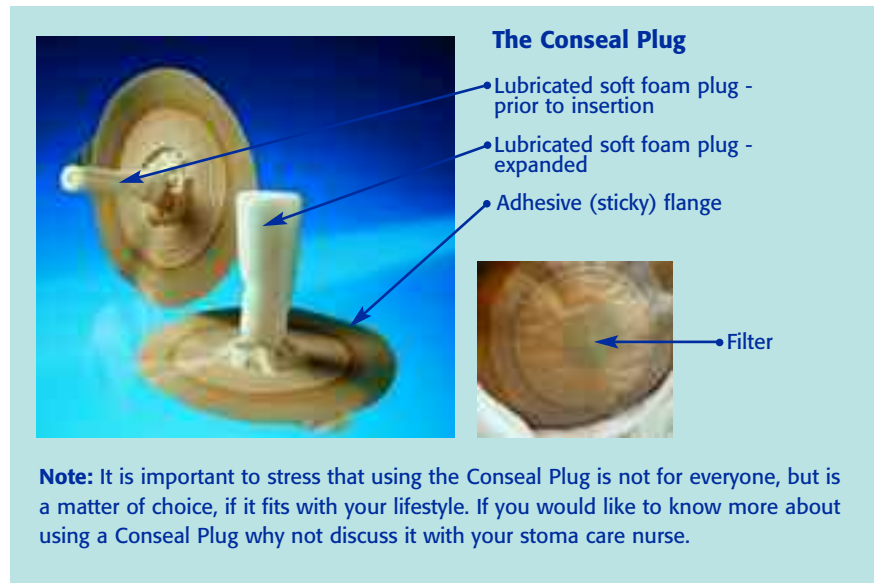
The Conseal Plug is an additional method that can be used to assist in the management of your colostomy. It is a very innovative product and there is nothing else like it available on prescription for people with a colostomy. It is very easy to use and can give you great freedom and control; you do not have to wear a colostomy bag/pouch all day if using the Conseal Plug. Importantly, the Conseal Plug is extremely discreet and can be used at your own discretion either as a part of your daily routine or (just) selectively as your activities vary throughout the day. The plug is not suitable for people with an ileostomy or urostomy.

What is the Conseal Plug?

The Conseal Plug is a lubricated soft foam "bung" which is attached to an adhesive ring (flange), see Figure 1 above. The stalk of the Conseal Plug is inserted gently into your colostomy, the coating then breaks down, which allows it to expand (like a tampon) the difference being shown in figure 1 above. This prevents faeces from leaving the bowel. On the outside of the Conseal Plug, there is a filter which allows gas/wind to be expelled without noise or odour. This filter is very effective and allows for the normal amount of wind to be expelled.

Who can use the Conseal Plug?

The Conseal Plug would ideally be used for colostomists who have a left sided, end colostomy and who produce a regular solid stool. If you are unsure of the type of stoma you have – you should contact your Stoma Nurse and discuss this further prior to using the Conseal Plug. Due to the flange size of the Conseal Plug you would need to have a stoma size of less than 45 mm as the cutting zone on the back of the flange can't be cut any larger than this.



In this article, the term "training period" is referred to. This means the time taken for you and your bowel to adapt (become used) to using the Conseal Plug. For some this may be a matter of days – for others it may take a little longer.

Q: How long can the Conseal Plug be worn?

A: 1-24 hours. This would depend on your normal bowel pattern and what activity was being undertaken. This would dictate how long you could wear the Conseal Plug. After the initial training period, it can be worn for as long as you find it comfortable and on how active your bowel is. The Conseal Plug should ideally be inserted into your Colostomy after a normal motion has been passed into your usual stoma pouch. The Conseal Plug should be removed when it is anticipated the bowel needs emptying or you have a feeling of fullness which means the stoma needs to work. People with a colostomy who have a regular (bowel) movement may use the Conseal Plug for up to 12 hours or more. Those that irrigate

have stated they have worn the Conseal Plug for up to 24 hours.

Q: Do you have to wear the Conseal Plug regularly?

A: No. The plug can be worn occasionally. Many people wear the Conseal Plug for short periods for example when swimming, undertaking exercise or for intimate moments.

Q: Do you have to irrigate to use the Conseal Plug?

