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welcome to autumn

Sue Hatton- Executive Trustee acknowledges...
The Late Margaret Bond

Sue writes: It was with great sadness that I learnt of the passing of Margaret Bond who was the Secretary of Devon IA. I first met Margaret at an IA Conference about nine years ago. We immediately hit it off, she was a lovely, jolly, wonderfully friendly person who had warmth and compassion and devoted a great deal of her time to helping anyone with a stoma. She said she was delighted that Devon IA has so many colostomists among its members and we both felt there should be more interaction between the Stoma Associations.

Cyril Smith and Janice Parkyn (CA volunteers) were members and sang her praises and admired the work that she put into the running and continuing growth of Devon IA. I was so impressed when I went to one of her meetings. The committee goes all over Devon running meetings in different parts of the county.

Our Vice President Mr Ian Daniels is also President of Devon IA and he went to Margaret's humanist funeral. He too thought Margaret was a remarkable woman and said her funeral service was very moving. He discovered so much about Margaret from the Eulogy, which his son sent me. It is a wonderful record of a remarkable woman's life. I admired her spirit and her generosity. Many ostomists whose lives she greatly influenced will sadly miss her.



Welcome to the autumn issue of Tidings...

Here we are tidying up and readying ourselves for the onslaught of what the British weather has in store for us over the coming months!

The garden needs sorting, the radiators need checking out to make sure they are working to full capacity as the chilly autumn air begins to creep through the house. Finding out our autumn jumpers, coats, brollies and wellies so that they are all to hand when the dog looks at you with those soulful eyes and you know you are just going to have brave the wind, rain and puddles to walk her!

Yes! It's autumn! Leaves are just about turning to their autumnal shades, red, yellow and brown and super shiny conkers lie scattered in the grass for eager little hands to find! I have to say I like this time of year - it's nice to feel warm and cosy inside whilst leaves blow around outside and people scurry about trying to protect themselves from the elements.

Autumn is a mellow season, it gently eases us from summer to winter without us realising. It eases us back into the school run, work and focuses our minds on what we are going to do with ourselves over the coming months when the clocks change and we find we're all in the dark!

For me! It's WeightWatchers and getting fit – something I've been meaning to do but just haven't made the time or had the positive mental attitude! But now I've made the effort – dare I say it – I'm enjoying it! Since I've been attending WeightWatchers I've realised what I've been missing. The company of others, warm human beings who want you to succeed, who have the same thoughts and worries as you but need the

companionship of others to help them towards their goal and keep them on track. It got me thinking about how powerful support groups really are! I'd been putting off going, why? Well, no reason really just the usual – I won't know anyone – what does that matter. It doesn't! But that's just human nature isn't it?

The CA Facebook article in this issue of Tidings, highlights just how much people can change when they join a support group. For a start they are not alone anymore dealing with their problems and concerns. The focus has changed. Now, its...there are people out there - just like me! The relief is overwhelming. Yes, there are people just like you - who have experienced similar difficulties, who understand, who can help, who change lives. So, if you, like me have been thinking about joining a support group - stop thinking - join! It could change your life for the better! There is a list of support groups at the back of each issue of Tidings and it is regularly updated. The CA helpline is also available 365 days of the year 24/7 if ever you are in need of support, reassurance or practical advice, here's the number 0800 328 4257 there's someone like you - waiting to take your call!

This issue of Tidings is packed full of interesting articles and favourites such as Dear Nurse and Readers' Writes – I hope you enjoy it! Don't forget! Keep those letters, emails and articles coming!

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!



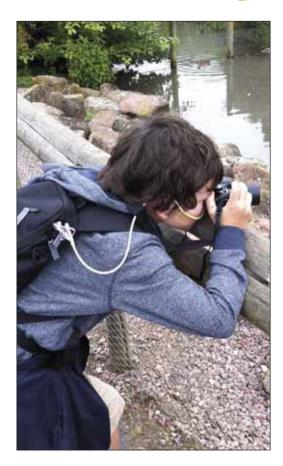
Email: editor@colostomyassociation.org.uk

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

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

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

About...the Colostomy Association

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

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

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

By telephone:

General Enquires: 0118 939 1537

Stoma care queries only: Freephone Helpline: 0800 328 4257

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

Find us on FACEBOOK:



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

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

Don't delay... Donate Online today!

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



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

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

Advertising Enquiries:

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

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EDITORIAL TEAM

Editor

Jane Wood

Executive Trustee
Colostomate
& Helpline Volunteer
Sue Hatton

Trustee
Colostomate
& Helpline Volunteer
Rosemary Brierley

Trustee
Colostomate
& Helpline Volunteer
Jackie Dudley

Trustee
Colostomate
& Helpline Volunteer
Duncan Wells

Trustee Colostomate & Volunteer Sarah Squire

Colostomate & Helpline Volunteer Georgina Williams

Senior Administrator Jo McKenzie

Stoma Care Nurse Advisor Amanda Gunning RGN, CNS

How to contact the Editor By letter write to:

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

By telephone: 0118 939 1537

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

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

Tidings Magazine:

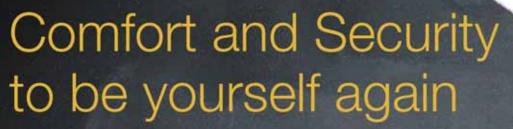
The views expressed by the contributors are not necessarily those of the Colostomy Association. Great care has been taken to ensure accuracy, but the Colostomy Association cannot accept responsibility for errors or omissions.

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





Confidence for new and existing ostomates alike.

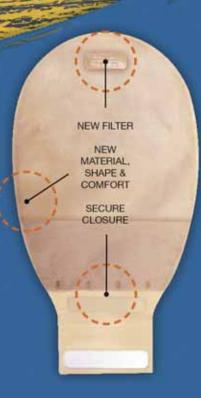




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Dear Readers...

The CA office continues its pivotal role – providing information, support and reassurance to colostomates, family members and carers. Fully trained CA volunteers run the 24 hour helpline (out of office hours) – they are there to support you, listen to your concerns and chat them through with you if need be. 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' and signpost to healthcare professionals and sister support charities.

We welcome all your calls, letters, requests, emails and donations – so do please keep them coming – we are here to help! However, when Tidings hits readers' doormats, the CA office can sometimes experience upwards of a 100 calls a day. As there are only a few of us to answer the phones and deal with email enquiries, we try to handle all requests as efficiently and effectively as possible but do please bear with us at this busy time.

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.

Here's a way of helping CA – that could make a difference to YOU this Christmas...

Join our 500 Club and WIN BIG with our end of year extra prize draw!

The 500 Club is a way of raising vital funds for the Colostomy Association. The club gives YOU the opportunity to win cash prizes ranging from £25 to £1000.

For the sum of only £24 per year, you will be entered into a quarterly draw for cash prizes of up to:

- £500
- •£250
- 3 x £100
- 3 x £50
- 3 x £25

Also...At the end of each year a further prize of £1000 is awarded. Draws take place at the end of March, June,

September and December and winners are notified and published in Tidings Magazine.

This December one lucky 500 Club member will have the chance of winning £1,000! Yes, £1,000! As they say on TV...You have to be in it...to win it! It could be you!

There are still a number of 500 Club places available (membership is limited to the first 500 applicants).

The 500 Club raises around £3,000 each year for the CA – this financial income is really needed and very much appreciated.



more people who join the 500 Club, the better it is for its members and for the CA!

If you would like to join the 500 Club please fill in the form opposite on Page 9. Or visit the CA website: www.colostomyassociation.org.uk. On the home page – click on the 'Get involved' tab and drop down to 'Join the 500 Club' where you will find a downloadable application form.

500 Club... June 2013 Draw Winners!

Mr R Clements	£	279.00	
Ms L Jennett	£	141.00	
Mr GGA Hancock	£	56.40	
Mrs M A Bebbington	£	56.40	
Anonymous	£	56.40	
Mrs J Neal	£	28.20	
Miss P Dawson	£	28.20	

Mr C Kendrick	£ 28.20
Mrs E Cowlishaw	£ 14.10
Mrs J Robinson	£ 14.10
Mr C Baker	£ 14.10

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

Miss Dawson donated £8.20 back to CA Mr Clements donated £20.00 back to CA

Here's how to join the 500 Club!...

Simply complete and cut out this standing order mandate and return it to: Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA as soon as possible.

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Title: N	ame:	Surname:
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Instruction to your B To the Manager: (Ban	ank/Building Society to pay by k or Building Society)	Banker's Standing Order
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Account name: 500 C	lub Account No: 89252314	Sort code: 60-17-21
the sum of £24.00	amount in words: Twenty fo	our pounds
Date of first paymen	t: (at least one month from sub	mission)
and thereafter on the	same day every year until further	notice.
Name: (IN CAPITALS)		
Signature:	Date:	/ / 2013

Note: If, at the time of any draw, the club is not fully subscribed, the Colostomy Association reserves the right to distribute prizes in the proportion of the subscriptions received. Colostomy Association: Lottery Licence no. LOT000141



Donations – 'the threads, which help bind us together'

Everyday acts of charity 'are the threads, which help bind us together'. The Trustees and staff of the Colostomy Association are doing a great deal to secure the future of this BIG hearted charity – so that it can sustain its current support services and build new ones which will reflect the needs of the ostomate, their families and carers in the years to come.

By embedding sustainability as a strategic concern, the CA will enhance its ability to deliver its values and vision;

- Values the Colostomy Association (CA) believes that every ostomate has the right to receive excellent care and ongoing support.
- Vision to reach out to and improve the quality of life of all ostomates, their families and carers.

The Colostomy Association cannot deliver its values and vision alone. It is clear that the 'threads, which help bind us together' – are your experiences and ours – common bonds of understanding. Your letters, emails and kind gifts of donations and legacies – reflect your passion – for our work, which is wonderful. However, we know that if we don't secure more permanent, regular donations from the 'many' –

ostomates, family members, carers and supporters – we will continue to stumble towards our goal of 'sustainability' instead of moving forward freely – secure in the knowledge that your support is a constant.

Every single and regular donation the CA receives is celebrated – we are not complacent, only respectful and grateful of your help.

The CA can only ask that all the readers of Tidings (some 19,000) and supporters of the CA consider 'the threads, which help bind us together' for the sake of securing the charity's future and those who continuously need our support, reassurance and practical advice, today and in the future.

Help CA support the work of our incredible Volunteers...

We have over 100 volunteers across the UK delivering a range of free services for us, such as answering the 24 hour helpline, dealing with adhoc callers who have concerns about specific topics, representing us at open days and visiting ostomates at home or in hospital.

The cost running our helpline, printing and posting literature, training volunteers and covering their travel costs amounts to around £40,000 per

Please help us continue to run these invaluable free services for ostomates, their families and carers.

Without our volunteers the CA would cease to exist! Thank you all so much.

The CA photo ID card is proving

challenged when entering or

very popular as it can be useful if

exiting accessible toilet facilities.

If you would like to apply for a

Photo ID card, please complete

the form opposite and return it

· A copy of your prescription

or delivery note as proof

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

downloadable from our website:

www.colostomyassociation.org.uk

Please allow 10-14 days for

Alternatively, the form is

delivery - thank you

of eligibility

Passport photo x 1

Payment – cheque

to the CA for processing with the various enclosures listed below:-

Photo ID Card...



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.

Name:

Address:

Postcode:

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

Telephone No; Email:

(if you have one) so we can include this information on our database - many thanks!

National Key Scheme (NKS) Radar Key

and optional Photo Identity Card...

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

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

National Key Scheme - Key and photo ID card purchase

Title:		
Name:		
Address:		
	Postcode:	
Tel:		
Email:		

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

Disability Rights UK

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

Signature of self or carer:

/2013

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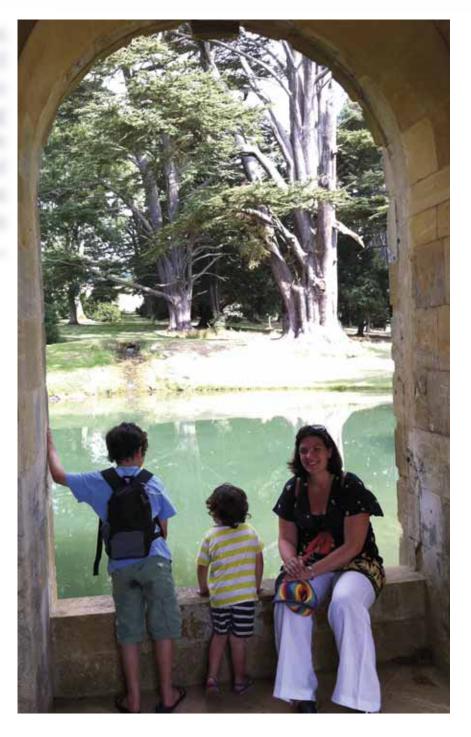
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Pathways to a Colostomy...

Annie describes her eight year old son Calvin's journey to a colostomy after being diagnosed with a rare inflammatory bowel disease known as Eosinophilic Colitis this is their story....



Dispelling the myth: children have ostomies too...



et's dispel the myth that only the elderly have ostomies.
Yes, there really are children with urostomies, ileostomies and colostomies. Not just babies but walking, talking children of all ages. It's not unusual and not a rarity.

My darling, bright-eyed, quirky eight year old boy was diagnosed with a rare inflammatory bowel disease, Eosinophilic (EEES- IN- O –PHIL- IC, see if you can say it) Colitis, after scopes and biopsies by the gastroenterologists at Great Ormond Street Hospital when he was four and half years old.

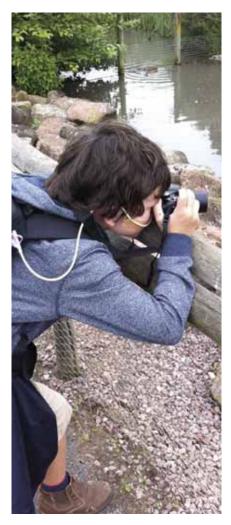
It was a tough journey to diagnosis, his treatment has been unrelenting. There is no cure. His doctors are hunting for elusive answers whilst the families affected keep struggling on with a myriad of misunderstood, often misdiagnosed, complex body symptoms, hoping for answers (see www.fabed.co.uk a small, essential UK support charity).

A year ago Calvin's colorectal surgeon at GOSH formed a colostomy to ease the chronic pain he endured and to rest his battered bowel. After years of clinical intervention; food allergies, medication making him rattle like a pill box, endless pain, scopes and operations, we were

at a desperate point. Calvin had been doing headstands ALL night long for the previous four weeks to try and ease his rectal pain. I would check on him every two hours through the night, with dawn breaking he was bleary-eyed, still upside down on the sofa. It was no life.

With few clinical answers, just complex management of a capricious disease, a colostomy was suggested, with 50/50 odds of success and a week to mull it over. It was a lose, lose situation but we consented as we felt frantic with anxiety watching his body struggle. Calvin was already averse to hospitals and suffering emotionally and physically. He was so fragile, we understood so little about a colostomy so we asked a stoma nurse to explain the procedure to him. Handing over responsibility to someone else is something I will never, ever forgive myself for. He retched, shook, hyperventilated, collapsed and sank onto the floor after being shown a picture of a wrinkly old lady with a stoma. It is seared onto my memory and still makes me shudder. Never again will I allow someone else to undertake that task.

How do I begin to condense the trauma he, and we, experienced afterwards into a handful of words? I simply can't. It was such a mammoth adjustment, he was so horrified by the whole >



experience and all we could all do was place one foot in front of the other.

