

Spring 2014 | Issue 33

# Tidings

colostomy association

Dedicated to Colostomates their Families and their Carers



**Cover story...**  
Introducing our  
new President  
**Mr. Ian Daniels FRCS**

**Pathways...Rob's story -**  
A colostomy changed my  
life for the better!

**Travel...Hints & Tips**

Happy Easter to ALL our readers from the Colostomy Association...

NEW

Soft Convex  
generation

Introducing the new

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NEW NovaLife Soft Convex with EasiView viewing option

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## welcome to SPRING



### Welcome to the spring issue of Tidings...

Thank you to everyone who has written in, emailed me and telephoned! It's great to receive your letters, article suggestions, emails and queries. So do please keep them coming in!

Tidings magazine is here for YOU...to provide supportive information, reassurance and to keep you abreast of the latest developments in stoma care products and services. It also provides an insight into NHS changes that may affect you.

This issue introduces our new President Mr Ian Daniels FRCS. Ian is delighted with his role and will no doubt meet it head on with great enthusiasm and keen perception. Ian is passionate about 'raising awareness of quality of life for patients with stomas throughout the patient journey'. Describing himself as 'a cocktail' of the people he's worked with over the years (specifically surgeons) who have influenced his professional development in becoming a colorectal surgeon. 'I am fortunate to have worked with the best!' Ian has what he calls – 'the force' – an intuitive understanding of the patient's situation. 'As a surgeon it's about two way communication – being honest, being in tune with the patient's feelings and understanding their needs'. Quality of care equates to quality of life. Read more about Ian on page 32.

Every Tidings magazine is packed full of interesting articles – this issue is no exception. As you may know April is Bowel Cancer Awareness Month. But what you may be unaware of is that Bowel Cancer is the second most common cause of death in the UK. Did

you know that every thirty minutes someone dies from bowel cancer in the UK? Seems unthinkable doesn't it, but there is hope: if treated early there is a very good chance of recovery, the problem is that currently only 9% of patients are diagnosed early. Ian Jackson and Pauline Morgan write about the importance of bowel screening. As Editor of Tidings and on behalf of the Editorial team – let's join together to really highlight 'Bowel Cancer Screening' and help to prevent the needless deaths of family or friends! Be brave...shout out loud about bowel cancer screening...it saves lives.

Other articles – a response to M.B about disposal, readers' stories and favourites such as Dear Nurse and Readers' writes – I hope you enjoy this issue and don't forget to keep those letters, emails and articles coming. Enjoy your Easter Holidays!

**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](mailto: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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all your regulars

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Mr Ian Daniels FRCS**  
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**Don't forget your travel certificate this Spring...**

Contact CA office on 0118 939 1537 or email: [cass@colostomyassociation.org.uk](mailto: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](mailto: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](http://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 criteria:-

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

### Advertising Enquiries:

For a media pack and advertising rates. Contact Jane Wood: 0118 918 0500

### Publication:

Spring	April	2014
Summer	July	2014
Autumn	October	2014
Winter	January	2015

## EDITORIAL TEAM

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### Colostomate

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### Tidings Magazine:


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

### Disclaimer:

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



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1. ConvaTec data on file. Esteem® PLUS product evaluation survey conducted in 100 patients (2012).  
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**Dear Readers...**

The CA office continues its pivotal role – providing information, support and reassurance to ostomates, family members and carers. If you need help no matter whether you deem it to be too small a query or think it too difficult a subject to talk about...remember CA is here for you!

Our trained volunteers (colostomates, ileostomates and urostomates) run the 24 hour FREEPHONE helpline: 0800 328 4257– they are there to support you, listen to your concerns and chat them through with you if need be. Feel free to phone at anytime as there is always an ostomate on call 365 days a year!

The CA does not give medical advice but we can pass on our knowledge from 'real life' experiences gained from 'living with a stoma.

We welcome your calls, letters, requests, emails and really appreciate your donations – so do please keep them coming – we are here to help you!

**Prescriptions...**Are you having difficulty obtaining your usual supplies through your SCN or GP? Would you like a letter template that can be used to champion your cause? We can send through the wording (ideally by email), which can then be personalised with your own contact details.

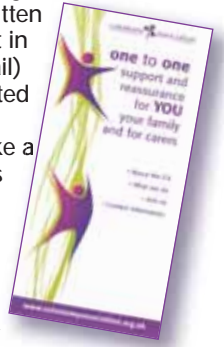
The letters will need to be copied to key people in your area so some research may be needed to find out who they are, such as your local Clinical Commissioning Group or Health Board. We'll be happy to help as we appreciate how vital certain product items are to your quality of life, especially adhesive removers, deodorants, barrier creams, etc.

It's also worth bearing in mind that supplies can now take as long as two weeks to reach you so start the prescribing process early to ensure you don't run out of vital stocks!

**Your help is needed!** Do you have any time to spare? Would you like to help raise funds for the CA or assist with promoting our charity? Do you have any special skills that could be put to good use? Are you a sports person or do you belong to a local amateur dramatics group or art group? We're looking for

anyone who may be willing to organise a simple fundraising activity, e.g. coffee morning, quiz night, cake sale, etc.

Alternatively, perhaps you could help us raise our profile so that we can reach more ostomates across the UK. If you'd like to submit information about the CA to your community magazine - we can provide a specially written paragraph – so do get in touch (ideally via email) and we will be delighted to send it to you. Or perhaps you could take a CA poster, some flyers (see opposite) or Tidings to your local GP surgeries. Please check in advance that they will be accepted, then let us know how many you require that would be great!



We're also looking for good public speakers who could give a talk to their local Rotary or Lions Club – we can provide the script, props and slides!

**We'd really value your help so hope to hear from you soon. Thank you so much!**



**Photo ID Card...**

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

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

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

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

Alternatively, the form is downloadable from our website: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

**Please allow 10-14 days for delivery – thank you**

**National Key Scheme (NKS) Radar Key and 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](mailto:cass@colostomyassociation.org.uk))

**National Key Scheme - Key and photo ID card purchase**

Title: \_\_\_\_\_  
 Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 \_\_\_\_\_  
 Postcode: \_\_\_\_\_  
 Tel: \_\_\_\_\_  
 Email: \_\_\_\_\_

Please tick the following as appropriate:

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

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

Signature of self or carer: \_\_\_\_\_ Date: / /2014

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



**Please remember to send your letters and donations to our new address... Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA.**



**STOP PRESS...**

**Ostomy Lifestyle** and its project **OstomyAid** having experienced some recent financial difficulties are currently being supported by the **Colostomy Association**. **Ostomy Lifestyle** with its own Trustees, will continue as a completely independent charity with the **Colostomy Association** providing management and admin assistance. It is early days but, in the near future, we do hope that we can devote space within **Tidings Magazine** for supporters of **Ostomy Lifestyle**. Further details will follow in the Summer issue.

**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: Mr J Bloggs  
Address: 20 Blogg Hill, Reading  
Postcode: RG1 4QA  
Telephone No: 0123 456789  
Email: jbloggs@bloghill.co.uk

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

**The Colostomy Association will be celebrating its 10th ANNIVERSARY in 2015! We hope YOU will join with us to celebrate this important milestone...**



The **Colostomy Association** is well on the way to organising its **birthday celebrations** marking a **ten year milestone** of providing **support, reassurance and practical advice** to thousands of people 'living with a stoma and colostomy', their families and carers around the UK.

This **BIG hearted charity** will **celebrate its achievements** by holding a **special Two Day Patient Open Day Event** in Reading at the **Royal Berkshire Conference Centre**. Be sure to put the **following dates...Saturday 11th July and Sunday 12th July 2015** in your diary!

Further details about the Open day event, and other satellite events will unfold in future issues of **Tidings Magazine** and on the **CA website**. Look out for our **10th Year Anniversary logo (above)** to keep up to date with event information.

# Pathways to a Colostomy...

Readers'  
PANEL  
contributors



Rob pictured with his wife Helen...out and about..attending a recent country music concert

## Rob Fearn...an emergency operation due to Diverticulitis ended with a colostomy and put a stop to his long term struggle with IBS changing his life for the better...

Rob is 45 and lives with his wife Helen in north Nottingham. Rob is recovering from an emergency operation in October 2013 due to Diverticulitis.

Rob says: 'I woke from the operation to find I had received a stoma. I'm sure this must horrify most people but I love it! I have suffered with IBS for 15 years – my whole life has revolved around locating the nearest loo. IBS has held me back and pretty much ruined my social life'

This is Rob's story...

I had an emergency operation due to Diverticulitis leading to a perforated colon. Prior to that I had spent 15 years gradually getting worse and worse suffering with Irritable Bowel Syndrome – IBS. I had been tested for various illnesses and when they found nothing else it was declared that I must have IBS.

My whole life had revolved around where the nearest toilet could be found. I work as a sales representative so spend all my working life on the road. I would eat my breakfast, and then starve myself for the rest of the day due to the constant fear of needing the loo and getting caught out. I would avoid all situations where I wouldn't be in control. If I was planning to go out for a meal I would

load myself up on Imodium then I would plot on a map how quickly I could make it home from the restaurant and decide if it was worth the risk. I refused to go on days out or to go to concerts, as the thought of not being able to make it to a loo in time was unbearable.

This constant fear slowly started to pervade every thought of every waking hour. I remember watching a nature programme on TV where the presenter was floating high over the Serengeti in a hot air balloon watching the wild animals running below. Any rational person watching would have been thinking what a beautiful way to see animals in their natural habitat – all I could think was that it would be hell on earth to be trapped in a hot air

balloon basket with a dozen other people and no toilet!

While on holiday my wife and I went on a boat trip and instead of enjoying the experience I sat calculating how much it would cost to refund everyone their money if I had to ask them to turn the boat around. Basically I ended up living in fear of 'what if I can't get there in time' – my wife and I had no quality of life at all.

Then as fate would have it I was taken into hospital and following an emergency operation I found I had received a stoma – out of the blue. I guess a lot of people would be devastated to wake up from an unplanned operation to find they have a stoma and a bag. Although it was a complete surprise to me I realised immediately that it would change my life for the better! And it did!

The feeling of freedom was unbelievable. I couldn't wait to get out of the hospital to enjoy my new found freedom.

The early part of my recovery included walking for miles. Not only was it the safest way to rebuild my strength and improve my fitness but it was such a buzz to just leave the house without having to take medication and plan my route via local supermarkets and public toilets.

In the months following my operation I have been out for meals, been for walks and been to two concerts! All things that I wouldn't have dreamed possible previously. One of the concerts was in Nottingham city centre – we travelled in on a tram. Again this is something I just wouldn't have done before. It would have been a nightmare to even consider riding on a tram with no toilet and lots of people around.

Christmas came. For the first time in years I was able to sit and enjoy my Christmas dinner without having to disappear half way through and return to eat my meal after it had gone cold and everyone else had finished. What joy!

My stoma (Arthur) has been very well behaved. I have been lucky enough to have had no leaks at all and I seem to have found the perfect combination of

products that suit me down to the ground. Arthur is officially a temporary measure and I will be invited to see my consultant soon to discuss a reversal.

Due to the massive improvement in my state of mind and my lifestyle I will be refusing this option. This is the best that I have felt in years and cannot think of anything worse than going back to where I was before.