A: No. However, if you do irrigate this is an option for you and you may wish to wear the plug in between irrigations.

Q: Will the Conseal Plug ever pop out or be ejected from the stoma?

A: No. The Conseal Plug will not pop out. The adhesive flange will keep it securely attached to the area around your stoma. However, during the training period, the Conseal Plug can be pushed out of your stoma (under the flange) simply because your bowel is not used to the plug (this is

Step by Step Guide for applying Conseal Plug



1. Remove Plug from packaging



2. Remove backing from adhesive.



3. The Conseal Plug is lubricated but apply extra if required.



4. Insert the plug into your stoma.



5. Apply the adhesive flange to your abdomen.



6. Enjoy the freedom and confidence of wearing the Conseal Plug.

because of the contraction of the bowel against something new being inserted. As you relax and get used to the Conseal Plug this will usually stop happening) If this does happen to you, remove the Conseal Plug and re-insert another one. In most cases the flange will retain a seal around the stoma.

Q: Will there be rapid evacuation of faeces when I remove the Conseal Plug?

A: No. You will have a few minutes before faeces will start to come out of your colostomy. You will have time to attach your normal pouch or if you irrigate to insert the cone and begin irrigating.

Q: Can the Conseal Plug cause constipation?

A: The Conseal Plug will not cause Constipation. The most important advice to prevent constipation is to follow a healthy, well balanced diet with plenty of drinking water to reduce the risk of constipation. However, during the training period a few people have experienced constipation, as the bowel gets used to using the Conseal Plug this will settle back to your normal pattern. If you do experience constipation at any time, use your regular pouch until the faeces are normal again and then go back to trialling the Conseal Plug. Try to follow a healthy, well balanced diet with plenty of drinking water to reduce the risk of constipation.

Q: What should I do if I have diarrhoea?

A: It would be advised that a Conseal Plug should not be used if you are experiencing diarrhoea. If diarrhoea occurs suddenly you should remove the Conseal Plug and wear your closed or drainable pouch. Once you are back to your normal regular bowel pattern you can restart using the Conseal plug.

Q: Will the Conseal Plug leak?

A: If you experience unexpected diarrhoea, there may be a possibility of leakage under the flange or through the filter (please see above question related to diarrhoea). During the initial training period, you can sometimes experience some faecal leakage underneath the flange, this will settle as the bowel becomes more used to using the Conseal Plug. If you do experience a leak, it is worth considering if you have left the Conseal Plug in for too long. If you

have any concerns please discuss with your Stoma Care Nurse

Q: Can the Conseal Plug cause any irritation or discomfort to the bowel?

A: It is possible you may feel some slight irritation or discomfort initially, within the bowel (because the bowel is getting used to the Conseal Plug). If this is the case, the Conseal Plug should be removed and the bowel rested for a day or two before a new Conseal Plug is inserted and re-tried. Although the Conseal Plug "stalk" is lubricated you can always add more lubricant gel and this may reduce irritation of the bowel wall.

There is no evidence to suggest that the Conseal Plug causes any long term trauma to your bowel and there have been no reported allergic reactions.

Q: Will the Conseal Plug give me more freedom?

A: Yes. The Conseal Plug will give you greater freedom of movement. You may find it easier to do physical activities such as swimming, football, dancing etc. The Conseal Plug is also a nice alternative for intimate moments and can be used for these times alone if wished.

Q: How is the Conseal Plug available?

A: The Conseal Plug is available on prescription. It is advisable that you speak to your Stoma Care Nurse to find out which size they feel would be most beneficial to you and most suitable for your needs.

If you are interested in trying the Conseal Plug please seek further advice from your own Stoma Care Nurse Specialist.





Dear Nurse

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

Q: *I have a colostomy. The stool is very narrow and quickly gets blocked because of the size of the canal. To keep it running I need to take more diphylac, used to keep the stool fluid. Because of that I have to create permanent stool fluency close to diarrhoea.*

Are there insertions that can be put into the colostomy canal so that it becomes wider and stays wider? I can't find anything on the Internet because I am probably not looking in the right place. Can you help me finding out more about this application, the reason I am interested is that I already have a hernia and I would like to reduce the pressure on my colostomy.

