

WINTER 2014 | Issue 32

colostomy  association

Tidings

Dedicated to Colostomates their Families and their Carers



Cover Story

Jo-Ann's second chance at life...

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welcome to WINTER



Happy New Year! Welcome to the winter issue of Tidings...

We've just said goodbye to the old year and welcomed in the new but it's always worthwhile to take a few minutes to reflect on the recent past. It's important to take stock of our experiences – particularly the high's – but also to acknowledge – the low's – so that we can understand and put things into perspective, taking forward the positives into the New Year!

The 'real life' experiences within the pages of each issue of Tidings last year were amazing and the first pathway story this year is no exception. The human spirit of endurance over adversity is a constant theme. This same spirit can be found in YOUR letters, emails and fundraising efforts!

YOUR amazing contributions to Tidings have brought tears to my eyes on many occasions. It is important to note that through YOUR 'real lives' stories, Dear nurse queries and Readers' writes you have changed peoples lives for the better - YOU have made a difference to others through the pages of this magazine.

I would like to thank the Editorial Team for their ongoing support, they keep me focussed on the detail, their passion, ideas, observations and articles shine out from the pages of Tidings.

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

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

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

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

Email:
editor@colostomyassociation.org.uk

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

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About...the Colostomy Association

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

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

Simply contact us by post:

Colostomy Association

Enterprise House, 95 London Street
Reading RG1 4QA

By telephone:

General Enquires: 0118 939 1537

Stoma care queries only:

Freephone Helpline: 0800 328 4257

By E-mail:

cass@colostomyassociation.org.uk

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There are NOW two ways to donate online...



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



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

Tidings is YOUR Magazine...

Editorial Submissions:

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

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

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

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

How to supply digital images:

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

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

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

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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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Message from our President...

I am very encouraged by the variety of work accomplished by our Association during 2013. Congratulations to everyone involved with the Colostomy Association's continuous striving to reach out and support ostomates across the UK and further afield.

Although the Colostomy Association is a lesser known charity there is no doubt that the charity has worked hard this year to increase awareness of its work through differing arenas across the UK and by doing so has raised its public profile.

Many lives have been changed overnight by the efforts of this big-hearted charity! Indeed I am increasingly convinced that organisations such as our own – today and in the future – are best placed to continue to support those 'living with a stoma and colostomy' – long term.

The willingness of our supporters to assist the charity via donations, fundraising activities and time given freely is key to implementing its goals and must be applauded, encouraged and embraced! As your President – I thank you!

I continue to visit and operate in many countries throughout the world. Visits this year have included Germany, Barbados, France, Czech Republic, Switzerland, USA, Italy, Qatar, Malta, Serbia, Poland, Belgium, and Austria. The list never seems to stop. To acknowledge my tireless efforts I was awarded a CBE in the Queen's Birthday Honours List, for services to UK surgery internationally. I also received an Honorary Fellowship of the American College of Surgeons in October and will receive the same from the Royal College of Surgeons of Ireland in February.

As you must know by now I am an enthusiastic exponent of colostomy irrigation and couldn't be more delighted to tell you that the two Colostomy Irrigation DVDs have now been completed – '*Colostomy Irrigation: a reference tool for clinical nurse specialists (stoma care)*' and '*Colostomy Irrigation and You: an educational DVD for healthcare professionals and patients*'. Both DVDs are exceptional pieces of work as there is very little information in the current marketplace that explains and showcases in such detail – this alternative method of bowel management!

The Association of Coloproctology of Great Britain and Ireland this year covered topics ranging from problematic stomas, peristomal skin problems, high output stomas, colonoscopy paediatric colorectal surgery, and quality of life with a stoma. There was much stimulating debate amongst the speakers at the end of each session, prompted by cases presented for discussion.

Mr Ian Daniels FRCS of the Peninsular Medical School in Exeter (an established international expert in the repair of all forms of incisional and

stomal hernias) and current Vice President continues his focus on the issues surrounding prevention and repair of parastomal hernias. However, it gives me great pleasure to announce that Mr. Daniels has been invited by the Colostomy Association to take on the role of President and he has accepted.

I have no doubt that Ian will bring his expertise, bright ideas and energy to the charity! I am delighted to hand over to such a talented colleague and friend. In stepping down I am very happy to say that I will become the very first Patron of the Colostomy Association and I am very proud to have been given this special honour.

Finally, I think we all need to express our Christmas good wishes and thanks to the people who work in the Colostomy Association office and who commit themselves to the running of the Association in many different ways. Tidings continues to be a marvellous magazine, and I will still look forward to reading what you have to contribute to it during 2014.

**Season's Greetings
and a very Happy New Year
to everyone!**

**Professor Bill Heald CBE
President
Colostomy Association**



Message from our Chairman...

2013 has been a year of change in many ways for the Association. This time last year I told you that we were 'on the move' that took place last April when we left London Court and moved about 300 yards up the road to a newly refurbished suite of offices. The move went smoothly and we now have a much improved working environment and a training room for volunteers. The official opening was presided over by the Mayor of Reading Councillor Jenny Rynn who cut the celebratory cake! We entertained volunteers, manufacturers and suppliers to a reception where we were able to thank them all for their generous support in making the move possible.

We had to say goodbye to two of our stalwart Trustees, Mary Thomas and Rosemary Brierley both of whom have given sterling service to the Association. Rosemary is however retaining a close link by her involvement as part of the Tidings Editorial Team. Mary's expertise in governance and strategy helped enormously in taking the Association forward but she is still on hand to give us her valued advice when needed on administration and compliance matters. Their replacements are Alfred Levy who set up and runs a support group in Stevenage and, as a retired chartered accountant, brings a wealth of financial experience to us. We were also delighted to welcome Sarah Squire a

research biologist who will be known to many of you through the CA 'Closed' Facebook group. Sarah is the youngest member of the 'team'. Trustees are particularly conscious that we need 'continuity' and I have been anxious to recruit a younger Trustee and Sarah has already proved to be an extremely valuable addition to the Board.

You will have been aware throughout this year that we have made several references to finance and in these difficult times we are very much aware that everyone has had to 'tighten their belts'. However, the Colostomy Association receives no government funding and is totally reliant on donations and fundraising efforts. We are very grateful for the funds we receive from both our Members and the manufacturers and suppliers. Tidings is our contact with you all and, by the correspondence and comments we receive, know how much our Magazine means to so many of you. If you do make a regular donation, on behalf of the Trustees, I thank you sincerely but if you do not and enjoy reading Tidings may I encourage you to think about becoming a Member. We feel that £15 per year represents extremely good value for money – there is a form at the back of this issue to do so or you can make a donation either by telephone to the office or online by visiting our website of whatever you feel you can afford.

Our campaign raising awareness of Colostomy Irrigation is gathering pace and we have just released two DVDs, one for patient/nurse and the other as a reference tool for stoma care nurses. This has been a very complex task to complete involving a lot of filming and editing but Jane Wood, Amanda Gunning SCN and Wendy Osborne SCN have worked extremely hard to produce such a professional production and the volunteers who appeared were amazing. The real 'star' was volunteer Judy Colston who bravely agreed to be filmed in her bathroom taking us through the whole procedure from start to finish. Having seen and been 'put off'

by an early video I have shunned irrigation for ten years but Judy was such an inspiration to me that I have now been irrigating for four months, purely as a result of seeing the DVD and, if your stoma nurse is happy to recommend you to try it, I would say 'do so' the freedom it offers is immense.

It was a great morale booster to The Association when we were nominated by the Thames Valley Business Magazine for their 'Charity of the Year Award' (sponsored by James Cowper) we were one of the Runners Up. Sarah Squire and her husband together with my wife and I were guests at their Gala Dinner and the Award was presented to us by John Sargent the well known broadcaster.

We have a lot to look forward to in the coming months – in 2015 we will celebrate the tenth anniversary of the founding of the Colostomy Association. We have come a long way since those early days due to the tireless enthusiasm of the full time staff and volunteers in the office and those throughout the UK, and our support and sponsorship from the stoma care product/supply industry to whom we owe enormous thanks. There is still a lot to do to ensure that all pre and post-operative colostomates get the help and support they need and deserve but we shall, with your help, rise to that challenge.

On behalf of the Trustees, Staff and volunteers I would like to thank you for all you have done for us throughout the year and wish you all a Very Happy Christmas and prosperous New Year!

**Monty Taylor
Chairman of Trustees
Colostomy Association**

Dear Readers...

The CA office continues its pivotal role – providing information, support and reassurance to ostomates, family members and carers. If you need help no matter whether you deem it to be too small a query or think it too difficult a subject to talk about...remember CA is here for you! Our trained volunteers run the 24 hour FREEPHONE helpline: 0800 328 4257– they are there to support you, listen to your concerns and chat them through with you if need be. Feel free to phone at anytime as there is always an ostomate on call 365 days a year!

The CA does not give medical advice but we can pass on our knowledge from 'real life' experiences gained from 'living with a stoma and colostomy,' send out patient literature related to your concerns and signpost to healthcare professionals and fellow support charities. We welcome your calls, letters, requests, emails and really appreciate your donations – so do please keep them coming – we are here to help you! Remember you can contact the Editor direct see page 6 for details.

May we take this opportunity to thank each and every one of you who recognise and value the services this BIG hearted charity offers to those 'living with a stoma and colostomy!' We thank you for your continued support, encouragement and of course your invaluable donations without which we could not survive in these challenging times.

Appeal letter – response report...

Firstly, a big THANK YOU goes to everyone who responded to our first ever targeted appeal letter, which went out to 13,500 supporters in the autumn. We're pleased to say that of the 455 people who responded, almost half wished to set up a standing order. Thank you all so much!

This regular income will greatly help us plan our services and allow us to reach out to more ostomates and campaign for your rights.

Additionally, we'd particularly like to thank those of you who have been supporters for many years and have been providing on-going donations via standing order – some from as long ago as the British Colostomy Association Days (pre-2005!). Thank you all!

Photo ID card and RADAR – pay by new (unused) stamps...

Whilst on the subject of finances, we appreciate that some people don't have bank accounts and the use of postal orders becomes expensive. So, if you'd like to purchase a photo ID card or a RADAR key, feel free to send us new (unused) stamps to that value as these can easily be used on letters. Hope this helps!

Pre-op and carer support calls...

Some of you will have benefited from our pre-op and carer follow up calls which are now in place and this is run by one of our invaluable admin volunteers, Margaret. Feedback has been very positive about this special one-to-one service and Margaret says: "People are very touched by the fact that a national helpline is following up their call – they feel so much more supported."

CA third place at the Thames Valley Business Magazine 'Charity of the Year' Awards...

Last Autumn, the Colostomy Association was put forward for the Annual Thames Valley Business Magazine 'Charity of the Year' Award (this award was sponsored by James Cowper – a firm of accountants based in Reading).

Monty Taylor – Chairman of Trustees (with wife, Susan) and Sarah Squire – Trustee (with husband Steve) went along to the Gala dinner held in

November at the Royal Berkshire Conference Centre in Reading for the presentations.

Guest of honour, television and radio journalist and broadcaster, John Sergeant presented the awards. The ceremony was attended by 300 of the region's top businessmen and women.

The shortlisted charities the CA were up against included: Style Acre (who were awarded the main prize), The Oasis Partnership, Royal Berkshire Charity and Corporate Health. The Colostomy Association was one of the runners-up coming in third.



L-R: Monty Taylor, Chairman of Trustees and Sarah Squire, Trustee with the Award Certificate and Prize

"This was a big accolade for us. It helps raise our profile and put the subject of colostomy on a major stage.

Our main aim is to support and reassure people living with a colostomy, their families and carers. To continue our good works we need to raise awareness of the charity and at the same time raise funds, by doing both we hope to change public perceptions.

We do this through our fully trained volunteers, 24/7 helpline, quarterly magazine 'Tidings', patient support literature, bi-annual patient open day, our website and a very active Facebook group with over 1,500 members – to ensure that no one need ever feel alone," said Monty Taylor – Chairman of Trustees.

"We really try and do everything we can to raise awareness," says Sarah Squire, CA Trustee. "We work with medical professionals – colorectal surgeons and GPs, support the work of clinical nurse specialists (stoma care) and engage

with fellow organisations, IA (the Ileostomy and Internal Pouch Support Group) and the Urostomy Association to influence government/NHS policy."

"A colostomy is not the end of the world – far from it," says Sarah. "It has helped me overcome a serious medical condition and live a completely normal life."

"I hope that my own story and the contribution I can make as a trustee will help break down the taboos that surround colostomy."

Are you aware of any other Charity of the Year awards that the CA could benefit from? We'd love to know about these special opportunities.

The Colostomy Association is a relatively small charity with a big heart. It has just four full time members of staff, seven trustees and over 100 active volunteers. For such a small team, the charity achieves a huge amount and has big ambitions. Prestigious awards such as these are a vital way of raising our profile to businesses and reaching the wider public. We'd really appreciate your help. Thanks!

Photo ID Card...

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

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

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

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

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

Please allow 10-14 days for delivery – thank you

Donation Notice: Help CA further...

Dear Readers and Supporters,

We really value all the donations we receive, but more so when they are regular donations – standing orders.

However, often the date of the first payment stated on the forms gives us insufficient notice to get them

processed at the bank. This means that sometimes we miss out on a whole year's donation as the banks ignore that start date and take the payment a year later! It would be very helpful if around one month's notice could be given on the forms to ensure we can maximise the benefit from your kind donations.

Additionally, we often receive cheques without a covering letter and cannot trace the supporter on our records. If sending in donations, please include a note of your name, address and postcode, telephone number and email address (if you have one) so we can include this information on our database – many thanks!

Name:
Address:
Postcode:
Telephone No:
Email:



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

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

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

National Key Scheme - Key and photo ID card purchase

Title: _____
Name: _____
Address: _____

Postcode: _____
Tel: _____
Email: _____

Please tick the following as appropriate:

- I would like to receive a key for a charge of £3.50 (including postage and packing).
- I would also like to receive an optional photo ID card for an additional charge of £6.50 and enclose a passport photograph.
- I attach a copy of my prescription or recent delivery note as proof of eligibility and a cheque made payable to 'Colostomy Association' in the sum of £3.50* key only/£6.50* ID card only/£10.00* both the key and ID card (*Please delete)

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

Signature of self or carer: _____

Date: / /2014

Finally, come March 2014 we'll have been based at Enterprise House for one year. Please remember to send your letters and donations to our new address... Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA.

Pathways to a Colostomy...



Jo-Ann L. Tremblay is an ostomate, mother, grandmother, speaker, author, blogger, life coach, water colour/oil artist and photographer. She is also a member of the United Ostomy Association of Canada, National Capital Region Support Group.

Jo-Ann's mantra: 'the human spirit incumbent in us all – triumphs over adversity.'

This is her story...

A second chance at life, it's the icing on the cake, the cherry on top. Everyone we meet has a story to tell, and this is the story of an ordinary woman taking a stand against an extraordinary nemesis called diverticular disease.

I have my illness story – my individualised version. What I have discovered is that every ostomate has their own unique and at times, scary version of struggle, endurance and eventual triumph.

It's hard to pinpoint the actual beginning of my intestinal problems. As far back as I can remember I've had issues. Having said this, my slippery downhill path started in 2008. With each passing month, and then year, the pain in my abdomen was becoming more debilitating. As time passed beyond the pain, there were, of course, my frequent bowel movements. Well... let's just say I knew where every toilet was in every facility, everywhere.

"It's hot isn't it? Don't you find it a bit warm? Oh, you're right. I do have a fever. It's pretty low grade though. Gosh, it's awfully warm. Oh my goodness, it's really cold isn't it? Are you cold? Oh, it's not that cold? Hmm... you're right. I do have a fever. It's low grade, though. Well, it's been a couple of months now that I've had this fever. Be back in a minute. Just have to go to the bathroom. Again."

"Yes, doctor, I feel just awful. I'm going to the bathroom, about 10 times a day now on average. But there are some days when it's more than this."

"Well, Jo-Ann your colonoscopy shows that you have quite severe diverticular

disease. We're going to put you on an anti-inflammatory prescription. And as for the low-grade fever, your blood tests are showing a high white cell count. This happens when a person is fighting an infection and/or dealing with pain. I'll also prescribe an antibiotic. Take seven anti-inflammatory tablets per day, and make sure you complete the whole antibiotic prescription."

"Hello doctor, it's now been six more weeks since I was in your office. I'm going to the bathroom so many times during the course of a day, I don't bother counting anymore. I still have the low-grade fever. My body pain is quite intense. Even my hair hurts some mornings. I'm so tired. And, the chronic pain is completely affecting my quality of life. I really feel I'm surviving, but I'm sure not thriving. I think I'd like to be referred to a gastroenterologist. Something really bad is happening in there. I need help."

"Up your anti-inflammatory medication, Jo-Ann. I think we'll try another antibiotic. Here's your prescription."

This continued for 2 years, and by November 2010, all was not well. While sitting at my computer that Wednesday, all heck started breaking loose in my body.

I was rushed to hospital and with a CT Scan behind me, I was in hospital for a week. Hooked up to oxygen, I had an intravenous line containing four types of powerful antibiotics that dripped into my veins constantly. Unfortunately, even with a great medical team and state-of-the-art medical technology such as CT Scan and ultrasound, the doctors at the

hospital were unable to pinpoint what my health issue was.

After a week of morphine for the pain, and loaded up with antibiotics, I was sent home with no definitive diagnosis. I had apparently been suffering with Sepsis, Systemic Inflammatory Response Syndrome (SIRS). All the symptoms and test results pointed in that direction, but apparently, no one knew why. In retrospect, this inability to diagnose the source of the problem is still mind-blowing to me to this day.

The antibiotics administered at hospital worked quite well and I had a really nice Christmas that year. But, this was not to last very long.

Things went from bad to worse as 2010 ended and 2011 arrived. By July 20th, 2011 I was experiencing the lowest of low days. I was falling apart both physically and psychologically, I was broken. Many times that day I found myself mulling over the thought, "I think I'll have to throw in the towel!"