Throughout this whole process, many people have asked how I have coped with it all but to be fair I have found it easy. The one who had the toughest time was my wife Helen. We have been married for twenty years but have been together since we started dating as 13 year olds at school. We got married on the 11th Anniversary of the first day that we started dating.

I can't ever imagine the pain and the fear that she went through while I was facing my life saving operation.

I woke up early one day and wrote a poem to thank her for her support, not only during my time in hospital but also for the last 15 years as my illness got worse.

I haven't written anything since leaving school but it just seemed to flow. We are now both enjoying the freedom that my colostomy has led to and we are planning so many things that I wouldn't have dared to plan before.

Although I have found the adjustment to life with a bag very easy I am pleased to have the support of so many people. My stoma support group at my local hospital, the CA group on Facebook and obviously the inspiring stories in Tidings.

**Rob Fearn**

## For Helen...

*Here's a massive thank you  
and it's meant straight from the heart.  
But I'm not really a poet  
so I don't know where to start.*

*It all began one Friday night  
with bad pain in my tum.  
You took me to the hospital  
when the ambulance didn't come.*

*They prodded, poked and tested me  
to see what they could find.  
But with you sitting next to me  
It helped to ease my mind.*

*Injections, drips and tablets came  
and testing of my blood.  
Eventually they did a scan  
And found it wasn't good.*

*'Put your gown on, time to go'  
there wasn't time to waste.  
This must have been the hardest time  
that we had ever faced.*

*You did your best to keep me calm  
though you were full of fear.  
I don't think I'd have made it through  
without you being near.*

*So I was gone for 4 long hours  
It must have seemed so long.  
I don't know how you made it through  
you had to be so strong.*

*The next thing, I was waking up  
You're the first thing that I saw.  
The relief was clear on your face  
you couldn't take much more.*

*They'd given me a stoma  
and a bag to catch my poo.  
I wouldn't have to spend my life  
depending on the loo.*

*15 years of IBS had took  
its toll on me.  
Suddenly my life had changed  
and I was feeling free.*

*You've stood by me through all those  
years and never once complained.  
But now it's time to start again  
with this new life that I've gained.*

*So thanks for all the love you give  
I'm proud that you're my wife.  
Let's enjoy our new found freedom  
Now I have a 'bag for life.'*





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The new extensive range of Aura™ pouches feature our tried and tested skin-friendly Hyperflex® hydrocolloid flange, but now with the added benefit of medical grade Manuka honey. The inclusion of Manuka honey in our Hyperflex® hydrocolloid may help to promote healthy skin around the stoma.

New Aura™ also has an accurate cutting guide for a perfect fit, Easy2peel™ tab for easy removal, a super-soft water-repellent cover for outstanding comfort and a new Dual-Carb®2 and Dual-Carb®i filter for better odour management and reduced leakage.

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Mr/Mrs/Miss/Ms: \_\_\_\_\_ Initials: \_\_\_\_\_ Surname: \_\_\_\_\_ Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Tel. No.: \_\_\_\_\_ Email: \_\_\_\_\_

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

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



## Fundraising Focus...



### Community Matters...Waitrose

In January, Janice Parkyn, CA volunteer collected a cheque for the sum of £280.00 from the Okehampton Branch of Waitrose. An article appeared in the Okehampton News as a result, which was great publicity for the Colostomy Association! Jo Hammond CA Administrator put an application in to the Tilehurst branch of Waitrose, which raised £607! To date this form of fundraising has raised £2,889 in total! Thank you to everyone who has put the Colostomy Association forward to benefit from the local Waitrose – Community Matters fundraising initiative!

### Help CA raise funds...

For your **FREE** donation box simply contact the office – telephone: **0118 939 1537** or email: **cass@colostomyassociation.org.uk** to order yours today!



### Easyfundraising...

Sarah Squire, CA Trustee, suggested 'easyfundraising' an online shopping website as a way of raising funds for CA. Sarah says: "It's very easy to register, it's free and it raises money for the CA every time you make an online purchase through a range of retailers." So, why not give it a try? Thanks to Sarah, there are now 70 Facebookers registered and raising money for the CA in this way! To find out more please go to [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk). We hope those of you who are online will join in too!

### Bowls Clubs raise more funds for CA!...

Members of the Erewash Indoor Bowls Club and Attenborough Village Bowls Club displayed a 'universal Christmas Card' in lieu of sending individual cards to each other raising funds of £50 for CA!



**Recycling Appeal is a multi-product technology appeal...raise funds for CA.** Freepost envelopes are available or collections can be organised simply call: 08450 75 58 82 or 08451 30 20 10

#### What can be recycled?

- |                                     |                                   |
|-------------------------------------|-----------------------------------|
| Unused and Un-pulled ink cartridges | Laptops/DVD DS/Wii games consoles |
| Mobile Phones                       | DS/Wii games                      |

### Mediterranean Shipping Company (UK) Ltd nominates CA to receive funds...

A donation of £250 was gifted to the CA from the Staff Charity Ocean Fund in recognition of the care and support given by the charity to a member of staff's mum.

**From Ed:** Thank you to everyone for your kind donation!

In Memory	
Mr M Webber	£ 25.00
Mr N C Greensitt	£ 20.00
Mrs B Wade	£ 600.00
<b>Thank you</b>	



**If you are having a fundraiser for the Colostomy Association write in and tell us about it...you could be featured here!**



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

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

The **Donald Forrester Trust** have consistently donated over many years firstly to the British Colostomy Association and now to the Colostomy Association - the total received to date is **£43,000 – Thank you for your continuous support!**

Thank you  
everyone  
for your kind  
donations

### Passionate supporter...

Mrs Agnes Mckenzie...is a passionate supporter of the CA kindly giving a donation of £50 a year. At her recent Golden Wedding celebrations, Agnes gifted £350 to the CA from funds raised by friends and relatives in lieu of presents. Agnes and fellow tenants of the Rosebank Sheltered Housing Complex in Dundee also donated further funds of £250 from a recent fundraiser...The Editor contacted Agnes to thank her for her ongoing support and after a lovely conversation during which Agnes praised Jackie Ingles (Manager of the Rosebank Sheltered Housing Complex) for her help resulted in the following story...

**Jackie writes:** Back in 2006 I was diagnosed with Bowel Cancer. After the diagnosis, the colorectal nurse informed me that because of the position of the cancer I would most definitely require a colostomy which could not be reversed. During the time of my initial investigations Agnes and her husband moved into the complex I was managing. When I was taking medical information from Agnes I found that we both had bowel problems. Over the next few months both of us had to have colostomies. Although both Agnes and I have given each other support over bad times, we have also had great support from doctors, nurses and staff at Ninewells Hospital in Dundee.

**Agnes writes:** My problems started in 2005 when I was suffering with severe stomach pains. During this time my husband had to have major surgery on his spine which resulted in us having to move into sheltered housing. One of the requirements for residing in sheltered housing is that a record of your medical details be kept on file and this is when I became aware that

Jackie also suffered from bowel problems too. This was my first meeting with Jackie and in 2006 I was diagnosed with Diverticulitis which resulted in me having a Colostomy.

In 2006 we both went through our operations within months of one another where we were told that due to the type of surgery to the bowel; it could not be reversed. Over the next three years I was admitted every three months for Dilation but in the end I had to go through more surgery on my stoma site. Jackie was also having problems, so in our own way we supported one another. I have a special bond with Jackie not just as Manager of the Rosebank Sheltered Housing Complex but as a friend and fellow ostomate. We still both attend hospital to see our stoma care nurse and we are also just a phone call away from our nurse's help when we feel the need for extra support.

We both receive Tidings magazine which we find very helpful and show our appreciation by giving our own personal donation, which in turn goes to help fellow ostomates.

**The Tenants write:** We are a small Sheltered Housing Complex and a few times a year we have social evenings to raise funds. This allows us to go on day trips and visits to concerts and we also try to help local charities. i.e. Red Nose Day and Help For Heroes. Our most recent fundraiser was a Bingo Evening and raffle. It was decided after a Tenants meeting, and with all the tenants in agreement that a donation would go to Jackie and Agnes's charity, the Colostomy Association. On behalf of the tenants of Rosebank Sheltered Housing Complex – thank you for all the work you do – we are pleased to fundraise for such a worthy cause!

## 500 Club... December 2013 Draw Winners!

Mrs C Kendrick	£1000.00
Ms J West	£ 302.00
Anonymous	£ 151.00
Anonymous	£ 60.40
Mr EP Lowe	£ 60.40
Ms GD Maple	£ 60.40
Mrs DM Sagar	£ 30.20
Miss L Ferris	£ 30.20
Ms J Cooper	£ 30.20
Mrs E Dugdale	£ 15.10
Mrs M Van Pelt	£ 15.10
Mr P Grogan	£ 15.10

**Note: The following winners Mr C Kendrick donated £500 and Ms J West donated £100 of their draw prize back to CA... many thanks!**



**Remembering Brenda...** It is always sad to lose a true friend and member one of my support groups but the tribute paid to Brenda Wade by her friends and family was astounding. It was Brenda's wish that only family flowers should be at the committal and any monies that were raised be donated to the Colostomy Association.

Her friends and family have raised the wonderful sum of over £600.00 and this money will be used – as Brenda wished – to support colostomates who need help and support while they are learning to live with their stomas.

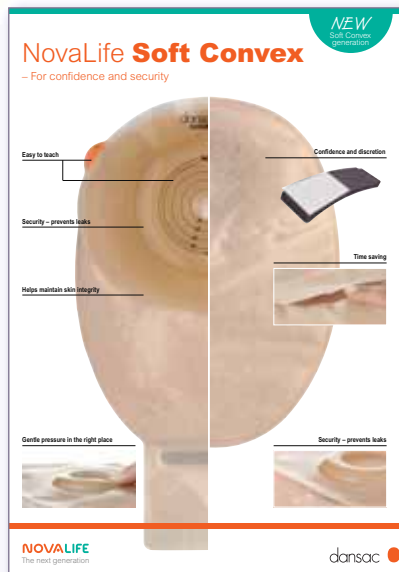
Thanks to her family and friends this wonderful tribute to Brenda will help so many new ostomates who will receive support from the Colostomy Association.

**Jackie Dudley  
Volunteer and Trustee  
Colostomy Association**

# 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.

## New – Dansac NovaLife Soft Convex – the gentle and flexible solution



Dansac are very proud to announce the launch of their newest product addition to the NovaLife range; NovaLife Soft Convex.

With its unique flexible construction, the new NovaLife Soft Convex skin barrier gives a gentle push to help even out peristomal skin, creating an enhanced skin seal for greater comfort and security. It is the flexible and skin-friendly solution that gives a comfortable and reassuring fit.

The New Dansac NovaLife Soft Convex is available in one-piece, both closed and drainable and introduces the new EasiView viewing option to give that extra confidence in a glimpse.

These products are available on Drug Tariff from the 1st April and if you would like free samples please call our Customer Services Department on 0800 581117 who will be happy to help.