Days turned into weeks as I struggled to find a bag and base plate that didn't crinkle, spring a leak or simply peel off, cause his super sensitive skin to react or burn and make us both miserable. Our stoma nurse was a diamond and patiently kept trying. It took ten weeks of endless products but we did eventually settle on a two piece system. It's not perfect but it was the best of the lot, bearing in mind nothing is designed and manufactured for active, lithe children's bodies (a small bug bear of mine).

Unfortunately Calvin's stoma refused to co-operate and began developing significant prolapses. By December he was readmitted for an emergency

revision and bowel resection, so we started all over again. The prolapses have continued but are just about being tethered in place by internal stitches. If another stoma is formed yet more bowel will have to be removed and the surgeon thinks it will just keep prolapsing. The Herculean task is to try and control the underlying inflammation. What should have been a temporary colostomy has turned into a long-term solution, of sorts.

Calvin's health has deteriorated further resulting in him being fed an elemental, artificial nutrition by a nasal gastric tube into his stomach and he's nil by mouth except for water. Theoretically it should reduce the inflammation making it easier for his bowel to process food. Artificial feeding makes the colostomy look like a walk in the park. That hasn't been hugely successful either and he is booked in for yet more scopes in the hope of yielding some answers.

On reflection I've learnt a great deal since his first colostomy; I never thought I would cope yet now my husband and I change it without blinking, finding it utterly unremarkable (although I do wish it wouldn't explode on me); that and educating a primary school about how they can cope with a child's colostomy had been an eye-opener; that there is absolutely no reason why Calvin shouldn't be in school and fully supported (my goodness me, you have to fight for it); that our stoma nurse has been a Godsend who went above and beyond the call of duty to help us (they are a remarkable breed of nurse who we would have been lost without); that there is stigma and prejudice out there about bowel diseases and ostomies but that for every ignorant comment we have encountered, there are countless kindnesses and that the human spirit is remarkable because it adapts and keeps going, even in young children who make huge social, physical and mental adjustments.

I want a bigger, more honest conversation about the impact of chronic illness in children (and adults) on their mental health. Funding for emotional support after diagnosis should be a number one priority but it often isn't. Calvin was deeply affected and has since been supported by a psychiatrist and a psychologist to help him accept his fickle body and manage his fury. Accessing psychological help for children often becomes war, not just a battle. We were lucky; I know others are less so. It's taken twelve long months before Calvin has stopped referring to himself as a freak and to begrudgingly accept the stoma but it's a fragile status quo.

Without the colostomy his quality of life would be considerably poorer. It's opened my eyes onto a whole new world of disability, hope, fortitude, frustration, different illnesses and others' lives. Joining Facebook groups and sharing our journey with waspish honesty through my blog has been healing. If I make my readers smile and feel less isolated and if I can raise awareness into childhood bowel diseases and the fundraising support it desperately needs then I've made a silk purse out of a sow's ear. Above all, if I help heal my son's scars, guide him to find his strengths love him and hold him tight through the rough and the smooth and teach him not to define himself by this illness but by his zest for life and humanity, then I've done my

You can follow our journey on my blog: www.afeedersdigest.wordpress.com or Twitter@MumAnnie123

To protect his privacy, Calvin is my son's pseudonym after the uproariously funny cartoon strip Calvin and Hobbes about a small boy and his mischievous tiger, which we often read together when he is up late at night in pain. If he chooses to use his name when he is older and wiser then it becomes his choice, not mine. I've made so many decisions about his body, it feels positive to hand him back control at some point in his future.

Raising awareness...for children and (adults) with chronic illness and long term conditions...reversing the stigma and prejudice out there about 'bowel diseases and ostomies'...

Brava™

"I didn't think I could find a tape that would fit my body shape."

Steve, an ostomate since 2003



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How to use

Apply the Brava Elastic Tape to the baseplate and the skin where desired. Remove the remaining protective paper and smooth the tape onto the skin to ensure the baseplate is kept in position.

See full instructions for guidance on how to use this product.



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www.coloplast.co.uk



To receive your free sample please complete the following:

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Surname	
Address	
Town/City	Postcode
Telephone	Email

Place the coupon in a sealed envelope and send it to: Coloplast Limited, FREEPOST ANG3545, Peterborough. PE2 6ZX

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



Dear Editor, 80th Birthday... celebrations

Please accept my donation of £150.00 in lieu of gifts to celebrate my 80th Birthday. My friends and family gave me £300.00. I am giving half to the Colostomy Association and half to Cancer Research UK.

I had emergency surgery and had a colostomy. I had Diverticulitis for years. I had leakage and all the other things that go wrong including a hernia. A friend of my daughter's sent me a Tidings Magazine, which gave me a lot of help. I now get it myself and if I think anyone needs help I send it to them. So thank you for all your good work!

Best regards, Mrs Robinson Thank you everyone for your kind donations

Dear Tidings, Golden Wedding... celebrations

Please accept my donation of £185.00 in lieu of gifts for our Golden Wedding Anniversary!

J & M. W

Dear Tidings, In lieu of Funeral Flowers

My husband passed away recently and it was decided that donations be given in lieu of flowers. Therefore please accept this donation of £127.00.

B.S

Welcome donations from...

Mr. R.J. B	£100.00
Mr T. J	£500.00
Mrs R. F	£100.00

Dear C.A. Annual Coffee Morning

I had my annual Coffee Morning in respect of your Association having been a colostomist for the past 17 years. Funds raised amounted to £300.00 please accept this donation towards your good works.

Yours faithfully, R.G (Mrs)

From Ed: Thank you to Mrs R.G for organising this event and a BIG thank you to everyone who attended the Coffee Morning – raising much needed funds – wonderful!

Legacies...

J.G. Theodosiades	£5,000.00
Anonymous	£2,000.00
Thank you	

In Memory

D. J. Judges	£230.00
Mr. M.C. Plummer	£ 19.38
Mrs E. Roy (friends)	£ 50.00
Mrs E. Roy (family)	£225.00
Mr D. S. Whitlock	£125.00
TI I	

Thank you

'The Llanelli Star Cup' – Cup Winners Evans & Williams AFC donate £150.00 to the Colostomy Association!



Above: Winner of this year's Llanelli Star Cup, Evans & Williams AFC.

Dear Colostomy Association, I am the secretary of a local football pre-season competition called 'The Llanelli Star Cup' which is sponsored by our local newspaper. Each year, finances permitting, we make donations from the gate at the 'final' to charities and like minded associations. The cup winners are given £150.00 to donate to the Association of their choice. The winners this year - Evans & Williams AFC chose your Association please accept a donation of £150.00.

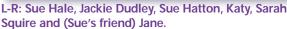
Kind regards, M.D. H – Secretary



Above: Winner of this year's Llanelli Star Cup, Evans & Williams AFC. Captain Robert James is presented with the cup by Llanelli Star editor Rebecca Davies.

Wroughton Midsummer Charity Fete...June 2013 An all round great day and huge fundraising success!







Wroughton Midsummer fete in full swing!

Sue Hatton writes: We had a marvellous day on Saturday 22nd June at the Ellendune Community Centre, Wroughton, near Swindon. Bouncy Castle, Face-painting, Tombola, Raffle, Kids Lucky Dip, Book stall, Craft Stall, Gift Stall, Plant Stall and more...Plus Tea and Cake sale and other refreshments AND Entertainment including the Ellendune Entertainers! Proceeds raised were to be split between 'Together for short lives' and the 'Colostomy Association'.

My daughter Katy pulled off the best Fete ever and having vowed that she would never do one again, she is keeping her Colostomy Association polo shirt and planning next year's event! It was marvellous to be away from home and to see all the family, a real occasion! The Colostomy Association will be putting the funds raised towards the Bob Buckley Fund.

Katy writes: A huge thank you to everyone who helped out, baked cakes, supported us, donated etc. The fete was a great success and we completely smashed my initial target of £1,000.00, as the W.H. Smith Trust will match £1,000.00 of the fundraising which brings the total to just over £3,000.00 and I'm still receiving funds in from my cake sale at work and the Justgiving page!

Sue Hatton continues: I felt very proud of Katy for taking on such a huge project and to the rest of my family and friends who came to help. Chris Bonney was brilliant on the Raffle, Sue Bonney sold books, Jackie Dudley - CA Trustee and volunteer helped my daughter Joanna on her children's stall, Sarah Squire - CA Trustee and volunteer - made a huge decadent cake and Sue Hale -General Manager at the CA - brought friend Jane to assist on the cake stall, Sue's husband Stuart appeared on his bike having cycled 25 miles to support her!

Open Garden... A picture of paradise!

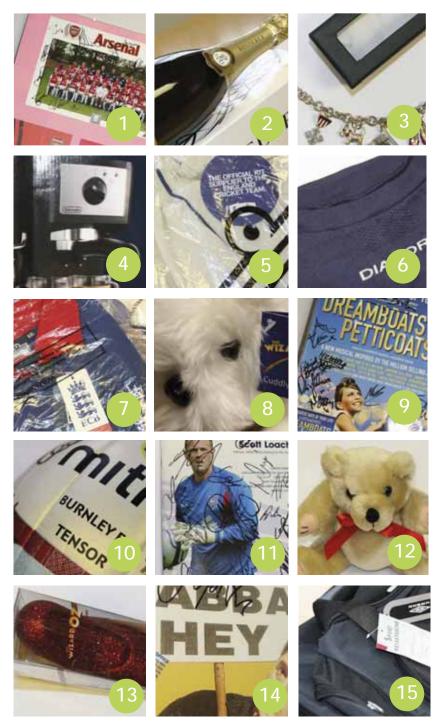
The beautiful garden (pictured right) was opened up to the local community in Hartlebury to raise funds for the Colostomy Association. The photograph allows us all to peer in and enjoy this spectacular show of plants and shrubs on what must have been a lovely Summer's day! The gardens are clearly tended by a passionate gardener with loving green fingers!

The CA is very grateful for the £300.00 donation that has been received as a result of the open garden fundraiser and it was wonderful to learn that a further £110.00 has been passed to the local support group.



Many thanks to the organisers D.M and M.R and to everyone who attended and donated so generously!

Help the Colostomy Association raise extra funds... Bid on the items listed – go on...make us an offer we can't refuse!



Guide for Bidders...

Send your bid in to CA by the 30th October 2013. Highest Bid wins the listed item. Please be sure to record accurately the item number/s and description/s and the maximum price you are willing to pay for each item. Please provide your name, address, telephone number and email address (if you have one). So that we can contact you to confirm your success and arrange payment.

Send in your Bid by post to: Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Or send in your Bid via email to: cass@colostomyassociation.org.uk. Collection of large items and fragile items is required.

Description of Bid Items...

- 1). Framed Signed Print: Signed photograph of the Arsenal First Team Squad and accompanying Certificate of Authenticity Serial no. ARS002277.
- 2). Bottle of Champagne: Louis Roederer BRUT Reims 750ML
- 3). Warner Brothers (WB) Wizard of OZ Collectable Charm Bracelet (boxed).
- 4). De Longhi. Espresso and Cappuccino maker. Brand new in original packaging.
- 5). ECB Cricket Trousers. Colour: Ecru Style: BRK-01 Size; 13/14 years
- 6). DIADORA Running shirt Navy Blue: Size: XL
- 7). ECB/Admiral/Vodafone Cricket shirt. One Day International (ODI). Adult Size: XXL (Red/Blue) and ECB/Admiral/Vodafone Cricket shorts. One Day International (ODI). Adult Size: L (Red/Blue)
- 8). Warner Brothers (WB)
 Wizard of OZ Collectable
 Cuddly Toy. Beautiful Hand Made Toys
 TOTO x 2. Length 8"
- 9). Framed Signed Print:
 'The greatest days of your life'
 Dreamboats and Petticoats Poster and
 Programme Strictly Limited Season –
 Savoy Theatre.
 Signed by the Cast.
- 10). Football Ephemera: 1 x Mitre Leather Football (Training quality). Burnley F.C signed by the team.
- 11). Programme Ipswich Town vs. Blackburn Rovers. Saturday, August 18th 2012. Official Matchday Programme signed by the players.
- 12). Magic Kingdom Teddy Bear (jointed arms/legs). 6" high
- 13). Warner Brothers (WB) Wizard of OZ Collectable Ruby Slippers Lip Gloss x 1
- 14). A2 Tour Poster: The Tour De Force Phil Jupitus. (Never mind the Buzzcocks Fame) Signed by the artist.
- 15). 1 x Black Wheelie Umbro Sports Bag. Brand NEW with original tags. Size: Large capacity.

JustTextGiving...Donate via texting

You can now make a donation to the Colostomy Association with via text message!

It's simple – whatever mobile network you're on, simply text our unique code **CASS01** and an amount of £1, £2, £3, £4, £5 or £10 to **70070**

Many more supporters are now using their mobile phones to donate. The cost of donating via text JustTextGiving by Vodafone is a free service. There is no cost to you for sending the text message and your free allowance or bundle will not be affected - the only



charge will be the donation itself. What's more, 100% of your text donation (including Gift Aid) will be sent to the Colostomy Association. The amount you donate will be added to your mobile phone bill or deducted

from your pay as you go credit. JustTextGiving will send you a link in a text message confirming your donation. Donations will appear on your JustGiving page – if you have one set up.

To learn more visit:

http://www.justgiving.com/ en/justtextgiving

From Ed:
If you are not on the Internet a
factsheet JustTextGiving by
Vodafone will be available from CA
shortly.

CA reaching out via new... QR (quick response) technology!

You may have noticed the rather curious patchwork square boxes appearing on posters, in magazines and on the television more and more recently.

What are they? It's called a QR (quick response) code. They have been around since 1994, but the sudden increase in use is due to the phenomenal growth of smartphone usage. The impact of mobile devices cannot be ignored; around half of the UK uses a smartphone. By 2016 Cisco have predicted that there will be a monumental 10 billion mobile devices (smartphones/tablets) in use worldwide and in 2011 there were an estimated 1.2 billion mobile web users.

A QR code is simply text that has been encoded in a 2D barcode format, therefore the less text there is the less



cluttered – and prettier – the QR code will be. There is no cost to the charity as they are free to create. The Colostomy Association now has its own QR code (pictured above) that takes people direct to our website: www.colostomyassociation.org.uk.

It's another example of how the charity is reaching out to support colostomates, their families, carers and healthcare professionals.

How Do I Use/Scan QR Codes? Well, it's actually pretty easy...but you have to have the right tools. To use QR codes conveniently you must have a smartphone equipped with a camera and a QR code reader/scanner application feature.

Luckily, the newer smartphones models available today often have an app preinstalled on them. However, don't worry — if you aren't lucky enough to have that work done for you, it's nothing a quick push of a button can fix. All you have to do is visit your phone's app store (examples include the Android Market, Apple App Store, BlackBerry App World, etc.) and download a QR code reader/scanner application (app).

So, now that you have the app you need. Get out your phone and open the app you've downloaded or that it came with. Do your best to steady your hand while the Colostomy Association QR code is centered on the screen. Voila, as soon as it is done scanning, the CA webpage URL stored in the QR code should present itself to you!

Give it a try, there is a wealth of information on our website including back copies of Tidings!

Used Stamps... CA needs yours!

The Colostomy Association has just received a £15 cheque for the used stamps we've been collecting for a while which is good news...Do you have any used stamps you can donate? People are refunded their postage in full as long as they mark the envelope for the "CA" when sending direct to Fundraising Stamps Ltd.