That night the hammer fell, so to speak. Throughout the evening on that fateful Wednesday the pain was the worst I had experienced yet, and the sickness intolerable. My husband Mark rushed me to hospital. The young lady at the registration desk took my blood pressure and it registered 54 over 38 and plummeting.

I was then rushed into an emergency triage room, and the activity started. My earth angels disguised as nurses and a doctor worked with me.

After another CT Scan, tests and a number of hours later, the doctor raced into my room, "We found bubbles! Not good! What we do know right now is that you have peritonitis. We don't know the source yet, but you will be undergoing surgery. Arrangements are being made now."

My earth angel doctor helped us know if I had arrived an hour later, I would probably not be alive at this point. The rest of that night is a blur.

Before entering the operating theatre the doctor stated my odds on surviving surgery was 50-50 at best, and suggested that my husband and I say our goodbye's. I underwent the emergency surgery, and in the process I became a survivor, it changed me

though but that goes without saying. It made me think about how I'm going to live the rest of my life.

My descending colon had multiple perforations. My abdominal region was filled with poisonous excrement and pus, organs had been pushed out of place, and there were perforations into my urethra and vagina. My descending colon was removed and part of my rectal stump was also removed. A colostomy was created that I now affectionately call "Percy", and I didn't have the faintest idea what an ostomy was.

As I recovered step by step, I found out about the United Ostomy Support Group in my region, and in time realised people with ostomies do not have to endure alone. My continued research brought me to Tidings Magazine, which continues to provide a platform for sharing interesting and important information that is valuable for all ostomates.

Through the healing process from the illness and the first surgery, and yet again another major surgery 21 months later, I am alive and well on my way to recovery. Every ostomate I have met has accepted/coped with their stoma in vastly different ways, we are all unique in this area. With the support of our caregivers, family, friends and/or colleagues we eventually return to our lives, our work, hobbies and interests. I'm not going to let a mere ostomy stop me.

We as ostomates have hopes, dreams and a 2nd chance to live a joyous life to the fullest, in spite of it all. A colostomy is a beginning again!

Jo-Ann

About Jo-Ann...

Now a permanent ostomate and an author, Jo-Ann has written and published the book, "[Better With A Bag Than In A Bag](#)", click (<http://youtu.be/gwrW4Xmfne4>) for more book trailer information. In addition, she is committed to joining with fellow ostomates through creating the blog, "[THE OSTOMY FACTOR](#)", click (joanntremblay.wordpress.com).

These endeavours have been created in an effort to support ostomy awareness that is intended to benefit people with bowel disease, colorectal cancer, fellow ostomates, their caregivers/advocates, medical professionals, and our community of humanity around the world.

"[Better With A Bag Than In a Bag](#)", will make you laugh and make you cry, as it inspires everyone who wants to live life to the fullest, in spite of it all. A 2nd chance at life is the icing on the cake, the cherry on top. "[Better With A Bag Than In A Bag](#)", is available in **KINDLE and paperback format from**, www.amazon.co.uk.



THE OSTOMY FACTOR, is a remarkably candid blog telling the story of the adventures of an ostomate's point of view. With a mix of humour, inspiration, and a large dollop of empathy in celebration of 2nd chances at creating and living a full and joyous quality of life, this blog shares everyday stories that will give you a chuckle as you enjoy a good read. **To enjoy THE OSTOMY FACTOR**, click joanntremblay.wordpress.com.

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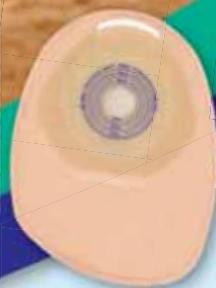
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Reference: 1. Flushability test based on the UK and European standard for domestic waste, Würzburg, Germany.

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Business Globetrotter... shares his top travel tips with a coathanger in tow?

Adam is a director at an international engineering business with offices and customers around the globe. He is frequently required to visit them, and other businesses, in person and has built up a lot of experience of international travel. Adam was diagnosed with bowel cancer in 2002, aged 43, and has had a permanent colostomy since then. He lives with his family near Leicester.

I am that annoying person who jumps to the front of the boarding queue at the airport, waving his airline gold card. I don't keep exact count, but I have taken around 500 flights since my bowel cancer was diagnosed and my colostomy created around ten years ago. Along the way I've picked up some experience of airports, hotels and foreign food that I would like to share with readers of Tidings.

My travel is quite varied: business is mostly USA, Europe, Japan and China. Pleasure has included trekking in the Andes, a safari in Tanzania, diving in the Red Sea and off road driving across the Sahara. A colostomy is no excuse for a quiet life!

After my surgery, I went back to work for a British manufacturing company, selling our products internationally which required frequent overseas trips. Since then I have moved up the corporate ladder and now am mostly involved with acquiring other businesses. These days I tend to meet with the owner of a business and enjoy the comfort of using their boardroom. The upside of this is that the seats are well padded and the coffee is excellent. The downside is that it's nice and quiet so any "unusual" noises are very audible and everyone knows where they came from. Managing my stoma for comfort during travel and good behaviour while on business is therefore very important to me.

An excellent guide to travelling as an ostomate is available from the CA website by following the "Information" link from the home page, and selecting "Travel advice and Insurance". As a frequent traveller I tend to take a more relaxed approach than they advise. However, I hope that my comments will

give any reluctant travellers confidence, and more experienced travellers some tips from my experiences.

And the coathanger? For irrigating, which I'll come to later.

How many supplies to take?

I pack supplies on the basis of usual usage for the period I'll be away, plus one week extra, plus "emergency stock".

I irrigate every other day, so "usual usage" for me is one pouch and one irrigation tube per two days. I usually bump this up a little to allow for the occasional upset stomach, which is an inevitable consequence of different food and water. In the case of bad diarrhoea, a drainable pouch allows multiple emptyings without getting through vast quantities of my usual pouches, so I always include a couple of these. Also, if you are going somewhere warm, be sure to include adhesive remover, as appliances can get very sticky when you are hot and sweaty.

The "one week extra" is based on typical travel delays. Over the last ten years, major travel incidents have been 9/11, Eyjafjallajökull, tsunamis and various air traffic controllers' strikes. I have been caught up, directly or indirectly, in all of these and none has caused a travel delay of more than a week. Note that a day trip to Paris suffers the same delay risk as a three week cruise, so needs the same margin for error on supplies.

My "emergency stock" is half a dozen drainable bags. I know that I can easily get a day's use out of a drainable pouch, even if I am not irrigating. At a stretch I can get two days' use. Therefore, my "emergency stock" gives me up to two weeks extra coverage. In

all my travels, I have never had to use these emergency supplies, but it gives me peace of mind.

To pack or to carry?

If I am not away for a weekend I will usually try to travel with hand baggage only. Clearly, this then has to include all my stoma supplies. The critical thing about hand baggage is to know the rules and keep to them. Key amongst these are size, weight and restricted items, all of which vary a bit according to who you fly with and which airports you travel through. Claiming "medical necessity" or similar may not help you to get through. Waving your colostomy "travel certificate" may not make a difference – just keep to the rules.

Size and weight are the usual problem: measure and weigh your bag before you go to the airport if you want it to go as hand baggage. If it is oversized, they will probably force you to check the bag into the hold. Not only will it cost you money, but also you will be separated from your supplies, which you may not be comfortable about. Ryanair is the strictest in this regard: for instance, be careful if you buy anything in the airport, such as duty free, as they will require you to get it in your one piece of carry-on and still be within size and weight limits. If not – off it goes to the hold, with all your supplies in it, and £60 billed to your credit card for the pleasure.

If you are going to check-in bags, then the question is where to put your supplies. The CA recommends carrying all of them in your hand baggage. If the thought of arriving without them fills you with dread, then do so. However, I take a more relaxed view and hand carry enough to get me through a few days, plus I always have my emergency

stock with me. Despite popular rumour, lost baggage is very rare: twice in ten years my bag has not arrived with me, and even then it has always turned up within 24 hours.

At the airport

I strongly advise you aim to arrive at the airport at least two hours prior to your flight so that you have some leeway for delays getting there, and so that you are not stressed while getting to your boarding gate.

Almost all airlines allow check-in online before you go to the airport, at which time you can choose a seat. Some even allow you to pre-select seats (possibly at a fee) online as soon as you have booked. I suggest you use this facility, and look for an aisle seat as it allows you to escape quickly to the toilet if necessary.

Having got your bags checked-in, security is the next hurdle. Getting through is more straightforward with an empty pouch so, if you have the need and the time, change it before you join the security queue.

As mentioned previously, know the rules and keep to them. In 500 security inspections I have never had a stoma related issue. I do not unpack my stoma supplies, carry a doctor's letter or prescription or declare my stoma to the airline or security officials. The most likely issue from an ostomate perspective for baggage screening is scissors. Recent rule changes allow scissors with blades up to 6cm in Europe and 4 inches in the US: I do not carry scissors so have not tested these rules. Liquids and gels up to 100ml are allowed – remember to put them into a clear plastic bag separate from your other carry-on. Any larger amounts of liquids or bigger blades – pack in your checked bag.

Next is the personal check. Again, this has no specific issues for an ostomate. Follow the guidance at the airport to remove anything metallic or electronic from your pockets – I find it makes life easier if I put everything in my hand baggage while standing in the security queue. In the US your shoes have to go through the scanner with your bag, but this is unusual elsewhere unless you are wearing shoes with large heels, or boots.

A new addition to the security arsenal is the body scanner, which is becoming quite widespread, especially in the US. I have noticed that these will pick up my pouch, even if it is empty. This is not a problem: there is a quick pat down of the tummy area on the way out, and

that's it. Lots of people are checked so there is nothing unusual or stigmatising about being patted down. One scenario I have no experience of is a body scan with a filled pouch. If you are aware this might apply to you, keep your travel certificate to hand, and ask for a private room if the security officer wants to inspect further.

On the plane

I have changed appliances on aeroplanes, but it is generally to be avoided if possible. A quick change before you board, and avoiding irritating food (like curry) the day or two before flying is sensible. I have not had to change a bag on a plane since I started irrigating which is my way of dealing with it, though I find the depressurisation at altitude does make me a bit "gassy". The issue is that the loos are small, and there are usually people queuing, which add a degree of peer pressure to be quick. Depending on your bowel habit, using a drainable pouch throughout your travel can make life easier as you can just empty the bag rather than having to change it. However, don't put off an on-board change too long and risk a leak – it may be awkward, but a little care and dexterity will get you through.

And so to irrigation...

Irrigation helps me when travelling because:

1. I don't have to change appliances at an airport or on a plane
 2. The volume of supplies I have to carry with me are significantly reduced
 3. I can be confident in meetings
- It has changed my post-colostomy lifestyle from "manageable" to "it makes negligible difference", and this is particularly true for travel.

Irrigation has been covered by a number of articles in Tidings over the years, so I will skip over the mechanics and dwell more on travel related aspects.

When at home I irrigate every other day, in the morning before I go to work. However, it is easy to flex this schedule. If I have an early start on an irrigation morning I will usually irrigate the evening before to avoid an even earlier start. When I have to fly long-haul I try to irrigate as close as possible to departure: this way I don't have to change a bag while travelling even though it's often over 24 hours from home to hotel.

When away from home I try to keep to a similar schedule. This can be hard when I have to start early to drive to a company, attend a full day of meetings and then drive to the next hotel. It's

usually sleep that gets sacrificed! However, if I know I've got a busy day coming I will irrigate a day early (i.e. after 24 hours, not 48) if that is easier.

Keeping free of breakthrough for 48 hours can also be more challenging away from home. With hotel breakfasts, business lunches and then being entertained for dinner, it is easy to get through a lot of food. Holidays can be much the same with all those enticing local delicacies! I try to ameliorate the situation by avoiding high fibre foods. Fish, chicken, white rice and white bread are low fibre. Wholemeal anything, vegetables and fruit are not. This may not be the healthy solution, but I can live with it for a few days.

The only times I do not irrigate while travelling are when there is no running water: so far this has only been when trekking in the Andes and the Sahara. On both occasions I reverted to using a drainable bag, as there was a shortage of conventional toilets as well, so being able to pop behind a bush or sand dune was convenient.



And finally...what's with the coathanger? It's to hang my water reservoir from whatever fitting is at a suitable height above the toilet. Usually this is the shower rail, which is next to the toilet in a typical hotel en-suite. However, over the years I've used extractor fan grilles, mirrors, light fittings, pictures and doors. A simple wire coathanger can be bent into a suitable shape to use with any of these options, and goes with me wherever I travel.

Happy travels!

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, their families and carers...



Fundraising Focus...The Bob Buckley Fund



The Buckley family complete the Great North Run (GRN) raising funds for the Colostomy Association's Bob Buckley Fund...

The Buckley family share their experiences of running in the World's biggest half marathon – The Great North Run. They explain why running this event and raising funds for the Bob Buckley Fund (set up in 2012 in Bob's memory) means so much to them.

Kevin Buckley (Bob's son): The challenge – complete the Great North Run – raising funds and awareness for the Colostomy Association's Bob Buckley Fund. The approach – months and months of training in all weathers and whenever I could fit it in. Finding runs that were over 10 miles in order to get ready for the GNR proved difficult but not impossible. Driven by the love and memory of my Dad, a great man, friend and brilliant father who lived life to the full and even after suffering terribly with bowel cancer and a colostomy, only saw the positive side and wanted to help others. Just a year after his operation he helped me train for my first ever Great North Run in 2006. Passionate about running, he was a much better runner than I'll ever be. The Colostomy Association works hard to raise awareness to ensure that people living with a stoma and colostomy can benefit from the great support the charity offers. I hope the money we raised can help make lives easier – out of darkness cometh light.

Lyndsey Watson (Kevin's fiancée): So proud of myself for completing the GNR. I couldn't have done it for a better man than Bob. He was such a lovely person with a very kind heart.

Jennie Buckley (Bob's niece): I trained hard, my main aim to finish, I put so much effort in to it. It was one of

the proudest moments of my life when I crossed the finishing line! Such an amazing feeling!

Derek Doyle (Jennie's partner): I originally signed up to the idea to get Jennie up to speed as she was very unsure about completing the route. It's fair to say, the first time we went out and ran (not even a quarter of a mile) we were a little worried. But when we finally heard we had been accepted we both knuckled down and trained really hard, realising what we had signed up for! On the day during the latter stages of the race I found myself struggling, my thoughts turned to Bob. I focussed on why we were running, the charity we were running for and the difference the funds would make to people's lives. I'm looking forward to the Birmingham run this year and doing it all again.

Marie Ainger (Bob's niece): Having never run in any running event in my life, taking part in the GNR was a major personal achievement for me. My training involved plenty of walking not running. The aim was to raise money and awareness for a cause that meant so much to my uncle – who I loved and respected – for all the volunteer work he did for the Colostomy Association.

Gemma Ainger (Bob's nephews wife) A really great achievement for such a good cause. I'm so proud to have been part of it!

Two family members due to run on the day had to pull out – **David Buckley (Bob's son)** through injury, and **Natalie Buckley (David's wife)** after she found out she was pregnant but they intend to raise more money in the future, which is wonderful!

This amazing family have through their joint memories of a much loved family man 'Bob' – important in all their lives – committed their love, time and energy to a cause that will make a difference to other ostomates, families and carers who come forward in search of support, reassurance about 'living with a stoma and colostomy'. Together they have raised a much appreciated £2,939 (inc Gift Aid). Thank you!



I was extremely proud to represent the CA and support members of the Buckley family who ran in the Great North Run last September. Bob was the person who first got me involved with the CA through the FACEBOOK group. He encouraged me to write my story for Tidings and to train to become a CA volunteer. Now a Trustee I was delighted to be asked to head the Bob Buckley Fund it is such a special honour.

About the Fund...The Bob Buckley Fund was created by the CA in 2012 in memory of Bob's work as a dedicated volunteer and volunteer trainer. Bob was an exceptional person – a consummate professional – an excellent trainer and volunteer who took time to listen, encourage and support all those who were just beginning to learn how to live with their colostomies.

The Bob Buckley Fund now standing at just over £5,000 will be used for specific research projects and is a living legacy for Bob's family, while benefitting others longer term. More news items will follow in future issues of Tidings magazines.

If you would like to donate to this cause in Bob's memory, please send a cheque to the CA (see page 6 for the CA address details) with a note marked for the Fund or go to: www.justgiving.com/kevin-buckley78

Sarah Squire – Trustee

Thank you everyone for your kind donations

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Update on stoma care products and services...

OSTOmySecrets™...

ConvaTec Ltd. is delighted to present OSTOmySecrets™, a brand new range of underwear and swimwear, created for ostomates by ostomates with a secure inner pocket that provides a new sense of freedom! OSTOmySecrets™ have had a great success in the USA and due to the increasing interest from UK patients, the company have decided to settle in our country to offer a better service.

Wearing OSTOmySecrets™ you will experience how it keeps stoma pouch supported & flat against your stomach, completely covers the pouch up to the base of your skin barrier, supports the weight of the pouch as it fills, smooths "bumps" as the pouch fills, prevents pouch from "swinging" under clothing.

OSTOmySecrets™ underwear and swimwear is available in a range styles, colours and sizes from XS to XXL. Further details and prices can be found on www.ostomysecrets.co.uk where you can visit the virtual fitting room to select the most appropriate size for you. See our advert opposite.

New Clinifilm Spray...

Two years ago, stoma care patients welcomed a unique new arrival – the revolutionary Peel-Easy adhesive removal spray from CD Medical. Using sophisticated bag-in-can aerosol technology, Peel-Easy completely eliminated chilly, noisy propellants and could be used in any position – even upside-down!



Not surprisingly, Peel-Easy became quite a favourite for people who appreciated its comfort, discreetness in use and its ability to reach awkward areas easily. Peel-Easy also came as wipes that could remove any stubborn adhesive traces.

Now, CD Medical brings you the same people-friendly aerosol technology in their new Clinifilm spray, delivering a safe, non-sting silicone film that protects skin from damage caused by adhesives and body fluids. The spray is supported by soft Clinifilm Wipes which can be used anywhere at any time. Another newcomer from CD Medical is Clinifresh Spray, a Lime/Lemon deodorant that can freshen up bags or as an air freshener.