A: It may be that your problems are due to the parastomal hernia you say you have causing an intermittent problem with the outlet. Alternatively it may be that your stoma has stenosed since it was fashioned causing the opening to narrow. If it is stenosis then there is a stomal dilator, which you can be trained to use. This should only be utilised following careful assessment of the problem by your local stoma care nurse or consultant surgeon. Once they have assessed this as a possible solution to the problem they will demonstrate and teach you to dilate the stoma yourself, directing you on the



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

necessary frequency of dilatation. This is not a permanent solution and a review by the surgeon should be undertaken to identify if the hernia or stenosis can be rectified by surgery.

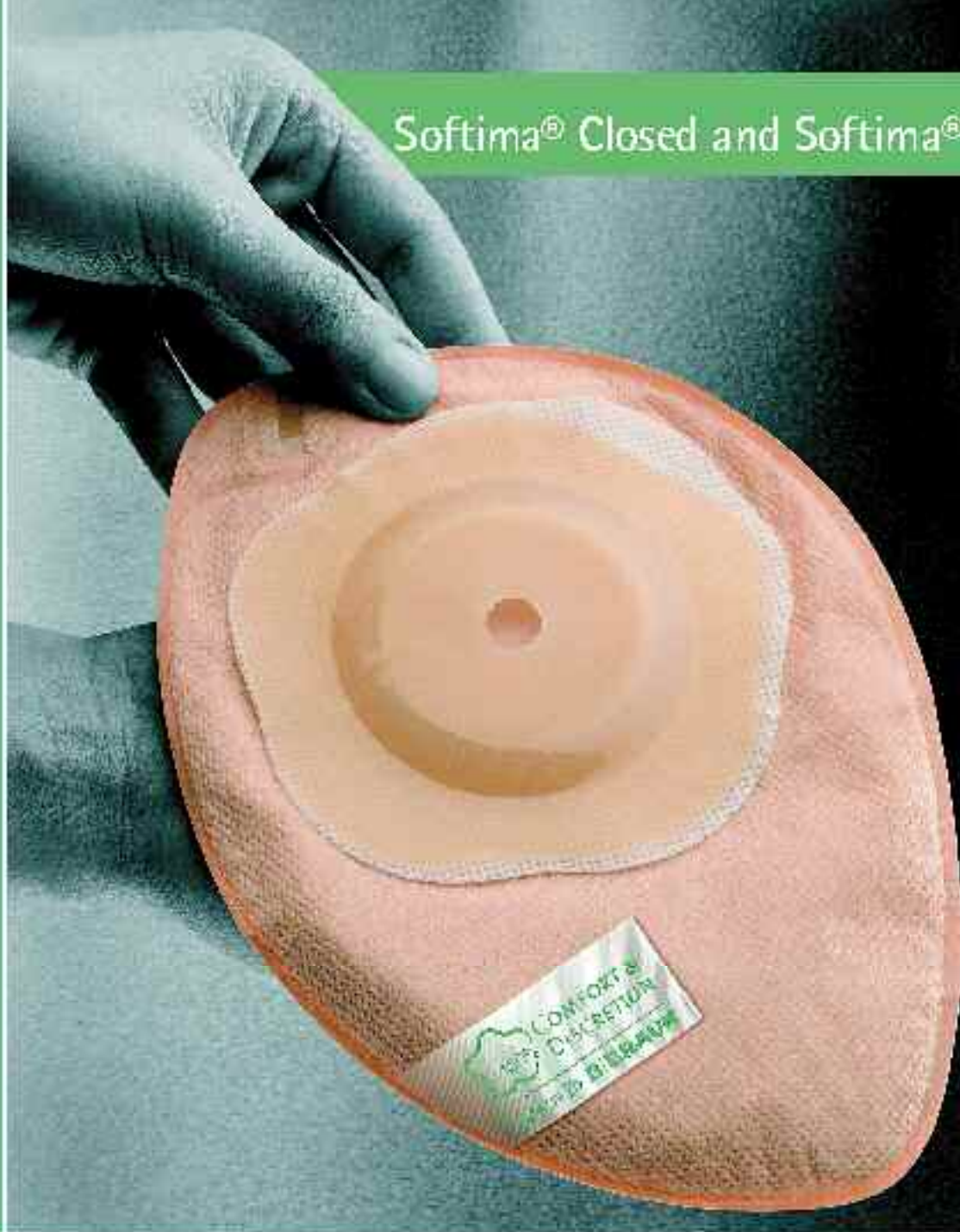
Q: *My wife was admitted to hospital because a perforated colon was discharging into the vaginal passage and she had lost two stone in a month. Because of her frail condition they performed keyhole surgery forming a stoma. She has now started to discharge stools from*

the rectum as well as the bag. She also has a large hernia forming around her stoma and is in much pain. The hospital stoma nurse has been off sick for two months now and there seems no one to help us.