Any stamps are taken but the commemorative stamps are the most valuable. £10 per kilo, is paid including the weight of the envelope.

Instructions to stamp donors: No more than 1cm of envelope left around each stamp. Not trimmed too close so that the perforations are damaged.



Please mark your envelope 'CA' then send your stamps to:

Fundraising Stamps Ltd 35 Wrecclesham Road Farnham, Surrey GU9 8TY

Update on stoma care products and services

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

Just Launched – Welland Aura™ With Manuka Honey! CliniMed's Kindest New Stoma Pouch Range



Innovative stoma care company, CliniMed®, has just unveiled it's latest revolutionary stoma range; Welland Aura, with medical grade Manuka honey.

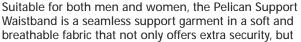
The Aura range is the newest addition to a portfolio of stoma, incontinence and woundcare products designed to enhance and improve lives, setting CliniMed apart in a continually growing and evolving market. All 53 products in the Aura launch range (including mini, midi and maxi versions; closed, drainable and urostomy pouches, plus a handy stoma cap) feature CliniMed's tried and tested skin-friendly Hyperflex® flange - developed with Welland Medical - with the added benefit of

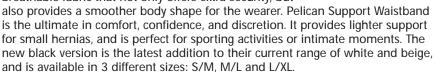
medical grade
Manuka honey in
the hydrocolloid
which is well
known for its
therapeutic
properties.
CliniMed is
confident these
products are
their kindest
pouches yet,

with a number of enhanced features alongside the Manuka honey, including a 22% larger flange, specifically designed to prevent leakage, a new and improved filter for better deodorisation and reduced ballooning and a handy Easy2peel™ release tab to help make pouch changing quick and easy. Early feedback from patients has been very positive so why not try a free sample of Aura today and see if you too can benefit from the new unique features, designed to give you the confidence and freedom to live life to the full.

For more information please visit: http://goo.gl/uxHNG Tel 0800 0360100

Pelican Healthcare are pleased to announce that their Pelican Support Stoma Waistband is now available for the first time in Black.





Unfortunately Pelican are unable to sample the Pelican Support Waistband. However, if you would like to obtain this product which is available on NHS prescription, please call their customer service team on Freephone 0800 318 282 who will be happy to take your order.

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

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

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

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

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

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

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

Sash Medical Ltd..Update

Do you need stoma protection either at work, when playing sport or at home? Sash Medical has added a new product which might be exactly what you need. The Sash Stoma Shield (ref: no. SS104) is now available on prescription in England and Wales and in Scotland. The Shield is made-to-measure from information given on an order form obtainable from Sash Medical Ltd. Please use their Freephone 0800 389 3111 to discuss your requirements. See their advert on Page 56.



Select Afresh Closed & Drainable

Designed for maximum comfort & security





- Unique & comfortable skin protector
- Shape designed to suit your body form
- Silky soft fabric for comfort & discretion
- High performance charcoal filter

Also available in Convex Now cuts up to 60mm



Pelican Support Stoma Waistband

Now available in BLACK

- Suitable for both men & women
- Available in 3 different sizes
- Holds your pouch securely in place
- Lighter support for small hernias
- Creates a smoother body shape
- Provides extra security, support and confidence

Unfortunately we are unable to sample this waistband, however if you would like to obtain this product or require further information, please contact us on 0800 052 7471



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Irrigation and you...

Sue Hatton Executive Trustee writes...I hope you will enjoy Derek's article a response after reading Steve Clark's article in the Summer issue of Tidings. As I mentioned in that issue I am now an ileostomist, so I do not have the luxury of being able to irrigate – but I am still a passionate advocate of this amazing method of bowel management! So much so that I am delighted to announce that at the Association of Stoma Care Nurses (ASCN) annual conference – a workshop will take place promoting the benefits of colostomy irrigation to SCNs. Please let me know your experiences – sharing is so important!

Colostomy Irrigation - Derek's experiences...

Derek writes...I read with interest Steve Clark's Irrigation article in the Summer 2013 edition of Tidings, but am rather surprised at the length of time he spends in the bathroom each day.

I have had my stoma for over 10 years now and it took me 8 years to try irrigation. I think this was because I could not envisage spending a long time in the bathroom each day. Two years ago I was talked into giving it a try by a CA volunteer (Thank you Judy!). I contacted my stoma care nurse who obtained my consultant's approval and after two short training sessions I was on my own. I must say that it is the best decision I could have made and I have never looked back. Life is now so different and I can go 24 hours, or more, without even thinking that I have a stoma.

I have irrigated in many hotels in the UK, Italy, Australia, Madeira, Malta and on two different cruise ships. It was great on the cruises knowing that I could leave the ship in such places as St Petersburg without even having to wonder where the next toilet would be found

However, the procedures I use could not be more different to Steve's and I will try and explain my technique. As Steve said, it should be remembered that we are all different and what works for me will not necessarily work for another.

I normally irrigate daily, starting anytime between 7am and 8am, depending on my day's plans. If I am going on holiday then I could start at 5am, or even at 10pm the evening before. I know I can safely go 36 hours, but 48 can be a bit dicey. Occasionally I give myself a day off. I achieve this by first going 36 hours and then irrigating before I go to bed. That means that the next day is clear and I next irrigate on the morning of the day after.

So, I usually make a cup of tea which I take to the bathroom. The reservoir and tubing is already hanging in place within close proximity to the toilet. I take the reservoir down and fill it to the 2 litre water mark with warm water that I take directly from the tap. I have never tested the temperature of the water, I just make sure that it is warm, but not too hot. I then hang the reservoir back up.

The next step is to remove the previous day's plug that I regularly use, or occasionally a pouch. (The plug leaves my torso almost completely smooth – a good confidence booster.). I clean around the stoma and then attach a sleeve which I hang into the bowl. Standing, I then insert the cone into the top of the sleeve and into the stoma, having first ensured that there is no air in the tubing and the water is flowing. I usually have the flow control fully open and check that the water is flowing into the stoma. If it does not immediately flow then I will move the cone around to ensure that there is no internal obstruction. In practise you get used to the direction that produces the best flow. I then infuse one litre of water and turn off the flow. At this point I remove the cone and hang the tubing up. There is still one litre of water in the reservoir which I will later use for cleaning purposes. Up to this point the

process has taken around 5 minutes, with 3 of those infusing the water.

I now fold the top of the sleeve over and attach 2 or 3 pegs, which ensures that all the output is directed into the bowl. I usually remain standing for about 5 minutes as I find that in this position the body reacts faster and within that time there has been a fair amount of output. At this point I usually flush the toilet. Like Steve, I have a folding chair by the WC which I find easier than sitting on the toilet. So I will then sit down on the chair grab my book and cup of tea and remain seated for around 10 minutes. At this time, 15 minutes from removing the cone, the output has usually stopped.

I then use the rest of the water in the reservoir which I flow through the sleeve flushing out any output left, hence cleaning it. Once satisfied it is clean I flush the toilet again still with the sleeve in the toilet bowl. That will clean the outside too and enable me to fold it up from the bottom and seal it with the pegs.

With the cleaned and odourless pegged sleeve still attached to me, just in case there is any further output which will be safely held in the sleeve, I then go to our en-suite and have a shower, shave, brush my teeth etc. At this point I will normally return to the separate bathroom where I remove the sleeve together with any adhesive that might have remained putting all of this into the disposal bag with the old pouch. I then wipe on some skin barrier protection and attach a new plug or pouch.

If I have any doubt about the output not having finished then I will get dressed leaving the folded up sleeve and pegs in place and to complete the task later. I have been known to forget that I have not completely finished the process and go shopping, only to remember sometimes hours later. I suppose that just shows how comfortable and confident I am with the whole process.

The procedure normally takes me around 40 minutes, but that includes having a shower etc. and I have only actually spent about 25 minutes in the

bathroom itself and 10 minutes of that was reading.

I use Dansac's irrigation equipment, but I know there are other suppliers on the market that may well suit others more.

Well this is what works for me, but we are all different and I guess that a few ideas from Steve's procedures and a few from mine or others might be worth putting together and prove best for someone else.

I wish well all those that irrigate and would encourage, if able, those that

don't to give it a try. It certainly makes life so much easier and you do not have to worry about where the next toilet is. Over the 8 years before I irrigated I think I got to know where every supermarket was on all my journeys, just in case!

Derek

Colostomy Irrigation - what is it?

What is Colostomy Irrigation?

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

What type of equipment is needed?

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

The Colostomy Irrigation procedure

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

Gather together the items needed prior to irrigating:-

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

To start the procedure make sure the environment e.g. bathroom/toilet is warm, comfortable and private. Layout your items and wash and dry your hands, ensure everything is within

reach. Fill the jug with approx. 500ml tepid tap water 36-38°C (body temperature is 37°C) pour into the graduated water bag. The bag should be hung on a hook preferably behind the toilet bowl, with the base of the bag at shoulder height. When ready remove your clothing and position yourself on the toilet ready to irrigate.



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

Allow a little water through the tube via the clamp/flow control to expel air that might be trapped in the tube then close off. Fit the irrigation sleeve over the stoma, place the smallest end between the legs and into the toilet bowl. Lubricate the cone and pass it through the top end opening of the sleeve, then insert the cone gently into the stoma, so that it forms a dam between stoma and cone. Open the

clamp/flow control to allow water to run slowly into the bowel (approx 8-15mins). Once the water has been instilled, remove the cone from the stoma, fold over the top of the sleeve and fasten securely with a peg. Wait for around 20mins muscular contractions (peristaltic motion) within the bowel cause the water and stools to flow out of the stoma into the irrigation sleeve then out into the toilet bowl. After the main flush, clean the lower end of the sleeve, fold up, and clip to the top end of the sleeve. After 10mins has passed and no further motion is felt remove the sleeve leaving it hanging over the toilet edge. Wash the stoma and skin with warm water and gently pat dry. Apply a clean stoma pouch or cap. Clean the irrigation sleeve (if using a reusable one) by holding it over the toilet bowl pouring warm water from the jug into it or add a basin showerhead attachment to a nearby washbasin and use the spray. Hang the irrigation kit up to thoroughly drip dry then store in a cool place. Dispose of the rubbish as normal then wash and dry your hands.

Remember...says Sue...The next issue of Tidings will feature the ASCN workshop and introduce our new Colostomy Association DVDs.



CA 'Closed' FACEBOOK Group... Membership reaches 1310... and it is a fabulous group!



Picnic in Hyde Park...

Natty Moo files a report...Summer's finally here!! Beautiful blue skies. People stampeding to the coast. Birds chirping, ducks quacking, dogs catching balls, the sound of children's laughter filling the air. People with shocking sunburn across their shoulders. Bumble bee's and butterflies. Pretty coloured toenails. Magazine covers plastered with the: 'ONE HOUR BIKINI DIET'. That undercurrent of excitement and hope. Smoke from BBQ's, wafting aromas of burnt to a crisp sausages fill your nose. The sound of men wolf whistling at pretty girls....yes, summer's here and it's a perfect time for a picnic! So why on earth am I standing outside Hyde

Park tube station with a beautiful pashmina on my head, droplets of rain dripping off my lashes and my Dior lipgloss vanishing without a trace? The only reason I'd stand anywhere in a puddle - is to meet my CA Facebook friends! Stephanie and I arranged the place and date. The plan was to have a casual picnic in the park, lovely! But we live in Britain and true to form the weather on the day was HORRIFIC fortunately we had a great turn out! Those who came met up with friends they'd met before, made new friends, chatted about friends we'd loved and lost. All friends together - people who understand - who share and will cherish each other forever. Two years ago I never knew this group existed. Two years ago I was a completely different person. A shell really, not a

person at all. These people saved my life and I'd do anything for them.... Including standing in a puddle with my gorgeous li'l floral lace up shoes! We must have sent M&S's takings through the roof that day as that's where we ended up! Lots of cake and coffee, chat and laughter and best of all...friendship. Thank you to each and everyone of you for being there and many thanks to Sarah S & Duncan W you are much appreciated! So...where to next...what about Regents Park? In a snow storm!?!

Who was there...? Natty Moo, Stephanie Dickinson-Williams, husband Peter and daughter Bryony, Rashi Bhasin, Christopher Lumber Martin, Emma Louise and Jimmy, Shirley and Chris Tanner, Jenny Fitzgerald, Helen Nobbs, Sally Armstrong, Deb O'Reilly and daughter Madison, Helen Nobbs and daughter Lois and Jenny Juliff.

Facebook Group Meet...

We are having a Facebook Group meet on the 19th October in Crawley. This has been very kindly sponsored by CliniMed/Welland. We will be having a tour of the Welland factory, a presentation by CliniMed at the nearby Premier Inn and supper at the hotel. It's a great chance for CA Facebook Group members to meet up!

We are in the process of sourcing a company to supply CA Facebook Group polo shirts.

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

Don't get the hump on holiday!



Even when you are away, if you have an emergency, we are here for you!

We have a range of information sheets available, please tick	the relevant boxes and we will post them to you.
I am interested in: Stoma	
Name:* (Mr/Mrs/Miss)	Date of Birth:*
Address:*	
	Postcode:*
Telephone No:*	E-mail:*
* All fields must be completed	Tiding(002012

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Lost in transition: the reality of living with colorectal cancer and a stoma...



About...Pat Black CNS/SCN:

Pat's team at the Hillingdon
Hospital has increased over the
years from two surgeons and
herself to four surgeons and
three more nurses. Apart from
clinical work Pat runs two
university accredited stoma
courses and has set up in
conjunction with colleagues
from The Royal Marsden
hospital, a nationally recognised
qualification in stoma care for
Health Care Assistants.

Over the years at Hillingdon Pat has published extensively in the nursing and medical press, the national media and spoken on the radio and television, she has also spoken at national and international conferences around the world and has won nine national awards for stoma care.



I have been concerned for a long time about the reality of living for many years with a stoma that has been formed as the result of cancer. In medical terms we talk about cancer survivors. A cancer survivor is an individual who has had cancer in the past. WE know that many cancer survivors consider the process of living with and beating cancer as a life changing experience. As a result, many of you are living with the long term physical and psychosocial implications of cancer and its treatments. For those of you left with a stoma there is the constant reminder of what has happened to you. Although cancer research has resulted in much new medical knowledge, treatments and expertise, few studies have considered little beyond the post treatment time. Even with Macmillan and the survivorship programme for cancer survivors, many patients say that there is little support once treatment is finished and the five year point reached. Therefore I want to find out what is necessary to help healthcare professionals understand your long term needs.

We also know that people with cancer need information to make sense of their treatment and outcomes. Some of you will have been involved in patient groups where comparing with others provides the opportunity to discuss issues of mutual concern. However, from my professional practice it appears that many people stop attending these after 1 or 2 years. This leaves me with the question of whether such support is needed on a longer term basis or if not, what type of support would you prefer? Some of the patients I work with tell me that their biggest worry is how they will cope after they have been" cast a drift by the health care system". They know that they are considered cured after 5 years, but say that they would really like to keep a link with a professional that they could approach if they developed

problems. However, they repeatedly tell me that they think stoma care nurses are too busy to be troubled with what they (the patients) describe as their" little problems". This has meant that some people have lived with problems for a long time and things that could have been easily treated have become difficult to resolve.