For more information visit www.cdmedical.co.uk

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exclusive UK distributor of EuroTec ostomy products and accessories is pleased to announce the arrival of the very first OVAL SOFT CONVEX Closed Pouch. Available in two cut to fit options: 13-44 x 29mm and 13-54 x 37mm. Also available in a drainable and urostomy pouch. Designed for a more accurate fit for non-round, irregular shaped stomas, and those in skin folds and creases, the unique, soft, flexible oval insert provides noticeable comfort when moving and bending. Optimum depth and oval profile for maximum benefit, providing gentle oval pressure where needed. May help to improve pouch wear time and reduce the need for additional accessory items. Made from a 0.9mm traditional hydrocolloid adhesive skin barrier backed with a SuperFlex stretchable foam layer for optimum skin protection. For more information and to order your complimentary samples please call Freephone 0800 652 0424. See our advert on page 29.



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OstoMART are pleased to announce that the award-winning NUMBER 1 US preferred air release method called Osto-EZ-Vent® is now available on prescription in the UK (order code OEV1 for a pack of 10 vents).

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For more information or to order Osto-EZ-Vent® please call Freephone 0800 220 300 or email enquiries@ostomart.co.uk

Osto-EZ-Vent® - the simple solution to your ballooning problems!

HiLINE Activ News...

Take control, be proactive...with the NEW HiLINE Activ support wear range from OstoMART.

The HiLINE Activ range is designed to provide Medium Level hernia support or prophylactic support for those who are more active through sports, swimming, work and leisure activities or who are more conscious of body image and want a support belt that does not look like a conventional support belt.



A HiLINE Activ belt completely hides the stoma appliance and has a leak proof inner lining so you don't have to worry about embarrassing accidents or leaks. The front zip allows for ease of draining or changing of your appliance without the need to remove your belt. The belt provides comfort, support and discretion. The material is so soft and flexible that it does not restrict pouch functionality yet provides additional support for the weight of your appliance.

The new HiLINE Activ range is available on prescription now in a choice of 5 plain unisex colours plus 2 additional women's lace options and in sizes Extra Small up to 3XL.

For further information please see our full page advert on the back cover of this edition or call our customer care line (freephone) 0800 220 300.

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ConvaTec

Irrigation and you...

Sue Hatton Executive Trustee writes...following significant feedback from the WCET Conference in 2012. A workshop (the first for the Association of Stoma Care Nurses UK) took place at 07.30am on Tuesday 8th October in conjunction with the Colostomy Association – the subject – Colostomy Irrigation! Amanda Gunning CNS (stoma care) and Wendy Osborne MSc, RGN, ENB 216 (Stoma care) Charter Healthcare Nurse Manager, Coloplast Ltd represented the stoma care nurses, Jane Wood, Sarah Squire and I represented the CA. The workshop offered a fantastic opportunity to introduce in more detail the DVDs that the CA has produced. Colostomy Irrigation – A reference tool for stoma care nurses and Colostomy Irrigation and You for patients/healthcare professionals who wish to learn more about irrigation. A great deal of discussion followed the presentation – a questionnaire given to each stoma care nurse captured their practice knowledge of Colostomy Irrigation. The DVDs received a great response.

Sue writes: As you know I encourage everyone who irrigates to write in with their experiences. Derek Curtler recently phoned in to the CA offices to make an enquiry about the use of softened water when irrigating. He was referred to me and I asked him to write the following article. Thank you Derek for provoking such an interesting discussion!

Derek writes...Are you irrigating with softened water from an installed device in your home?

I have recently enjoyed a weekend away visiting family in new accommodation in Poole, Dorset and as usual all my irrigating equipment came with me. Steve, my cousin was proud to show me the water softener installed in their property. My initial reaction was, will this upset my bowel when irrigating? I soon had my mind put at rest, when he explained that the water supply to the kitchen sink was not linked to the softener so I just got the water from the kitchen when carrying out my routine each morning.

The water in the shower and bathroom really made a big impression on my wife and I. We decided to make enquiries as to the suitability for our home when we returned. I was aware that an unknown level of salt is used in the water softening process and needed to satisfy myself that using softened water would not have any long term health implications? So, I made a call to

CA and left my enquiry knowing they would be the ones who would be able to put my mind at rest. Little did I appreciate what a 'can of worms' I had opened? I do appreciate the lengths the CA went to trying to find a satisfactory answer to this question! Emails began flying and the solution was pretty much unresolved.

In the meantime I had been in touch with a company who came out to survey the suitability of our property. Yes, it could be done, but would involve a great deal of disruption which, both my wife and I were not prepared to face, as we had gone through major works a couple of years back. Gill and I came to the conclusion we didn't need or want any more disruption. So we decided to say 'No thanks' to the company we had called. They too were unable to really answer my health question relating to the salt content!

I received a phone call from Sue Hatton and had quite an extended discussion with her on this subject. Our conclusion was that some research was needed (or needed to be found). To ensure that all irrigators can continue with this well tried and tested method of bowel management without any water safety concerns.

This did bring us onto the type of hot water system users have installed in their homes/property. We have a high pressure combination boiler which means the hot water is heated direct

from the mains on demand. So we have mains water supply in the bathroom, direct from the main supply (hot and cold). There are no storage tanks in the property hence no concern that any potential contaminated water may be going through my colon.

Our previous property did have an indirect water system, which means we did have a storage tank in the loft and a hot water cylinder in the airing cupboard. I was aware that using the water in the bathroom would come from both these storage tanks therefore I decided I would get my water from the mains supply in the kitchen. It can be inconvenient at times but as I make the tea each morning it has become routine.

I do think it is very important to know where the water is coming from. If you irrigate perhaps readers could let the Editor know their experiences.

I will soon have been irrigating for seventeen years and certainly wouldn't want to manage my stoma in any other way/method. Yes, I have had my moments but who hasn't?

Derek Curtler

Sue Hatton writes: As Derek has said, he has provoked a series of emails flying between Amanda Gunning our Specialist Stoma Care Nurse and Sarah Squire, a Trustee who is a Research Assistant at the Dept. of Physiology, Anatomy and Genetics at the University of Oxford. Here are the exchanges...

15 Oct: Sue Hatton's thoughts were that it is personal choice. Some irrigators will have been using softened water for years, as it is convenient and therefore wouldn't be bothered to warm up bottled water, or go downstairs to use the hard water tap.

16 Oct: Sarah felt that there was advice out there in the ether not to drink softened water and that she was taught to irrigate only using water that you would drink. She did some research

and it seems that most softened water is fine to drink unless you are on a restricted sodium diet or making up baby milk.

16 Oct: Mandy commented: 'There should be guidelines to give to both stoma nurses and potential irrigators. If the research is unproven, maybe each person should be assessed accordingly?'

17 Oct: Sarah writes: I am struggling to find evidence either way – just information from water companies. There is no regulation stating that a mains water tap must be installed alongside a softened water system although it is recommended. In most cases the increased amount of sodium is not very significant, but in areas of hard water it can be quite a lot. <http://www.ukwta.org/technology-areas/faqs/>

Sue comments: Sarah's 'Gut' feeling is that we should be advising irrigators not to use softened water (which we do in our literature).

17 Oct: Mandy confirms that she and fellow clinical nurse specialist (stoma care) Wendy Osborne are in full agreement with Sarah, especially for those on low sodium diets and suggest using bottled water until we have ascertained further facts on sodium content of softened water systems.

In conclusion: The CA would advise not using softened water to irrigate until there is more firm evidence with regard to salt content. This will undoubtedly provoke a lot of further views and opinions, which we look forward to sifting through!

Introducing...the two Colostomy Irrigation DVDs

DVD 1: Colostomy Irrigation and You (for patients/healthcare professionals)
DVD 2: Colostomy Irrigation: A reference tool for Clinical Nurse Specialists (stoma care)

Both DVDs are in their final stages – duplication of each DVD is in progress and the design and packaging has been approved and is in production. Here's a sneaky preview of how the finished DVDs will look with an outline of some of their key features.

- **Introduction from President of the Colostomy Association, Professor Bill Heald CBE**
 'Since my appointment as President of the Colostomy Association in 2005, I have been amazed at how many colostomates are unaware of Colostomy Irrigation'.
- **Sue Hatton - Executive Trustee, Colostomy Association**
 'I firmly believe that patients facing an irreversible colostomy should be given the opportunity to discuss colostomy irrigation with their colorectal surgeon and stoma care nurse prior to their operation, wherever possible. I also believe that patients offered the opportunity to learn are given support, encouragement and time to adapt to the techniques involved with this method of bowel management'.
- **Who can be offered Colostomy Irrigation**
 A group of stoma care nurses discuss colostomy irrigation.
- **A stoma care nurse introduces – Colostomy Irrigation to a patient**
 A stoma care nurse discusses 'colostomy irrigation' with her patient and demonstrates how to use the equipment.
- **Two stoma care nurses review – Colostomy Irrigation equipment**
 A stoma care nurse and a colleague discuss 'colostomy irrigation' equipment.
- **Experienced Irrigator**
 A film sequence shows an experienced patient irrigating at home from start to finish followed by a personal testimonial.
- **What patients say**
 A group of four patients (male/female) discuss the benefits of 'Colostomy Irrigation' and explain how this procedure has changed their lives.



Editor's comment: An order form for DVD 1: Colostomy Irrigation and You (patient/healthcare professional version) will be included in the spring issue of Tidings magazine.

Note for stoma care nurses: If you have pre registered your interest to receive the DVDs they will be despatched to you as soon as they become available.

CA 'Closed' FACEBOOK...Meet up!

Membership reaches 1500 and rising...

Pauline reports...Every so often the members of the CA Closed FACEBOOK Group start to think about meeting up, we constantly harass Sarah and Duncan, then we leave them to arrange everything, I hope they both realise how much we appreciate what they do for us.

We were quite excited when Gatwick was mentioned; would it be somewhere exotic? Not quite, it was Premier Inn Gatwick, but it was a great venue. Some of us decided to add on a day, so we arrived Friday 18th, I think the Hotel Staff wondered what had hit them, but we were all warmly welcomed, and gradually we began to gather in the Bar (where else?).

These meet ups are invaluable, we discuss issues and pass on tips, but when the ladies started to compare vests, one or two of our gentlemen got a bit hot under the collar! I wonder what people sitting nearby thought if they overheard our conversations.

Our partners gain from these meet ups too, don't forget, they have to live with our day to day problems just as we do! A get together like this gives them support as they realise they aren't alone either.

Thirteen of us sat down to dinner, it was good to welcome some new faces this time. After a lovely meal, it was back to the bar, where we caught up on all the gossip, talked about friends who couldn't make this meet up, and remembered friends no longer with us, but in true CA Closed FACEBOOK group style we had a great time!

Next morning at Breakfast, there were quite a few bleary eyes I can tell you, but as more and more members arrived and joined us, the 'party' sorry, I mean 'the weekend' began.

We met up over coffee and biscuits with 'meet up' sponsors CliniMed/Welland, that sounds very formal, but what wonderful, friendly people they are, they made this weekend event very special for all of us, I cannot thank them enough for their hospitality.



CA 'Closed' FACEBOOK Group members pictured with CliniMed/Welland staff and CA Trustees (in purple poloshirts) Duncan Wells (back row) and Sarah Squire (middle row), Pauline is standing to Sarah's left.

CliniMed/Welland provided transport to take us to their factories for a visit, their staff had volunteered to work on the Saturday. It was fascinating – to see all machines working and to learn about the different stages and processes that go into making the pouches and other products. We must have looked a strange lot in our paper overalls and hats.

Back at the hotel, CliniMed/Welland gave a short presentation followed by a question and answer session – all very interesting. As the session finished we were each given a 'goody' bag as a memento of the occasion. Guess where we went next – that's right – the bar, where we met up before going into dinner.

The staff from CliniMed/Welland enjoyed the evening as much as we did, there was much swapping of seats so that we could all talk and catch up, photo's were taken, a few of our male members provided us with some impromptu entertainment! Members of the CA Closed FACEBOOK group have no doubt seen the photos, we then followed the well trodden path to the bar, where we continued to enjoy the evening.

I know lots of our members who are new to living with a stoma – worry how it will affect their life – we would have inspired them, all anyone would have

seen is a group of friends having the time of their lives, and I challenge anyone to spot who was wearing a bag!

None of us were quite so bright eyed and bushy tailed next morning, we all sat reminiscing about the weekend, the one question on all our lips – when and where – shall we 'Meet up' next! By the way – the only reason we spent so much time in the bar – was because it was the only room big enough to hold us all. That's our story and we're sticking to it!

For those people who may not know about the CA Closed Facebook Group – the group gives online support to ostomates, their families and their carers 24 hours a day. I coped with having a stoma, (you don't have much choice do you) but I didn't know anyone else with one, no matter how understanding your family are, you can feel isolated and alone. I've found a group of people who know exactly how I feel and it's wonderful! I had been told I couldn't irrigate with a loop colostomy, but these amazing friends, researched, advised and encouraged me, and I gave it a go with help from my stoma care nurse, it's been so successful – I forget I have a bag most of the time. I am not exaggerating when I say this group has changed my life – hugely!

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Colostomy to Ileostomy – a fifteen month trial

Sue Hatton – Executive Trustee returns and shares her patient journey...

Sue writes: It seems incredible that it is fifteen months since I had my first operation to remove my large bowel and become an ileostomate.

Fifteen years ago, at the age of 46, I was diagnosed with bowel cancer. Then for a year, until I had a permanent colostomy, I endured chemotherapy, radiotherapy, a deep vein thrombosis and humiliating incontinence. I was more than ready to have a stoma and to regain control of my bowels.

I was fortunate, in this grim year that I had been referred to Prof Bill Heald – who at the time was Consultant Colorectal Surgeon in Basingstoke Hospital. In Dec 1997 he conducted my surgery, which included a total hysterectomy. Six weeks after the op I was back in hospital to have the stents removed and it was then that my wonderful stoma nurse, Ann Leppington Clarke, insisted that I irrigated my bowel before I went for surgery. I was a passionate irrigator from that day and have been trying to promote irrigation to the stoma world ever since.

It was a real shock to have a routine colonoscopy in 2011, and to be told that there were a lot of pre-cancerous polyps and that I should have an ileostomy. I have always been very glad that I had a colostomy and felt sorry for ileostomates as it seemed their lot was much more difficult to deal with. Before

going ahead with the surgery I asked for a second opinion. Mr Ian Daniels, Consultant Surgeon of the Royal Devon & Exeter (RD&E) Hospital and Vice President of CA, agreed with the original diagnosis and that the only option was an ileostomy.

On Thursday July 12th 2012 I became an ileostomate. As an overweight 61 year old I knew the chances of herniation were high. However, Mr Daniels brought the remaining bowel out through the site of my colostomy, so that I wouldn't have to have two openings on my abdomen, to reduce the possibility of a hernia.

I made a good recovery and the stoma functioned well. The results of the biopsy showed there was no cancer, which was a huge relief. I saw the stoma nurses, discussed the change in consistency and continual output, and was given new drainable stoma bags. I can honestly say that I just accepted this new stoma and draining the bags, and did not shed a tear for my old way of life. Mr Daniels said I could go home on the Thursday. I was so pleased that I didn't think to get anyone to give me an overhaul before I left.

By Monday my stoma began to look a bit dark and wrinkly and appeared to shrink back inside. Over the next few days the stoma continued to shrink and looked like a wrung out teabag. My skin was very sore around the site and I was

miserable. In hindsight I should have seen the stoma nurses earlier or gone back to the RD&E. As it was, when my local stoma nurse visited she insisted I was admitted to Treliske Hospital immediately.

The operation lasted six hours. There was a mass of adhesions for the surgeon to wade through before he could reform my stoma. He was able to bring it out through the same opening and it was a nice, neat, healthy looking stoma. However, my bowel did not like being mucked around with and went into 'Ileus', a state of paralysis. I was very poorly and anything I ate or drank made me sick. So I had to have a tube passed up my nose and down into my stomach so the fluid which was going no- where could be syphoned off. I also developed three fistulas.

I became so weak I could hardly get out of bed and couldn't reach the bell to ring for a nurse. I was on my own in a single room and felt utterly miserable. There were some lovely nurses who I got to know very well and who would take the time to talk to me, but mostly they would rush in and rush out again. I then had kidney failure and my heart went into atrial fibrillation and my blood pressure dropped.

As I was unable to eat normally I was started on Total Parenteral Nutrition (TPN). This is where nourishment is delivered via a special line directly into



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the blood stream. The composition of the feed had to be formulated depending on the results of daily blood tests. Little did I know that this method of feeding would still be going on over a year later. After nine weeks in hospital I was extremely low and very depressed. My eldest daughter, Katy, made an official complaint and it was at this point, that the nutrition team agreed that they couldn't do any more for me and decided to send me to the RD&E where Mr Daniels agreed to take me on again. Here I was in a room with six ladies. There were three of us on TPN. What a difference! There was a lot of hilarity, wonderful nursing care, all I am sure down to better management and communication. Every hospital complains of being short staffed and nurses have a very heavy work load, but here the stresses that they have are not inflicted on their patients. I began to get better and began to get more mobile, even making it to the loo to fill my sample pots as TPN input and output had to be recorded.

By late October, Mr Daniels and the Nutrition team decided that I could go home and that a team from BUPA, contracted by the NHS, would take care of my TPN. It was heaven to leave hospital. My daughters and their families all came for Christmas. I was able to join them and I nibbled on tiny mouthfuls of yummy M&S canapés! First food I'd had for six months. On Boxing Day the pic-line, going into my arm through which the nutritional feed was administered, broke. I was admitted to Treliske Hospital for another line to be put in. The children all left the following day and I did feel cheated to miss out on my time with them.