## OstoMART Ltd is pleased to announce the launch of OstoPEEL - a brand new Medical Adhesive Remover Spray with Blackberry fragrance

OstoPEEL is a non-sting propellant free medical adhesive remover spray which uses bag-in-can technology which means you get 360 degree dispensing - it can be sprayed at all angles, even upside down. You also benefit from 100% product usage from each spray; it does not spray cold on the skin and is quieter to use than standard aerosols.

OstoPEEL users also benefit from a subtle Blackberry fragrance that makes changing of stoma appliances and removal of stubborn adhesive residue easy and pleasant.

OstoPEEL is over 20% cheaper than the market leader and no like for like prescription medical adhesive remover spray is cheaper than ours!

OstoPEEL – No propellants, No wastage, No sting, No fuss!

OstoPEEL is available to order now on prescription in a handy 50ml spray, just quote order code OPB50.

For further information or to request a sachet sample of this new product please contact us direct by calling freephone 0800 220 300, by email to enquiries@ostomart.co.uk or visit our website www.ostomart.co.uk.



## Fill, Seal, Secure... NEW Welland Stoma Paste

We are pleased to announce the NEW arrival of the Welland Stoma Paste. This new product is for use on uneven skin and smooth over scar lines and an ideal base to improve the fit of your stoma pouch. With Welland Stoma Paste, you can be confident that your stoma pouch will be held safely and securely in place.

- Welland Stoma Paste is:
- Alcohol free – No sting
  - Gives a smooth, sealed surface
  - Easy, pliable application
  - Quick to dry and long lasting
  - Is hypoallergenic
  - Suitable for most skin types

The paste is presented in a squeezable 100g tube and available on prescription.

### Ordering Information:

- CliniMed Product Code: WSP100
- PIP Code: 384-0758
- Description: Welland Stoma Paste
- Qty: 100g tube

Discover what Welland Stoma Paste can offer you...contact us today to receive your free sample:

Call Freephone: 0800 036 0100 for more information or visit our website at [www.clinimed.co.uk](http://www.clinimed.co.uk)





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26cm Easy Peel Support Belt



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Available with or without lace

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COLLECTION



# 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.



**Tough on leaks, soft on skin.... Introducing Pelican Platinum, the brand new closed pouch range from Pelican Healthcare.**

Unlike many conventional products, the Pelican Platinum Closed pouch features a unique foam backed skin protector, which offers unrivalled levels of comfort and security. The secure cushioned adhesive will adhere immediately to the skin, with adhesion continuing to improve over the lifetime of the pouch, helping to reduce leakage.

The innovative foam backed skin protector is extremely soft and comfortable against the skin, whilst the ground-breaking Pelican "EvoFlex" System ensures that pouch flexibility will not be compromised.

The advanced dual chamber hydrophobic filter system is an extremely efficient deodoriser, whilst the waterproof element helps maintain filter performance.

Available in four sizes: Mini, Standard, Maxi and a version that cuts up to 80mm.

To request your complimentary samples, please contact Pelican Healthcare on Freephone 0800 052 7471.

## NEW LOOK! Adapt™ Medical Adhesive Remover – No Sting

Hollister Limited are pleased to announce their Medical Adhesive Remover spray has been rebranded in the Adapt™ range to complement our already popular, Adapt™ Deodorant, Adapt™ Paste, Adapt™ Barrier Rings and Adapt™ Stoma Powder. The packaging has been updated to indicate the Adapt™ Medical Adhesive Remover spray has a no sting solution. This product is a silicone-based, alcohol free – no sting formulation. Adapt™ Medical Adhesive Remover spray breaks down adhesive bonds, which eases removal of skin barriers or adhesive borders (tape) and helps reduce the potential for skin stripping.



To discover more about the Hollister Essentials range or to order samples please visit [www.hollisteressentials.co.uk](http://www.hollisteressentials.co.uk) or call customer services on 0800 521377.



## C D Medical Ltd supplies the NHS with innovative and competitively priced medicines and is constantly looking to improve products which will enhance an individual's quality of life.

The recently introduced Stoma Care products are a perfect example of this philosophy: PEEL-EASY – The first non-sting medical adhesive remover aerosol which does not contain standard liquid aerosol propellants making a spray so cold on the skin. PEEL-EASY not only sprays at room temperature but will always function properly, even when held upside down. The PEEL-EASY Wipe will gently clean away any adhesive remaining on the skin.

CLINIFILM – Will apply a non-sting flexible water proof film to sensitive or sore skin at risk to damage from body fluids, again a first in the field with a non-cold aerosol spray and a gentle Clinifilm Wipe to reach difficult areas. CLINIFILM – A special lemon and lime ostomy deodorant spray to neutralise odours.

For more information visit [www.cdmedical.co.uk](http://www.cdmedical.co.uk)



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

# Travel

## hints and tips

### Travelling abroad by plane

#### Plan ahead

- Contact your Doctor, Stoma Care Nurse and/or your supplier and request an order 50% larger than usual to ensure that you have sufficient supplies while on holiday, allowing for tummy upsets, accidents and travel delays.
- Ensure you have other medication in sufficient amount for the holiday period.
- Request a travel certificate and an ID card from the colostomy association, proving you are an ostomate.
- Buy good insurance.
- Cut, in advance, any flanges you may need for the journey, as you will not have scissors available.
- Investigate drainable pouches – to cope with an upset tummy while travelling or on holiday
- Scan or photocopy your documents – such as passport, travel documents, prescriptions, place these in a different place to the originals.
- Ensure you have the telephone and contact number of your supplier.
- Check in 24 hours before your flight where possible and choose your seat.

#### Carrying your supplies

- Unpack your pouches and flanges and repack them in clear see-through bags (sandwich bags)
- Cut off the end of the boxes and enclose this with the pouches – to prove the items are medical. This could also be a copy of the prescription.
- Ensure that all your supplies are carried in your hand baggage so they stay with you at all times.
- If the amount you are carrying is too

much for your carry on bag ask a travelling companion to carry some for you. Avoid placing them in your hold baggage.

- Important - Do not pack scissors or sprays larger than 100ml in your hand baggage.
- Adhesive remover and skin barriers are available in sachet form to pack in your carry on bag.

#### On the journey

- From the night before and during the day of travel, avoid foods and drink that might cause your stoma to become "lively."
- Remove any item of clothing that might trigger the security scanners; jewellery, belts, large metal buckles or buttons on clothing.
- Change your pouch just before you go through security. Try and have an empty pouch when going through the scanner.
- Wear loose clothing so that your pouch is not restricted and therefore uncomfortable on a long journey.
- Carry your ID card and your travel certificate on your person. If you need to produce proof of a colostomy to a security officer you will have it readily available.
- Carry a small bag with a days supply (pouch, flange, sachet of adhesive remover and barrier wipe, dry wipe and disposal bag) – this can be removed from your carry-on bag as you take your seat on the plane to be available for the journey.
- Carry some form of medication to firm up or loosen output.
- It is worth taking some Dioralyte or some form of electrolyte replacement in case you become dehydrated.
- You may need to take Loperamide or Imodium to firm your output or Movical to loosen the output. This should cover you for all eventualities.

- Drink bottled water while abroad unless you are sure of the safety issues of the local supply. Check that the seal on the bottle has not been broken.

- While abroad, use bottled water to clean around your stoma area or ask your supplier for a number of (free) surgical wet wipes.

#### Security

A number of incidents concerning security officials have been reported to the Colostomy Association. Whilst we know how distressing these encounters with officialdom are, and the CA takes these complaints up with the bodies concerned, we are still unable to change the individual's attitude. The CA is endeavouring to run training sessions for the security staff at airports, seaports and important public areas to make the staff aware of what a stoma is and how the staff should handle the travelling ostomate.

It may help, if you have all your medical supplies in clear see-through bags. In this way the member of staff should not need to touch them while having to examine them fully. The medical information within that bag should also state that it is a medical appliance.

**Remember** Unfortunately – we could carry anything in our pouches! Gems, drugs, gold – anything but the true purpose of the pouch – poo! It must be up to the professional to make sure that, in our case, this is not so.

**The above hints and tips are relevant, however you choose to travel – air, sea or on land. If you are staying in the UK, apply for a Radar Key this will give you access to disabled toilets. The Colostomy Association has a Travel Advice booklet available for download from the CA website: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk). The Travel Advice booklet, Travel Certificate and factsheet listing Travel Insurance companies are available from the CA office.**





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# Irrigation and you...

Sue Hatton Executive Trustee writes...following on from the winter issue of Tidings I had a conversation with a wonderful gentleman – Ken Peplow. I suggested Ken write up his irrigation experiences using 'soft water'. Tidings also received a letter from Jill who had also been using 'soft water'. Please let me know your methods and what you think about Ken's article and Jill's letter and whether you have been offered 'colostomy irrigation' by your stoma care nurse in your region...

**Sue writes:** As you know I encourage everyone who irrigates to write in with their experiences. If you have an irrigation story to share – it would be great to hear from you!



Ken pictured with his wife Megan

**Ken writes...**The article 'Irrigation and You' in the Winter 2014 edition of Tidings, wherein reference was made to the use of 'SOFT WATER', caught my attention and prompted me to respond and relate my own experiences concerning 'soft water'.

I am an ostomate of 85 years of age and for the past 21 years been immersed in the vagaries of irrigation. During this time I have irrigated some 4,000 times and, apart from holidays etc., have always used Soft Water – with no ill-effect – so what's the problem?

When I conveyed this information to Sue Hatton, she suggested I provide a short article on my experiences as an ostomate (I wish they would change this word to an optimist).

So here goes...I began my saga when I noticed, while on holiday in 1993, blood in my motions. I mentioned this to my wife and, before I knew it, I found myself with my doctor and three weeks later lying in bed reflecting on my future as an ostomate.

Being at the tender age of 65 years, I decided to opt out of my business and get down to an appropriate lifestyle that

embraced my basic interests. To the forefront I wanted, as a life long sportsman, to continue playing squash and tennis. I discussed this with my stoma care nurse, a great lady, and she suggested that irrigation might be my best route to this goal. As a result she obtained some sketchy information from the USA – an A4 sheet of paper, the centre of interest being, someone sitting on the toilet with a plastic type sleeve placed over their stoma and into the bowl, armed with a cone and tube attached to a water bag, located at a specific height.

I soon found as I took up irrigation that the position shown on the sheet could be quite uncomfortable so instead I placed a folding chair in front of the toilet and put the end of the sleeve into the bowl. I next found the height specified for the water bag did not work. As a result of this, and as a former drainage and irrigation engineer, I realised the height of the water bag was crucial in order for gravity to do its work sending the water from the bag down through the tube – so I adjusted the height of the water bag by 9" and never looked back.

Having solved my irrigation technique, my next step, apart from eating, was to get back to playing tennis and squash, which was accomplished in four weeks for tennis and six weeks for squash. I eventually retired from my major sports activity at 81 years but still swim and garden (not my greatest love!).

In relation to my squash and tennis activity, there was the perceived worry concerning possible embarrassment. For example, when appearing in the shower room at the club clad in a supportive corset, I gritted my teeth but was soon put to rights by comments such as 'I prefer black suspenders'. As a result my embarrassment soon disappeared.

In regard to the above basic lifestyle ambitions, there was also the parallel

requirement of eating and it's impact on how I functioned. In general I found, with certain exceptions, that I could eat anything both at home and away. The exceptions as a rule being anything with skins, particularly tomatoes, another 'No No' was sweetcorn, which seemed to go through me like machine gun bullets – great fun!