I would like to ask you to help me as a Nurse Consultant at the Hillingdon Hospital NHS Foundation Trust, with my research into this area and to that end wonder if you would be willing to take part in focus groups and individual interviews.

If you are interested in this project I would be very happy to give further information about the project and what participation would mean for you.

Editors Comment

If you would like to get involved with Pat's research

Write to:

Pat Black Clinical Nurse Specialist (Stoma Care)

Coloproctology Department The Hillingdon Hospital Pield Heath Road, Uxbridge, Middlesex UB8 3NN

Email: pat.black@thh.nhs.uk

Telephone: 01895 279881



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Getting what you need...

Duncan writes: All I ask of fellow colostomates is that they order what supplies they need and they order sensibly.

All I ask of the prescribers, GPs and SCNs is that they prescribe sympathetically that which we need to manage our colostomies comfortably and confidently.

That is all I ask.

We live in times of cutbacks and slashed budgets and while most of us continue to be very well served by GPs and SCNs who are sensitive to our needs, there are a tiny few who are taking the axe wielding to heart and reducing choice and in some cases trying to restrict supply, or at least to question a colostomate's order.

I have heard of a couple of small areas in far flung parts of the UK who have introduced restricted choice formularies they are called - when it comes to 'Additional Products' such as deodoriser sprays, adhesive remover, inner rings and the like. One I heard had stopped prescribing adhesive remover. That could be tricky if you have sensitive skin and have relied on a particular product to prevent your skin from becoming red and sore. And you can understand that they are trying to control costs. But they must not do this at the cost of the colostomate's health and well being.

Clinical commissioning Groups (CCGs) in England, Local Health Groups (LHGs) in Wales and Health Boards (HBs) in Scotland all have a Clinical Lead. They also have an Accountable Officer who sometimes may also be the Clinical Lead. And if we do not get what we need then we need to bring these people into play.

First, it is absolutely vital that if you wish to change your repeat prescription for any reason, you get

the approval of your prescriber, usually your GP but also possibly your stoma care nurse. There is nothing more likely to upset a GP who has just been told by their Practice Manager that they need to watch all costs carefully, than to see your prescription come across their desk with some extra product added on to it which will cost the practice more money and which the GP has not sanctioned. You can almost guarantee that this extra will be knocked off the prescription and you will be distressed as a result.

If you have been offered samples of some product which works for you and which would improve the 'comfortable and confident' management of your colostomy, then you must speak to or write to both your SCN and GP to ask them if it might be possible to add these products to the prescription. They may agree immediately, or they may ask you to see the SCN for a review or check up, which is always a good idea.

Once the SCN has recommended the product the GP will sign the prescription and off you go. If, having gone through this process you are still having difficulty, I recommend that you write to your GP and SCN and copy in the Clinical Lead at your CCG and the Accountable Officer. You will need to find out which CCG you come under and who these people are and Google is a powerful ally in achieving this. This is the web address of the list of all CCGs in the UK for example: http://www.england.nhs.uk/ccg-details/#ccg-s

By copying in the Clinical Lead and the Accountable Officer you are alerting them to the fact that you are having a problem. They are responsible for working within budgets but they are also responsible for not being careless with the health of the public who are in their care. The Accountable Officer is also accountable.

If any restriction of product has resulted in causing anyone worsening health - for example the adhesive remover which you used to use is no longer available and as a result of not using it you now have sore skin, one could make a link between the removal of adhesive remover from the list of prescribed drugs and your worsening health (sore skin) and so the Accountable Officer is responsible/accountable for your worsening health. Pointing this out to them would do no harm.

It is always important to point out whenever you write to any medical professional that 'NHS England are committed to putting patients at the heart of improving care now and for the future.' If you are in Wales or Scotland or NI adapt this to read 'NHS are committed etc...'

This is not intended to frighten anyone. As I said at the beginning most of us are very well served by our local GPs and SCNs. And we order sensibly that which we need. And I don't think for a minute that there will be a general move towards restriction of formulary.

But if anyone having played fair with the system, experiences any difficulty, the above is the way to go to ensure that the GPs and SCNs prescribe that which one needs to manage one's colostomy 'comfortably and confidently'.



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Alternatively, you can vote by post or in person at any Salts Health and Wellbeing Open Day. You have 12 months to cast your vote, until 31st July 2014.







Twisted bowel – something I knew nothing about...

Derek writes: This is the story of the experiences I have been through over the last two years (2011-13). Firstly throughout 2011 my wife suffered from very high blood pressure together with severe incontinence problems. Despite all the help and care I gave her she sadly got progressively worse, which may have taken its toll on my own health. Over a weekend in March 2012

I became very ill suffering great internal pain I could not sleep and had no appetite. My symptoms got so bad I telephoned the NHS Helpline explaining my condition. The Helpline contacted the local paramedic services who promptly came to see me. They called out the duty doctor who came out very quickly to investigate. He saw how seriously ill I was and called for an ambulance to take me into the Alexandra Hospital in Redditch.

Upon my arrival I was diagnosed as having a 'twisted bowel', something I knew nothing about which needed operating on straight away. The operation took place and was not a success and I was told that I had to undergo another operation which was life threatening. I had to give them my consent to have this second operation.

It was then my daughter gave me the shock news that my wife had died very suddenly at home. This of course put me in very deep shock, which did not help me at all. (My wife had died just five weeks away from what would have been our golden wedding anniversary). Just after the second operation my family were informed that I was very ill and that they thought I would die

myself – my daughter – was thinking the worst, the possibility of losing both her parents.

Luckily the second operation was a success. After six weeks in the Redditch Hospital I was transferred to my local hospital in Evesham to recover fully before being allowed home with a care package, which the hospital arranged for me. Fortunately I made such a quick recovery so much so that I have been dubbed the 'miracle man!' I do feel very much better nowadays.

The operations I had led to a stoma and a colostomy bag, which I have been informed, I will have for the rest of my life. I am slowly coping and adjusting to 'living with a stoma and colostomy', and do have some emergency moments, but I have learned to put up with these. Since I came home two very experienced and helpful stoma nurses, regularly visit me and help me out for which I am most grateful. My only real problem now is I have to live without my wife who I miss greatly. She was such a good wife and an excellent mother to my two daughters. I have numerous happy memories of our married life together.



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Focus on additional ostomy products

Solidifying agents...

Some of us may have loose output which can be troublesome in a number of ways. It can clog up the filter on our appliance, or "swosh" around in the bag making it uncomfortable. Leaks can occur more frequently as the liquid stool may find a path under the flange of the bag easier than more formed output. It may be possible to thicken output through diet but for those with liquid output, ileostomates or colostomates with less large bowel, solidifying agents in the form of capsules or sachets can help overcome these problems. You pop them into the bag when changing or emptying and then as the loose stool enters the bag the soldifying agent will thicken the output into a more manageable consistency. As well as extending the life of your bag by keeping leaks at bay and filters unclogged these products can also help you feel more confident and comfortable with your stoma.

Pastes...

How many of us can say we have a perfectly flat stomach, with no scars, lumps or bumps? OK so some lucky people out there do but not all of us. We may have dips, skin folds or creases around the stoma which all hinder the effective application of a stoma bag. As discussed in the last edition of Tidings, seals may help create the flat surface we ideally look for when applying a stoma bag. But pastes can be a useful alternative or used in addition to a seal. They can be used to fill dips in the skin that would otherwise be a path for leaks and also help the bag adhere. Pastes often contain alcohol so you do need to be careful as it will sting if applied to broken skin. Top tip: It may be possible to apply the paste directly to the underside of the flange rather than the skin. Only use a small amount and leave for a moment before it makes contact with the skin, allowing some of the alcohol to evaporate. Paste isn't needed if you get a good fit with your stoma bag, but in cases where it can fill a dip or crease it can be very helpful in managing your stoma with comfort and confidence.

Barrier wipes and films...

Many of us suffer with sore skin from time to time. We all know it is very important to keep the skin around the stoma healthy but occasionally we may have an issue. Barrier film in the form of wipes, sprays or creams coat the skin with a protective layer. If you are prone to leaks they provide a barrier between the output and skin, thus preventing sore skin as well as being very effective at treating any skin that has become irritated. They are normally alcohol free, so don't sting when applied to sore skin. They dry quickly and are non greasy, forming a good surface to allow easy and secure application of your stoma product. I'm sure anyone who has suffered from skin irritation can relate to that toe curling soreness when you try to clean the area and reapply a bag. It can be hard to get a bag to stick to sore skin, resulting in leaks, and in turn more sore skin. For people with sensitive or irritated skin, or those who suffer regular leaks, these barrier film products can make all the difference. It is really important for healthcare professionals to understand the need for these products. If ordering of barrier films is discouraged in patients who rely on them for the health of their skin, this could result in more product use rather than a saving as we all know a bag will last much longer on good healthy skin.

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 life 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.

Colostomy Association: Open Day 2013 A busy...well attended patient event... and all round success!

Building on the success of previous Colostomy Association Patient Open Days in Swansea, Gaydon, Warwickshire and Leeds. The Colostomy Association's Open Day at the Royal Berkshire Conference Centre in Reading buzzed with excitement and anticipation!

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

There was a warm welcome at the venue foyer from Sue Hale – General Manager, Jo Mckenzie – Senior Administrator and helper Alivia McMichaels, CA Chairman of Trustees Monty Taylor and fellow Trustees Jackie Dudley and Ernie Hulme Vice Chairman of Trustees and CA volunteers – Paul Foulger and Colin Allum, Terry Bryant and Mike Weller as attendees arrived and registered. Tea, coffee and biscuits were served in the Windsor Lounge which housed over 20 stoma care company exhibitors.

The day kicked off in the Princess Suite – Monty Taylor Chairman of Trustees welcomed everyone and introduced the content of the day.

Presentations then got underway:-

- About the CA raising awareness of the work of the charity from Jackie Dudley – Trustee and volunteer
- Patient focus changing NHS and stoma product supply Duncan Wells – Trustee and volunteer
- Stoma Care Overview
 Wendy Osborne, Charter Healthcare –
 Nurse Manager, Coloplast
- · Purple Iris Awards Ceremony

At times there were some lively discussions and very poignant questions from the audience! The Colostomy Association launched its first ever Award focussing on 'excellence of patient care' within a stoma care department in a hospital or community setting. The Award ceremony was eagerly anticipated by nominees sitting near the front of the stage.

Professor Bill Heald CBE – President of the Colostomy Association gave attendees a superb address which outlined his own surgical work and encouraged everyone to support the work of the CA recognising the charity's outstanding support for ostomate, their families and carers. Professor Heald then hosted the Award's ceremony.

The nominees for the Purple Iris Stoma Care Department Award (in memory Anne Leppington-Clarke) were St.
Mary's Hospital – Andie Coates, IOW, St. George's Hospital, Tooting - Ms Clare Gough, Luton and Dunstable University Hospital - Ms Heather Illet, Royal Berkshire Hospital Liz Harris/Gilly Thomsett.

The overall Purple Iris SCD Award winner was St. Mary's Hospital – Andie Coates. St. George's Hospital, Tooting - Ms Clare Gough, Luton and Dunstable University Hospital - Ms Heather Illet, Royal Berkshire Hospital Liz Harris/Gilly Thomsett all received 'Highly Commended' awards.

There were several special Awards – recognising the work of long serving and outstanding CA volunteers – Robin Mills and Jean Scott who both received 'volunteer lifetime achievement' Awards – both were visibly moved as they accepted their awards in front of their respective partners and fellow ostomates. A tribute Award celebrating

the contribution made to the Colostomy Association by volunteer Bob Buckley (who sadly passed away in 2011) was presented to his sons, Kevin and David Buckley (in recognition of their fundraising activities and the Bob Buckley Fund) and of the very valuable contribution Bob made to the CA through volunteering, training volunteers, raising awareness of colostomy irrigation and research was presented jointly by Sue Hatton -**Executive Trustee and Professor Heald** CBE. It was an absolute delight to see Sue Hatton up and around again as she has been very poorly and very sorely missed!

All in all it was a very informative and excting morning session – the audience were visibly moved at times by the acceptance speeches of the well deserved Award recipients.

A buffet lunch served in the Windsor Lounge – was well received and enjoyed by everyone! The exhibition area buzzed with people chatting, looking at and searching through the displayed array of stoma care appliance and additional products, explaining concerns and asking questions.

Several of the exhibiting stoma care companies ran raffles on their stands and Duncan Wells travelled around to each microphone in hand announcing the winners – his voice resonating around the Windsor Lounge – over the tannoy.

The afternoon was an open session for attendees it included a Parastomal Hernia Workshop – held in the Princess suite.

There were also SCN and patient – One to One appointments – were available all afternoon this year hosted by Coloplast. SCNs Wendy Osborne and Helen Cox gave their time freely to those who attended. Appointments took place in a private room which gave ostomates the opportunity to air their concerns or just chat.

An ad hoc showing of the Colostomy Irrigation promotional video took place which encouraged people to visit the specialist discussion area. The specialist discussion area was non-stop, hosted by CA volunteers – Margaret Simister, Judy Colston, Janet Bradley and Jackie Dudley its themes:-

- · Colostomy Irrigation
- Exercise and Well-Being
- · Insurance and Travel

Sister charities attending were – IA, Mr Phillip Horsely and Breakaway, Ms Melanie Bingham and Mrs Lesley Nickell as well as other local support groups and guests.

Many who attended the Open Day enjoyed the event and took away an improved knowledge of their stoma and its care, a greater awareness of stoma care appliances and additional products plus an increase in confidence and a sense of belonging to a charity which is there to encourage, support and reassure.

The event closed around 4pm. Needless to say a good open day was had by all!

We'll be back at the Royal Berkshire Conference Centre in 2015 for an extra special Colostomy Association 10th Birthday Celebratory Open Day Event – 10th and 11th July 2015. So put it in your diaries today! We encourage...YOU to – join with us – to celebrate an achievement that YOU have helped make possible!



May 1st 2012 was the day that life changed drastically for my partner Tom; he was diagnosed with colorectal cancer which resulted in him having a permanent colostomy. I remember squeezing his hand when Mr Elsmore his surgeon told us; I was trying to write all the information down in my notebook, but not doing very well at all. I knew about colostomies having spent many years working as a hospital play specialist on paediatric wards so was used to seeing children with them. My work as a play specialist meant that I would prepare children for invasive procedures, and relieve their anxiety associated with hospital admission.

I believe that my experience helped me and in turn I was able to support Tom, although he was a lot older than my previous patients!

Tom had a course of radiotherapy prior to his surgery, he had to travel to Southampton for this, as living on the Isle of Wight this was our nearest centre. We made the decision for Tom to stay in Lymington, with family and be driven their daily for his treatment. I

insisted that he take our shit zuh Buster to stay with him for the week, I knew the therapeutic value of dogs, as I had worked with a shit zuh at Great Ormond Street Hospital, (Ripley) on the pets as therapy scheme and had witnessed the valuable work he had done with in patients there, strange how we now have a dog of the same breed!

Tom made a speedy recovery from his operation leaving hospital after five days, complete with his stoma kit. Tom being his usual self had quickly got on with his no nonsense attitude and adapted to this life changing surgery. Tom had his ups and downs over the following months, coming to terms with a change in body image and dealing with the day to day procedure of changing his bag, which we had affectionately named Billy.

Tom has always been an active man enjoying gardening, dog walking, bowls, DIY, indeed just before his operation he went on a sailing course in the Solent. Tom was keen to get back bowling and with his amazing spirit he was playing



bowls by the end of September. He started his chemotherapy in August, his mind set was focused, yes he didn't play to his usual standard but he was determined to do it.