Two days later I developed pains in my shoulder. What a time to have problems, between Christmas and New Year. The pains were blood clots caused by the new pic-line, so it was removed. It was decided that I needed a Hickman line into my main artery, but there were no specialist nurses to carry out this procedure. So I had not had TPN for five days and was eating small amounts and enjoying my food. The nutrition team agreed that maybe I could have time to try to eat again. However, after two weeks I began to feel very dehydrated and poorly and so I asked to go back

into RD&E. Then the leakage from the fistulas, including a new one that discharged faeces through my vagina, became much harder to manage. The nursing staff were wonderful, so kind and considerate as I had to have help to clean me up. It has to be one of the worst times of my life. So no food and back on daily TPN.

After six weeks I was sent home again, but just on TPN. I was still very weak and walking, even around my bed, was painful and left me gasping for breath. My GP came to monitor my blood pressure, and it was extremely low. After six weeks, I saw a community nurse, who arranged for me to have a care nurse visit me for three quarters of an hour daily to help me get washed and dressed. Although I was determined to be independent, it took me a long time to get mobile and I had two more stints in Treliske Hospital because of dehydration.

However, I did manage two trips to see my family. One was to Swindon, where Katy had organised a Summer Fete to raise funds for the Colostomy Association. She worked so hard and pulled off a really well organised, happy and very successful day. The only thing she would change was the ice cream as she had bought over 70 tubs, none of which sold as it was a cold rainy day, but her family have now successfully eaten the lot!

The other was to Reading. I organised for TPN to be delivered to my daughter, Jo's, house. There was a reunion of thirteen friends who had all joined the Army 43 years ago and I didn't want to miss it. It coincided with an Open Day that the CA was holding at the Royal Berkshire Conference Centre and I wanted to be there to support them. The BUPA nurses came to give me TPN every other day and I ate small amounts of soft easily digestible food. It was wonderful to be part of these events and I was so proud to be able to present an award to Bob Buckley's sons in memory of their very special dad who had given so much of his time and talent as a trainer for the CA.

However, all this frivolity took its toll on me and I asked to be admitted to RD&E at the end of July. Mr Daniels and I

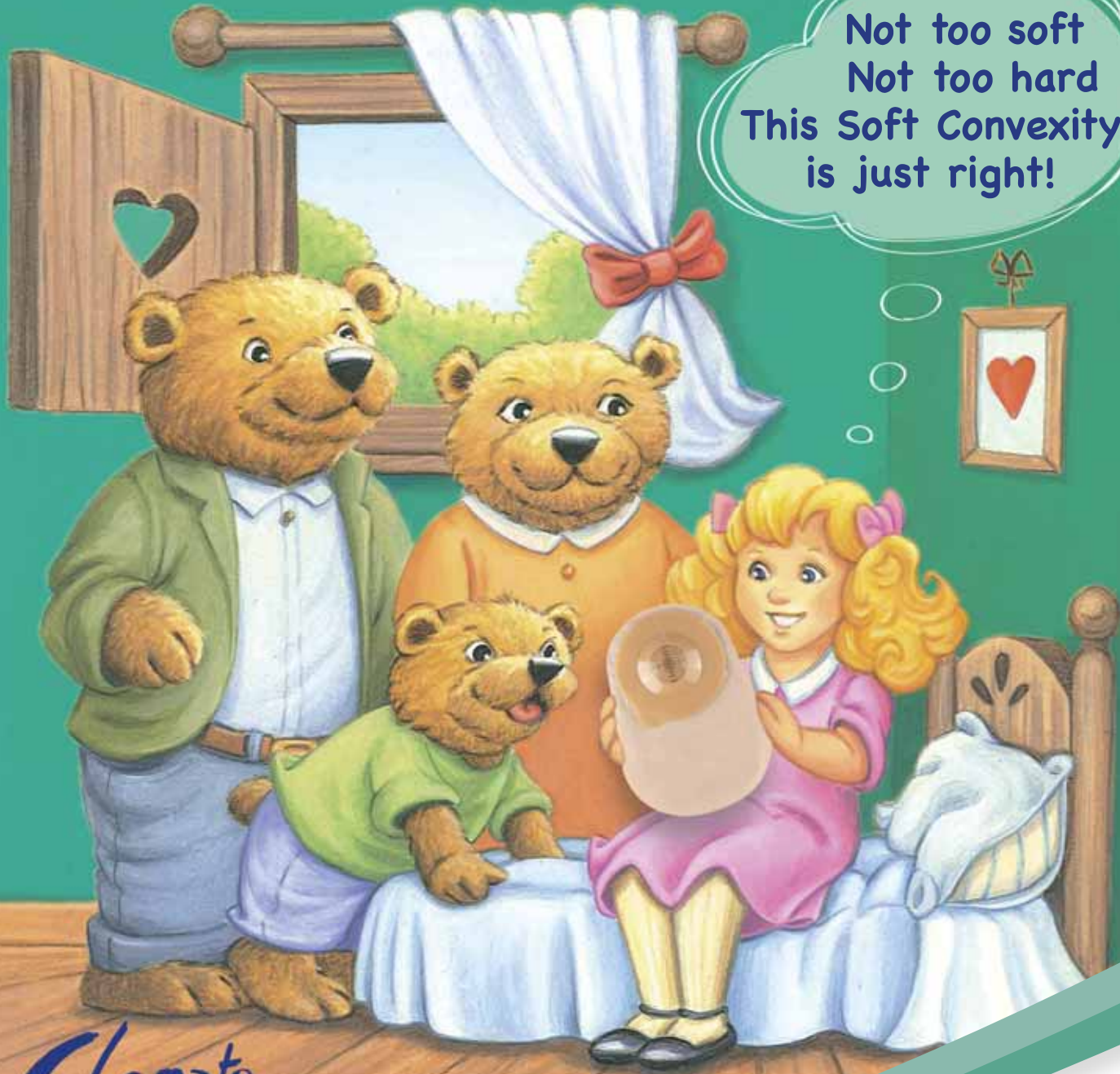
agreed that it was the fistulas that were preventing me from recovering and so we agreed that I should have a planned operation on 5th September 2013 to get rid of them. I was able to have a good time with the grandchildren when they came to Cornwall for their summer holiday. We had lots of pirate adventures and I even managed to eat mussels and chips!

The operation was a success. Mr Daniels said he had opened me up, taken everything out and shoved it back in again and stapled me up with 41 staples! I had to spend three days in Cardiac Care as I was having problems absorbing the medication for my atrial fibrillation. However, once this was sorted out I started to eat small amounts and drop the TPN. I was soon up and bouncing around the ward and the hospital, feeling fit and well. I was discharged after two and a half weeks. Ten days later I was able to attend the Association of Stoma Nurses Conference in Wales and I am now finishing this article in a holiday cottage in North Devon, eating steak and chomping Thornton's chocolates! I have walked around the gardens of Rosemoor and been to a market town to shop. I feel well and confident that I am on the road to becoming a fit ileostomate.

So what do I feel about becoming an ileostomate? To my mind there's very little difference from being a colostomate. However, it was a very extreme way of converting! It could have been a lot simpler, but the journey has given me a greater understanding of amazing nursing care, dreadful bowel problems that other women have endured and has made me accept that however I have to manage my bowel, I just have to get on with it, live each day, know where the loos are and be very grateful that I have had an excellent surgeon getting my health and my fighting spirit back.

Sue Hatton
Executive Trustee

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Living with a stoma and diabetes...

My name is Sue and I am a volunteer with the CA. In 2004 I was diagnosed with bowel cancer and, true to form, I don't do things by half. From October to December 2004 I had five weeks chemo and radio therapy followed by the op, which left me with a stoma and, the belt and braces bit of the job, having my bottom sewn up.

Having spent three years learning to accept my stoma (George - it helps me giving it a name, so that when we are out I can say I have to see George therefore saving an explanation) I started to feel tired, thirsty, and was losing weight. Time for a trip to the doctor. In a very short time I was diagnosed with type 2 diabetes and was started on metformin tablets, which helped bring my blood sugar levels down. However, not only do I have a stoma but I also irrigate (best thing ever as it helps me stay in control) and in a very short time we found that the metformin was going straight through me and only having a limited effect, so I was started on insulin. The first day I sat there for about an hour looking at the needle thinking I can't do this, but once done no looking back.

With insulin as well as the tablets things soon got on an even keel.

My doctor sent me on a 'Diabetes Education and Self Management for On-going and Newly Diagnosed' (DESMOND) course, a six-hour programme, usually lasting one or two days. Up to ten people with type 2 diabetes meet with two trained DESMOND healthcare professionals, to learn about hidden sugars, how to read food labels and lots of other very helpful information.

Now that I am on insulin, when I go out I have to take a sugary bar or some glucose and keep an eye on the time as I have to eat at regular times or I can have a bit of a "shaky episode". If we go out for a meal with family or friends I make sure they know that I cannot go past a certain time to eat.

There can be a problem when I have to have a colonoscopy or surgery as I have to go several hours without food, often being given laxatives. I usually stop metformin 24 hours before and only take a quarter of my normal insulin dose. However, everyone is different.

My doctor and diabetic nurse have told me that, as I have researched my condition, I know as much as they do about diabetes especially about me. I like to find out as much as I can as I don't want the alternative! So don't let your stoma, diabetes, or anything else you might have, take control. It is your life - you take control.

Being a volunteer with the CA has helped so much, as, apart from meeting people and sharing ideas, you realise you are not on your own.

S.H.

Editors Comment

Ostomates who have diabetes are advised to consult their diabetes specialist nurse if they suspect that the treatment for their diabetes is causing problems with their stoma. Also to seek their advice if they are to undergo investigations or treatments which involve a bowel preparation and/or long periods without food.

For more information contact:
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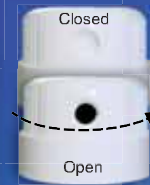
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Focus on additional ostomy products

Odour, Filters and Drops...

One of the first questions a colostomate asks about their stoma and output is 'will it smell.' This is a very natural and understandable query. But this shouldn't be misconstrued into 'will I smell.' Confidence is everything to the colostomate – wearing the correct appliance from the outset, which suits their body, and lifestyle will quickly build confidence allowing them to adjust more easily.

The fact is – the output does smell, due to bacterial action. About 75% of stool is water and the other 25% is made up of waste your body can't break down (like those sweetcorn kernels which we were convinced we'd chewed properly) plus some salt, bile and bilirubin. Bilirubin comes from the breakdown of red blood cells and is what gives stool its characteristic brown colour. In simple terms, the bacteria in the gut produce sulphur containing compounds and the gas hydrogen sulphide. The classic faecal smell comes from a substance called skatole, which is produced in the digestive tract, but diet can influence the smell too. For example, we know that by eating some of the brassicas we will always produce wind and an odour this gives us clues as to what has entered our food chain! Avoiding vegetables – Brussels sprouts, cabbage and broccoli, onions or garlic and spicy food will help you prevent wind and odour.

Today, modern stoma appliances come with an integral filter to release wind. But did you know that each appliance manufacturer uses a different type of construction for their treated carbon filter? A colostomate may find one filter ineffective but by trying another brand of appliance (after discussion with their stoma care nurse) may have a completely different experience! Filters can become ineffectual if made wet, so covering the filter when bathing or swimming is advisable. (Filter covers can be found in each box of appliances – and look like small sticky labels). Covers can be useful if you need to keep some wind inside your pouch to prevent pancaking. Colostomates can therefore have great confidence in stoma care appliances in

the knowledge that much research and development has gone into the many products available today – ensuring that there's a pouch out there – that's just right for you!

Several manufacturers and suppliers of stoma care appliances, produce drops, granules or sprays (these are available on prescription) designed to neutralise any odour. These can be introduced into a clean pouch before you put it on (however if you believe you can smell the content of the bag whilst you are wearing it there is usually a problem, either a nick in the front of the pouch where you have cut the template or it could be that the appliance is leaking or faulty. (Those of you who use a drainable appliance may find the end is not clean or not closed properly).

Some ostomates find that drinking tomato juice or buttermilk, or eating natural yoghurt or parsley, helps to control odour. Others take peppermint capsules, or recommend lighting a match in the bathroom after a pouch change. It's natural to worry about odour when you have a stoma but hopefully some of these suggestions will help overcome any issues you might have.

Extensions...

Leakages can also lead to the embarrassment of odour. Perhaps a flange or pouch is not fitting securely around the stoma so allowing faeces to escape under the flange? It is always wise to contact a stoma care nurse to discuss if the hole for the stoma is the correct size and have it resized to ensure a snug fit around the stoma.

If you use extension flanges due to pancaking or leakage this may hide the real problem i.e. requires convexity or a seal due to creases in the skin, changes in diet or because the peristomal skin may have become excoriated).

If you continue to have problems, because the faeces are too firm and this therefore lifts the flange, (pancaking) or too loose so that it

leaks under the flange, an ideal solution is to wear extension strips of adhesive around the flange itself. Many of the manufacturers and suppliers of your pouches make these and they are so simple to apply. Putting one or two of these extensions around the flange will help make it secure and ensure that the flange does not lift off causing the faeces to escape and therefore make a mess of your underclothes or bedclothes. I tend to advise using flange extenders when the edges of the appliance lift either during exertion, golf, gardening or in bed when you roll over!

Flange extenders give you that extra confidence. If you have an issue they will buy you some time to locate a bathroom to change your pouch. They stick incredibly well - so well that you will probably need to use an adhesive remover to lift them off, but they may make all the difference to the management of your stoma.

Note: All of these products are available on prescription. Ask manufacturers for samples, and talk to your stoma nurse if you feel you would benefit from any of the items described. All we ask is that you use products sensibly. If you feel you need a product to manage your stoma then ask for it. Explain why you think you need it and discuss all the alternatives available. At the end of the day your stoma nurse and GP want you to live a happy life with your stoma and should help you achieve this with sensible use of additional products.

Editors Comment

If you use any of these products in your change routine. Please write in any tell us about your experiences or hints and tips. See Page 6 for CA contact details.

Journeying towards... a stoma and colostomy

Some patients may have either ignored the tell tale signs in their poo or have no idea why their poo seems different somehow or may have had years suffering from Crohn's or another type of bowel condition. Some may already be on their journey with bowel cancer. There are several reasons for receiving a colostomy – too many to list here – but each one will have caused – great distress, pain and anxiety.

What emotions strike the hearts and minds of those sat in the consultant's office when they hear the words – 'I think I need to perform a colostomy.'

As you sit there, in a state of disbelief your mind going over and over those words. The consultant is already on to the 'why's and wherefores' – hopefully you are lucky enough to have a partner or friend sitting beside you taking in all the reasons why the procedure is necessary.

There cannot be many of us who would welcome the thought of wearing a pouch containing our poo on our tummies! The immediate thought is – 'I can't bear it', 'I don't want to think about it', or 'No, I am not going to have it'. These thoughts are completely natural but as the consultant continues to outline the reasons why you require this life changing and life saving operation – your mind returns to what he's saying and you begin to realise that life with a colostomy may be better – much better – than your initial thoughts and reactions!

After 'that' meeting with your consultant will come an appointment with a stoma care nurse – this dedicated clinical nurse specialist is your greatest ally – they will be beside you to explain everything you need to know about a 'living with a stoma and colostomy'.

The stoma care nurse will help to allay your anxieties and concerns and may show you what a stoma will look like and where it will be sited on your tummy. The specialist nurse may talk in greater detail about how your operation will be performed, your aftercare and give some insight on how to manage your stoma and colostomy. You will probably be taken through the various appliances and products available to you and may also be introduced to an alternative method of bowel management known as colostomy irrigation. All this may seem daunting at first – a great learning curve – but little by little you will begin to feel more at ease with having a stoma and colostomy.

To give you an understanding of wearing an appliance, the stoma care nurse may suggest that you experiment with some pouches, placing them onto your tummy and removing them to get you used to the idea (it may be suggested to fill a pouch with a little porridge and then apply this to your tummy so that you can experience the weight of the pouch). This will give you a good appreciation of the strength of the adhesive. It will also give you the opportunity to practice with an adhesive remover – taking the pouch off without damaging the skin around your stoma. More information will follow post op, such as caring for your stoma and colostomy, getting into a routine and how to order, receive and store the products and supplies that you will need once you leave hospital.

You may have many questions pre-op – 'will it smell' – 'will my appliance fall off' – 'will people be able to see my appliance'. Natural concerns, but ones that can be answered.

• Will it smell? – Output does smell but this is due to bacterial action in the bowel, which is a natural

phenomenon. There are two main reasons why odour may sometimes be detected – firstly, when an appliance is emptied or changed and secondly, when an appliance is fitted incorrectly causing leakage.

• Will my appliance fall off? – Adhesive on the flange area of the pouch is very strong and sticky hence the possible need for adhesive removers. These ensure that the skin remains intact when removing the used appliance. Adhesive extenders can be added to the flange for extra security.

• Will people be able to see my appliance – will everyone know I have a colostomy? The answer is NO! Receiving a colostomy will not change how you look to others. You are the same person but how you adjust to your stoma and colostomy is up to you – try keep an open mind and stay positive. Discussing your concerns with someone else 'who knows how you feel' and is a little further along the journey is extremely valuable. You could ask your stoma care nurse if you could chat to another colostomate pre-op. Mixing with other ostomates may help you to discover – that no one will know you are wearing a pouch unless you choose to tell them – you are in control.

• Will I still be as attractive? – How you feel about yourself is so important but equally important is sharing your feelings with your partner and family or a very close friend – talking is crucial. Intimacy is always uppermost in our minds when we realise that we will be wearing a pouch 24/7. (The Colostomy Association has trained volunteers who can discuss this subject with you in confidence). Your stoma care nurse will also be able to discuss this subject and offer advice.

Choice of pouch – there are many pouches available to the colostomate.

Tidings magazine includes several advertisements that give you an idea of the different types – closed, drainable, flushable, one piece and two piece. These are just words in the early days. Your stoma care nurse will assess you post-op to find the best appliance to suit your specific needs.