My wife and I love overseas travel and, in addition, overseas consultancy was always a great joy. In relation to water for my irrigation, I found that bottled water or the use of sterilisation tablets sufficed. I have, in the course of my travels, discovered I could write a book on the plumbing of the world, particularly that relating to the Greek Islands.

I have irrigated using the above guidelines in diverse situations such as a Malaysian Steel Works and a Greek ferry. The latter was somewhat problematic in that the ship's water was definitely not suitable. Unfortunately ice-cold bottled water was the only available choice and I had to have recourse to heating the water on the deck. Talk about mad dogs and Englishmen out in the midday sun!

Having got to a variety of destinations, the next requirement concerned the placement of the water-bearing irrigation equipment, such as used in my own shower room. I found, again by trial and error, that this could be accomplished by using some of the following accessories:-

- Length of stout string
- 'S' shaped meat hook
- Wire coat hanger
- A plastic over the door hook
- Hook (with a sticky back) – allow 12 hours or a shower could ensue
- Wife or partner (not an accessory)
- Good sense of humour
- Sterilisation tablets

With these items and a fertile imagination, I found that I could travel anywhere.

Almost in conclusion, I have found with the establishment of the Colostomy Association and its attendant TIDINGS a basic 'LONELY HEARTS CLUB' and Information Centre. I wish I'd had such a contact centre in my early days of being an ostomate but, on reflection, I would not have experienced the fun to be enjoyed in finding the solutions provided by trial and error.

In reviewing my possible next objectives, it would be great to achieve my 90th birthday and, more importantly, to celebrate my 70th Wedding Anniversary with the love of my life – my wife Megan. Allied to the above, it would be fulfilling to have over 5,000 irrigations under my belt – all with 'SOFT WATER'. Maybe entered in 'GUINNESS BOOK OF RECORDS?'

**Jill writes...**

I have had a colostomy since September 2010 - due to bowel cancer - and have been irrigating since about May 2011. We have a 'water softener' and I did ask my stoma care nurse if was okay to use

the water and she said that it was - so I have been, with no side effects that I know of.

Although it took a while to get going properly, irrigation has been a godsend as I suffered from pancaking. I have a very high fibre diet and drink plenty of fluids (if one more person tells me I don't drink enough I shall pour a bottle of water over their head!) and no matter what different products I used nothing worked. Pancaking makes you feel dirty, smelly and uncomfortable!

Thank you for your magazine it is very helpful and if it hadn't been for Tidings I wouldn't have heard of irrigation!

**In conclusion:** The experiences of Ken and Jill provide us with 'real life' insight into irrigating with 'soft water' however at the present time the CA would advise not using softened water to irrigate until there is more firm evidence with regard to salt content. Keep your experiences coming in, they help to build a clearer picture of 'colostomy irrigation'.

**Sue writes...**

I am delighted to announce that the Colostomy Association has taken its first delivery of both DVDs – Irrigation and You (Patients Version) and Colostomy Irrigation – a reference tool for Clinical Nurse Specialists (stoma Care). (Nurse to Nurse version)

The DVDs are the culmination of a personal ambition to raise awareness for colostomy irrigation as an alternative method of bowel management.

I would like to take this opportunity to thank everyone involved with the project who gave their time freely with such enthusiasm to make the DVDs a reality!

Colostomy Irrigation (where possible) is life changing!

# Colostomy Irrigation and You DVD1: (patients version)

## Order Form Colostomy Irrigation and You (Patients)

**Colostomy Irrigation and You** is an educational DVD aimed at patients, it has been produced by the **Colostomy Association** to raise awareness about '**colostomy irrigation**' as an alternative method of bowel management. **Note:** Please be advised that not all colostomates have the potential to irrigate it is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

To obtain your single copy of Colostomy Irrigation and You at the special introductory price of £4.99 (inc postage and packing) simply fill in your details below and make your cheque payable to the Colostomy Association. Return your completed form and cheque for £4.99 (inc postage and packing) to:  
Colostomy Association, 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](mailto:cass@colostomyassociation.org.uk))



Title: \_\_\_\_\_

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# pelican platinum

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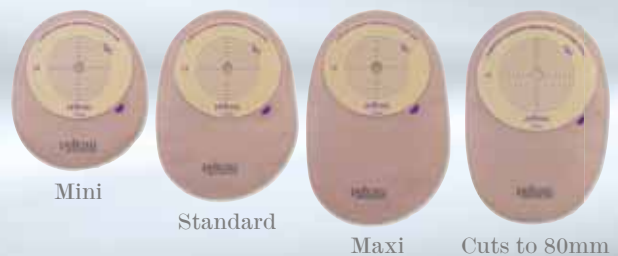
Pelican Platinum is the brand new closed pouch range from Pelican Healthcare.

Unlike many conventional products, the Pelican Platinum Closed pouch features a unique foam backed skin protector, which offers unrivalled levels of comfort and security.

The innovative foam backed skin protector is extremely soft and comfortable against the skin, whilst the ground-breaking Pelican "EvoFlex" System ensures that pouch flexibility will not be compromised.

The advanced dual chamber hydrophobic filter system is an extremely efficient deodoriser, whilst the waterproof element helps maintain filter performance.

- **Unique foam backed skin protector**
- **Ground breaking Pelican 'EvoFlex' system**
- **Advanced dual chamber waterproof filter**
- **Available in 4 sizes: Mini, Standard, Maxi ... and a version that cuts up to 80mm**



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..... Post Code: ..... Telephone: .....

Size: Mini  Standard  Standard  Maxi  Stoma Size: ..... mm  
(12-65mm) (12-65mm) (15-80mm) (12-65mm)

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HEALTHCARE

# CA 'Closed' FACEBOOK...on the up!

## Membership reaches 1800 and rising...

**Sarah writes...**The CA 'closed' Facebook group has gone from strength to strength. In January 2012 we became a 'closed group' at 248 members. We felt it was important to have a closed group where people could comment, safe in the knowledge that nobody outside of the group could read what they'd posted. After all, no matter how open you are about your stoma, you may not want your other Facebook friends to read about your stoma issues. As of March this year our membership has risen to an incredible 1800 and is still rising. Every new member is greeted enthusiastically and soon made to feel part of the family. It still amazes me how people arrive often 'in tatters' and within minutes have answers to the issues they are facing, from people who really understand.

As the group has grown, fellow Admin Duncan Wells and myself have come to realise it's quite a responsibility to keep a caring eye on the group but at the same time – very rewarding – its a bit like being parents of a very large family. Duncan has taken a step back from the group for a while due to work commitments so we decided this was the time to expand the Admin team. We debated long and hard as to whom we should ask but three names kept cropping up. The three became admins in January and have already been a huge help to me. I asked each one to write a little about themselves for Tidings so that you could get to know them too!

So it's with great pleasure I welcome to the Admin team and introduce you to – Ian Jackson, Natalie (Natty) Slow and Steve Clark!

**Ian Jackson:** Hi I'm Ian. In January 2011 I was diagnosed with colorectal cancer (Bowel cancer) 10 days before my 50th birthday. I had a round of chemo and radiotherapy and after a few months to get over that had a permanent end colostomy formed in August 2011. Soon after I found a small support group on Facebook called the Colostomy Association and on joining the group I found a wonderful bunch of people who helped me adjust to my new life with a colostomy and supported me through the next round of chemo. As well as now being involved with the CA I also take any opportunity to try to raise

awareness of bowel cancer. I consider myself a lucky ostomate as I have very few problems with my stoma. I work full time and mostly live my life the same as I did before the operation.

I irrigate as I feel this gives me back control and would encourage others (where possible) to try this method of managing their colostomy. On the CA Facebook group I give reassurance, share knowledge and encourage others. As I'm at work in the daytime you'll find me on the group most evenings and into the early hours. Well that's all from me – keep safe, keep fit and healthy and most of all – NEGU (Never Ever Give Up).

**Natalie (Natty) Slow:** At just eight years old I was diagnosed with Ulcerative colitis (UC). Fast-forward seven years and I was having semi emergency surgery to create an ileostomy at the age of fifteen. I couldn't even say 'ileostomy' let alone tell you what it was! When I first saw my stoma, I cried my eyes out, nothing had prepared for that. I contracted a terrible wound and MRSA infection and was in isolation for six weeks with a hole the size of a football in my tummy. For a while it was touch and go whether I would make it. This entire experience really gave me the hump and although I appeared fine to everyone – inside I felt like I was dying. I hated myself and this in turn made be bitter. Ten years later I had to have my rectum removed. I was twenty-five. I was told I'd be back to work within eight weeks...that was six years ago! I've had various struggles since my operation but the biggest one was the deepest, darkest black hole I fell into – there was nothing – no light – penetrated my blackness. I just didn't want to live anymore.

Out of sheer desperation I searched for the CA Facebook group and clicked 'join'. I didn't really want to. I'd already convinced myself that no one would be able to help me. I didn't even want to talk to anyone. The warmth and kindness I found that day is almost indescribable. Those 'people' not only helped me, they saved my life and I will never be able to thank them enough. I have my life back and the black hole is no more, light fills my world! Now I'm an Admin I beam with pride...the bitter little girl is now a proud young, HAPPY

lady and it's all thanks to the CA Facebook group.

**Steve Clark:** I'm Steve Clark and I'm 59. I was in Toulouse, France, in February 2011, loading a trailer with furniture to return my son and daughter-in-law to the UK, I had been suffering stomach pains for a week beforehand and during the drive down and back, was in even more pain. I went to see my GP on Monday morning and by Monday evening was in emergency surgery being converted to that special being, a colostomate! My bowel had ruptured and I had desperately needed life-saving surgery. After a long time in hospital with a sepsis, caused by a leak from the rectal stump, I had a further operation, in May 2012, to relocate the stoma, remove the rectum and 'sew me up.' It was about this time, feeling very alone in the world, that I found the Colostomy Association website and, thence, the CA 'Closed' Facebook group.

The group turned out to be almost as valuable a lifesaver as my first surgery. The support, friendship, love and laughs were instrumental in changing my mindset and teaching me to live with the positive side of being a colostomate. Through the group, I discovered that I may be a suitable candidate for irrigation and in November 2012, I gave it a go with the approval of my stoma care nurse. It is fair to say that I haven't looked back since. I have returned to my job as a Taxi Driver in Fareham and have a wonderful wife, married son and daughter and the three most gorgeous grandsons on the planet! As I have put in my Twitter profile: 'life is sweet'. One Saturday morning, I logged on to the CA 'closed' Facebook group to find a message from Sarah inviting me to join the Admin team. I was delighted to accept I consider it to be real honour and hope I can make a valuable contribution to the role in the foreseeable future.

**If you would like to join the 'closed' CA Facebook group, search for 'Colostomy Association' on Facebook, choose the group and you will see a tab to click to join. Once you've requested to join, one of the Admins will greet you. We look forward to seeing you there!**



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# Focus on additional ostomy products

## Stoma protectors...

One of the big worries after stoma surgery is that your life will have to change. Underlying disease or health issues may be a factor, but there are many activities you can continue to enjoy with a colostomy.