The chemotherapy took its toll it wasn't easy at times, but we always tried to make the best of it. We would go to our local on the evening before his treatment for dinner as we knew in the following two weeks the medication would make it difficult to do our 'normal' things.

My personal distraction was knitting, the winter evenings found me taking up this hobby that I had not done for years, I completed a few scarves, which I gave as Christmas presents!

Life with a stoma is challenging at times, and can be frustrating, but we always had the support of the stoma team at our local hospital St Mary's. If we had any queries our calls were always answered and advice given, this was a lifeline for us. We felt confident with their care both in the clinic and also in the community setting.

Tom had a few accidents with his bag; this was beginning to get him down, so in turn he was nervous about going out. The bag was not coping with the amount of waste so this was leading to pancaking out of the sides.

The final straw was on a shopping trip to Marks and Spencers, when Tom had to use the disabled toilet and his travel pack. I was left wandering the store in a daze feeling helpless and so sorry for Tom, we returned home quickly. Tom decided to phone Andie Coates the stoma nurse, Andie has always displayed care and concern whenever we have dealt with her, and for this we have been grateful.

Tom's words to Andie were 'I can't carry on like this'. Andie was as ever supportive she suggested irrigation to Tom, firstly checking with Mr Elsmore that it was alright to do so as his chemotherapy had now finished. Tom was more than happy to try this if it meant he was going to have more freedom and confidence.

Within days Andie had done a home visit and showed us the procedure, it went very smoothly. Tom started the irrigation procedure and has carried on ever since. It is amazing the difference it has made to both our lives, Tom fits the

procedure around his day, and it now means he can go out without fear of accidents. This has since lead to us going on holiday to Majorca in July, Tom felt assured and comfortable doing his irrigation before the flight, and this usually lasts him 24 hours at least. Andie advised us again before our holiday on the travel information specifically for Tom's needs and to take equipment even down to product numbers in case he ran out of supplies.

The holiday was a real boost for both of us, and my inspirational Tom, joined in most of the hotel activities, boules, crazy golf and the most liberating of all swimming in the hotel pool, we could not have imagined this before irrigation.

I'm sure this would not have been possible without the dedication of the stoma team at St. Mary's. By the way Tom is in a bowls final, his amazing spirit continues!



Island Stoma Team are first recipients of Colostomy Association's prestigious 'Purple Iris' Award...

This new Award recognises and celebrates the clinical and professional care and outstanding contribution beyond the nursing remit given by a team/department in a hospital or community setting directly involved with provision of high quality stoma care to patients.

The Award was made at the Colostomy Association's Patient Open Day at the Madejski Stadium, Reading, Berkshire on Saturday 20th July 2013.

It is estimated that around 6,400 permanent colostomies are carried out each year in the UK and 30 are

carried out on the Island each year. There are approx 200 patients on the Island with a permanent colostomy.

Matron Sue Biggs says: "It wasn't until Colostomy Nurse Specialist (CNS) Andie Coates was on stage to receive certificates recognising outstanding service with three other groups from across the country that it was announced that we were the recipients of first ever 'Purple Iris' Award. Our aim in the team is to provide patients with quality care every time and it is great to know that this has been recognised with this award. Everyone in the team is thrilled."

The Stoma care team on the Island comprises (L-R pictured above):

- · Michelle Houchin, Secretary
- Amanda Broadbridge, CNS Stoma Care
- Andrene (Andie) Coates, CNS Stoma Care
- · Sue Biggs, Matron
- Jill Hambley, Admin Support

VVork, Rest or Play





Lauren

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Focus on Support Garments

If only...

Jackie writes: I have often heard this expression used in conversation but I never thought I would use it in relation to my stoma.

Now I hear it all the time when I chat with ostomates who have a parastomal hernia. 'Why didn't someone tell me about support garments?" they say. If only...they had told me - I might have been able to prevent my hernia.

Back in 2001 I received a stoma and once out of hospital I learnt how to live with it. However, after a few months I noticed a change around stoma – a 'lump' forming. When I suggested to my oncologist that I thought I was starting to get a hernia she said, "you are just getting fat". So, believing her I took no further action.

A few years later – the 'lump' had now become a very large parastomal hernia. A stoma care nurse visiting the offices of the Colostomy Association (where I was volunteering) asked me what support garment I was wearing. She was astounded to learn that I didn't wear one, not even a light support garment! She sat me down, and gave me a long lecture on how important it is to wear a support garment to stop a hernia developing. I heard myself say, "you're too late." I then had a lecture about wearing a support garment to support my hernia!

I uttered, those two little words - 'if only'. If only, someone had told me when I was in hospital about the importance of wearing a support garment. If only, someone had told me after my hernia had developed that I needed to wear a support garment, I would not have been in such discomfort. If only...!

I chat with lots of ostomates and I hear this phrase again and again...'If only'. It seems that many stoma patients leave hospital without advice about parastomal hernia prevention or the use of support garments. A patient may be told not to lift heavy items, to rest the

body, take things easy - but if I am to believe what I hear - very few of us are told the importance of wearing a support belt or garment.

Since that day at the Colostomy Association – I have made it my mission to learn all I can about the various support garments and belts - available to ostomates. I also chat with anyone I know who is about to have stoma surgery or is post op to make them aware of the possible development of a parastomal hernia.

Many articles have appeared in Tidings magazine (notably in Issue 14) about parastomal hernias, with advice on how to avoid them, manage them and the use of support garments.

An excerpt follows from **Tidings Summer Issue 14:** Support Garments...

Fortunately, there are a number of support belts and garments that have been specifically designed to effectively support the hernia as well as reduce "the lump" – available on prescription.

If you suspect a hernia is developing the first thing to do is to contact your stoma care nurse, she will have a look at your hernia and be able to advise on the most suitable item for you, one which will offer you the best support.

Once decided upon, your stoma care nurse will arrange a fitting session where you can try on the support garment and be correctly measured. If you are to have an aperture for your pouch to fit through then it is important to be correctly marked up for this.

If you have a colostomy you may choose to have a garment with no hole for the pouch as your stoma only works occasionally. If you have two stomas, (usually a colostomy and a urostomy) the garments will need to be tailor made to ensure that both the fit and support is correct. It is so important to discuss your requirements with your stoma care nurse; garments need to be

made to measure to ensure the holes are in the right place.

Helpful Advice – Always consult your stoma care nurse before using a support garment in any of the following situations:

- · if you wish to wear the garment whilst sleeping
- if you use a convex appliance
- if you are in discomfort or pain
- · if a drain is situated in the area, which will be compressed

Also consult your stoma care nurse if whilst using your garment:

- your bowel function changes
- if you have gained weight and the garment feels small

Jackie continues: You might be reluctant to wear a support garment at first - women have a choice of 'Sloggi's', a light but firm support pant there are many others, men have a choice of boxer shorts with a support pocket to hold the pouch firmly. Any kind of support is better than none and there is always advice available on what is best for the stoma patient from your stoma care nurse and the Colostomy Association.

If you are best suited to a firm support belt or garment then the choice is a wide one. Companies specialising in support belts and girdles do them in a range of sizes, colours and designs. A discussion with your stoma care nurse should give you an idea of the best support garment for you.

Let us get rid of the - "IF ONLY" - and replace it with 'what kind of support garment are you wearing!

Editors Comment

Support garments are not worn in the immediate post-operative period, but after the abdominal wounds have healed.

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Breakaway...goes to Woodrow High House, Amersham

Unique...weekend activity breaks designed for young people aged 4-18 with bowel and/or bladder diversions/dysfunctions and their families.

Our second family weekend of this year has been and gone. We chose a new venue, Woodrow High House in Amersham. We picked this venue as we are aware that for some of our families who live further South it can be a long trek in the bank holiday traffic to the YHA at Moira in Derbyshire.

We were full to bursting with seventy three people arriving on the Friday, many were new families, unsure about what the weekend would bring, worried if they would 'fit' in. But, as often happens at Breakaway events, within a very short time it felt like we'd all known each other for years! The children ran off to explore the big house while the adults traipsed up and down what seemed like endless flights of stairs, trying to remember where their rooms were.

The activities started on Friday with a scavenger hunt, a great way for everyone to get to know each other, and to explore the wonderful grounds at Woodrow. Saturday dawned bright and early, well not so bright as in typical Breakaway style it was raining, but at Breakaway a little bit of rain doesn't stop play! It was into the sports hall for some team games. And as sometimes happens, who became a little too competitive? Yes, you've guessed it - the parents! Fun was had with the parachute games, and then after lunch the younger children had a great time pond dipping, and swimming (though not at the same time!), while the older ones got very wet and muddy doing the low ropes and nightline.

On Saturday evening parents had a Q&A session with Lesley and Jeni, our two professional volunteers. Some of our parents have very little support in





NEW... Breakaway Leaflet



did you want to come to Breakaway?'

Typical responses are often: 'to get support for my daughter and myself and to feel that we are not alone and that there is help available,' and 'to be amongst other families with similar issues to share experiences'. It can become easy for the trustees and volunteers to take what Breakaway does for granted, after all we live and breathe it, but when we gathered in our families stories for our new 'making a difference' leaflet we were truly humbled by the words that were written. To hear from not just the children, but from mum and dad, sisters, aunties, grandmas, best friends, and even an ex 'Breakaway kid.' Our new leaflet showcases what Breakaway is all about and we hope it will help us to reach out to even more families.

But we need your help to continue doing what we do. You don't need to climb mountains or run marathons, you can donate as little or as much as you'd like to via our Just Giving page, or if you are employed you can donate via the Give As You Earn scheme where your donation is deducted from your salary before tax.

the community, a Breakaway event is often the one time where they really feel someone is listening, we are very grateful to our professional volunteers who give up their time to be with us. Sunday came round quickly there was archery, team activities, more swimming and then toasted marshmallows round the campfire!

On Monday those families who seemed unsure on Friday night went away with smiles on their faces and a renewed strength to face the challenges ahead – much needed with the start of the new school year just around the corner. They told us:

'This weekend has been amazing. We have had much needed family time. We have laughed constantly and felt the stresses of everyday life just disappear. Most importantly we no longer feel isolated we feel like part of the big Breakaway family.'

'The weekend was quite simply a life-saving experience...once again. As you know, we have been struggling this past year and seeing you again this weekend has given us the opportunity to regain some strength before the new school year and to make new fantastic friends!'

More information about Breakaway...

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Keep on dancing..



My journey with bowel cancer began one day at the beginning of November 2008 - just before my 71st birthday. I felt some sticky stuff on the toilet paper; it looked like pale pink jelly. I thought I'd better keep an eye on it so each time I went to the toilet I looked at the paper. Nothing happened the next time but it did occur again, and again a few days later. I had no pains, no other symptoms, but decided it was time to get it checked out.

My GP examined me, and said he thought it was piles, but wanted me to have a barium enema to be sure. My appointment arrived for the 19th November. A week later I got a phone call from the surgery to go in straight away. The results of the barium x-ray were back and it was bad news. My GP explained fully what happens next. At 3.30pm the following day while we were dancing, I got the call on my mobile. The receptionist said I had an appointment at Doncaster Royal Infirmary on Friday 5th December at 3pm.

My new bowel consultant, Mr. Khetan, introduced himself, did an internal examination and a camera test. He said there was something there that needed treating, but he didn't know if it was benign or not, and would not commit himself until I'd had a CT scan and an endoscopy. The CT scan was on 11th December, the colonoscopy on 22nd December and then I received a phone call to say Mr.Khetan, wanted to see me at 10am on Christmas Eve.

Mr Kehtan had a cancer nurse. Diane. with him. He said she would be looking after me and if I had any questions or anything I wasn't sure about she was at the other end of the phone and would see me through it. She said she had been doing this job a very long time and seen a lot of improvements and changes in the treatment. Weston Park Hospital in Sheffield is a Cancer Research and Teaching Hospital and is always experimenting to find new drugs and improving ways to treat cancer -Dianne said I would be sure to get the latest and best treatments for my cancer. Mr. Khetan said I had a polyp on one side of my bowel and a cancer on the other. I needed an urgent operation, but the theatre was closed over Christmas and the earliest he could book me in was 5th January.

I was told I would need a colostomy. I asked how long would the operation give me, and Mr Khetan said "Do you really want to know?" I said "Yes please" and he said about two years. "And without it?" I asked, and he said about ten months. I was devastated. "Why me?" went buzzing around in my head. I have never smoked a cigarette in my

life, and I never drink alcohol, so why me? But I couldn't let my daughter or my husband see my anxiety, and if I didn't come through the operation, I didn't want it to be the worst Christmas they had ever had. So I pulled myself together, and we got through Christmas, and we did have a good time.

×

My Consultant was lovely. He came to see me before the operation, and when I opened my eyes after it, he was there by my bedside. He said the op had taken four hours, and it was a success, and he hadn't needed to do a colostomy. I said "Thank you" over and over again, as I was so relieved and grateful to him.

Next came chemotherapy. The doctor was just as patient and caring as my bowel consultant, but my first experience of chemo was not good. I should have had eight sessions: the injection followed by two weeks of extra-large tablets, and a week's rest, then start again. I got through the first month but then then started having problems and was admitted to hospital twice. So my chemotherapy doctor stopped the chemo after three sessions.

When I had got my strength back, it was time to talk about an operation, and I was introduced to my liver consultant. He said I needed another operation, but he would have to go in front of a panel to get permission for me to have it. The first time he went, they said I wasn't well enough, so I had to build myself up. Then he went back a second time and again the panel refused. Eventually when I was really well again, he said he



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The photograph above was taken on a dancing holiday at Bournemouth in April this year. We travelled down by coach, arriving at 4.30pm, had dinner, then danced from 8pm to 11pm. On Tuesday, Wednesday and Thursday we danced from 10am till 12 noon, had lunch, rested, had baths, then dinner from 6pm to 7.30pm and danced from 8pm till 11pm. We had a casual evening dance, a fancy dress night and the photo was taken at the formal dance on the Thursday night. I gave my liver consultant a copy of the photo and asked him to show it to the panel that rejected my first liver operation twice, to show them how well I am now.

was going back to the panel because he wanted me to have the op. However, at first they refused and asked why he had brought my case back a third time. He told them I have a very healthy body, a positive attitude, and a very good quality of life, and he wanted that to continue. My chemotherapy doctor backed me, and so did Mr. Khetan. After a lot of persuading the panel finally agreed to an operation.

My second operation, this time to remove a tumour from my liver, was on 6th January 2010, just a year after the first op. Unfortunately my consultant said he could only do half of the operation, as it was on both sides of a vein, and I would have to go back for the rest of it. Since then I have had another four operations, one being a dual operation to remove a polyp from the outside of my bowel and another tumour from my liver. This op took twelve hours and two surgeons, and I woke up with the colostomy.

One of the others was to remove a tumour from one of my lungs, and I had another consultant on my team. He asked me if I would take part in a research programme Sussex University are doing into bowel to lung cancer, and it would take five years. I figured that if they think I will still be here in five years' time, I have to go for it, so I agreed. I am now just two years into the research programme.

In between these operations I have had two ablations, so I have spent a lot of the last four and a half years in hospital. The strange thing is that I only ever have pain when I am in hospital recovering from an operation. My first words when my consultant tells me I can go home are how long before I can dance again? Then how long before I can start bowling again? My surgeon usually puts his arm round my shoulder and says "Please be patient, my dear, and let's get you better first". I absolutely hate being in hospital, and the minute I am home I begin to feel much better. We go dancing four afternoons a week, and in the winter we play indoor bowls three nights a week as well.