A: You do not say what sort of stoma has been done but if it is a loop colostomy/ileostomy then you may get some overflow from the active (proximal) end into the defunctioned (distal) end which may then be causing the stool to exit via the rectum. This is not a major problem but can obviously be very distressing if it is unable to be controlled or if it is causing anal irritation and soreness. I would suggest the use of baby wipes to help prevent or treat the anal soreness, preferably ones without alcohol, as these can sting. If possible use a cream such as any nappy rash cream, which is available to buy, or a skin barrier cream. Instead of toilet paper, one of the manufacturers of stoma care supplies should be able to help. If this problem continues to concern you then maybe a review by the consultant surgeon could be asked for to investigate further.

With regard to the parastomal hernia I would suggest trying some supportive underwear which can be purchased from most high street stores now. You could also ask for a review by a girdle-fitting supplier such as Moorlands or Coloplast, there are several providers; your local hospital orthotics department may also be able to help. This would need the approval of your GP, as support garments are available on prescription.

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Q: *I wonder if you can help me, I am 94 years old; I have had a colostomy for 14 years. I have pains in my back and stomach; they feel like they are pulling me down. I cannot walk far as it tires me out, I have been for X-rays twice but they say there is nothing wrong with me. I wonder if there is any support garment or belt you could advise me on which doesn't interfere with my colostomy bag.*

A: If this problem has been investigated and any underlying cause for the pains ruled out then it may be that you have a parastomal hernia, although you do not say if there is a swelling around the stoma. A support garment may help. I would suggest a review by your local stoma care nurse who can assess the possibility of a parastomal hernia and arrange a review for a fitting of an abdominal support garment, which is available on prescription from many different sources; you should be able to get one that is suitable for you to wear easily.

Q: *I have a problem, the skin around my stoma is very sore and aggravated, and my pouches don't stay on either. Is there anything I can do or use to help this?*

A: Sore, wet skin around the stoma will prevent the pouches sticking well and can cause regular leakages, again leading to further irritation and soreness. Although it is a very painful frustrating problem it can easily be rectified. I would suggest a review by your local stoma care nurse who can advise on the many and varied products available to solve this for you. I would suggest the use of a powder (such as Recessive from Convatec) applied to the sore area and the use of an adhesive seal, such as Cohesive (Salts Ltd) or Adapt (Hollister Ltd) under the pouch to provide extra security in the short term. It will also be necessary to identify the original cause for this problem. It may be several things including the incorrect fitting appliance, leakage or even an allergy to a specific appliance. All of which your Stoma Care Nurse should be able to advise on.

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
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or e-mail your query to:
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Stoma Care Open Days...

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

List of forthcoming Open Days:-

Date: Saturday, 24th April 2010
Venue: Short Stay Unit, Princess of Wales Hospital, Bridgend
Time: 10.30-12.30
Organiser: Colorectal and Stoma Care Dept, Princess of Wales Hospital

Date: Saturday, 24th April 2010
Venue: Academic Street Foyer, Level 3, John Radcliffe Hospital
Time: 10am-2pm
Organiser: Colorectal Nursing Dept, The John Radcliffe

Date: Monday 26th April 2010
Venue: Executive Lounge, Lincoln City Football Club
Time: 10am-1pm
Organiser: Salts Healthcare

Date: Wednesday 26th April 2010
Venue: Ramada City Hotel, Glasgow
Time: 7pm-8.30pm
Organiser: CliniMed

Date: Tuesday 27th April 2010
Venue: The Bistro, Rowley Mile Racecourse, Newmarket
Time: 10am-2pm
Organiser: Salts Healthcare

Date: Thursday 29th April 2010
Venue: Lighthouse Arts Centre, Poole
Time: 10.30am-1pm