You will have all kinds of questions about living with a stoma and post surgery. Some will be related to previous interests you were involved in such as keeping fit. Others may be about returning to the workplace, especially if it is to an environment that demands a great deal of physical activity.

Exercise is an important step forward to good health. Walking, as has been proven recently, is not only good for your body but good for your mind too. When starting exercise take it easy at first and little by little you will find yourself able to do more. Be careful not to strain yourself, wear a support garment as this may help protect you against developing a hernia. At some point you may find you want to return to playing a contact sport such as rugby. When starting any strenuous exercise it's always best to discuss it first with your stoma care nurse or GP.

When exercising or playing sport, some ostomates worry that their stoma could get knocked or the appliance pulled causing damage to the stoma. We do need to look after our stomas – so it's good to know that there are solutions out there to help the ostomate overcome their concerns.

Specialist products known as – stoma protectors or shields are available to protect your stoma. They are made out of hard plastic which is formed into a cup. The cup is attached to a belt. The cup fits over the appliance to give extra protection and peace of mind, whilst not restricting the function of the pouch and the belt holds the cup in place.

Some people may find stoma protectors or shields useful when driving in the early days too. Once you have recovered enough to drive, on your doctor's advice, you may still feel



a little tender where the seatbelt rests on you tummy. It is tempting not to wear a seatbelt if it is uncomfortable and you may also be worried about damage to the stoma - but far more damage could occur in a car accident so always wear your seatbelt. A stoma protector could be used to stop the seatbelt rubbing, or another hint for driving is to try a device designed for pregnant ladies to keep the seatbelt in a lower position. Some ostomates with a stoma in a tricky place, such as on the waistband may benefit from a stoma guard too, as it will keep clothing away from the stoma and may help with problems such as pancaking. A factsheet is available from the Colostomy Association website entitled Seat belt protection and extenders. Visit: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk) or for a paper copy contact the CA office details can be found on page 6.

Stoma protectors may also be useful for children with a stoma. We all know children like to play rough and tumble and don't give a thought to the consequences. In this case it may be mum or dad who then have peace of mind that their child can continue to play as they wish without risk of damage to the stoma or a burst bag after a fall!

Stoma protectors are available on prescription from several companies OstoMART (OstoSHIELD pictured above) FREEPHONE 0800 220300, Comfizz Tel: 0113 266 2096 and SASH Freephone: 0800 389 3111 (UK only). It is always advisable to discuss stoma protection with your stoma care nurse

or GP to ensure that the product suits your needs. Other stoma protectors such as Ostomy Armor (an American product) are available to purchase online visit: [www.ostomyarmor.com](http://www.ostomyarmor.com). Please be aware that not all American companies ship to the UK and products can be expensive.

Some stoma protectors can be worn within a hernia support belt, therefore protecting against the dreaded hernia too. It is important to look after your stoma but it is also important to live as full and active life as possible. These additional products may help an ostomate continue to take part in activities they enjoy while keeping the stoma safe.

Thousands of ostomates enjoy a wide range of sporting activities such as golf, cricket, bowls, sailing, cycling, running, climbing as well as going to the gym and activities like gardening and rambling. So why not you!

**Note: Additional products** – are invaluable to the ostomate many are available on prescription. However certain products may attract payment. Ask manufacturers for samples, and always talk to your stoma care nurse/GP if you feel a particular product may be of benefit to you. Explain why you think you need it and discuss all the alternatives available. All we ask is that you use products sensibly. At the end of the day your stoma care nurse and GP want you to live a happy life with your stoma and should help you achieve this with sensible use of additional products.

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### Editors Comment

**If you use additional products in your change routine. Please write in any tell us about your experiences or send in your hints and tips. See Page 6 for the Editor's contact details.**


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## Introducing your NEW President...

# Mr Ian Daniels FRCS

I was delighted when I was asked by my surgical mentor and colleague Professor Bill Heald (past President) and the Trustees of the Colostomy Association to take on the Presidency of the Colostomy Association.

I have been working with Bill for over 10 years, during this period Bill has demonstrated excellence in surgical technique in rectal (lower bowel) cancer and techniques to restore bowel continuity. In recent times we have moved forward the surgery for anal and rectal cancer, where a permanent colostomy is created to improve the survival in these patients. However,

survival is not just about length of time lived from cancer surgery, but living with the effects of cancer surgery, quality of life as well as quantity of life.

My personal interest is in managing the complex abdominal wall problems relating to hernias – of all varieties, and this has led me to study hernias associated with stomas but from the causes and effects, as well as surgery to repair them...no simple answers here.

However, with support from patients and a desire to promote further research, we are beginning to define different types and effects, as well as

considering whether there is a group of patients at risk for hernias, because the risk is in your genes!

Tidings represents a great opportunity to conduct research, unite ostomates and to share experiences and advice. Colostomy Association patient open days offer an opportunity to talk face-to-face, away from the Out-patient clinics which are so pressed for time!

I look forward to meeting many of you throughout my Presidency and will work very hard for this big hearted charity.

**Ian Daniels FRCS**

## A little background information...

### Where were you born and brought up?

I was born in Nantwich, Cheshire in a hospital that I would later go and work in as a Nursing Auxiliary. By then it was a long-stay mental hospital.

### What qualifications did you get at school?

Twelve O levels and eight A levels! I took them twice after getting the grumps when the school did not think me bright enough to do medicine at University!

### When did you decide to study medicine and do you come from a medical family?

I don't know the answer to this only to say that the lady who worked in the local sweet shop always called me 'Doc' when I was a kid. My mother worked as a secretary in a chicken factory and my dad worked in a steel foundry. Both had worked for British Rail in Crewe and I was the first in the family to get an O level.

### What University did you go to?

After being rejected by every Med School in the UK and Ireland and then getting the grades, I was sat on the steps to the University of Wales College of Medicine ready to hand a letter in, on the Monday after the A level results, asking to be considered for a place at Medical School (this was part of a UK tour to every Med School). A nice lady (I would find out later was the Admissions Officer) asked me in and to wait until it was open. One hour later, I'd





been interviewed in my jeans and rugby jersey, offered a place and accepted it.

Two hours later I'd had a few beers in Cardiff, eventually found my way back home on a train, the next day having to phone Cardiff to check they really had offered me a place. Later I was to look after the 'nice lady' when I was a junior doctor (Oh! And I later broke the arm of the registrar in a staff v student cricket match who also interviewed me – needless to say he forgave me). I was to become President of Cardiff University School of Medicine (UWCM the 3rd smallest University in the UK) in my senior years. In the early 2000's UWCM was absorbed into Cardiff University after more than seventy-five years of working in partnership, creating a new era for university education in Wales and one of the biggest and most powerful universities in the UK.

**When during your training did you decide to become a 'plumber', as you call it, or a bowel surgeon as we would refer to it?**

My usual answer is...Not being bright enough to be a brain surgeon, suave enough to be a heart surgeon, I found a natural opening' so to speak! However, like so many people in life my teachers influenced me and Mr. Nick Carr, Colorectal Surgeon in Swansea set me on this path, so I owe an awful lot to Nick for the opportunity he gave me. He also suggested leaving Wales and going to London and then Basingstoke. I have been very fortunate to work with the best throughout my career.

**What is family life like, given that you are a workaholic!**

In a word 'Chaos'. Fortunately my family Halina, Domi, Holly and Jazzy are all

very understanding – operations and patients, research and academia can take their toll – surgery can often have a negative effect on so many families, but I think that is the nature of this profession.

**What has been your Medical Pathway so far?**

I trained in Wales gaining a Degree in Genetics. Worked in Swansea with Nick Carr – Colorectal Surgeon, then London, Basingstoke and Oxford and finally took up my current post – Consultant Colorectal Surgeon, Royal Devon & Exeter NHS Foundation Trust in 2006. I am also a Consultant Colorectal Surgeon at Pelican Cancer Foundation, Basingstoke.

I belong to the following organisations:-

- British Medical Association
- Association of Surgeons of Great Britain and Ireland
- American Society of Colon and Rectal Surgeons
- British Association of Surgical Oncology /Association of Cancer Surgeons
- Association of Coloproctology of Great Britain and Ireland

**Where do you hope it will lead?**

I once wanted to be a serious academic and ultimately become a Professor of Surgery, but I enjoy operating too much and will always put other things to one side if someone needs an operation that I think would be best done by me, which leads to lots of late nights!

**You travel abroad a great deal, what do these trips entail and what work are you doing?**

Professor Bill Heald inspired in me the ability not just to talk about surgery in lectures but to do surgery live, showing how difficult cases can be and to have discussions with fellow surgeons about how to improve. I learn something from every trip and bring that knowledge back to the UK.

**What research do you want to do and how can the CA get involved?**

More research into quality of life for people 'living with a stoma'. Gain greater understanding of the pathways that lead people to receive a stoma, particularly Diverticulitis. Individualised care will be an important factor in the future and CA can play its part through 'quality of life' studies which could change care and patient outcomes.

**What will you bring to the CA and what can we achieve together?**

Influence in terms of forward thinking and raising awareness of the CA and its amazing work. Build ever closer relationships between all the stoma support patient associations, as many of the issues such as poor siting, hernias and high output are shared. To strengthen the patients' position and increase awareness in others.

**What would you like your legacy to be?**

Being remembered for doing a 'Proper Job' for patients. Supporting trainees in medicine and surgery as they will be the generation to look after me!





## Breakaway Foundation... introduces Family Information Days



As the Breakaway Foundation has continued to grow we've realised that people often find us really late in the day, they've often been struggling alone for years not realising that there is help and support out there, and then once they do find us they often have to wait until the following year to come to one of our family weekends.

So last year we decided to do something about this and the Breakaway Family Information days were born. We held days in Leicester, London and Newport, giving families the chance to come along, find out more about the Breakaway Foundation and what we do, meet some of the trustees and volunteers, and more importantly to meet others who are going through the same thing.

The events in 2013 were really successful, and some of those families have since been to a weekend or are

booked to come this year. So for 2014 we set ourselves a challenge to spread the word about the Breakaway Foundation far and wide across the UK.

Our first information day was held in Birmingham on the 23rd February, our Gold sponsors, Salts Healthcare, very kindly offered us the use of their nurse education centre. Thirteen new families joined us on the day, along with some of our parent and professional volunteers and trustees, there were around seventy people, including what felt like millions of children running round everywhere!

Zoe and Tracy had put on some great craft activities for the children to try and keep them occupied. Hannah and Tiegan, never ones to miss a fundraising opportunity, had spent Saturday baking cakes and raised a magnificent £60 from their cake sale, Ian Jackson and his wife Julie drove up to join us and Julie

spent hours face painting just about every child that was there! Pauline Morgan and her husband came along with some homemade cakes and did a sterling job keeping everyone topped up with tea.

Everyone really enjoyed the day and there were some very relieved parents heading home, having realised that they are no longer alone and that there are others who understand. 'So pleased we went along to the information day today. It was great to meet other families in the same or similar situations, after such a long time we are not alone anymore!!', 'I never thought I'd meet another family like ours. Thank you Breakaway and Salts, you made my little boy smile again today!'

Our next information day is on Friday 11th April in Newcastle. We've been overwhelmed with the interest in that event, so many families in the North east who think they are alone, they are going to get a wonderful shock! We've further events planned for Scotland, Leeds and Cambridge, keep an eye on our website and Facebook page for more details.