We go on holidays, although insurance has become a problem, not for me, but my husband is 91 years old, and it costs him a fortune. He is very fit, and we have a wonderful lifestyle, and I don't want

to spoil that. We have just celebrated our eighth wedding anniversary, and the day we got married I told him he couldn't go and leave me until he has had his telegram from the queen. He is a wonderful nurse and looks after me while I am recovering from an op. Sometimes in the night I feel a sticky patch and know my pouch has leaked. I wake him up and tell him and he says go and get yourself cleaned up, I will see to the sheets. When I am grumbling about my colostomy, I am sore, or it is irritating me, my daughter will say, "Mum, be patient, remember it saved your life", and suddenly everything is OK again.

I am now on my fifth session of a six session programme of chemotherapy, the same drug that I had before but a lesser dose. This time I have a PICC line and an infusion bottle on for two days following the injection, instead of the extra-large pills. My daughter has been taught how to change my dressings and remove the bottle. I have had no pain, no side effects except a couple of days of sore lips, tingling fingers, and a few loose bowel movements, but my colostomy is erratic anyway. So hopefully the chemo will have done its work.

I am very lucky. I have a wonderful medical team who I trust completely, looking after me, a devoted husband, daughter and son-in-law, who back every decision I make about my health, without question, and lots of lovely friends to support me. I am still here dancing every afternoon from 2pm to 4pm, and bowling in the winter, four and a half years later.



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New series...Ostomy Myths...

Travel: Do ostomy bags blow up on aircraft? How often are we told that our bags will inflate when we travel on aircraft? Is this true?

Rosemary writes: All the seasoned travellers I have spoken to say it isn't. Having taken several long haul flights myself, I would agree. So why is this rather worrying information so often repeated?

When an aircraft gains altitude, the pressure inside decreases. To ensure a safe and comfortable journey the cabin is pressurized and maintained at about three pounds per square inch lower than it is on the ground. Any air or gas trapped inside an airtight bag will therefore expand. You may have seen this happen to a bag of crisps. So what's the difference between a bag of crisps and a colostomy bag? Well a bag of crisps doesn't have a filter. So maybe the fear of a stoma bag blowing up originated in the days before most bags had filters.

If you get on the plane wearing a bag that doesn't contain any air or other gas, there's nothing there to expand. However, any gas in the gut may also expand and pass out of the body as wind. But this applies to everyone on board, not just ostomates. Although ostomates may produce more wind in the early days after stoma surgery, once the bowel has settled down we do not necessarily produce more wind than anyone else. The problem, as we all know, is that we cannot control when we expel it. If we do pass wind into the bag there is a filter to release it, with the added advantage of deodorising it at the same time.

Now, I can hear you all saying, 'But filters don't work.' It's true some are better than others, so it is worth trying out different bags to find the best. Another thing to remember is that filters aren't so effective when they get wet. This can happen to the inside of the filter if it comes into contact with a very liquid stoma output, or to the outside when you take a shower or a bath, or go swimming, if you don't remember to cover the filter with one of the sticky patches you will find in your box of supplies.

To make sure your filter is at its best, it's a good idea to put on a fresh bag before you board the plane. And, if you usually cover your filter with the sticky patch, leave it off for the flight. However, if you normally produce a lot of wind and are still worried that your filter won't cope there's always the option of using a drainable or a two-piece appliance. Any gas in the bag can be released in the aeroplane toilet through the opening at the bottom of a drainable, or by partially releasing the bag from the baseplate in a two-piece.

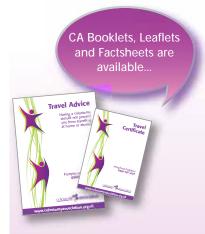
So is there any truth in it? Do bags blow up on a plane? Well it is probably no more likely to happen than when our feet are still firmly planted on the ground. So perhaps it is time we stop spreading this rumour and increasing the anxiety new ostomates feel when they go on holiday with a stoma for the first time.

Your Travel Checklist...

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

- · Take sufficient supplies for your stay
- Take all supplies and travel stoma kit as hand luggage
- Ask the airline in advance if you need extra hand baggage for your supplies.
- 'Check in' online 24 hours before departure to secure your preferred seat.
- Avoid food and drink the day before you are to travel that are likely to cause upset or excessive wind.
- Take medication to firm up or loosen output.

- Carry your Travel Certificate with you especially when passing through immigration or security areas.
- Take some form of electrolyte replacement solution in case you become dehydrated.
- Drink bottled water in foreign countries, avoid ice in drinks and use bottled or boiled water to clean around your stoma area.
- Store your supplies in a cool place, out of direct sunlight.



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into healthy stoma skin





Dear Nurse

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

Q: I read with interest, the letter to nurse Julie in the spring edition of Tidings (Issue 30), regarding anal discharge being a dark colour. I have had this for 4 years since I had the Hartmann's procedure and was told it would clear up in time, which is not the case. I cannot get to the cause of this, having seen my stoma nurse who suggested it was an infection, so my doctor prescribed antibiotics, which hasn't helped. I asked about it at the 6 monthly review clinics I attended and the doctor just shrugged his shoulders and said I could extend my reviews to yearly as I was doing so well. I then contacted the surgeon, who organised a CT scan, this being two months ago, and I have no feedback yet. I was wondering if any of the readers' have this problem. There is no join (anastomosis) in the bowel as far as I am aware so I cannot understand this.

A: Following a Hartmanns procedure you are correct there is no anastamosis (join) in the bowel. However there is a rectal stump and one of the problems you can get is that the bowel continues to produce mucous, which may be discoloured. This mucous can, on occasion, form a 'plug', which gives the sensation of needing to empty the rectum. Some people find they occasionally require a Glycerine Suppository, prescribed by their GP, to help to move this mucous plug. Other people find they can pass it normally themselves. Many people do find this 'dries up,' however there are some patients who continue to have a discharge for a long period. If this is problematic it may be worth another visit to your stoma care nurse who may be able to suggest glycerine suppositories or possibly the anal plug, this however should not be used without a health care professionals advice and support.



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

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

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

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

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

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

I am a little anxious however about the existence of the abscess, whether it's growing in size, whether it might 'burst' and whether there might be some new treatment that has evolved over the last few years that might deal with it. Or should I just stop worrying about it! I'd welcome your advice.

A: I would suggest a review by your colorectal surgeon who can investigate the abscess and advise with regard to treatment or offer reassurance.

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

A: You do not state how long ago you had your recent surgery or why it was performed. You can still get support from your local stoma care nurse and she may be able to offer dietary advice or even refer you to a dietician for advice if she herself cannot help. With regard to the pain it is usual to have some discomfort immediately following surgery and can require taking regular painkillers (analgesics) to manage this. However as time progresses if the pain continues you may need a review to investigate the cause. Again it is difficult to advise, as I do not have your full history.

Q: A 'Dear Nurse' letter in the summer issue of Tidings caught my attention. The writer mentioned that they had developed an abscess near the top of their rectal stump, which drained close to the anus. Like them, I have had a colostomy for about 10 years.

Unlike them, my rectum has been removed. However, I have recently been found to develop a sinus, which drains serous fluid close to where my

anus used to be. This sinus has defied several attempts at closure, and I am about to be referred to yet another hospital in search of a solution. I note that abscesses are reckoned to develop in about 5% of cases. Are there any statistics on the occurrence of a sinus, does you know?

A: I have to admit I am unsure of the current statistics on the occurrence rates for sinus formation. If you are due to see a surgeon at another hospital they may be able to advise with regard to statistics. I hope that you are able to find a solution to the problem of the sinus soon.

Q: I have had a permanent colostomy since 2001 due to Bowel Cancer. I read Tidings with interest, and have always found it very helpful. I irrigate every day or sometimes every 48 hours, and have travelled abroad with no problems.

There is one thing I would like to mention that I have read in Julie's column, which I would like to give my opinion on, she has mentioned on several occasions that the Plug will stop output from the stoma, this is certainly not the case. When the stoma wants to work it will no matter what. I think to expect the Plug to stop output is impossible. I spoke to my stoma nurse about this and she agreed with me, no one should rely on the Plug to stop output. Hopefully you will be able to comment on this. Many thanks.

A: I am sorry to hear that the plug did not work for you. It is obviously all a matter of personal experience. There is obviously no 'one solution suits all' system and each patient's care and stomal management should be assessed on an individual basis. I do have patients who found the plug did not work for them at all and we have looked for another solution, such as irrigation to manage their stoma. However I do have a lot of patients who find the plug works extremely well for them, with no leakage at all and also have patients who find that irrigation did not work for them. This is why we have the option of using different systems for different people.

Q: I am about to have a colonoscopy and that I will have to take 'Picolax'. Should I take and can I still irrigate?

A: Picolax is a bowel preparation used prior to colonoscopy as well as for other investigations and treatments. If the colonoscopy is to be performed via the stoma then you can take Picolax, although I would not irrigate as well and would use a drainable pouch whilst taking bowel preparation. If you are unsure you should contact the endoscopy unit, the telephone number should be on the appointment letter, for advice.

Q: I had a colostomy but now have an ileostomy. I was prescribed sixteen Imodium tablet a day but I only take four. I'm having problems with my bag and the barrier cream is not working, I don't know what to do my skin is very sore and red. Can you help?

A: The output from an ileostomy is much looser than from a colostomy and can be very difficult to manage if it is a very loose output. The consistency should be like a soft paste. If the output is very loose then Loperamide (Imodium) can be used to help to manage the output. The amount of Loperamide required varies for each patient but the best time to take it is 20 minutes prior to eating. The problems you are having with the pouch and the skin excoriation could be due to the loose output. There are many treatments for these problems but you would need to see your local stoma care nurse for a review to ensure the correct treatment plan is made for your situation.

Q: My stoma is causing me a lot of stress; it's bleeding and seems to be coming away. I haven't knocked it. I don't eat very much but had a huge movement recently and diarrhoea. My family is not very patient with me and sometimes gets frustrated and angry. Where can I go for help?

A: You can ask your GP to refer you to your local stoma care nurse who will be able to check the stoma for you and to advise with regard to any treatments you need to address any problems found. You may also find that locally to you there is a support group. Your local stoma care nurse or the Colostomy Association will be able to advise with regards to local support groups. Talking to people who have undergone similar surgery to yourself can be very helpful and help you to feel supported. I hope this helps.

Q: I had my colostomy fairly recently. I have a hernia and obstructed colon. Is it normal to get a hernia after a couple of weeks? My surgeon won't operate on the hernia – what can I do? Can I request a second opinion?

A: It is not uncommon to get a

parastomal hernia, although this soon after surgery is unusual. If the surgeon is unwilling to operate this soon after your initial surgery you may benefit from an abdominal support to help to prevent the parastomal hernia worsening. Your local stoma care nurse should be able to advise, she may have a contact, either at your local hospital or with a company who supplies supports. You will need to be assessed prior to this to check if this is necessary and then will be seen to be measured for the support. These supports are usually available on prescription from your GP so it may be worth discussing it with him as well. You can ask for a second opinion but it may be that the surgeon is not willing to repair the hernia at this moment in time as your recent surgery was so recent. If you discuss the repair with him you may find that there is a reason for the reluctance or that he is willing to operate at a later date.

Q: I have a few concerns I have been advised that I will require a colostomy. I am losing weight and I'm on Imodium and Loperamide eight tablets per day. My family is not very supportive and I lost my husband several years ago. My GP is not very helpful either. I just want some medical advice that I feel is taking on my concerns.

A: It is very difficult to answer your queries without knowing your full history. You do not say what condition you have been diagnosed with and what information you have already been provided with. You should firstly talk to your GP or your Consultant and they will be able to answer any questions you have. They can also refer you to a local stoma care nurse who can provide more detailed information regarding stoma formation and care. She will also be able to refer you to a local support group so that you can talk to a patient who has undergone a similar operation and who lives with a stoma. I hope you find the information you need to allay your concerns.

Q: I have had my colostomy for 10 years. I have been passing motions from my back passage. I have high output and recently have had the sensation of needing the loo. Can you tell me if this is normal?

A: I presume you had surgery, which preserved your rectum and anal canal. If you did it is not uncommon to have a discharge from this area and to occasionally get the sensation that you need to go to the toilet and to pass something out. If this changes,

becomes more frequent or painful, or if you start to pass blood then you will need to see your GP who will refer you to a specialist if needed.

Q: I had my colostomy in 2011 due to bowel cancer; I seem to have many problems associated with my stoma. My bag doesn't stick and I can't cope with the smell when I change my bag. I just feel so low. I keep vomiting and I'm losing weight. My family is very supportive. But I'm finding it difficult to adjust. Is this normal your advice would be much appreciated.

A: I'm sorry you are struggling with the stoma, both on a practical and a psychological level. With regard to the practical problems you are experiencing you will need to see your local stoma care nurse who will assess the issues and advise with regard to solutions. The smell may be due to your diet and your stoma care nurse can advise with regard to this. Leakage from the pouch can be due to the consistency of the motion or to the condition of the skin and again the stoma care nurse can advise on a one to one basis. You may also find it useful to speak to a local support group or to someone at the Colostomy Association. Obviously talking to someone who has undergone the surgery can be very useful as they can talk from personal experience. I do hope you find some solutions to the practical problems you are having and also begin to accept the

Q: I am having difficulties sleeping at night. I only seem to get between 3-4 hours of good sleep per night. I just can't relax. I get so fidgety and keep checking my bag to make sure it's not leaking. I had my op in 2004. Can you suggest something that could help me?

A: You state you had your surgery in 2004, which is a long time ago. Is this sleeping difficulty a new problem or have you had it since surgery. If it is a new manifestation then you may need to see your GP to investigate why it is occurring. If it is a long standing problem then are there any specific concerns you have which are exacerbating it? It may be helpful to have some counselling, either with you local stoma care nurse or your GP may be able to refer you to someone who can help you to manage these concerns which may then in turn help you to relax and sleep. If you are experiencing any practical problems with the stoma, such as a leaking pouch, then it may be beneficial to see

you local stoma care nurse who will help to address these problems.

Q: My bag isn't sticking and I have a hernia. I am using extension flanges. Can you tell me the best way of using these or can you suggest any thing else?

A: Flange extenders are used to help the pouch to adhere to the abdomen and are useful if you have a hernia. You apply the flange extenders around the edge of the pouch, overlapping each flange extender and also the adhesive on the pouch so that it secures to the skin. However there are different pouches which may also be of use and a review by your local stoma care nurse would be useful to ensure you are using the correct product, especially if you are having leakage problems. You may also benefit from an abdominal support and again your stoma care nurse or your GP can refer you to the relevant people for this.

Q: I am a new colostomate and I have come out of hospital fairly recently. I have been coping quite well but my bag leaks all the time and comes away from my stoma. I have had to change my bag several times so much so that I have nearly depleted the supplies I came home with, I don't feel able to go up to the hospital and fear my bag supply will run out what do you suggest?

A: You really do need to contact your local stoma care nurse who will be able to advise with regard to a different pouch or accessories. There are many reasons as to why the pouch is not sticking well to the skin and these should hopefully be easily identifiable and a solution found. You will need to obtain further supplies on prescription from your GP. Once you have the prescription you can either take it to your local chemist who will be able to obtain the stock within a few days or you can post the prescription to a delivery company. I am unsure which options your stoma care nurse has suggested but you should have been given some information on discharge from hospital.