Apart from the flushable pouch (or if you are irrigating) you will need to dispose of the used pouch. Place the pouch into a plastic disposal bag, and, once properly sealed, drop into the household waste bin. Some colostomates find this quite a difficult task to do at first but try to think objectively – ‘it has got to be done so I’m going to do it’. There are excellent nappy disposal bins such as the one available from Tommy Tippee that individually wraps and seals each nappy so no smell can escape (many colostomates use this disposal system) when the bin is full simply remove the contents and place in your household waste bin.
(For more information:
Freephone: 0500 97 98 99 or visit:
<http://www.tommeetippee.co.uk/product/nappy-disposal-system>).

Once you have recovered from the operation you may like to discuss the idea of colostomy irrigation with your stoma care nurse – not everyone can irrigate but it’s definitely worth investigating. The Colostomy Association can provide a booklet and DVD, which explains all about this method of managing your bowel. Very simply – using a water reservoir, tubing, a flexible cone and gravity, water is instilled into your colon, which starts peristalsis (contractions and relaxation of the intestinal muscles) this action then moves faeces along the colon washing them out through the stoma into a plastic sleeve and out into the toilet. With the colon free of faeces there is little or no output from your stoma for 24 – 36 hours. This method of managing a stoma and colostomy needs to be professionally taught by your stoma care nurse.

Many colostomates ask if they can travel? Can I still fly? Can I go on a cruise? Can I cycle? Can I continue to run marathons? The answer is an overwhelming yes – you can! There is nothing that you cannot do once you have a stoma and colostomy that you could not attempt before you had the operation. In fact, if you read some of

the ‘pathway’ stories in Tidings you will realise what people have achieved – small steps to get them out of the house or fantastic feats to prove to themselves that this life changing operation was for the best.

Sometimes, especially at the very beginning of your ‘journey’ so much written information is too much to take in but it is always good to have it to hand to refer to. It is also a good idea for family members to read about what the operation means to you and them. From knowing very little about a stoma and colostomy – what it looks like – how it will feel? – will it make a difference to your life? – how will you cope? – you and your family will gain confidence through knowledge – and this will help reduce your concerns and anxieties.

I am not going to pretend that adjusting to a stoma, colostomy and wearing an appliance is easy. You do not have to like your stoma, but you do need to – accept it – as in most cases it will have either saved your life or reduced your suffering.

Tidings magazines contains inspirational stories written by colostomates, explaining how they live with their stoma and these in themselves may lead you to say – ‘I can do that’. You will find your own way of managing your stoma and getting on with your life. A positive attitude is what will get you through – your journey – if you embrace that, then you will continue to enjoy life to the full.

All of us, who have begun the journey of living with a stoma and colostomy, have asked the questions that are in your mind. However, with the love and support of family and friends you may soon realise that by having this procedure – you are getting on with the rest of your life.

**Jackie Dudley
Trustee**

About the CA..

We are the only dedicated charity that specifically represents the interests of people living with a colostomy.

We exist to help colostomates and the wider world learn and understand what it’s like to have a colostomy and to care for and live with a stoma on a daily basis.

We represent and give continued support to this special community.

What We Do

Listen & Reassure
Empathise & Support
Understand & Help
Discuss & Refer
Encourage & Motivate

What We Provide

24 Hour Telephone Helpline
0800 328 4257

Contact volunteers*

- Home or hospital visits to chat about what it is like to live with a colostomy
- Discuss emotional or practical problems you may have
- A volunteer can be matched to a patient by age, sex, location or by problem
- * All our volunteers are fully trained and adhere to guidelines set out by the Colostomy Association with the support of stoma care professionals.

Practical knowledge

- Hints and tips for living with a colostomy
- Impartial advice to those who have or are about to have a colostomy

Advisory literature

- Leaflets and booklets written by health care professionals and colostomates

Tidings magazine

- A quarterly magazine written especially for colostomates, their families and carers

Website

- Containing a wealth of information and support for colostomates, go to:
www.colostomyassociation.org.uk



“If I concentrate really hard they will think it was someone else”

Views of a New Boy... the immediate thoughts of a new colostomate

Walking out of St Thomas' Hospital with my wife Bea was like stepping into a fresh new world. It was a crisp evening and Big Ben was striking seven. Although it was October and I had no coat, the only feeling was one of exhilaration. While I still had some way to go, in that there were now bits of me missing and I still carried stitches, I felt that this was the beginning of another round of my life.

And so we strolled up onto Westminster Bridge. Bea had the wheelie bag containing, amongst other things, the accessories with which I was to become all too familiar. As for me, I tentatively took to the streets of London again. Home was by London Bridge and so only a cab ride away, but as usual, at this time of night, cabs were hard to come by.

Lest I am painting an over dramatic picture I should stress that I was only in for ten days, and, while cancer and surgery was involved, it turned out not to be an overly traumatic experience. Mind you I had been in the year before for a quadruple heart bypass and a valve repair so that may have had something to do with my attitude.

So how did it all start? Well a trip to my GP with concerns about spots of blood led to a series of tests, which concluded with the revelation that there was a growth in my bowel, but the biopsy had not shown cancer...yet. However they did recommend surgery to catch it early. I of course went into denial. At first I did not remember surgery being suggested at the first meeting, despite my wife being with me and there being a drawing indicating what might be removed.

When I finally met the surgeon, the seriousness of the situation, and the impact on my life finally hit me. And so to the “not me” stage and the questions. My father survived stomach ulcers without this type surgery! How long had the growth been there? Is it fast or slow growing – or is it even growing? Can't we just watch it to see what happens? Would exercise help? Should I change my diet? And there was the question of life style. Life or death didn't bother me. How I lived did. The thought of living with a bag initially strikes terror into the heart of most people, and I was no different.

Next came the “why me?” stage, but that was short lived in that the explanation given was Life Style. I sought to blame the food producers and their chemical, the quality of the air we breath, anything ...until I recalled the care I had taken over what I ate and drank through out my life and the phrase “fair cop” came to mind.

Finally, while testing out all the reasons why I might not need to go under the knife, I spoke to a nurse who put it simply by suggesting that she would much rather nurse me through this operation than what I was likely to face in a few years time without it – and then briefly described the possible later stage. At this point surgery became the obvious choice and I moved on. Only now did I research life after the operation on the Internet. It seemed grotesque at first but quickly I realised that it was a process, slightly inconvenient but it should not overly affect my life. I could manage it. Amongst close friends, who were now aware of the upcoming change, I was able to joke. Having had a heart bypass this was to be an arse bypass. While I will have lost a part of me there was going to be great savings in the cost of toilet rolls. As you will gather our humour is less than subtle.

And so to the event. I was to be at the hospital at four in the afternoon to check in and for tests. I duly arrived at the designated ward only to be diverted to another, which diverted me back to the first. Everyone was very pleasant, if a little confused, and my wife and I were led to a day room while things were sorted out. We had been warned that there might be delays and had brought books. By seven o'clock things sprang

into life. Blood was taken, a bed allocated, and the surgeon arrived to explain everything. The family felt that he was a really nice guy and that I would be in safe hands. Okay, but it was me he was going to cut open. It was then suggested that, as one of my sons had arrived, the three of us go out for dinner. It was a pleasant end to a slightly confusing day.

And so to the pre op, the op and the post op, none of which I intend to describe other than to say that an epidural coupled with morphine is magic. The first can be difficult to connect, but well worth the initial discomfort. I never did find out if it was normal to supply these or whether it was due to my response to question “are you allergic to anything?” My answer was “Yes, pain”

The care I received was excellent and the staff were highly supportive. Okay, maybe I could nit pick here and there, but I felt that I was being well looked after. And then there was the view of London from my bed on the eleventh floor - it was stunning and all on the National Health Service. During my stay I weaned myself off the television, even though it was available, having brought books. I also used my phone to access the radio and in doing so discovered that I also had access to books on it. Isn't technology wonderful?

So, what lessons did I learn from this experience? Well first the experts are just that. They face this situation every day. They know how it evolved, what could happen next and what needs to be done now. Also, it is the NHS; there is no profit motive in their recommendations. Next, yes you have to doubt and question their recommendation, there could be something they missed, or more likely you forgot to tell them that could make a difference. Maybe there is an alternative route. But at the end of the day you need to draw a line and accept your fate.

I guess the only thing left to say is thank you to the staff of St Thomas' for identifying and then rectifying something that could have greatly affected my life... again.



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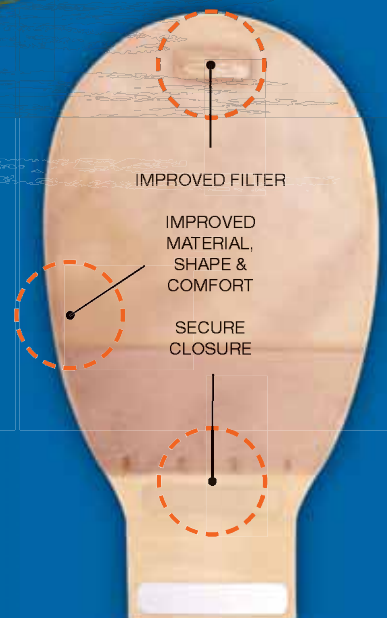


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Public Toilets – municipal facilities worth fighting for!

'A lack of accessible and good public toilets affects not only the quality of our town centres, parks or bus stations, it also reduces the dignity and quality of people's lives. After all, they are one of the basic facilities that residents and visitors alike depend on. Good quality provision instils confidence in public facilities as a whole, helps to inspire positive impressions, and contributes to many other important aspects of life. Whether it is families with small children or older people, it is important that people have the confidence that the facilities they need are available when they are out and about'. People rightly expect accessible, clean, safe and well maintained toilets.

Baroness Andrews OBE – Communities and Local Government Improving Public Access to Better Quality Toilets – A Strategic Guide

The first public toilet in Britain was opened over 150 years ago – and for a long time the provision of state-of-the-art municipal facilities was a matter of considerable civic pride. Over the years (in some places in the UK) public toilets have fallen into decline causing much public consternation. Today, in these times of austerity, when the cost of providing public services is under scrutiny – our nation's toilets – little by little, are falling under the 'cost cutting axe' of local government.

More and more stories are appearing in the press about public toilet closures in communities around the UK. Losing public toilets affects everyone but, much more so – the vulnerable – such as people living with long term bladder and bowel conditions.

A group of interested parties are working together across the UK to highlight and prevent (where possible) 'cuts' to scrap public toilets – placing those Councils under considerable pressure to reconsider their actions.

Trustee Jackie Dudley is spearheading a CA campaign against such closures. "I have been working with some amazing groups – the British Toilet Association, Truckers' Toilets UK, Department of Planning and Architecture University of West of England and several others to influence various Councils to take notice of our objections to closures and lack of facilities," says Jackie.

Isn't it interesting how much we take our town and country landscape for granted – it's only when we pull over onto that familiar lay-by or go to the park with our children or have a medical need 'to go' (that we can do nothing about) when we suddenly realise those all important public toilets have gone. Forever.

Knowing where to find good public toilets is essential when away from

home. A shopping trip or a long journey can be of real concern to the ostomate and requires some research prior to setting off on even the smallest of journeys. Armed with this information the ostomate is secure in the knowledge that if they need to change their pouch they know where to head to do it.

Losing access to these facilities is a tragedy. Cuts today could have implications on Council budgets in the future, getting it right today for tomorrow, makes much more sense.

So it's important we gain a clear understanding of what's happening around the UK. If you hear of any plans to shut public toilets in your area, please do let me know so that I can pass this information onto the various groups I am in touch with. The more voices raised against the closures the better!

There are some Councils suggesting that local shops and stores will be amenable to the general public using their toilets but, with so many public toilet closures happening throughout the country, I can foresee long queues forming in M&S, Tesco and other large stores!

You may have read about the lady in Bath who staged a sit-in to stop the Council closing the public toilets in the village of Twerton (just outside Bath). A brave stance – with a successful outcome! Bath Council is now rethinking the planned closures. This proves people power can make a difference – shout out loud – against these closures, please help!

If you have access to the Internet look up BTA – The British Toilet Association. (Contact: 02891 477397 or visit: <http://www.brittoos.co.uk>). Their mission is to represent the interests and aspirations of 'away from home' toilet providers, suppliers and users – to act

as a catalyst for change in the pursuit of standards of excellence in all areas of public toilet provision and management.

The Colostomy Association, working together with the BTA and other organisations will, with your help, speak with a 'very loud' voice to take public toilets out of Council cost cutting regimes.

With the help of BTA, the Colostomy Association will also focus in on other problems within the public toilet environment – the lack of coat/baggage hooks inside the toilet cubicle. Recently, I had a meeting with the manager of Reading Railway Station to talk about just this. I visited the new and very modern toilets that have been built as part of the refurbishment process – no hooks! Not one in sight, anywhere! Surely everyone needs a hook! We need them to hang up our coats, handbags, rucksacks or whatever to avoid using the floor. Ostomates especially need a hook on which to hang their change bags. So, if you do come across a public toilet, in whatever location, without this 'precious' item – please let me know so that I can contact the managing agent to ask to have one installed.

As colostomates we are often challenged when we use the disabled toilet. The Colostomy Association has introduced an ID card for use with the RADAR key. Both the ID card and RADAR keys are available from CA – details on page 11.

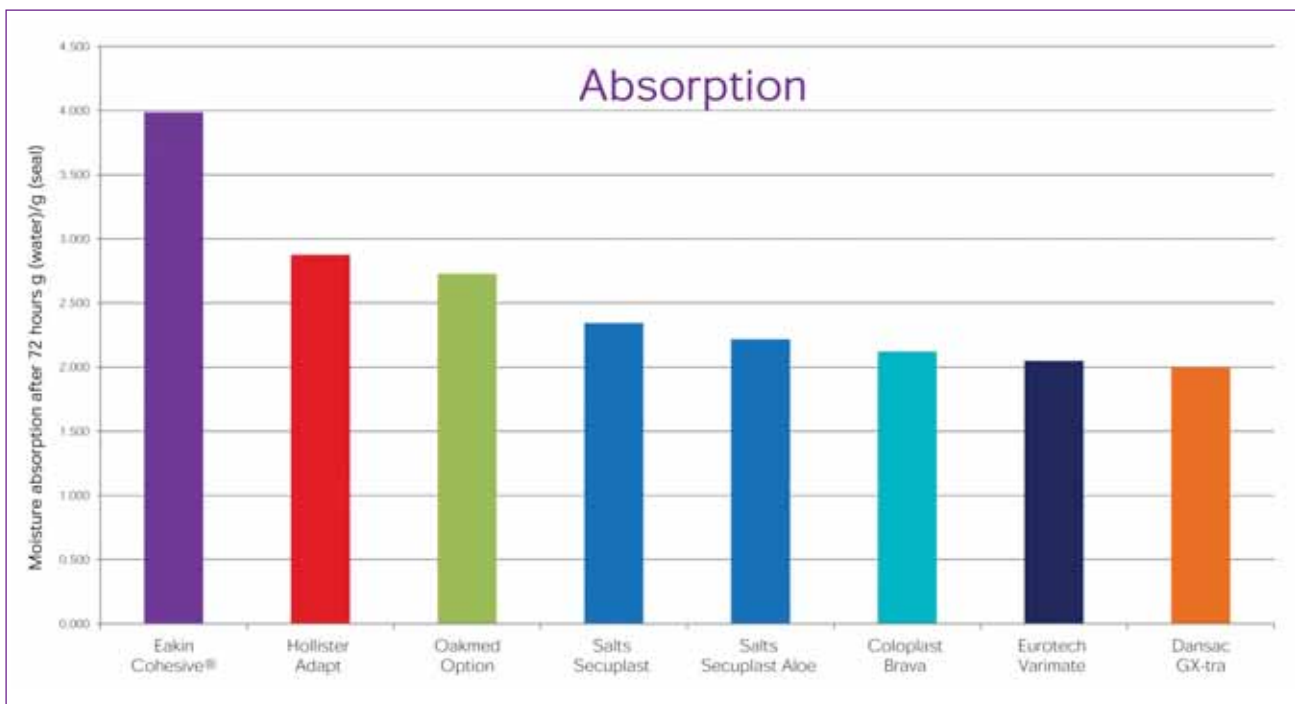
The Colostomy Association works hard to ensure all ostomates have access to clean and well designed public toilets. So please don't hesitate to contact me via the CA office – so we can work together against closures or improve these vital facilities in your area.

Please help us to help you!



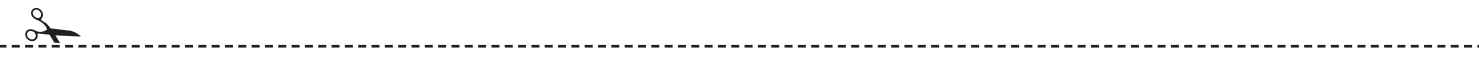
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Making a difference to young lives...



Hannah is twelve and is the inspiration behind Breakaway. She was born with a complex anorectal malformation and needed a colostomy at birth that was later reversed. She now has an ACE and a Mitroffanof.



Hannah says...

I go to Breakaway because I know I get to be with people the same as me. Through Breakaway I get to meet people like me and become friends with them and meet up with them. I wouldn't be as confident as I am now without my Breakaway friends.

My friend Ellie says...

My best friend Hannah has a funny tummy where she can't do her business like other people. It is amusing when Hannah does her washout (another word for a poo) because we laugh at the sounds we hear when she has a poo. Going to Breakaway gives Hannah the opportunity to socialise with people with the same challenges as her, also

she gets to do stuff that she can't do with people not knowing about her problems.

Before the end of our first year of secondary school, my form went on camp with another form and we all had lots of fun! When everyone was getting ready for bed me and Hannah went to the toilet to do her washout. When we went to do the washout we found out that there was no light switch so we did the washout by torch light!

Hannah's grandma says...

Breakaway was set up to help families that had no contact whatsoever with

other families in the same situation. Being part of Breakaway means that families (in such situations) can come together at an event where they can share their problems and concerns. Breakaway with its ever listening ear offers support to families from those who genuinely care, which is priceless.

Breakaway welcomes all the family – which is so important because when a child is ill their siblings can feel very isolated. Breakaway events – challenge the children and their parents to do and achieve things that they may never have thought possible – what a feeling of satisfaction that must bring! Everyone makes new and lasting friendships – for when times are tough and, for when things go well!