We're also trying to leave some form of support behind, so we now have our London and South East support group, who've had their first event and are busy planning a trip to the science museum, our Birmingham and the Black Country support group, who have their first event on Saturday 5th April, and plans are underway for something in the South Wales/Herefordshire area. The Breakaway Foundation really is going from strength to strength!

**More information about Breakaway Foundation...**

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## It couldn't happen twice?

**Ninel writes..My father and I both ended up with stomas due to diverticular disease. This is an account of our experiences...**

My father started to suffer from lower gut pain when he was 55. He was an active man and the pain and discomfort would render him totally inactive. No tests were undertaken but the doctor simply told him it was probably diverticulitis. This WAS nearly 30 years ago! He was given a drug called Colofac, which helped him with the discomfort. It became a way of life. No dietary advice was given then and he simply got on with it. He could never predict when an attack would happen and indeed one took place on a visit to my home in Kent for no apparent reason.

I took him to our local doctor who again said it was diverticulitis. My father had suffered from other serious illnesses in the past and was reluctant to do any more about the attacks so continued to take Colofac. The medical profession seemed to just pass diverticular disease off as insignificant and something that happened when you got older. At the

age of 60 he felt unwell, couldn't pass stools and noticed that his urine was brown. He had a couple of scans and examinations and was taken into hospital where he underwent immediate bowel surgery. There was a large blockage in the sigmoid colon and a fistula had formed with the bladder; hence the brown urine. A section of the large colon was taken away and a colostomy was formed. There were no problems with the formation of the colostomy and my father got on with his life. Although there was a possibility of bowel re-connection at a later date if he so chose but he decided against it, as the colostomy caused no problems. The connection point would have been very low down making surgery difficult (at that point in time) and worst of all to him was the possibility of being bowel incontinent. He was content with his colostomy.

Fast-forward to my experience. Tidings magazine and colostomy bags were a

familiar sight to me. I used to read Tidings when I visited my parents as I found the magazine very interesting. Little did I realise the significance of this! Lightening couldn't strike twice could it? But it did. Neither my father nor I suffered from constipation. Diverticulitis is often characterised by constipation but this didn't fit either of our bowel habits. I had always been regular. I was a muesli child – I ate everything I should do, brown bread, loved vegetables, and had a good diet. My father had a different diet – white sliced bread, lots of protein, and not so many vegetables. He was a child of his time.

At the age of 45 I noticed that I needed to go to the bathroom more regularly but this didn't bother me much. I figured I was healthy better to be this way than constipated. I often used to get gut pain but put this down to period pains. I didn't think it could be my diet. Sometimes I would simply just have to stop what I was doing and sit or lie down for a while until the discomfort wore off. In January 2006 my husband and I went to India. This was the second time we had visited India and I hadn't suffered from any problems before. This visit also went well, apart from the fact that the day after we returned I suffered from raging diarrhoea.

I carried on for four days then went to my doctor taking a stool sample with me. We were going away for the weekend and I didn't want to pass anything on. The sample came back clear. I continued to suffer with serious diarrhoea for about a month. I couldn't go out without finding out where the nearest toilets were sited before hand. Luckily I was working from home otherwise it would have been dreadful. It was bad enough as it was. There was a suggestion from the doctor that it might be Irritable Bowel Syndrome (IBS) so nothing moved forward. I mentioned my father's experience – 'no, not at your age!' I had my first appointment with a colorectal surgeon in October 2006 followed by a failed colonoscopy – the colonoscope couldn't traverse the colon due to acute angulation at the rectosigmoid junction.

In January 2007 a barium enema confirmed gross diverticular disease complicated by stenosis in the distal sigmoid colon. Prognosis: removal of the sigmoid colon! Suddenly I was

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where my father was all those years ago. I didn't want the surgery and I remember saying I would much rather be dead than wear a bag! My father tried to console me. He had experienced no problems with his colostomy. However, I felt this wasn't for me. Enter Mr. Daniel Lawes, consultant colorectal surgeon, Maidstone and Tunbridge Wells. Mr. Lawes has been absolutely marvellous!

I didn't want surgery and I didn't want a bag. He listened to me and agreed a conservative approach of 'masterly inactivity' – if anything changed we would reconsider. I read everything I could – monitored foods, which seemed to cause problems (nuts, lentils, sweetcorn primarily – so much for the muesli!). Much to Mr. Lawes amusement I also introduced 'slippery elm' (a herbal remedy), which seemed to help. I had follow-up appointments once a year, at which I would say that I had only suffered two bouts of diverticulitis that year – upshot – carry on as usual. This sounds quite minor but actually it wasn't. I was bed-bound for days. I carried antibiotics with me so that I could self-medicate when I knew things were getting really bad. My social life was affected. I couldn't go to the theatre or cinema, as I couldn't sit through a performance. Life was pretty miserable.

On 30 December 2012 I suffered a bad attack of diverticulitis. The antibiotics took a long time to work and I was very concerned. At my routine appointment in February I knew I had to face up and make a decision before I ended up in the same position as my father. Planned surgery is always the best option. Mr. Lawes had told me in a previous appointment that surgery at my age (55) had a much better outcome. After much deliberation following the appointment I decided I simply must have surgery.

Mr. Lawes carried out a laparoscopic surgical colectomy on 31 October 2012. In order to let the join heal a temporary loop ileostomy was also made. It was planned to reverse this two or three months later. So, I woke up following surgery with a 'bag.' From the word go I just got on with it. I shed no tears. All the nurses at Maidstone Hospital were

fantastic. The colorectal nurses and stoma nurses at Maidstone and Tunbridge Wells hospitals, well, I just can't praise them enough! They were so professional in their roles and made all the difference to me. I felt great after the surgery – no pain to speak of. I felt better than I had felt for a long time. The surgical procedure was quite long and quite difficult – my only regret I should have had it done much earlier. Sorry, Mr. Lawes! I carried out my first bag change two days later and was discharged after five days. I had a new diet, which I followed to the letter! I created a space for all my stoma paraphernalia and made good use of a trolley I already had, and got on well with things at home.

Two and a half weeks later my father became gravely ill and was taken into the Royal Berkshire Hospital in Reading. Whilst he was in the HDU I visited him every day. In the bed next to him was a lady who'd had emergency bowel surgery abroad and experienced complications. So, there we were, all three of us, with our stomas! I introduced the lady to Tidings and told her of my experience.

Whilst visiting my father in hospital I had to change and empty my bag throughout the day, but it was no problem. In my father's case, a stoma was quite advantageous as a bedpan was totally unnecessary! I was really helpful to my father's as I could cut his drainable bags to the correct size. We were very close and to my great relief my father survived.

After three weeks I was driving again. I actually saw the benefits of wearing a bag – I could empty it when I chose and I could 'see' how different foods affected my digestion. I can honestly say that I never had any problems with my bag – 'Stinker' (named by my daughter).

At the end of January 2013 my ileostomy was successfully reversed. I was dreading the possibility of not being able to control my bowel motions. However, after a couple of weeks I was pretty much back to normal again. A year on and it all seems like someone else's life – a time when I suffered so much. In July last year, my

father passed away at the age of eighty-four of an unrelated illness. He had managed his stoma successfully for nearly twenty-five years. It caused him no bother at all. In fact, it gave him a better quality of life, more time with his family, which was a blessing to us all. I am so pleased with my outcome – reversal – which was right for me.

Thank you to Mr. Lawes and all his team and thank you Tidings for publishing this article.

**For about one in ten people with a colostomy, their stoma was formed following a severe attack of diverticulitis. For some the stoma may be permanent, others may be offered a reversal.**

#### What is Diverticular Disease?

The term Diverticular Disease includes diverticulosis (the presence of small pockets or sacs or diverticula, in the intestine wall) and diverticulitis (inflammation of these small pockets or sacs). Diverticular Disease occurs in the bowel from problems relating to the presence of diverticula and/or diverticulitis. Diverticular bleeds, and long-term effects of recurring episodes of diverticulitis, may result in narrowing, thickening and poor function of the bowel in a specific area.

#### What are the Symptoms?

The symptoms vary depending on the level of the disease. If there is mild disease where the symptoms are vague for example lower abdominal pain may be felt usually on the left side. Any further features of inflammation, such as a temperature could mean Diverticulitis. Pain is generally associated with eating and is relieved by passing faeces.

In Diverticulitis the symptoms are similar, abdominal pain, fever, a change in bowel habit, feeling sick or being sick and in some cases passing blood.





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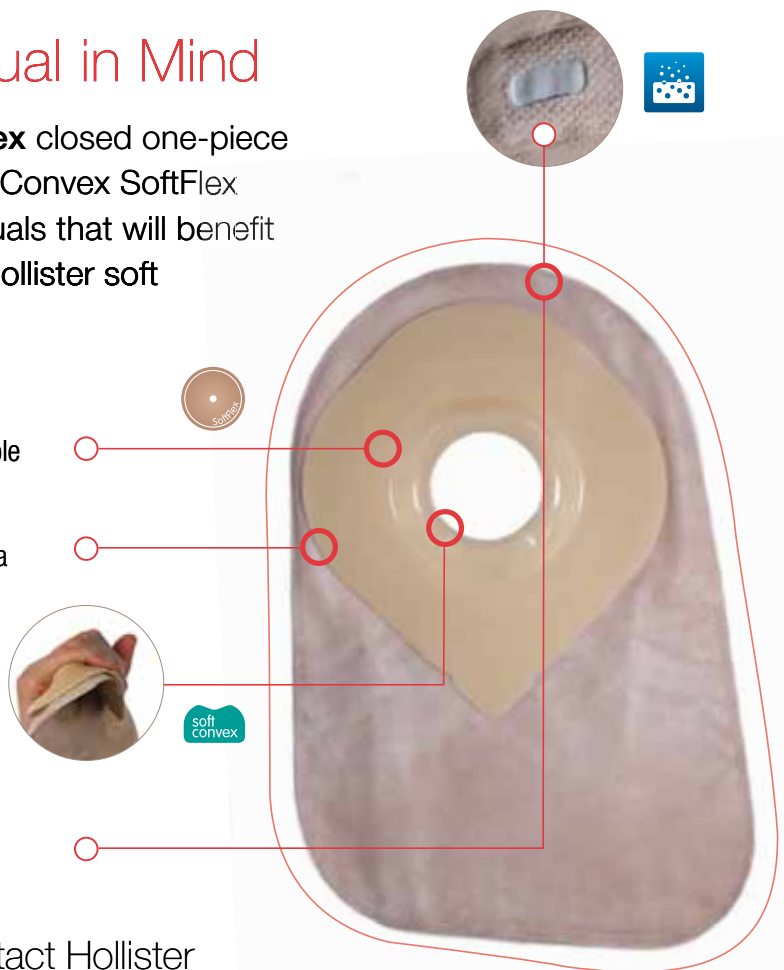
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## Bowel Cancer Screening Awareness... Shout out loud...about Bowel Cancer!