What kind of stoma do you have?

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

Five facts about an ileostomy

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

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

Five facts about a colostomy

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

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

Editors Comment

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

If so write in and tell us:
The Editor
Colostomy Association
Enterprise House
95 London Street
Reading RG1 4QA

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



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Distributed by:

AAH Pharmaceuticals Ltd,
Coventry, CV2 2TX.

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

Thank you all for the support your magazine has given me over the last five years. After my emergency surgery which resulted in a colostomy, somehow your magazine always seemed to have an article that related to any problem I was experiencing. It was my crutch when I needed it. I recovered well, resumed my normal life, which is very active and varied. In fact I almost seemed to enjoy the challenge of pushing myself even further. My only disappointment was not being successful with irrigation but I suppose you can't succeed at everything.

Eventually I had a reversal. This wasn't thought to be possible initially. I found it was a difficult decision to make - I was feeling so well and dreaded the thought of a return to hospital again. Eventually I went ahead. I did develop complications but after a further six months I was well again. It was the right decision to go ahead but you only know that retrospectively.

I haven't cancelled your magazine but I don't really know why - I think I was scared to accept that I don't need it any more. A friend had a colostomy at the same time as I recovered so I have been passing your magazine on to him. He is due to have his reversal in a few weeks so I am being brave and asking you to cancel my issue of Tidings so that someone else can benefit just like me.

Best regards,

P.C

Dear Editor

Just a line to say how much I enjoyed the Colostomy Association Open Day in July. It was an extremely informative day. So great, to meet people with stomas and not feel embarrassed when talking to others about problems and concerns – just to be free to have a laugh and a joke about them was amazing.

Yours sincerely,

C.N

Dear Editor

I would like to convey my thanks to the Association for sending me the 'Tidings' magazine during the past year. The information contained in the magazines and the free samples that have come with them have been marvelous.

On reading some of the adverts my friend calls the suppliers for various samples. I would very much like to continue to receive copies of 'Tidings' please accept a donation of £25 to wards costs.

Thank you so much for all your help this year!

Yours sincerely,

A.A.P

Dear Editor

It took me several days to 'come down' off the high experienced at this year's C.A. Open Day, it was such an inspiring event. I've tried, with limited success it has to be said, to explain it to friends – how even for someone with an 'upfront and open' attitude to my colostomy, it is such an uplifting experience to be among others with the same interests, nothing to hide and an eagerness to share stories.

It was a pleasure, too, to see 'my' stoma nurses from the Royal Berks Hospital, Gilly and Liz, accepting an award for their department; it was richly deserved.

Disappointments, too – I had hoped to hear from Breakaway again in the presentations on Saturday morning, but later found their stand and had a good chat anyway.

Then I looked for the Irrigation Discussion Group and found Judy giving a young nurse an impromptu demonstration and joined in with the questioning. I spoke to at least five others who use irrigation, all differently(!), but all very keen on its benefits. All right, I give in — I've since booked a couple of appointments with Liz to take me through my first attempts.

All in all, a great day, and thanks to everyone for making it possible. It is remarkable how my 'passport from cancer' has brought so much more into my life – long may it continue.

Best regards,

P.R

Dear Editor

The article by Mr Nigel Scott on Roadblocks and Assumptions I found most helpful, informative, and easily understood. I was told after my ileostomy (5 years ago at 80, after 30 odd years of U.C.) that I had adhesions following hysterectomy and spinal surgery, but this has never been mentioned again when I have sought medical advice for the episodes of severe pain and vomiting I have had. The diagnosis has been gastritis. I found it very reassuring to know that I am all unwittingly a 'roadblock pro!' It will be so much easier to cope with future episodes now I know the reason for the pain I experience.

Yours sincerely,

J.M

Dear Editor

Thank you so very much for the article in Tidings written by Mr. Nigel A Scott regarding blockages and pain. I have been trying for such a long time to find an answer regarding my stoma pain, blockages etc. problems - this article answered them so well. The relief I felt after reading Mr Scotts article was over whelming. I am sure it will help so many people.

THANK YOU, THANK YOU.

Kind regards,

J. E

From Ed:

Credit must go to Sue Hatton – Executive Trustee of the Colostomy Association for requesting the article Roadblocks and Assumptions written by Mr Nigel Scott, BSc MD FRCS be reproduced in Tidings Magazine – Summer Issue 30. Kind thanks go to the IA (The Ileostomy and Internal Pouch Support Group) for allowing the article to appear in Tidings Magazine.

Dear Editor

There seems to be something of a conspiracy of silence about the general effectiveness of colostomy pouch filters. My stoma was installed four years ago and I have experimented with a number of brands and designs of pouch. One unsatisfactory feature has been common to them all. In none of the models tried have I found a filter that works satisfactorily. My perpetual problem has not to do with escaping odour but with the experience that in not one case have I found a filter, which operates spontaneously in allowing gas to escape, and I have to resort to the solution of a pin prick in the centre of the filter to release the gas.

I have sought advice about this from my hospital's stoma team and a number of other expert sources, including representatives of pouch manufacturers. I was somewhat surprised to be told by one rep. (a colostomate herself) that the only satisfactory way of activating the filter on her particular brand, which I was using at the time, was to scarify the inside of the filter with a finger nail before mounting the bag! I have since moved on to another brand. Same problem, but it was at least refreshing to encounter a leading manufacturer's representative who acknowledged this was a problem with her own product and confessed that filters were the least

satisfactory aspect of modern pouch design.

It would, perhaps, save users a good deal of concern if manufacturers would acknowledge this deficiency and include specific advice with their product on how to deal with the problem of ballooning when it happens - and it will happen to most, despite the customary warnings about what foods and drinks to avoid. For me, as I have said, the quick and easy solution has been a pin through the middle of the filter. Though a word of warning here. With some brands the carbon has a moist quality that can cause it to seep through the pinhole. To avoid the possibility of staining clothing it is sensible to seal the hole, after expelling the gas, with one of the adhesive filter seals provided with the pouch; this is probably a wise precaution in any case to avoid the unwelcome release of odour or more sinister leakage! More publicity about this problem would have saved me a lot of trouble and anxiety in the early days of living with my stoma. Not least it would have helped me avoid the unwelcome and unnecessary frequency with which I changed bags in my ignorance when ballooning occurred.

Yours sincerely, M.J.W

Dear Editor

I would like to share my most recent (and much the worst ever!) disaster in the hope that it might enable others to avoid a similar incident. It is an unpleasant story, for which I apologise.

Like most colostomates, I never go far from home without an adequate

Readers' writes

supply of pouches, disposal bags and wipes. However, I had not had to make use of my emergency pack for several months, which I believe to be the factor at the root of my problem.

I was out for the day with relatives. Playing safe, I changed my pouch at lunch time, though it could have been left longer. I did notice a slight stickiness around the flange, but did not investigate it further. Several hours later, in the car on the way home, the pouch leaked disastrously. When I reached a toilet I was in a complete mess. On examination, none of the faeces had gone into the pouch at all, and I realised that the flange must have adhered to the inner surface of the pouch, preventing access.

My theory is that this softening of the adhesive was due either to the length of time that the pouch had remained in my emergency pack, or perhaps to the high temperatures that we had enjoyed a month or so ago. Whatever the cause, I have resolved always to check before use that the flange can be moved freely, especially when using a pouch from my emergency supply.

I hope others can learn from my experience.

Best regards,

J.D.W

Dear Editor

I am writing to let you know of my irrigation experience as I hope to reach others who have been in a similar state of mind to myself.

When I was diagnosed with bowel cancer a few years ago at the age of 68 I was in complete denial – me, the person who found bodily functions something to be hidden away and never talked about, was told he had to wear a bag. I pushed the idea to the back of my mind and

convinced myself that a reversal would be offered to me. And I wouldn't have to deal with things down there. Of course that made matters a hundred times worse when I finally came to realise that my stoma was here to stay and I had to deal with it. I felt dreadful at times. To make matters worse I refused to change my diet of eating plenty of fruit and juices (ironically to prevent me from getting cancer) and I had no wish to give up on my favourite foods which are curries with plenty of chilli. All this and I kept my stoma a secret from everyone except my

The result of my diet (I think) meant that for the first year I experienced several very embarrassing leakages, a very toxic smell at times, and skin soreness. My stoma nurse tried to help but I just kept wishing for a miracle - new bowel to be stitched back preferably, and I felt extremely anxious and depressed about any social situation. My wife asked about irrigation, but my aversion to even look at my stoma and deal with the outpourings from it made my stoma nurse feel it was not a good option also she felt that as I passed a frequent loose motion I would not be a good candidate as I would be unlikely to be able to wear a plug.

However, at a meeting with another nurse I was more or less told I HAD to give it a try, Hallelujah! To my complete surprise I managed to do it! I felt so much cleaner when I found I could go for 12 – 24 hours with nothing passing into the bag. I get no smells, no sore skin, and although I will always wear a bag to contain the occasional curry meal and to feel safe, my confidence is SO much improved – I can do all the things I did before such as golf, walking and swimming. I would advise anyone of any age to give irrigation a try.

Kind regards,

G.W

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



NATIONAL KEY SCHEME

How to obtain a key to gain access to toilets for the disabled

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

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

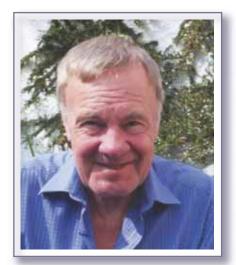
Keys can also be purchased for £3.50+VAT from RADAR:

Tel: 020 7250 3222 Web: www.radar-shop.org.uk

From RADAR

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





Norman Croucher OBE gives
Tidings readers an insight into his journey –
with bowel cancer – a challenge of a
different nature – yet equally fraught with
danger and set backs but overcome by
resilience...humour and positive thinking!

Profile:

As a double leg amputee Norman's mountaineering has certainly been challenging but as Norman says: 'the greater the challenge the greater the reward - if you succeed'.

Norman achieved his ambition of climbing a mountain of 8,000 metres by many stages and over many years has explored his physical and mental limits. Time and again there were knock-backs, but winners must have the courage to fail, must get up again and go back to the mountain with a positive attitude. They need to ignore, convert or circumvent the prophets of doom, the fainthearted, the blockers, the losers, the cynics and that applies not just in mountaineering but also in many other areas of life. Norman says: 'There has been an added motivation in that my climbing has been the base for campaigns promoting access, integration and adventure sports for people with disabilities'.

Aside from Norman's activities as a writer and motivational speaker giving talks and lectures, more recently his attentions have been focussed on climbing activities for older people. Norman gives ad hoc input into several organisations concerned with young people. He states: 'I make no bones about it, I do these things because they give me a sense of purpose; there is nothing self-sacrificing in my work'.

Norman writes: 'I know your legs are artificial, but are they still your own feet?' – Question asked after one of Norman's talks.

In the autumn of 2012, when I had just turned seventy-two years of age, I began passing blood. During an endoscopic examination there appeared on the monitor screen what resembled a closed, deformed sea anemone – the enemy (or anemone!) within. The doctor conducting the test said he was almost certain this was bowel cancer, which was confirmed by a biopsy.

Scans followed (how lucky we are to live where we do in the age we do) in preparation for chemotherapy, radiotherapy and surgery. The charming doctor in charge of the first two of these two treatments said, 'You will have sore hands and feet'. 'Wonderful', I told her, 'I've got my feet back!' In a similar vein, during a checkup, my GP asked if my ankles were swollen.

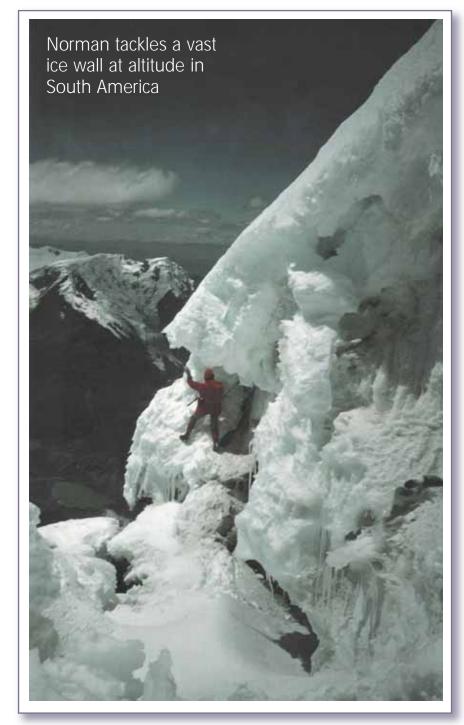
I soon accepted that an irreversible colostomy was the only alternative to a horrible death, but as less pragmatic when told my rectum and anus would have to go. The inevitability of the prospect of a stoma was clear, but I hoped, in vein, that would be the end of it. I had to persuade myself that unlike the loss of my nose or ears, the closing of one little hole would have no cosmetic or social consequences, even if I were a naturist. Since I would have a stoma that lower part of me would be redundant or even a nuisance; the area was cancerous and had to be excised. I joked with friends that I would never suffer from

haemorrhoids, or talk through my bottom (some disputed that) or have an endoscopy by the lower route. And my waterworks would function as normal, so I was lucky compared to some.

Take, for instance, Bobbie Minshull (article in the Summer edition of Tidings). Her catalogue of suffering includes cervical cancer, bladder incontinence, a urostomy resulting in bowel damage and adhesions, abdominal pain, severe bowel incontinence with anal skin too sore to wipe, a revised urostomy, a colostomy, no-absorption of nutrients resulting in extreme fatigue.

The loss of my legs fifty - three years earlier at the age of nineteen had in a way been easier to accept. I had drunkenly stumbled across a railway line and been hit by a train. I was fortunate to be on the outside of the track so my legs were squashed off rather than sliced off by the flange of the wheel, so I did not bleed to death.

Vaguely conscious, I called for help, and was heard by a fourteen year old school boy returning home form the cinema four minutes later than he would have been because the film had broken and he had waited for it to be repaired, he called the police, who found me. I accepted from the start that I could blame no one but myself and I just had to get on with life. Most importantly, I was convinced I could continue to climb, as I had done on the sea cliffs of Cornwall; disability would make climbing more challenging, and therefore more rewarding. Similarly, when faced with cancer diagnosis are highly individual,



'Without my mountains, life would certainly have been hollow, and I would not have been asked to put something into the pot of inspiration, from which all with an open mind can drink...'

and to be respected. One woman I know told no one except her partner, while another acquaintance told everyone apart from his mother. On being diagnosed with terminal stomach cancer my mother announced to all and sundry, 'the noose is around my neck now.' My way was to be open with anyone who asked.

May 30th, 2013. Five hours of surgery, then to intensive care. At 5 am came the discovery that I was in pain because of a blocked epidural, a problem soon solved with a patient controlled analgesic. On day five after the operation I vomited a great deal and went into shock. A pulmonary embolism was suspected but a CT scan revealed pelvic and chest infections instead. Under the influence of Tramadol painkiller I saw the neighbours 'black and white cat sitting at the foot of my bed looking very concerned. I asked him how he had travelled the three and a half miles to the hospital and he mouthed, '57 bus' behind him appeared an eight feet tall knitted rabbit which I was convinced my wife Jude had made and brought in, Paranoid hallucinations involving grotesque people followed, and then for a long time I believed I was in clinic in Scotland which Jude could not reach on the 57 bus.