As a grandma, I have hands on experience of the challenges a youngster with bowel and bladder problems can bring. These can be made a lot easier when you know you are not alone, by joining Breakaway – families realise – they are not alone!

Owain is fourteen and has a colostomy. He was born with imperforate anus and had a colostomy performed at birth. This was reversed when he was two, however he had to go back to a colostomy when he was three.



My sister says...

My brother, Owain now has a colostomy and has grown to be happy and comfortable with the condition as he hasn't known any other way. Before he started school he was very nervous, as he didn't want anyone to find out about his problem. As he

has got older he still won't tell anyone, that he doesn't have to tell, but of course his close friends know he's got a condition but he's no different to any

other children. It doesn't stop his swimming, playing tennis, canoeing abseiling, orienteering.

Before Mum came across the advert about Breakaway, we didn't know any other child that had a colostomy. After attending an event every year since that day, he has made many friends that have got a colostomy and many similar conditions. This has made him a lot more confident and has also given him more understanding of his problem and helped him to take care of his colostomy himself, and be more independent.

Max is four and was born with Hirschsprungs disease, and now has a colostomy. Max has a sister, Georgie, who is eight.

My mum says...

Max has Hirschsprung's disease and bladder incontinence which impacts on all of our lives on a daily basis and we are all on his journey together as a family; we have very little support locally.

Aside from the medical professionals & a specialist stoma nurse in Birmingham we all needed another form of support, I wanted to talk to other Mums about poo & wee not a medical professional, Neil wanted to speak to other Dads



over a pint about the same thing, Georgie needed to spending time with siblings & children with bowel condition to understand how they deal with their brother/sisters conditions. She can be very resentful of the time Max spends with us whilst giving him his daily cares and Max just needed to be allowed to be himself with children similar to

himself.

I spoke to his nurse who suggested Breakaway. I was quite anxious as to how the other parents would be & would the children be very shy. In fact the atmosphere was amazing and everyone was so welcoming; all of the parents were so open and friendly, and we discussed the same things such as guilt, fears, relief, anxiety etc. It was whilst I was at Breakaway I decided I would stop giving myself such a hard time about all of the surgeries we had put Max through, there were children there with far worse conditions than Max & they were still smiling.

As a family we will carry on facing new challenges as Max gets older but knowing all of the mums, after meeting them at Breakaway, I'm now friends with them through social media which offers me supports & a virtual hug when I need one.

Ethan is eight and has a colostomy due to constipation of an unknown cause. Ethan had an ACE, but that didn't work well so he had a colostomy formed. He has a twin brother called Tom.

My auntie Debbie says...

The charity Breakaway means a great deal to my nephew and his extended family. Ethan has had numerous operations and some bad times with his bowel; and this has affected the whole family.

Seeing him so ill and in pain at such a young age was distressing for everyone especially his mum Nicki. But since finding Breakaway and receiving their



help and taking part in their holiday weekend's things are a whole lot better. Ethan is more confident and doesn't feel like the only kid with these problems, he takes parts in activities such as high rope walking with his brother and mum, laughing and shouting without having to worry about

his bag leaking or smelling. As a family they have been canoeing, bridge building, rock climbing, held snakes and other creatures.

They've made crafts and new friends, new friends who have helped at all stages of Ethan's care.

The main benefit are the helpers who are there to help with any problems offering advice and help at anytime. Sharing information on different products that are available and how to use them has helped find the best products for Ethan.

Having someone to talk to when things seem to be going down hill or someone to offer a helpful word of advice or support has helped my sister to get through the bad times. The connections the charity has with the professionals means that there is always someone to answer the questions.

Note: Above excerpts taken from the 'Breakaway leaflet – Making a difference' reproduced with kind permission from Breakaway. This article and its content must not be reproduced in any form without prior permission from Breakaway.

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Millennium year – bolt from the blue! Tore shares his story...13 years on



The year 2000 proved to be eventful in more ways than one. What started off so promisingly after a fantastic all night New Year's Eve party was to take a dramatic turn.

Married to Nicola, with a daughter Kari and a son Kurt, and a well paid job, I enjoyed a full and active life. Vice Chairman of our local Parish Council, Chairman of the Scouts and secretary of a local organisation called the Brinsley Senior Citizens Tote, I was very actively involved in our local community. All of this was going to be put in jeopardy soon early in the New Year when, out of the blue, I was diagnosed with bowel cancer at the age of 56.

There was no prior warning as such, no pain or discomfort, life, to all intense and purposes, was great. On Sunday 19th April 2000 I had just arrived home from leading the Scouts on the St. Georges Day parade in Brinsley and gone to the toilet, quite normally so it seemed! What I discovered next was a bowl splattered with blood. As I was going to the doctor next day about another problem, my throat, I didn't need to book an appointment. Whilst there, I mentioned my previous day's problem.

An immediate examination by my doctor confirmed that there was something there that shouldn't be. I went to work after telling my wife what had happened and just over an hour later I got a call from my GP that I had an appointment at Nottingham Queens Medical Centre (QMC) nine days later, now that's what I call service! Nicky and I, although in shock at the time, decided not to tell the children until we knew the result of the biopsy.

We both looked at the worst case scenario so as to prepare ourselves for the results of the preliminary investigation. We decided, right at the outset, that we would both go together to all meetings as "two heads are better than one" so to speak. This proved invaluable as during discussions one could miss something that the other would pick up, and vice versa. No one else, apart from Nicky and myself, was aware of what was going on.

My first appointment when the biopsy was done - not a particular pleasant experience but necessary - was on Wednesday 29th April. A fortnight later we went back to the QMC for the results and already we had made up our minds to expect the worst. Waiting in a large room with other people, some coming for the first time, some for the results, was agonising. Although we arrived well in time, all appointments were running late. Eventually my consultant called us in to give the news. It's surprising that even though you prepare yourselves for the worst news it still comes as "one great big shock"! After the consultant explained all the "ins and outs" of what would happen over the next few weeks I will never forget the words he said as he left the room. At the door he just turned round and said, 'We're going for cure.'

A stoma nurse explained in great detail about having a stoma and equipped me with a video and literature on the subject. I was thankful for the fact that I was being well prepared for life with a stoma because the consultant had warned me that the stoma would most likely be permanent, and that was the final outcome. One question the nurse did ask was: 'Do you both drive?' The

answer was Yes and how important this proved to be as initially I wouldn't be able to drive for at least four weeks.

The next hardest thing to do was to get the children together to tell them what was happening. This wasn't easy as one lived nearby and one in London, however, we managed it. After the initial shock we all knew what I was faced with and set about approaching it in a positive manner. We informed relatives, close friends, my workplace and anyone else we knew who should be among the first to know. News like this spreads like wild fire. It was amazing how supportive everyone was. This spurred me on, to tackle the situation head on and look forward to the future. It's at times like this when you need support and I felt I owed it to all my family, relatives and friends to come out on top!

The operation was set for Tuesday 20th June, the day after Nicky's birthday. What a present! I had four sessions of radiotherapy in the previous weeks and one last session on the Monday I went in. As my bed wasn't ready I was told to go out for a while and come back in the afternoon, so a pub lunch, with Nicky and Kari seemed to be a good way to while away the time. Back to the QMC and the final preparation for the operation next morning. A quick visit by my consultant, who was doing the operation, was comforting and a confidence booster too.

The operation went well, then "nil by mouth" for a week and lots of visitors. My first shower after a few days was bliss, and my first food, a slice of toast, with a cup of tea was heaven. After a fortnight I was discharged with strict instructions; no work or sport for three months.

Following "doctor's orders" I started gradually getting back into my local activities and eventually went back to work full time and started playing badminton and tennis again. All the time in the three months off I had been getting accustomed to my new way of going to the toilet. There were mishaps on the way but they were easily coped with at the time. I was to find out later about support groups and what an important part they can play in the life of an ostomate. Without my colostomy I wouldn't be here now thirteen years later enjoying life with all my family.

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REAL LIVES TORE'S STORY

Chemotherapy started in the August and lasted for six months. Five days a week, every four weeks which I did not look forward to. My firm was very understanding and it worked out that I was able to leave work every afternoon, have my treatment and then drive home. I have to say that my chemo was not very toxic and I had no real side effects.

Life got back to normal very quickly though another shock was to happen just a year later. Coming back off holiday I was informed that after 22 years service at my place of work, I was no longer wanted! So much for loyalty and getting back to work. Signing on the dole was not easy as the young lady who I had to see was the daughter of a friend. Thankfully I was only out of work for less than two months.

Periodic visits to my consultant and oncologist ensued and eventually after five years the oncologist signed me off followed by my surgeon two years later. I still have the dreaded colonoscopies every now and then, which will continue until I need them no more! I consider myself to have been very fortunate and to be living as normal a life as possible considering what might have happened. I am a proud grandfather to three boys and one girl

who I might never have seen. How precious life is!

Over the years we have been to Canada and New Zealand, been on four cruises plus lots of away days and weekends. On the Canadian trip I took plenty of supplies which took up quite a lot of room. When we went to New Zealand, my supplier sent supplies to the address at which we were staying. Despite being stopped a couple of times because I forgot to pack my scissors in my check-in luggage and had my hand luggage searched, travelling has been no problem. Cruising has been superb, with no unforeseen problems, and will continue until the money runs out.

Back in Brinsley I was delighted to be made Honorary Freeman of the Borough of Broxtowe in November 2002, evidently for my work in the community over the years, followed four years later in July 2006, with a surprise invitation to Buckingham Palace to attend one of the Queen's Garden Parties. Both of these events came totally out of the blue but are treasured memories both for me and my family.

Over the years I have been a member of the Nottingham QMC Support Group and with my wife Nicola have been

running a small support group at Kings Mill Hospital, Mansfield. The importance of these groups has become apparent to me over the years. Being an ostomate can be very traumatising and support groups can help people to readjust to their new life. Nicky and I get great satisfaction from the positive feedbacks we get from our members. Whilst we can't give medical advice we share experiences, whether it is about appliances, food, travel or how to overcome the mishaps ostomates may have.

As a result of all that has happened since my operation and the fact that I am still here to enjoy and share my life with family and friends I decided to try and put more back into supporting others with the same condition. I applied and was successful in becoming a volunteer worker for the CA in November of last year. Meeting fellow ostomates, and talking to them over the phone has been most interesting and gratifying. If I have been of help to someone, whatever the problem may be, then everything is worthwhile.

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Access for all: A campaign for fair and equal access to cancer drugs



Stuart Barber –
Head of Campaigns and Communications
at Beating Bowel Cancer

gives Tidings readers' an invaluable insight into the campaign **Access for all** – fair and equal access to cancer drugs in the UK

One of the key questions patients ask after being told they have bowel cancer is 'what are my options?' Unfortunately, what discussions you have with your doctor will differ depending on where you live in the UK.

A fundamental principle of drug access is that if your oncologist tells you that a treatment might work for you, then you should get it. Yet, while a patient in Carlisle can talk to their doctor about a range of drug options that suit their needs, a bowel cancer patient in Gretna or Llanelli will have far different conversations with more limited choices.

There is currently a list of life-prolonging cancer drugs, which can be used for patients whose bowel cancer has spread; yet they are not available on the NHS as they are deemed too expensive. In England, patients are able to access these drugs free of charge, as the cost is funded through a special government pot called the Cancer Drugs Fund. As a result, thousands of patients with bowel cancer have been able access these treatments. Many of them are still alive today and have been able to spend valuable extra time with their loved ones. Yet this was originally due to end in 2014.

In Scotland and Wales, patients don't have access to a similar fund. This leaves patients having to make some very tough choices between not getting the treatment their doctor recommends because the NHS won't fund it; using hard-earned life savings to pay for the drugs privately and at enormous expense; or making the ultimate decision to leave family and friends and move across the border where the treatments are freely available.

This growing postcode lottery for life-saving drugs across all nations of the United Kingdom means that Welsh patients are more than five times less likely, and Scots patients three times less likely to be prescribed cancer drugs that are routinely given out to English patients.

Worries that there is a widening disparity in accessing cancer drugs for patients across with the UK meant that the issues have been debated heavily in Westminster, the Scottish Parliament and the Welsh Assembly.

As a charity we have long campaigned, along with other organisations such as the Rarer Cancers Foundation, to allow greater access to drugs where there is clear, clinical evidence that a patient

would benefit. We believe in granting patients access to medicines based on clinical need, not cost, and which is equal for all patients wherever they may live.

Our campaign to extend the Cancer Drugs Fund in England
The Cancer Drugs Fund (CDF) was originally a three year commitment to enable patients in England to gain access to life extending cancer medicines. Over 10,000 bowel cancer patients have been given greater access to cancer chemotherapy drugs which their doctors had recommended, thanks to money released by the Fund. As a result, many of them have been able to spend precious extra time with their families and friends.

However, the CDF was only intended to be a temporary bridge to the Government's aim of introducing a new system, which was due to come into force in April 2014. As the transition deadline approached there was still no agreement on how the system might work.

We sought assurances from Government that it would keep the promise it made to all cancer patients before the last election and ensure that

patients' access to high quality cancer care wasn't disrupted by the transition to a new pricing system. We were worried that we would return to a time when cancer patients have to beg for treatment or be forced to fund it themselves.

Beating Bowel Cancer campaigned hard for an extension of the CDF. Back in April, we raised our concerns with the Secretary of State for Health Jeremy Hunt that the transition could result in access to cancer drugs moving backwards. We estimated that as many as 6,500 new bowel cancer patients a year in England risked having their access to vital drugs cut off in January 2014.

In September the Prime Minister David Cameron met with the Rarer Cancers Foundation, Beating Bowel Cancer and cancer patients, to hear what the Cancer Drugs Fund has meant to them. The visit was part of an announcement by the Prime Minister that the fund was being extended for a further two years until 2016.

Access for All campaign in Scotland
Despite the CDF success in England, we urgently needed to address the growing postcode lottery that existed between nations. The limits of the current process were leaving Scottish cancer patients being unfairly denied life-prolonging treatments under the NHS in Scotland.

The only hope Scottish patients had of getting these drugs was through a process known as the Individual Patient Treatment Request; but only if their doctor could demonstrate to the local health board that his or her patient was an 'exceptional' case. However, for many patients this was proving to be a lengthy, confusing and frustrating experience, with no guarantee that their applications

would be successful. As a result only a very small number of cancer patients were receiving particular drugs.

In response, in September 2012 we launched a campaign to highlight the concerns of patients who were unable to access the drugs that their doctors wanted to prescribe. We raised alternative solutions and pressed for policy change to establish a fairer system of access for cancer patients. Headline after headline in the Scottish media highlighted the stories of bowel cancer patients who were being forced to plead their cases for drugs.

The Cabinet Secretary for Health and Wellbeing, Alex Neil MSP, announced that there was to be a review of "every aspect of the introduction of new medicines" in Scotland. Following our campaign on behalf of bowel cancer patients, a group of influential Members of the Scottish Parliament acknowledged that the current system was not working and needed immediate reform. The review gave great consideration to all the criticism that has been thrown at it by bowel cancer patients, whose cases were highlighted in many of the Scottish newspapers.

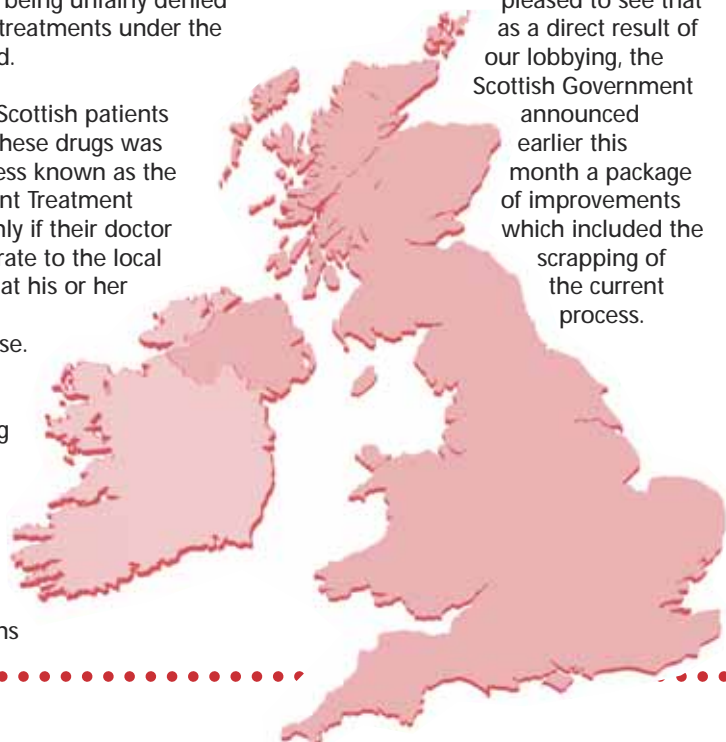
In what was another substantial win for bowel cancer patients, we were pleased to see that as a direct result of our lobbying, the Scottish Government announced earlier this month a package of improvements which included the scrapping of the current process.

The recommendation is to replace it with what will be called a Peer Approved Clinical System (PACS) based on the clinician's judgement of what their patient needs. In our view, the Government's announcement is a positive step forward.

The real test will be whether doctors feel they have the freedom to prescribe, confident that any decisions are based on the interest of patients.

However, we are seeking further detail on how the Scottish Government plans to develop the new system, before patients and clinicians alike can judge whether it will succeed in fully delivering the principles of fair drug access to Scottish patients.

Whilst we have seen huge strides in Scotland and England in terms of access to treatments, we still need to watch developments closely to ensure all patients get the medicines they need. Our attention now turns to Wales to see whether we can help patients there.



If you, or someone you know, is having difficulty accessing a bowel cancer treatment, you can contact Beating Bowel Cancer's nurse helpline on 08450 719 301 or email: nurse@beatingbowelcancer.org



Dear Nurse

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



Q: I'm nearly 80 and had my colostomy five years ago and have never had any problems until recently I now have sore skin under my bag. My doctor has given me some cream to apply to the skin around my stoma and stoma care nurse has suggested placing gauze, cut to shape beneath my bag to prevent direct contact with my skin. This is all a little tedious and fiddly. No one has given me a proper explanation as to why this keeps happening. Do you think I could be allergic to the bag? I would really appreciate your view as to why this keeps happening. Many thanks.