Sue Hatton – Executive Trustee is a passionate advocate of Bowel Cancer Screening – after reading a post by Pauline Morgan on the CA ‘Closed’ Facebook group. Sue asked Pauline if it could be reproduced in Tidings to highlight the importance of screening. Ian Jackson, one of the admin coordinator’s for the group, who is passionate about beating Bowel Cancer also contributed information for those of us with stomas who have had bowel cancer, reminding us of our responsibility to our – family and friends – to ensure they are aware of the importance of getting their poo checked.

### Pauline writes...

This is quite a long post, but I think it’s an important one, so please bear with me. Last year at the CA Open Day, I was talking to Ian about check-ups for people who have had Bowel Cancer, I mentioned that because I have had so many scans of some sort or another, they are reluctant to do more unless in an emergency.

We were talking about the Screening Kits that are sent out to people over a certain age, and I was surprised when Ian said even people who have had Bowel Cancer should do them. I had one when I came out of hospital six years ago and sent it back as it said if you have had surgery or treatment for cancer don’t use the kit. Typically, I didn’t do anything about it, then, just before Christmas Mr. M had his through, so I rang them about myself. They said it was really important that we have regular testing, and I said how talking to Ian had made me ask, and I told them about the CA and the Closed CA Facebook group. They asked me to spread the word that people should still have this test, to ring them if unsure, they are happy to talk and explain things.

I duly had my test and followed the instructions, not the big deal those, ‘Mere Mortals’ make of it, though I do admit to a bit of a quandary when trying to spread Poo on a tiny space and it wouldn’t spread. I then realised I was trying to squash a piece of peanut which must have come off an ice cream I had eaten the day before - I wonder what they would have made of that? Mr. M’s results came through within a week of his test, a little thin envelope with NHS on it, all was well.

I had my results, a thick envelope with NHS, my little heart started to beat faster, please don’t let one of my peanuts have cancer I thought.

As I am very brave I gave it to Mr. M to open, then realised I had another slim envelope with NHS on it, I opened that, my test was clear, the other envelope was an invitation for a Mammogram in March, I think my heart rate has returned to normal now. Now I just have to have the mammogram, no big deal, it’s even very handily on a Supermarket Car Park, and quite local. My only problem is squeezing my boobs within the plates, it’s quite difficult getting a 32AAA boob, between the plates, tweezers have been mentioned to lift the nipples on many occasions, the technicians get more stressed than me, what should take a few minutes takes ages, but again a very important check-up, another fun afternoon out!

### Ian writes...

**Bowel cancer awareness why?** I do think some people that know me wonder why I keep ‘going on about’ bowel cancer. I find it a shocking fact that while if it is caught early the majority of cases can be very successfully treated it is still the second most common cancer killer in the UK. I attended a local group meeting where my surgeon was talking about bowel cancer surgery.

He was talking about advances like enhanced recovery, keyhole surgery, harmonic scalpels and even the possibility of robotic surgery, but still shockingly 50% of bowel cancer cases are terminal mostly because of a late diagnosis, so in my mind there are vast

improvements to be made just by increasing awareness and getting quicker and more accurate diagnosis’s.

### So what do I mean by awareness?

To my mind awareness comes in two parts. Firstly the awareness of the screening program, at the moment only 50% of home screening kits sent out are completed. Picking bowel cancer up at this stage is by far the best chance of a successful treatment and cure as the screening program can detect a problem before any other symptoms would be noticed. Secondly an awareness of the symptoms of bowel cancer, this part needs to be for patients GP’s and even practice nurses, there also needs to be a broad understanding that although bowel cancer is most common for over sixty’s it’s also possible for younger patients to get this cancer, at the moment it seems all too common initially for anyone under sixty to be dismissed as too young to have bowel cancer.

### What do I do to help raise awareness?

On the social network sites I post about bowel cancer, share others posts like and comment and very recently I’ve started ‘tweeting’ about it, it may not seem much but a Facebook post with as few as five or six ‘likes’ can reach and be seen by hundreds of people. The problem with this is it does tend to be the same people as my ‘friends’ group is always the same. On Facebook I am also involved with a ‘follow the bowel cancer tie’ page where we encourage people to take a Beating Bowel Cancer (BBC) tie on holiday or just away with them then post a photo of where the tie has been, this makes for a talking point and can involve a greater group of people, quite a few from the CA

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## Bowel Cancer Screening Awareness... Shout out loud...about Bowel Cancer!



Facebook group have been involved and helped with this (and it's a bit of fun for us to do) anyone can join in it's not just for people connected with bowel cancer the more the merrier as they say. I was also lucky enough to be invited to attend a 'parliamentary event'



**Iain talking to his local MP about the bus pass covers at Westminster (wearing the BBC tie)**

at the houses of parliament this year where we had the chance to talk to MP's and to hear Secretary of State for Health talk about bowel cancer awareness. And finally I am involved in a RAIL (Raising Awareness In Libraries) project where the main idea is as people pick up their bus pass from the library when they are 60 they are offered advice about the screening program (that also starts at 60 in England) and a free bus pass cover with screening advice on it, this has seen my in the local library most Saturday mornings of December January and February on one occasion with a giant inflatable colon.

**So what next?** It's said that bowel cancer awareness is ten years behind the likes of breast cancer the government said they recognised this and have pledged to do what they can to increase awareness. In my mind breast cancer awareness was greatly helped by some high profile celebrities coming out and being brave enough to talk openly about it, everyone has to fight their own battle however they feel best, but it would help awareness if some high profile patients were to stand up and 'be loud about bowel cancer'. Hopefully with increased awareness understanding and

openness we can finally start Beating Bowel Cancer. In the meantime I'll just keep on doing whatever I can, at least all my friends and family should be more than aware. If I could ask you all to not only do the home screening when it is sent but to talk about it, and even if you are not old enough could I ask you to talk to friends and family that



**Iain beating the Beating Bowel Cancer drum (The drum is a toilet and the drumstick a toilet brush) at Westminster (With the tie)**

are, ask if they do it, it's not polite conversation but could save a life.

I can't say all of this without going over the main symptoms of bowel cancer...

- Bleeding from your bottom or blood in your poo.
- A persistent change in your bowel habit
- Constant unexplained pains anywhere in your tummy.
- An unexplained lump in your abdomen.

All very simple and clear signs, but if you have a colostomy, it's not at all unusual to catch your stoma when you're changing or cleaning your stoma and get a little blood in your bag!

Sometimes I seem to have a permanently changing bowel habit! And with a parastomal hernia I have a constantly changing lump on my abdomen, none of this worries me as I have a good idea why, but these all mask the symptoms of bowel cancer!

Now I'm sure if I asked who thought we should have a regular or routine

colonoscopy not many would agree (we already have more than enough of that) but maybe the home screening kits should be offered to everyone with a colostomy regardless of age? And what are the symptoms that would show a cancer in a 'redundant colorectal stump?' Maybe we could do with a set of symptoms aimed at people with a stoma as just because we have had one bowel problem does not make us immune from bowel cancer or further bowel cancer. Thanks for taking the time to read and NEGU (Never Ever Give Up).

### National bowel screening programmes: England, Wales, Scotland and Ireland each have a slightly different strategy for bowel cancer screening:

**England:** The NHS Bowel Cancer Screening Programme is offered every two years to everyone (registered with a GP) in England aged 60 to 74. People over 75 can request a screening kit freephone helpline 0800 707 60 60.

**Wales:** The Bowel Screening Wales programme is offered every two years to everyone (registered with a GP) in Wales aged 60 to 74. More information is available from: 0800 294 3370.

**Scotland:** The Scottish Bowel Screening Programme is offered every two years to everyone (registered with a GP) in Scotland between the ages of 50 to 74. More information is available from: 0800 0121 833.

**Northern Ireland:** The Northern Ireland Bowel Cancer Screening Programme offers screening every two years to all men and women aged 60 to 71. More information on the programme is available from: 0800 015 2514.

**Ireland:** The BowelScreen programme has begun on a phased basis started with men and women aged 60-69. Over time the programme will be extended until the full 55-74 age group is reached. More information on the programme is available from: 1800 45 45 55.

Do not assume that skin discomfort is normal after stoma surgery...

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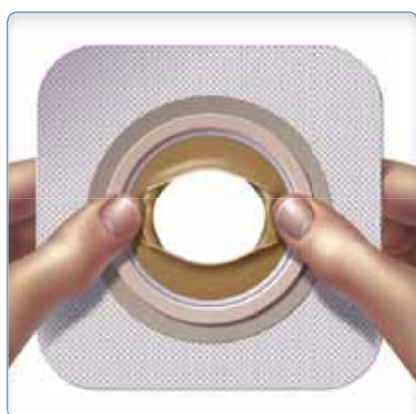
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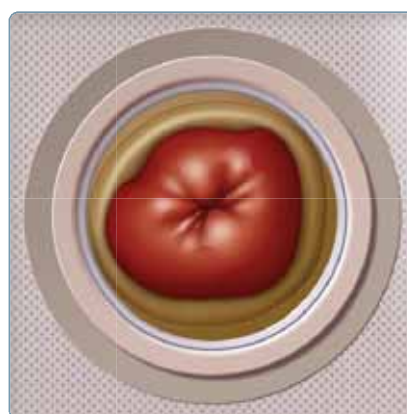
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# Disposing of used Stoma Appliances

You may recall the letter which appeared on the Readers' Writes page:

Dear Editor,

I am writing in to Tidings in the hope that I can gain the experiences of other ostomates in relation to rubbish collection in different areas of the UK. In Pembrokeshire our council has introduced a two weekly pick-up of black bags (used stoma pouches are placed in these), any plea for alternative sacks and pick-up has fallen on deaf ears. What are the arrangements in other parts of the country? I am unable to use the 'flushable' pouch owing to our local drainage arrangements. It would be helpful to know what happens in other areas of the country. Thanks for your most helpful magazine.

Yours sincerely,  
M.B.

## Many of you wrote to tell us that the clinical waste collection service worked well in your area.

"...I have an ileostomy and have a clinical waste collection. They collect every Thursday morning at 6am, and are very discreet, we leave the bag in a pre-arranged area, and they also provide cable ties to seal waste bags. This was arranged by the refuse collection service. You just need a letter from your GP stating that you have a permanent colostomy or ileostomy and the letter goes to refuse office, address can be obtained through your local council. They will arrange for orange clinical waste bags to be left and collected every week. I have never had a problem, they have been brilliant, I just let them know if I'm in hospital or going on holiday, and they know not to collect..."

S.G.  
Blackpool

"I am wondering after reading the winter edition why more people do not have the facility I have from my local council of having a yellow clinical waste bag for used pouches delivered and collected every week?"

B.C.  
Derbyshire

We are very grateful to all our readers who wrote in response to a question in the last issue of Tidings. A special thank you goes to Michael from Hereford who enlisted his stoma care nurse's help which led to a solution to this disposal problem.

"...if M.B. contacts the local council and asks for clinical waste collection, she should find that this can be arranged. I live in the Sevenoaks area, but many years ago I lived in Bexley and they too had a weekly collection for clinical waste."

A.W.  
Kent

"...I live in the New Forest and the District Council provide me with an orange clinical waste bag, which they collect once a week. I can also include 'sharps' in the collection, which is vital for me as I have to use syringes and needles twice a day. They have provided this service for almost 10 years with no break or further questions. I guess I am very lucky!"