A dietician came to see me urgently, concerned about my massive weight loss of 21lbs a week. I explained I had been weighed a week before with my legs on, and the day before her visit with them off.

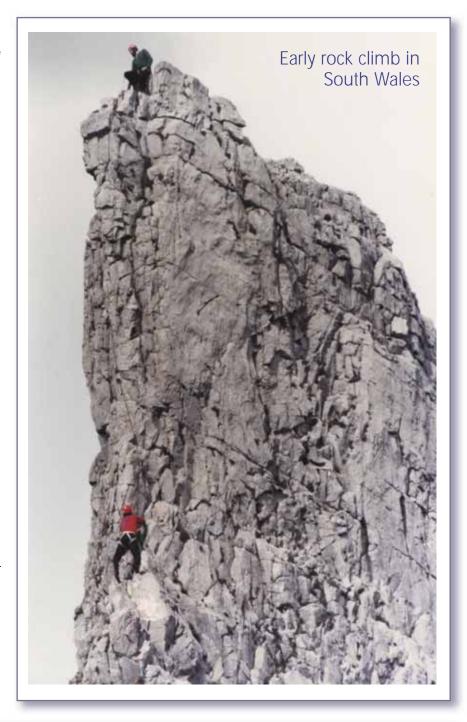
I was home after two weeks in hospital, and thirteen days later came the news that the lymph nodes and blood vessels surrounding the cancerous area were clear, and further treatment was not required; time to celebrate. While drinking with a couple in a local pub, the conversation turned, as it quite often seems to now, to quality of life, and death. The mother of the man who recently died of cancer, and his wife, who likes her wine, said she would feel it time to go when she became doubly incontinent and barely able to stand. 'That will be in about tow hours,' her husband said.

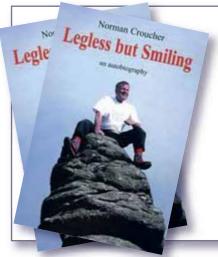
I plan to lead a survivors group to the French Alps next summer. Taking part

will be Claire, who survived an extremely dangerous brain tumour, and lan, who broke his neck but is one of the lucky few that can walk and climb. We will link up with British and French participants who have or have had cancer, with the objective of climbing two or three peaks, one provisional choice being Le Grand Flambeau, 11,676 feet (3559m). We will raise money for a local charity Hospicecare – Caring in Devon and the Colostomy Association. I have been very fortunate to find someone who wants to come as a support climber and also help with the organisation of the trip. During this tough, sometimes unpleasant, adventure with cancer I have experienced great kindness from caring professionals and friends, and of course from Jude, who, I think, has at times been more worried than me.

At the time of writing I am waiting for remedial surgery to my lower wound (I have a tissue issue!) three months after the operation. Several years ago I lost the tip of a thumb through frostbite; as a friend recently summed up, 'you seem to be going to the next world by instalments.'

Whatever the length of the extra life I have gained I thank all who have brought it about; I will value it. There are many things wrong in the world, problems for the coming generations – the economy, immigration, unemployment, crime, education, poverty housing shortages, pensions, inflation, flooding, global warming and son on – and now they concern me less. As the old expression goes, one good thing about life is its temporary.





Legless but Smiling...

Signed copies of Norman's autobiography – 'Legless but smiling' are available from the author for £16 inc.p&p

To learn more about Norman Croucher OBE visit his website www.normancroucher.co.uk

or to donate to JustGiving – Norm's Survivor's Climb: Visit: www.justgiving.com/Norms-Survivors

Contact: Jane Wood – Editor on 0118 918 0500 or email: editor@colostomyassociation.org.uk for details of how to contact Mr Norman Croucher OBE

Helpful Ostomy Support Groups & Organisations...

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

Stoma Care Patient Open Day event dates...

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

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

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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.



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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



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0800 220 300 www.ostomart.co.uk

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Mid Devon Ostomy Group Advance notice

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

October 19th 2013

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





If you have a product to sell, an event to advertise or a message to communicate, you can place a small advert for as little as £20. Stoma care nurses...if you would like to promote your Stoma Care Department, its services and events...for FREE...Then just get in touch...contact: editor@colostomyassociation. org.uk





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 OAS Tel: 01233 640 863 Email: ursulanaish620@btinternet.com

Support for stoma & bowel cancer patients with new group...The Pennine Acute Hospitals NHS Trust

The aim of the support group is to provide a relaxing atmosphere away from the hospital environment where patients and their families can learn from each other's experiences, devise solutions to manage their problems and look after themselves – Julie Meadows, SCN/CNS

If you would like to - get involved - why not go along to the next meeting...

Date: Wednesday 4th December 2pm – 4pm Venue: Victoria Hotel, Chadderton OL9 8DE Organiser:
Julie Meadows SCN/CNS
Stoma Care Department
North Manchester
General Office
0161 720 2815 or 07841206910



Single donation

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

	form to make a Single donation to the Colostomy Association. Simply complete this form and o the Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. 8 939 1537 if you have any queries.	
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Please ensure that we have	Postcode:	
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contact details: full name, addres		
and postal code telephone numbe		
thank you	Optional Information: Date of Birth: Reason for your stoma:	
Stoma Type: (Please tick) Colostomy Uleostomy 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)	
	on: I wish to make a single donation to the Colostomy Association in support of the charity a k. I have completed the Form below \Box (Please tick.)	
_	on/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	
(Please tick.) other amount (Yes I would like to make a single donation/gift of£15£20£25£50 or please state) £ to the Colostomy Association eque/postal order form made payable to the C.A. Ltd and attach the completed Donation	
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Other amount (I enclose my char amount in its entire Yes, I require a Single dona and greatly	Yes I would like to make a single donation/gift of fils fils fils fils fils fils fils fil	

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.

Oldest Swinger's in town...Airedale Stoma Support Group





L-R: Mavis and Trudy with North Yorkshire Air Ambulance

L-R: Mavis and Trudy together reading Tidings!

Here are some lovely photographs of Mrs Trudy Murgatroyd who has recently celebrated her 90th birthday! (pictured above right in each photograph with good friend Mavis)

Mrs Murgatroyd hosted nearly one hundred guests at her home in Draughton, Nr Skipton, North Yorkshire. Those invited to the celebrations were family, friends – young and old – fellow ostomists from her local Airedale Stoma Support Group, (where she is an active member) and residents from the village.

Trudy had emergency life saving surgery fifteen years ago, and has managed to live a very active life since, and has coped extremely well with her colostomy. Although she is hard of hearing and suffers from poor eyesight she lives a very fruitful life living with

her daughter Denise, son in law, Richard and only grand daughter, Hannah, as well as 3 dogs and a menagerie of other animals.

A year ago Trudy was involved in a severe road traffic accident suffering head injuries, multiple bruises and was airlifted to hospital, where she amazed everyone with her early discharge home and a miraculous speedy recovery despite her frailty, injuries and her age.

Since last year Trudy and her family have held fundraising events and raised thousands of pounds for the Air Ambulance who attended her. She has been a core member of the Airedale Stoma Support Group since it started over nine years ago, participating in trips out, and bringing to the group her speciality of home baking.

BUT Trudy is not the oldest member of the group, fellow ostomist and very good friend is Mrs Mavis Gurton, who celebrated her 92nd birthday in May this year. Mavis lives nearby in Ilkley, West Yorkshire and also contributes to the group with her baking specialities, exchanging recipes as well as books.

When they are together they are a pair of 'young giggling girls' who delight every one they meet with their good humour and wit.

Jean Ross Community Stoma Nurse. Salts Healthcare

Regional Stoma Support Focus: England – North, Yorkshire:

Acorn Ostomy Support Group Michelle Hurrell on 07580693155 (after 6 pm) Airedale Stoma Support Group Contact: Jenny Shaw 01535 652516 or Sue Hall 01535 210483 Behind You (Calderdale& Huddersfield Bowel Cancer Support Group) Contact: Stoma Care Nurse 01484 355062 Barnsley-Bottoms Up Stoma Support Group

Contact: Stoma Nurses 01226 432528 or Celia Utley (Chairman) 01226 284262 CROPS (Colo-rectal ostomy & internal pouch support)

Contact: Gloria 0114 2879503 Dewsbury & District Ostomy Contact: Janet/Eileen 0844 8118110 Rotherham Ostomates Caring Support Contact: Karen 0788 0575758 Scarborough Stoma Support Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446 The Hull and East Riding Colostomy Support Group Contact: Pete Smith 07989 565335 and Pete Rennard 01482 793966 **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'Donnel 01236 436479

Ayrshire:

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

Fife:

Fife Ostomy Support Group Contact: Ishbel Barr 01592 772200

England - North

Cheshire:

Cestrian Support Group Contact: David Burgham 01244

310461

Stockport Support Group Contact: Angela Simpson

0161 419 5059

TOMAS (The Ostomates of Macclesfield and Surrounding Areas)

Contact: Kath Wood 01625 875442 Warrington Ostomy Support Group Contact: Jane Shaw 01925 662103

Cleveland:

Oops Group

Contact: Julie Morrisroe SCN/Carol Younger 01287 284113

County Durham:

Bishop Auckland Stoma

Care Group

Contact: Betty 01388 814535 Jen 01325 311266 or Maureen 01388 818267

Cumbria:

Grange Cancer Support Group Contact: Marie 015395 33279

Derbyshire:

Stockport Support Group Contact: Angela Simpson

0161 419 5059

Lancashire:

Oldham Stoma Support Contact: June Wilde 0161

312 5538

Tameside Ostomisticles

Contact: Paul Seavers 0777 1359046

Trafford Bowel Care

Contact: Jackie Carey (Secretary) 0161 7489 659 Doreen 0161 9627 818

John 0161 7484 655

Merseyside:

Crosby Support Group Contact: Stoma Care Nurse 0151 529 2842 Aintree Stoma Support Contact: Stoma Care Nurse

0151 529 2842

I.C.U.P.S

Contact: Stoma Care Nurse

0151 604 7399

Northumberland:

Berwick Ostomy Support Group Contact: Bobbie Minshull 07714 479320 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: Jenny Shaw 01535 652516

or Sue Hall 01535 210483

Behind You (Calderdale& Huddersfield Bowel Cancer Support Group)

Contact: Stoma Care Nurse

01484 355062 Barnsley-Bottoms Up

Stoma Support Group Contact: Stoma Nurses 01226 432528

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CROPS (Colo-rectal ostomy & internal pouch support)

Contact: Gloria 0114 2879503 Dewsbury & District Ostomy

Contact: Janet/Eileen 0844 8118110 Rotherham Ostomates Caring Support

Contact: Karen 0788 0575758 Scarborough Stoma Support

Contact: Sister Jean Campbell 01723 342388 Amanda Rowe 01723 342446

The Hull and East Riding Colostomy Support Group

Contact: Pete Smith 07989 565335 and Pete Rennard 01482 793966

Isle of Man:

Stoma Support Group

Contact: Carole Cringle 01624 650212

England - Central

Buckinghamshire:

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

Leicestershire:

Kirby Ostomy Support Group Colostomy, Ileostomy & Urostomy

in Leicestershire

Contact: Janet 0116 239 2844

Nottinghamshire:

Nottingham Colostomy, Ileostomy & Urostomy Support Group

Contact: Rosemary Brierley 0115 982 6691

Nottingham Stoma Support

Contact: Mrs B Heath 0115 966 3073 North Notts Stoma Support Group

(Sutton-in-Ashfield)

Contact: Tore and Nicky Norman

01773 715460

Shropshire:

Oswestry Stoma Support group Contact: Irene Constable

01691 238357

Staffordshire:

Outlook

Contact: Ernie Hulme 01782 324441 Moira Hammond 01782 627551

Worcestershire:

Kidderminster & District Collossus

Support Group

Contact: Brendon Drew

01299 400843

West Midlands:

Coventry Stoma Support Contact: Martin Robbins

07947 385643 02476402616

East Midlands:

Newhall Stoma Support Group

Contact: Sarah French 07773 396236

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

Shepherd Bush Stoma Support Group Contact: Roslyn 0208 354 0121 or Jackie 0208 740 4790 South Woodford Support Group

Contact: Christina 0208 5356563

Surrey & South London Bowel Cancer

Support Group

Contact: Sue Berry: 01737 553134 or

John Amos: 0208 668 0796

Middlesex:

Inside Out

Contact: Bob (Chairman) 0208 4284242 Sarah Varma 0208 2354110

Semi-Colon Club

Contact: Pat Black/Katheryn Foskett

01895 279391

Oxfordshire:

Oxfordshire Ostomy Fellowship

Contact: Pat Longworth

01235 524163

Surrey:

Epsom & District Stoma Support

Group

Contact: Sheena 01372 735925

Sussex:

(SAS) Brighton & District Stoma Care

support

Contact: Sylvia Bottomley

01273 554407

The Ostomy Friends Group

Contact: Jane Quigley 01323 417400

Ext 4552

West Sussex Princess Royal

Stoma Support

Contact: Tina Walker 01444 441881

Ext 8318

England - South West

Avon:

B.O.S.S Bristol Ostomy Self Support

Contact: Janet 01275 472873

Rob 01179 668021

Cornwall:

Hayle's Angels Stoma Support Group

Contact: Sue Hatton 01326 340058

Ostomist and Carers Support Group

Contact: Christine Davey

01208 831471 Optimists

Contact: Sue Hatton 01326 340058

Devon:

Mid Devon Ostomy Group Contact: Janice Parkyn

01363 776417 Devon IA

Contact: Martin Hornby

01458 251095

01392 447374

Devon Stoma Support Group Contact: Donna Ashbrook

01626 854862

Dorset:

CUPID Colostomy, Urostomy, Pouch, &

Ileostomy of Dorset Contact: Beryl Andrews

CUPID Colostomy, Urostomy, Pouch & Ileostomy of Dorset - West Dorset

Contact: Colin Clare 01305 853 288

01202 483303

Wiltshire:

Swindon IA

www.swindon-ia.org.uk Wessex Stoma Support Group

Contact: Michael Slater 01722 741233

Wales

Blaenau Gwent Self Help

Contact: Celia McKelvie

01873 852672

Bridgend Ostomy Patients

Support Group

Contact: Anita Brankley (Secretary)

01656 645602 or Pat Jones 01656 786103 Royal Glamorgan Stoma Care Support Group

Contact: Domenica Lear

01443 443053

Swansea Ostomy Self Help Group

Contact: Glynis Jenkins 01792 418245

Northern Ireland

Antrim Area Stoma

Support Group

Contact: Chris Wright

07720 717771

Belfast Royal Victoria

Contact: Sarah Haughey/

Audrey Steele 02890 240503 Ext 3483

Causeway Patient

Support Group

Contact: Mary Kane 028 70 346264

Colostomy Association Volunteers Northern Ireland

Contact: Chris Wright

07720 717771

Daisy Hill Hospital Newry

Contact: Bernie Trainor

028 3883500 Ext 2222 Mater Hospital Belfast Contact: Karen Boyd 028 90741211 Ext 2329 North Down Stoma Support Group Contact: Adrian Ewing 07850 741511

Contact: Mary Jo/Bernie

028 38612721 Ulster Hospital

Southern Trust

Contact: Hazel/Martina

028 90 550498

Eire

Bowel Cancer Support Group

(Irish Cancer Society)
Contact: Olwyn Ryan
+353 12310500
Mayo Stoma Support
(Castle Bar Hospital)

Contact: Marion Martyn 094 902 1733

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