A: Sore skin can be due to many reasons such as a template that is too large, a leaking pouch or as you suggest to an allergy to the adhesive. To assess the cause of your sore skin you would need a review by the stoma care nurse as the treatment depends on the cause. If it is a template problem then cutting to the correct size will help the problem although it may be that it requires some treatment in the meantime. If it is due to an allergy then a complete change of products is required and if it is due to leaks, assessment of the stoma and current products but again treatment beforehand. If the skin is sore but dry then you could try a Barrier Spray such as Cavilon or one of the many stoma company sprays and a seal, which is a barrier that is adhesive on both sides so that it will adhere to the skin and to the pouch. If the skin is wet then a powder such as Orahesive, again under a seal would help. I hope this information is helpful but I would certainly suggest a review with your local nurse to assess the specific problem and then she can prescribe the correct treatment.

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

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

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

Q: I had an emergency stoma about five weeks ago and will be having chemo and radiotherapy shortly. I am experiencing ballooning and cannot seem to get any help from my stoma care nurse. I am also going through a lot of supplies. I know it's early days but can you suggest what might be the cause – help would be greatly appreciated

A: It is not unusual in the early days to have issues with ballooning but there are many products available to use with different filters so you should be able to find one that is suitable for you. Keeping a diary of the foods and drinks

that you are having will help you to identify any specific foods/drinks, which may be the cause of increased wind. Some patients find Peppermint (tea, mints or cordial), Fennel (as a vegetable, tea or mints) and Charcoal (as biscuits or tablets) help reduce wind. Hopefully you will find a solution that works for you but if needed you can ask for a review with your stoma care nurse.

Q: My mum is having problems changing her colostomy bag. She has arthritis in both hands and is finding it difficult to apply and change her bag properly. She is still in hospital and will not be discharged until she can manage her colostomy. What can I do to help her so that she can come home?

A: It may be possible to use a different product that your mum finds easier to apply such as an adhesive coupling two piece. The baseplate would need changing two/three times per week and it maybe that you could learn to do this for her or she could have carers to help with this part of the change. The pouch then sticks onto the baseplate and even with arthritis your mum may be able to manage this herself. If she cannot do any of the changes then it may be that you will need to take over the complete change routine for her and the stoma care team will be able to provide training for you. If you are unable to help with the stoma care then it may be possible for your mum to be referred for support in the community from carers and again the stoma care nurse can provide training for the carers if needed.

Q: I have been undergoing radiotherapy and chemo for bowel cancer. I was coping really well until my painkillers 'codeine' seemed to make me constipated. My GP has given me suppositories and Movicol, which has led to chronic diarrhoea. I am worried and have lost confidence. What should I do next?

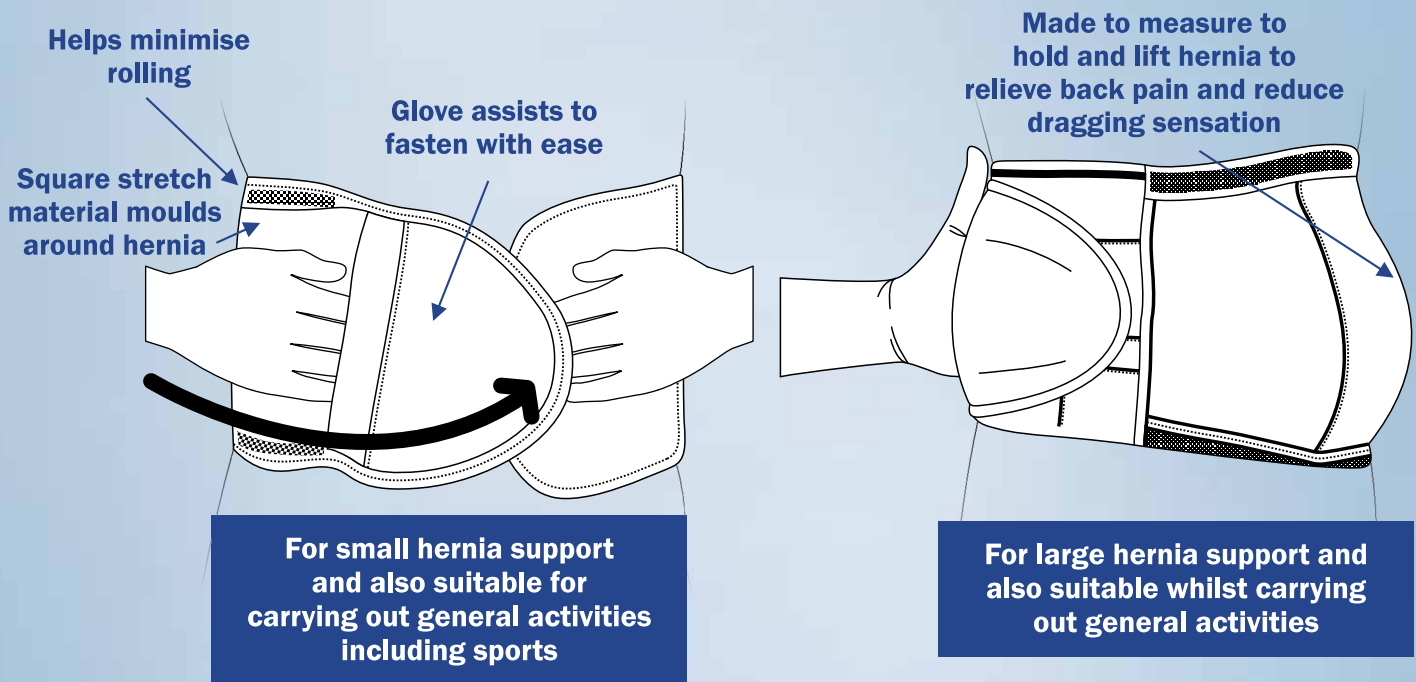
A: Codeine can cause constipation but there are many different things to try to help to solve the problem.



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Suppositories and Movicol may be too purging for you and something such as Fybogel, Lactulose or Senna may be better. Fybogel is good for regulating the bowel but you do need to drink plenty of fluids if you are taking it. It is a powder in a sachet that is added to water once or twice per day and helps to soften and regulate the bowel movement. Lactulose and Senna are also laxatives, which may help either alone or as a combination. If you are still undergoing radiotherapy and chemotherapy I would suggest speaking to the oncology team as you need to ensure that whatever you take is suitable with the treatment you are having. You do need to ensure that you are eating a healthy diet and drinking plenty of fluids as this will help to maintain a healthy output.

Q: I had a colostomy in 1995, due to cancer of the colon. Eight years ago I was given the all clear, then in April this year I saw the adverts for the bowel screening program on TV. My wife suggested I send for a kit, but before I sent away for the kit I gave them a ring to see if I still needed one (as I said it was eight years ago when I was given the all clear). They rang back and asked if I still had my large bowel I confirmed that I did and said that I had a colostomy. Their advice was to do the test – I received the kit and sent off the sample it came back as abnormal. I queried the result and they then sent another kit I sent another sample off and that too came back abnormal. I then received a letter from the surgeon with an appointment for me to have a colonoscopy. He confirmed the cancer had returned so he gave me an ileostomy (on my right side) in August this year – taking all my large bowel away – no problem – I'd managed a colostomy for 18 years, so I could manage an ileostomy! The only difference now is my diet as they say I have to eat more food with less fibre. The two main reasons why I have written this letter is, if anyone gets a kit for bowel screening DO IT SEND IT OFF and, where can I get a good book of recipes for ileostomists – explaining what foods are good and what foods to avoid.

A: You are absolutely correct that if people receive a Bowel Cancer Screening Kit then they must complete it even if they have had previous surgery for a similar problem. As your case has demonstrated, and thank you for sharing your experiences, you can still have further problems which need investigation and treatment.

With regards to booklets and diet for ileostomates I am not aware of anything specific except via information from the IA (the ileostomy and internal pouch Support Group). You can contact them via their website visit: www.iasupport.org, via email: info@iasupport.org, via telephone: 0800 0184 724 or by post write to: Anne Demick, National Secretary, IA (the ileostomy and internal pouch Support Group), Peverill House, 1-5 Mill Road, Ballyclare BT39 9DR. I hope this helps and again 'thank you' for sharing your experience.

Q: I had my non-reversible colostomy in April this year due to a Sigmoid Volulus. I have been coping very well with my day to day bag routine, my stoma is, (so I have been told), small but very healthy. The problem that I am experiencing is that of having a ten to fourteen day cycle. That is to say, on day one – I have severe gurgling, (water down a drain) and rumbling then, produce as much as six/eight full bags of liquid output, nausea/vomiting, discomfort, bloating and abdominal pain. This is followed by a non-activity period, of ten/fourteen days. I find this situation difficult to handle. I have been back in hospital twice for further tests – there are no blockages or obstructions, but I am informed that I am suffering from, very low potassium levels, severe constipation and have been prescribed laxatives, which apart from creating gas, do not help all that much. I'm told to always seek advice when required, which I do. As you may appreciate, this causes me a lot of physical pain, anxiety and distress. My query is – am I an isolated case, or are these types of occurrences common and all just part of the healing process? And, if so, how do I break this cycle? I look forward to your reply/advice.

A: This sounds very much like intermittent obstructions but what the cause is I cannot say. The information regarding seeking advice when this happens is correct and hopefully if you seek advice when you do get the problem then they will be able to investigate and identify the cause. Once the cause is identified then they should be able to treat it and prevent recurrence of the problem. It is not a common occurrence but I have had patients with a similar problem and have been able to find a solution. I'm sorry I cannot give you a definitive answer but your situation is quite complex and the best advice is to continue to seek help as needed until a solution is found.

What kind of stoma do you have?

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

Five facts about an ileostomy

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

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

Five facts about a colostomy

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

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

Editors Comment

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

If so write in and tell us:

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Readers' writes

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

Dear Editor

I really ought to feel really ashamed of myself for not sending a cheque in towards Tidings ages ago. It has been a case of 'I'll just do it tomorrow' and then never getting around to it. Even now, it has taken me too long since the Autumn edition to get round to it! There's always something else to do first – it's just not good enough! Yet in spite of my far too casual approach to this I have so much to be grateful for – I survived TB 1951-52, Bowel Cancer 1994, By Pass 1995, so even a small payment to your great magazine should not, in anyway, be too difficult a thing to do I count myself so lucky! I do make a contribution to other charities at times, but this one is long overdue.

Best regards,

G.S

Dear Editor

I would like to say how much I enjoy reading TIDINGS and although I have an ileostomy there is often relevant advice and tips from other ostomates. I came to have mine while I was receiving chemo for Hodgkin's Lymphoma (2011) and after my 5th infusion had to have an emergency operation for a Colovagina Fistula after 4 weeks. I have completed my chemo and have been in remission from my cancer for 18 months now and it is 2 years since my ileostomy. Over the last two years I have found great support reading how others in the same position have adjusted and coped with the changes. So I would like to thank all at the Colostomy Association for TIDINGS and the hard work that goes in to making this such an interesting and informative magazine.

Kind regards,
M.T

Dear Editor

This is a belated thank you letter to the Tidings Editorial Team. I cannot begin to tell you what a treasure this magazine has been to me. To begin with I have to go back to 2008 when I had my operation due to a polyp on the muscle of the bowel. I had a wonderful consultant and two stoma nurses who were always there when I needed them. I managed my stoma from the beginning, having a cry now and again, and a few mishaps. I could probably write a story about them, but all that faded into the background when my husband became ill. He had to have an emergency operation due to a tumour – it was a very traumatic time. Thankfully! He pulled through! It may sound strange, but I was glad I'd had my stoma as I was able to give him all the help and support he needed. So you now have two avid readers of Tidings!

Thanks and best wishes to you all,

E.W.R

Dear Editor

When I first had my ileostomy in 2010 it took me quite some time to get used to it for various different reasons. It was a few weeks before I could change my bag without retching because of the smell. I was half afraid to go anywhere as the output was so erratic and sometimes loose making the use of a nearby toilet necessary. One day I decided to keep a log of everything I consumed including drinks and my output (wind or otherwise). I found this exercise very useful for finding out which foods and drinks to avoid. I was really quite surprised at some of the results e.g. intolerance of fruit

squash drinks. I am pleased to say that over time things have settled down and I can now tolerate some foods that were previously no-no's and I hardly ever get wind noises now.

Yours sincerely,

D.N

Dear Editor

I have travelled through UK and foreign airports many times in the last five years with no problems. For the last four and a half years I have managed my stoma with irrigation and to this end I have taken, in my hand luggage, with the rest of my colostomy supplies, a selection of metal 'S' hooks on which to hang my irrigation bag. The security officers usually single out the hooks but after they have read my 'travel certificate', signed by my stoma nurse, they let me proceed.



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Readers' writes

However, after an unhappy experience at the hands of an over-zealous and rude security officer at Manchester airport, I decided to change the metal hooks for a less intimidating mix of plastic ones. These include large plastic hooks (carabiners) obtainable from Amazon and smaller carabiners from most outdoor shops. I also have two plastic 'over the door' hooks, a small one from a DIY store and a larger one which is a coat hanger airer from Lakeland. These are really useful if there is nowhere in a bathroom to hang the irrigation bag, however, many hotel doors are too deep to accept the bracket.

I still take my metal hooks on holiday in the UK including one with a spring which is for holding a paint tin on a ladder rung. They are available from a variety of suppliers, Ikea, B&Q and various kitchen shops. I also take a metre of very thin climbing rope and some string. In one instance I had to tie an adjustable walking pole to a radiator, extend the pole to the correct height and hang the irrigator bag from the wrist strap.

Kind regards

K. M.

From Ed:

If you would like more details of these hooks and where to obtain them, please contact CA head office details can be found on Page 6.

Dear Editor

I am writing in to Tidings in the hope that I can gain the experiences of other Ostomates in relation to rubbish collection in different areas of the UK. In Pembrokeshire our Council has introduced a two weekly pick-up of black bags (used stoma pouches are placed in these), any plea for alternative sacks and pick-up has fallen on deaf ears. What are the

arrangements in other parts of the Country? I am unable to use the 'flushable' pouch owing to our local drainage arrangements. It would be helpful to know what happens in other areas of the country. Thanks for your most helpful magazine.

Yours sincerely,

M.B

From Ed:

Thank you M.B. for your letter. It would be interesting to find out what happens in other areas of the UK. Please send in your observations so that M.B. can gain a clearer picture. Details of how to contact the Editor can be found overleaf or on Page 6.

Dear Editor

I've found a product that helps prevent ballooning. It's a pouch venting system from OstoMart. At first glance I thought it looked bulky as I took the little plastic 'plug' out of its packet, and wondered if it would show beneath my clothes – but it didn't. The instructions for attaching it to the pouch, looked quite complicated and were a little difficult to read owing to the size of the print. But I soon realised how it worked! It was quite simple – you just stick it where you like, on the frontside of the pouch, near the top – avoiding the filter. Then you open the little lid on the vent and with a thin, pointed implement pierce through both the outer and the inner water-proof layers of the frontside of the pouch. Put a couple of fingers from your other hand inside the pouch – through the hole (made for the stoma) – opening the bag up slightly to avoiding piercing the back layers of the pouch. It seems quite difficult, but really, it isn't – provided you have a certain amount of dexterity in both hands. When using this product I've found that you have to decide beforehand, whether in the course

of the life of that pouch, you're going to eat/drink things likely to cause 'ballooning', as you can't install the vent once your pouch is in place. It's the answer for me so why not give it a try.

P.P.

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

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

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

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

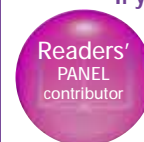
via email:

editor@colostomyassociation.org.uk

or write to:

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

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





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How can the NHS electronic prescription service benefit you?



Now we're in the throes of winter we're all looking for ways we can avoid unnecessary trips in bad weather. One journey that could be saved is a trip to the GP surgery just to collect a repeat prescription. With the NHS Electronic Prescription Service (EPS) many patients are being offered the chance to have their prescriptions sent electronically from their GP to the dispensing appliance contractor or pharmacy of their choice.

For a patient with a colostomy, ordering prescription items can be time consuming and inconvenient; you have to create your order, take it to the GP surgery where it is prepared and hand signed by the prescriber. It might then be faxed or posted to the stoma provider or you might have to collect it to send in the post. It relies on snail mail, envelopes and expensive stamps to get the prescription to the appliance contractor in enough time to allow them to prepare and send the appliances to you before you need them.

EPS is a more efficient way for patients with regular prescriptions to get their appliances. If you wish to use the service you choose or "nominate" the stoma provider you want to use. Your GP practice, dispensing appliance contractor (DAC) or pharmacy can

record your nomination for you. You then order your prescription in the same way as you do now. An electronic prescription is then produced by reception staff in the surgery and electronically sent to your GP to sign with a card and a PIN, a bit like a debit card. It is then sent safely via a secure NHS server to the stoma provider you have nominated and, because the prescription is electronic, it can't be lost in the surgery or on the way to the dispenser. The DAC or pharmacy then receives the electronic prescription within minutes allowing them to prepare and send the appliances to you for when you need them.

One DAC using EPS said: "With EPS we usually receive the prescription on the same day it's requested. This means we can dispatch the patient's prescription requirements in a timely fashion to ensure they have continuity of supply."

Every patient's experience is different, but if you consider a patient who spends half an hour collecting their prescription every other month, for perhaps 30 years, EPS could save them 122 days, or almost 4 months! It is not always solutions to the complicated problems that can make a difference to patients, but simple technology that allows convenience and choice.

If you receive the same products each month, electronic repeat dispensing can work with EPS to offer you even more benefits. With repeat dispensing your surgery is able to sign up to 12 months of electronic prescriptions at once, which will be sent automatically to the your nominated DAC or pharmacy at the right intervals, seven days before it is due. This saves you the hassle and inconvenience of ordering the same items each month and saves time at your doctor's surgery too. If there is a change needed to the prescription, your surgery can electronically cancel the remaining items and prescribe new items electronically.