Date: Friday 30th April 2010
Venue: The Winding Wheel, Chesterfield
Time: 10am – 2pm
Organiser: Stoma Care Dept, Chesterfield

Date: Friday 30th April 2010
Venue: Trainers Suite at Perth Racecourse, Perth
Time: 10.30am-12noon

Date: Saturday 8th May 2010
Venue: Marriott Hotel, Glasgow Road, Edinburgh
Time: 9.30-1pm
Organiser: Hollister

Date: Thursday 13th May 2010
Venue: Post Grad Education Centre, St Peters Hospital, Chertsey
Time: 4pm-7pm
Organiser: Stoma Care Specialist Nurses St Peter's Hospital

Date: Thursday 20th May 2010
Venue: Hatters Space Community Lounge, Nuneaton
Time: 10.45am-12.30pm or 2pm-3.30pm
Organiser: CliniMed

Date: Thursday 20th May 2010
Venue: The Briar Court Hotel, Huddersfield
Time: 10am-3pm
Organiser: Colorectal and Stoma Care Nursing Team, Huddersfield Hospital

Date: Thursday 27th May 2010
Venue: Best Western Monkbar Hotel, York
Time: 10am-3pm
Organiser: SCD York Hospital

Date: Saturday 5th June 2010
Venue: Wheeler Hall, adjacent to Leeds Cathedral, Leeds
Time: 1.30pm-4.30pm
Organiser: SCD, Leeds General Infirmary

About Open Days...

Open Days are organised by stoma care nurses working within the NHS, stoma care manufacturers and/or suppliers.

These events offer you the opportunity to chat to stoma care nurses about any problems you may be having, speak to company representatives who may order free samples for you, or meet up with CA volunteers who have everyday experience of living with a stoma. The IA or UA may also be represented.

As an added bonus you may receive free entry into a museum or garden, depending on where the open day is being held.

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

SUPPORT GROUPS IN YOUR REGION

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

Stoma support groups in your region...

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



Scotland

Midlothian:

GOSH

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

Glasgow:

Fittleworth Glasgow Stoma Support Group

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

Ayrshire:

North Ayrshire Stoma Support

Contact: Jim 01292 220945

Stoma Care and Recovery (S.C.A.R)

Contact: Rhona 01294 557478 or Maggie 01294 271060 or Mob 0781 7736147

Fife:

Fife Ostomy Support Group

Contact: Ishbel Barr 01592 772200

England - North

Cheshire:

Stockport Support Group

Contact: Angela Simpson 0161 419 5059

Hand in Hand

Contact: Julie Davis Secretary

Cestrian Support Group

Contact: David Burgham 01244 310461

Warrington Ostomy Support Group

Contact: Jane Shaw 01925 662103

Countess of Chester Hospital

Contact: Julie Clements 01244 365490

Drop in Clinic

Contact: Angela Perks/Deborah

Singleton 01625 661598

Cleveland

Oops Group

Contact: Julie Morrisroe SCN

01287284113

County Durham:

South West Durham Ostomy Group

Contact: Betty 01388-814535 Brian 01388 763684

Derbyshire:

Stockport Support Group

Contact: Angela Simpson
0161 419 5059

Lancashire:

Trafford Bowel Care

Contact: Jackie Carey Secretary 0161 7489659 Doreen 0161 9627818 John 0161 7484655

Oldham Stoma Support

Contact: June Wilde 0161 6787086

Merseyside:

Olivia Thomas Suite University Hospital

Contact: (Evening) Barbara Percy 0151 5292842

I.C.U.P.S

Contact: Carol Anderson 0151 3277589

Liverpool Support Group

Contact: Barbara Percy 0151 5292842 (Afternoon)

Northumberland:

Northumberland Cancer Support

Contact: Pat Fogg 0191 4102679

Teeside:

Bowel Cancer support (Semi Colon)

Contact: Mr G Dickson 01642 563747

Tyneside:

Gateshead Health NHS trust

(Stoma drop in clinic)

Contact: 0191 4878989 ext 2221

Royal Victoria Infirmary Support Group

Contact: Gordon Weatherburn 0191 2341109

NHS Molineaux Centre

Contact: Lesley Brown 0191 2195656

Yorkshire:

Airedale Stoma Support

Contact: Jenny Shaw 01535 652516 or Sue Hall 01535 210483

Dewsbury & District Ostomy

Contact: Janet/Eileen 0844 8118110

The Hull and East Riding Colostomy Support Group

Contact: Pete Smith 07989 565335

and Claire Price 07805 978151

Scarborough Stoma Support Group

Contact: Sister Jean Campbell 01723 342388

Rotherham Ostomates Caring Support

Contact: Karen Kilford 078880 575758

CROPS (Colo-rectal ostomy & internal pouch support)

Contact: Gloria 0114 2879503

Isle of Man:

Stoma Support Group

Contact: Carole 01624 650212

Optimistics

Contact: Stoma Nurse Lynne Webb

SCN 01983 534009

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:

North Notts Stoma Support Group (Sutton-in-Ashfield)

Contact: Tore and Nicky Norman 01773 715460 (Sutton-in-Ashfield)

Nottingham Colostomy, Ileostomy & Urostomy support group

Contact: Rosemary Brierley 0115 982 7868

Mansfield Stoma

Contact: Gerry Marshall 07794 159267

Staffordshire:

Outlook

Contact: Ernie Hulme 01782 324441

Joan 01782 710828

Worcestershire:

Kidderminster & District Collossus Support Group

Contact: Brendon Drew 01299 400843

SUPPORT GROUPS IN YOUR REGION

West Midlands:

Colostomy Group
Contact: Pat Keane 0121 4242730
Stoma Support Group
Contact: Anne Wilcox
01283 214389

England - East

Bedfordshire:

Saturday Social Club
Contact: CA for details

Essex:

M.E.S.S (Mid Essex Stoma Support)
Contact: Clive Blanchard 01245
468750 Jeanette Johnson 01376
511862
North Essex Stoma Support
Contact: Mr W Hatch 01255 503688
Brian Waller Secretary 01206 540449
Redbridge Ostomists Club
Contact: Stoma Nurses: Chris/Lisa
0208 9708321
South Essex Young Ostomy Group
Contact: Paul Gray 01708 501268
Optimistic Ostomates
Contact: Janet 01702 385510 Angela
01702 385509
STEPS

Contact: TBA

Hertfordshire:

Colonise
Contact: CA for details
Stoma Fellowship
Contact: Karen/Mandy 01438 781133

Lincolnshire:

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

Norfolk:

Stars
Contact: Anne Brown 01603 661751
Ostomy Friendship Support Group
Contact: Maureen Ford

Suffolk:

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

England - South East

Berkshire:

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

Hampshire:

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

Kent:

Dover & District Stoma Support
Contact: Marie Culleton SCN
01227 769679
Ashford Stoma Support
Contact: Chairwoman - Ursula Naish
01233 640863

London:

Whipps Cross University Hospital
Contact: Christina 0208 5395522
Ealing Ostomy Support Group
Contact: CA for details
South Woodford Ostomy Support
Group
Contact: CA for details

Middlesex:

Inside Out
Contact: Bob (chairman) 0208
4284242 Sarah Varma 020 82354110
Semi-Colon Club
Contact: 01895 179391

Oxfordshire:

Oxfordshire Ostomy Fellowship
Contact: Pat Longworth 01235 524163

Surrey:

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

Sussex:

Brighton & District Stoma care support
(SAS)
Contact: Sylvia Bottomley 01273
554407

West Sussex Princess Royal Stoma
Support

Contact: Tina Walker 01444 441881
ext 8313

The Ostomy Friends Group
Contact: Jane Quigley 01323 417400
Ext 4552

England - South West

Avon:

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

Cornwall:

Optimists
Contact: Sue Hatton 01326 340058

Devon:

Devon IA
Contact: Margaret Bond 01392
447374

Dorset:

Cupid (Colostomy Urostomy pouch
Ileostomy of Dorset)
Contact: CA for details
Wiltshire:
Wessex Stoma Support Group
Contact: Michael Slater 01722 741233
Swindon IA
www.swindon-ia.org.uk

Wales

Blaenau Gwent Self Help
Contact: Celia McKelvie 01873 852672
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245
Wrexham Ostomy Friendship Group
Contact: CA for details

Northern Ireland

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

Editors Comment

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

Here's how you can get in touch via e-mail:
editor@colostomyassociation.org.uk

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



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