Over a third of DACs are now able to receive electronic prescriptions and over one in seven GP surgeries have the ability to send them, with 100 additional practices switching on EPS each month. If you want to use EPS for your prescriptions talk to your current stoma provider and find out if they can receive your prescriptions electronically. They can record your nomination for you and when your GP goes live your prescription will be sent there electronically. This can be changed or removed at any time you wish, either at your GP surgery, pharmacy or DAC. If you get medicines you can also set a nomination at a pharmacy that is convenient to you.

Check NHS Choices to see if your pharmacy or DAC is able to receive electronic prescriptions.

Visit: <http://www.nhs.uk/service-search/pharmacies/appliancepharmacies>

Visit the EPS website for short videos on how EPS works and search the EPS map to see if your GP surgery is using EPS or will start using it soon.

Visit: <http://systems.hscic.gov.uk/eps/patients>

EPS is being rolled out by the **Health and Social Care Information Centre (HSCIC)**, the trusted national provider of high-quality information, data and IT systems for health and social care.

SUPPORTXTM



www.supportx.co.uk

Easy Peel Support Belts



Easy to wear

The unique attachment allows the level of support to be slowly "walked across" using the double Easy Peel tabs.



Easy to Adjust

Use the double Easy Peel tabs to give a more uniform fit by staggering them to conform to just about any body shape.



Easy to Access Pouch

Undoing the bottom Easy Peel tab and simply lifting the detached part of the belt allows quick and fuss free access to the stoma pouch.

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For further
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For further information or a prescription request form please call **FREE**

0800 9179584

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



ami
COLLECTION

Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group
Freephone: 0800 0184 724
www.iasupport.org
- UA Urostomy Association
Tel: 01889 563191
www.urostomyassociation.org.uk
- IOA International Ostomy Association
www.ostomyinternational.org
- Stomadata & Stomafit
www.stomadata.com
www.stoma.fr
- Macmillan Cancer Support
Tel: 0808 808 00 00
Mon - Fri: 9am - 8pm
www.macmillan.org.uk
- Mitrofanoff Support
Tel: 01202 937530
Email: info@mitrofanoffsupport.co.uk
www.mitrofanoffsupport.co.uk
- Crohn's and Colitis UK
Tel: 0845 130 2233
www.nacc.org.uk
- The Gut Trust
(Irritable bowel syndrome)
Tel: 0114 272 3253
www.theguttrust.org
- Bladder and Bowel Foundation (B&BF)
Formerly Incontact and Continence Foundation
General enquiries: 01536 533255
Web: www.bladderandbowelfoundation.org
- Bowel Cancer UK
Tel: 020 7381 9711
Email: admin@bowelcanceruk.org.uk
Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK
Tel: 08450 719300 (Lo Call rate)
Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)
(The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)
Web: www.glo-uoa.org
- Ostomy Lifestyle
Tel: 0118 324 0069
Email: admin@ostomylifestyle.org
Web: www.ostomylifestyle.org

Stoma Care Patient Open Day event dates...

For a comprehensive list of Patient Open Days events...visit the CA website.

Listings are updated throughout year.

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

Note: The Colostomy Association full contact details can be found on Page 6.

SASH

Freephone
0800 389 3111



Ref. No. HB102

Stoma Support & Hernia Belt Ref. No. HB102

The SASH Stoma Support and Hernia Belt is designed and manufactured by an Ostomist and gives support to the muscles surrounding the stoma.

Used by ostomists with a parastomal hernia (a bulging around the stoma) to help prevent muscle damage and enlargement of the hernia.

Eliminates most leakage problems and gives added security and confidence. Ostomists report relief from dull aches and pain in the stoma region when wearing the belt.

Ideal for work, sports, gardening, housework, DIY, or at any time stomach muscles require a firm support.

With support from a Sash belt and periodic consultations with a consultant some Ostomists are delaying, maybe permanently, the need for hernia surgery.



Ref. No. SR103

"The ring of confidence"

Security & Leakage Belt

This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the skin during all activities.

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



Ref. No. SS104

CUSTOM MADE BELTS ARE AVAILABLE ON PRESCRIPTION

No fittings required. Belts are processed and mailed within two working days

Stoma Shield Ref. No. SS104

The Shield will help protect the stoma from accidental chaffing or knocks.

Ideal for sport, gardening, DIY, housework, manual workers, builders, etc

Sash Medical Ltd.

Woodhouse, Woodside Road, Hockley, Essex SS5 4RU Tel: 0044 (0)1702 206502
Web: www.sashstomabelts.com



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S.O.G.S SHEPPEY OSTOMY GROUP SUPPORT

Meets monthly every 3rd Tuesday at the Alex Stride Hall, The Hope Street Centre, Wood Street Cark Park Sheerness ME12 1QH
Time: 11-30am to 1-30pm

All Ostomates, Families, and Carers welcome
Come for a Coffee, cake and a chat. Visiting speakers, raffles, Support and friendship, makes this the ideal place for all Ostomates

FOR MORE INFORMATION PLEASE CONTACT
VAL on 07449241005 or Email: sogs2013@hotmail.co.uk

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New Support Group: Channel Islands

Guernsey Ostomates
Venue: St Martins Community Centre
St. Martin, Guernsey GY4 6LL

Time: 7.30pm
Frequency: every 2nd Month – Jan/March etc.

Contact: Luci Deane 01481 236077/lucideane58@gmail.com

POUCH COVERS

Designed by Ursula Naish

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

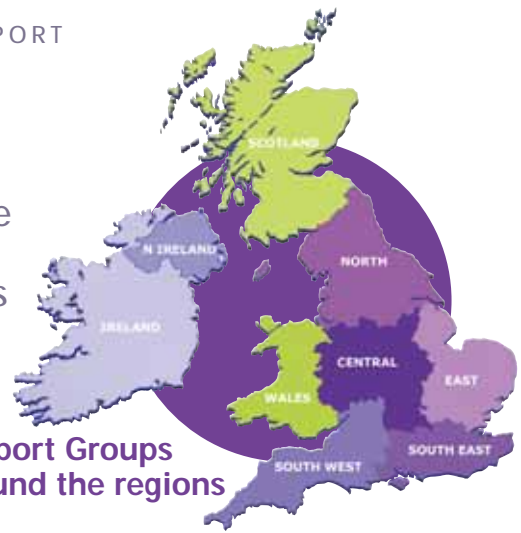
As Secretary of the UA Kent Branch she offers this service to raise funds for her local group.



For further information please contact:

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

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.



Shropshire: B.O.T.S (Bums on Tums)



We are a support group who meet on the second Thursday of each month in Oswestry. Our logo (left) represents 'new beginnings', as for many of us – a stoma – gives us our lives back after years in some cases of not being able to have a social life and, for some the inability to leave their homes.

Our aims are to:

- Socialise with other Ostomates
- Share experiences
- Pass on practical hints and tips
- Find out about the newest items on offer from suppliers
- Have a natter over a cup of tea or coffee
- Have talks on a variety of subjects

At our last meeting we had a very entertaining talk from the Castle

Manager of Whittington Castle here in Shropshire. She explained the history of the Castle from Iron Age times to the present; with illustrations via photographs on her laptop (unfortunately we do not have a projector). There is a possible link to Dick Whittington in that one of the resident servants managed to obtain an apprenticeship for one of their children, Dick of Whittington. He travelled to London to take up this apprenticeship, which represented to them that the streets were indeed paved with gold. There is no real evidence that he became Mayor, but it is a good story!

We also collect unwanted supplies and these are sent on to Ostomy Lifestyle – Ostomy Aid to help those in countries where they do not have the benefits that we enjoy.

We do enjoy meeting up and chatting to each other and passing on our own

tips on coping with the problems that having a stoma can throw up. One lady was having problems with very loose watery output and we were able to suggest the use of solidifying sachets which has helped her.

Another member was worried about going on holiday and everyone chipped in with loads of tips on that subject. The 'If only' article by Jackie Dudley touched a real chord and prompted us to ask Iain Norwood of Ami Medical/Supportx to come and give a talk on support garments as so many of our number had no idea that they should be wearing some sort of support.

Unfortunately, we cannot afford to pay speakers that often, but if we had more members this would be possible.

Irene Constable

If you would like to see your support group featured here...please contact Jane Wood - Editor: 0118 918 0500 or send your article and photos by post to: Editor, Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA or if you prefer email your article and photos to: editor@colostomyassociation.org.uk.



Thank you for your support

Regular donation

Your on going commitment means CA can plan its services with confidence safe in the knowledge that regular donations will be received. Help CA to reach out to more colostomates their families and carers to give support, reassurance and practical advice to those in need. With your help we really can and do make a difference - thank you!

Please fill in this form to make a **Regular donation by Banker's Standing Order**. Check your details are correct then return the completed form by post to: **Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537** if you have any queries.

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

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

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

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

To the Manager: (Bank or Building Society) _____

Bank Address: _____ Postcode: _____

Name(s) of Account holder(s): _____

Account number: _____ Sort code: _____

I would like to make a **regular donation*** of £15 £20 £25 £50 or other amount (please state) £ _____

monthly quarterly annually starting on the 1st 15th 25th of month: _____ year: _____

thereafter until further notice. *Please state your donation amount in words: _____

(Please cancel any previous standing order in favour of this beneficiary).

Please pay: **NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP**

Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS) _____

Signature: _____ Date: / / 2014

giftaid it

Thank you for your gift

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

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

Signature: _____ Date: / / 2014

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

Stoma Type: (Please tick) Colostomy Ileostomy Urostomy

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

To donate via standing order...Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you



Single donation

Thank you for your support

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

Please fill in this form to make a **Single donation**. Check your details are correct, then return the completed form by post to: **Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA.** Telephone: 0118 939 1537 if you have any queries.

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

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

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

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

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

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

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

Yes, I require a receipt (Please tick.)

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

Thank you for supporting CA – with your help – we can change lives!

giftaid it

Thank you for your gift

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

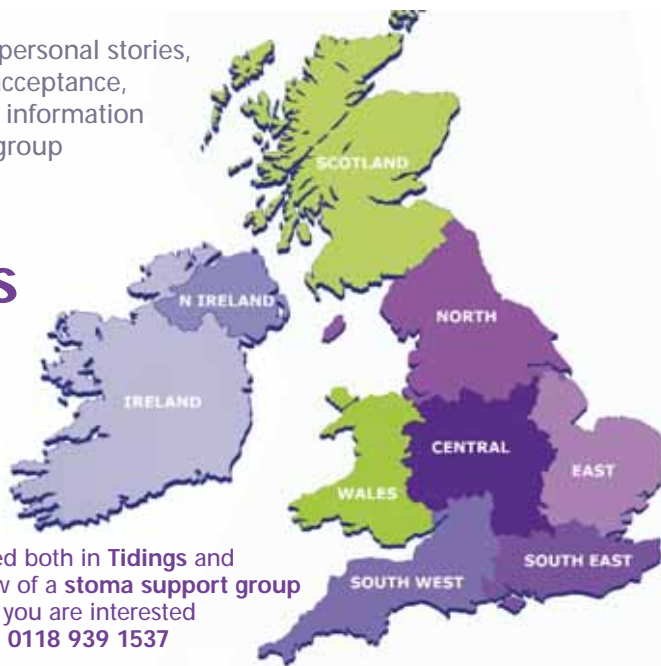
I would like the tax to be reclaimed on any eligible donations that I have ever made or will make to the Colostomy Association until further notice. I confirm that I pay an amount of income tax and/or capital gains tax at least equal to the tax that the Colostomy Association reclaims on my donation in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

Signature: _____ **Date:** / / 2014

To make a single donation...Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you

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

Stoma support groups in your region...



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

Scotland

Midlothian:

Maggie's Edinburgh
Contact: 0131 537 3131

West Lothian:

GOSH
Contact: Scott Pattison: 07502163644.4

Glasgow:

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

Ayrshire:

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

Fife:

Fife Ostomy Support Group
Contact: Ishbel Barr 01592 772200

England - North

Cheshire:

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

Cleveland:

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

County Durham:

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

Cumbria:

Grange Cancer Support Group
Contact: Marie 015395 33279

Derbyshire:

Stockport Support Group
Contact: Angela Simpson
0161 419 5059

Lancashire:

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

Merseyside:

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

Northumberland:

Berwick Ostomy Support Group
Contact: Bobbie Minshull 07714 479320
Hexham Ostomy Group
Contact: Judith 0143 4681972
Northumberland Cancer Support
Contact: Mary Miller 01434 622 392
Jim & Dee - 01434 230 398

Tyneside:

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

Yorkshire:

Acorn Ostomy Support Group
Michelle Hurrell on 07580693155
(after 6 pm).
Airedale Stoma Support Group
Contact: Sue Hall 01535 210483
Behind You (Calderdale & Huddersfield
Bowel Cancer Support Group)
Contact: Stoma Care Nurse
01484 355062
Barnsley-Bottoms Up
Stoma Support Group
Contact: Stoma Nurses 01226 432528
or Celia Utley (Chairman) 01226
284262
CROPS (Colo-rectal ostomy & internal
pouch support)
Contact: Gloria 0114 2879503
Dewsbury & District Ostomy
Contact: Janet/Eileen 0844 8118110
Rotherham Ostomates Caring Support
Contact: Karen 0788 0575758

SUPPORT GROUPS IN YOUR REGION

Scarborough Stoma Support
Contact: Sister Jean Campbell 01723 342388
Amanda Rowe 01723 342446
The Hull and East Riding Colostomy Support Group
Contact: Pete Smith 07989 565335
and Pete Rennard 01482 793966

Isle of Man:

Stoma Support Group
Contact: Carole Cringle 01624 650212

England - Central

Buckinghamshire:

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

Leicestershire:

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

Nottinghamshire:

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

Shropshire:

Oswestry Stoma Support group
Contact: Irene Constable 01691 238357

Staffordshire:

Outlook
Contact: Ernie Hulme 01782 324441
Moirra Hammond 01782 627551

Worcestershire:

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

West Midlands:

Coventry Stoma Support
Contact: Martin Robbins 07947 385643
02476402616

East Midlands:

Newhall Stoma Support Group
Contact: Diana Manning 01283 541311 or Helena 07932 331850

England - East

Bedfordshire:

Saturday Social Club
Contact: Karen Richards 01234 792278

Cambridgeshire:

Ostomistics
Contact: Alan Wright 01354 653290/
07836 661102

Essex:

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

Hertfordshire:

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

Lincolnshire:

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

Norfolk:

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

Suffolk:

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

England - South East

Berkshire:

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

Hampshire:

COGS (Colostomy Only Support Group)
Contact: Sarah Anderson 07907 820125
Solent Ostomates Support Group
Contact: Carole Summer 07527 707069
Solent Ostomates Support Group (New Forest Branch)
Contact: Carole Summer 07527 707069
Wessex Urology Support Group
Contact: David Morris 07910 786978

Isle of Wight:

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

Kent:

Ashford Stoma Support Group
Contact: Ron Huckstep 07941 310681
Margaret Webb 01233 628807
Atoms Support Group
Contact: Maria Culleton SCN 01227 769679 or 07827997424
Dover & District Stoma Support
Contact: Maria Culleton SCN 01227 769679
Dover Stoma Friends Group Support
Contact: Julie Bell & Ros Marshall 07771345701/01233616646
Maidstone Stoma Support Group
Contact: Judy or Kirsty 01622 224305
Medway Ostomy Group Support (MOGS)
Contact: Val Solly or Helen or Tracey 07773 605534
Thanet Stoma Buddies Support Group
Contact: Phil (Secretary) 01843 587769

London:

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

Middlesex:

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

Oxfordshire:

Oxfordshire Ostomy Fellowship
Contact: Pat Longworth 01235 524163

Surrey:

Epsom & District Stoma Support Group
Contact: Sheena 01372 735925

Sussex:

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

England - South West

Avon:

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

Cornwall:

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

Devon:

Mid Devon Ostomy Group
Contact: Janice Parkyn 01363 776417

Devon IA

Contact: Martin Hornby 01458 251095
01392 447374

Dorset:

CUPID Colostomy, Urostomy, Pouch, & Ileostomy of Dorset
Contact: Beryl Andrews 01202 483303
CUPID Colostomy, Urostomy, Pouch & Ileostomy of Dorset - West Dorset
Contact: Colin Clare 01305 853 288

Wiltshire:

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

Wales

Blaenau Gwent Self Help
Contact: Celia McKelvie 01873 852672
Bridgend Ostomy Patients Support Group
Contact: Anita Brankley (Secretary) 01656 645602 or Pat Jones 01656 786103
COSG (Cwmbran Ostomy Support Group)
Contact: Pippa Lewis 01633 791 339/07504713069
Royal Glamorgan Stoma Care Support Group
Contact: Domenica Lear 01443 443053
Swansea Ostomy Self Help Group
Contact: Glynis Jenkins 01792 418245

Northern Ireland

Antrim Area Stoma Support Group
Contact: Chris Wright 07720 717771
Belfast Royal Victoria
Contact: Sarah Haughey/Audrey Steele 02890 240503 Ext 3483
Causeway Patient Support Group
Contact: Mary Kane 028 70 346264
Colostomy Association Volunteers Northern Ireland
Contact: Chris Wright 07720 717771
Daisy Hill Hospital Newry
Contact: Bernie Trainor 028 3883500 Ext 2222
Mater Hospital Belfast
Contact: Karen Boyd 028 90741211 Ext 2329

North Down Stoma Support Group
Contact: Adrian Ewing 07850 741511
Southern Trust
Contact: Mary Jo/Bernie 028 38612721
Ulster Hospital
Contact: Hazel/Martina 028 90 550498

The Channel Islands

Guernsey Ostomates
Contact: Luci Deane 01481 236077

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

Did you know?

NHS Choices...Offers the opportunity to find Stoma Support services by postcode visit:
<http://www.nhs.uk/Service-Search/Stoma-support-services/LocationSearch/388>



Please let the CA know if you find one not listed in our group listings – thank you!



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