P.M.  
Hampshire

"...my Borough Council operates what they call a clinical waste collection service for people with colostomies and pick up your used yellow bag weekly. The yellow bag fits into the bin in my bathroom. The used yellow bags are then incinerated."

J.O.C.  
Surrey

So it seems that in many areas of England a clinical waste collection service operates efficiently...but what about Wales?

"...I would like to say that in Swansea we have weekly collection of all our colostomy items quite separate from the black, pink and green bags for household, plastics and paper. We are supplied with yellow plastic, very large bags with black markings on

them. They are collected weekly on separate days from all other collections and taken to the hospital to be incinerated..."

E.M.L.  
Swansea

"...if M.B. contacts her local council, either by email or telephone, and asks for clinical waste bags and labels, explaining what they are needed for, they will assist her. If they have the same arrangements as Powys Council, they collect the bags every two weeks. Could not be simpler! I was at a loss for disposing of my bags, we have septic tank being out in the country and could not use that facility - I emailed the council, and they were most helpful."

R.F.  
Powys

So I telephoned M.B. to ask if she had tried contacting her local council. Mary is ninety-five years old, has had a colostomy for about fifteen years and said that she had tried several times to arrange for a clinical waste collection, but failed. The day centre she attends has yellow bags for used stoma appliance and incontinence products and they are collected regularly so she couldn't understand why she had been refused this service.

And then we received this letter from Michael in Hereford:

Dear Editor,

I am replying with reference to a Letter in the current issue of Tidings (Winter 2014 No 32). M.B. from Pembrokeshire is writing about collection of used colostomy pouches.

In Hereford, at least in the city, I have a yellow bag, which is collected weekly. This morning my stoma nurse was in attendance at my house and in



connection with this she rang the Pembrokeshire Health Board (Hwyel Dda) and they do operate a yellow bag system; whether this is a weekly or fortnightly system I don't know. Please advise M.B. to contact the Health Board.  
Regards  
M.S.  
Hereford

So I rang Pembrokeshire Health Board, asked to speak to someone who dealt with domestic clinical waste collection and was put through to a very helpful lady. She said, 'Yes we do provide this service for individual households,' and gave me her name and direct line telephone number.

I passed this information on to Mary and she called the number straight away. Then she rang back, delighted to tell me that it was all sorted out. They were sending her yellow bags and would make a weekly collection.

A happy ending...but then...

We received another letter from Michael in Hereford

**Dear Editor,**

Further to my mail to you yesterday saying that we have a weekly yellow bag collection, this will now be terminated. A letter was delivered this morning when my bag was collected. The relevant paragraph states: Herefordshire Council has reviewed its waste collection services and has identified that it is not necessary to collect sanitary or incontinence waste/stoma bags/urine bags separately from the normal domestic waste when they are produced by a healthy person living in their own home. For this reason your last collection will take place on Friday March 14th 2014. After this please use the normal domestic waste black sack collection service to dispose of this waste. The letter goes on to say that the service will only continue for what in the health profession is known as 'infectious' waste i.e. items containing bodily fluids from a person who has MRSA or Hepatitis C or other notifiable infections etc.

Regards  
M. S.  
Hereford

So, it seems, it's not all good news. Other readers also told us that a clinical waste collection service is not available in their area:

"...Cheshire East Council don't provide black sacks, I just have to put my used pouches in the bin, which are emptied every 2 weeks. I have tried to get sacks

to keep used pouches "black bags" separate from household rubbish, to no avail..."  
E.C.  
Cheshire

"...My bins are collected every two weeks, alternating between household (non-recyclable) and recyclable in wheelie bins. I checked with my council (Wirral) some time back as to whether or not I needed to take extra steps when disposing of full bags. I explained that such waste was placed into individual bin bags and sealed before being put in the bin and this was said to be fine..."  
N.A.  
Wirral

So, if the local council don't provide a clinical waste collection, what should an ostomate do?

Well, as we see above, local councils like Cheshire and Hereford assure us that it is OK to put used ostomy appliances in the with the normal household waste. In fact, CA is aware that, even where a clinical waste collection service is available, some ostomates don't use it. They have always disposed of their used bags in the bin as they feel that having a yellow bag outside awaiting collection tells passers-by that they have a medical condition.

Some ostomates prefer to empty their bags into the toilet before putting them in the dustbin. In a previous article for Tidings 23 I described how, when I first had my stoma over twenty- four years ago, I was taught to empty the bag by cutting the bottom off, a practice, which I abandoned many years ago when I switched to flushable bags. But in response to this article I did receive this letter from a reader, which described a much easier way:

"... My stoma nurse advised simply emptying the majority of the contents of the used pouch into the toilet using the same hole it came in through. Thicker contents can be encouraged out like toothpaste from a tube! The flange is then folded over on itself - for a one piece appliance this then seals it, for a two piece it simply leaves a clean outer surface to hold on to. The folded pouch is then placed in a disposal bag which is tied up and dropped in the household waste..."

The other option, of course, is to use a drainable bag which can be emptied while still in place. However, these are easier to use if the output from the stoma is fairly liquid or well formed. If it is soft and sticky they can be difficult to empty. A drainable bag will also mean

there are fewer bags to dispose of.

However, if, like many other ostomates, you find it unacceptable to empty the bag before putting it in with the household waste you don't have to - after all this is where mothers dispose of baby's nappies. Just ensure that all used bags are double-wrapped and well-sealed in plastic.

So what does Michael do now that Hereford council had discontinued the clinical waste collection?

He mainly uses flushable bags. These have an inner lining which contains the waste and can be flushed down the toilet. Then all that needs to go in a disposal bag and into the household refuse is the clean outer cover and the swabs he has used to clean around his stoma.

All this just goes to show that there is more than one answer to dealing with the problem of disposing of used pouches. We all select the option that is most suitable for us and our lifestyle. However, I think most ostomates would agree that the best solution will be when there is more than just one make of pouch with a flushable liner and all ostomates are able to dispose of their bodily waste down the toilet like everyone else.

This article is based on the feedback about disposal we have received from Tidings readers, so we hope you too will write in with your comments.

**Rosemary Brierley**

## Disposal of used ostomy appliances

### The options:

- Use the Clinical Waste Collection Service, if this is available in your area.
- Double wrap used bags and dispose of them with the normal household waste.
- Use a flushable bag which has an inner liner that contains the waste and can be flushed down the toilet.

# Dear Nurse

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



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

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

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

*Q: I'm going on holiday at the end of July and will be travelling by coach. It will be a long journey with no toilet or disposal facilities on board, there will be comfort stops but I am worried about my stoma as it is very regular and works everyday – I don't want to have any accidents. I wonder if you could tell me if there is anything I can do to adapt my diet a few days before I am due to leave to avoid any problems. Many thanks.*

**A:** I would not suggest you alter your diet as if the stoma is regular then you should find that the pouch will be perfectly fine during your journey. I would advise that you change the pouch just before you are due to board the coach and ensure that you have equipment with you. Don't pack it all in your suitcase keep some with you in your hand luggage so it is easily accessible. You don't specify what sort of pouch you use but it may be useful to use a drainable pouch when you are travelling. Enjoy your holiday.

*Q: I had my stoma about eight months ago, I'm coping quite well although I have some challenging times. I really want to get my fitness back and wondered whether I can start some exercises or go swimming. I also wanted to know a little more about a product called 'a plug' and how it's used. I look forward to hearing from you.*

**A:** A Conseal Plug can only be used for end colostomies and the output needs to be semi to formed stool. It can be used on a daily basis with the idea that the 'plug' remains in situ in the stoma for up to 12 hours and then you wear a pouch for the remaining 12 hours of the 24 hour period. Most people wear the 'plug' during the day and a pouch at night. If you wish to be

assessed to see if it is a suitable option for you and then to learn how to use it, you need to gradually increase the length of time you wear the plug for over a few weeks, you will need to be referred to your local Stoma Care Nurse who will arrange everything. With regard to exercise and swimming there is no reason why you cannot gradually start to do these types of exercises. I would suggest that if you go to a gym or exercise classes then you speak to the trainer to explain that you have had surgery on your abdomen and they will advise with regards to suitable programmes. Good luck.

*Q: I am going to have a colonoscopy and I am concerned about whether it will cause any internal damage. Can you please advise and put my mind at rest.*

**A:** Colonoscopies are a routine test for examining the inside of the colon (Bowel) and are performed by qualified doctors or nurse with extra training to undertake these procedures and have a lot of experience in performing them. You will probably need to take some bowel cleansing medication prior to the procedure if they are planning to perform the colonoscopy via the colostomy and if so it would be best to use a drainable pouch. When you arrive they will explain the complete procedure and any potential problems that you may experience afterwards. You will then be offered some sedation or entonox (gas and air) to help you to relax during the procedure and you will be supported all the way through by the staff within the department. Once the procedure is completed you will be given some time to recover before someone comes to speak to you to give further advice prior to discharge. If you are still concerned it may be worth contacting the department where it is going to be performed and they can reassure you and provide further information as needed.

*Q: I have had a stoma since 2004 following an AP resection to cure my bowel cancer. I manage it by irrigating daily, which is generally fine. The only issue I have is the choice between odour or noise in terms of the appliance I wear. If I wear a plug any flatulence manifests itself as a smell. However if I use a midi pouch any flatulence is expressed as noise... Is there anything on the market that would cover both problems, i.e. a pouch with a built in plug or a plug, which successfully contains the smell? I would be grateful for any suggestions you could make.*

**A:** There are many different products on the market which may benefit you but it is a matter of trying several until you

find the one which best suits you as an individual. A review by your local Stoma Care Nurse would be useful. You can discuss your concerns and she can show you different products, which you can then choose to try. An assessment of your diet may also be useful if you have a lot of flatulence and noise from the stoma. Also some people find that the use of 'peppermint', either as a tea or a cordial; 'fennel' as a vegetable, mints or a tea or 'charcoal' as a tablet or a biscuit (available from health food shops) helps to reduce the amount of flatus produced and therefore reduces noise and odour.

**Q:** *I had my non-reversible colostomy in April 2003 because of bowel cancer. Since then I have coped well but I have had many messy accidents. I have been back to the doctors a few times, because I was concerned about stomach cramps pain and diarrhoea. I was told when I had my operation they saw that I had diverticulitis disease. I asked why wasn't I told. They said my cancer was more of a concern to them at the time. The cramps and diarrhoea has worsened. I asked the doctor is there anything you can give me. She gave me colofac which I find hasn't helped. My concern is – will it get worse and what will I do then. My stoma nurse is 12 miles away in Bath and I can't drive. Also I am 83 years old.*

**A:** I would certainly re-visit your GP and explain that the medication she has prescribed has not helped and that your symptoms have worsened. There are different types of medication that the GP could try or they could refer you to the local hospital to see the Gastroenterologist if that is deemed to be necessary. Diet can also help with diverticular disease and the GP should be able to give you a leaflet or refer you to a dietician.

**Q:** *I have only just had my colostomy. My skin is sore and my bag feels very uncomfortable. My daughter measured my stoma at a particular size but my nurse has cut the flange smaller. I take the bag off when possible during the day, as I feel cleaner without it. Please can you tell me if there is a correct method for measuring the stoma?*

**A:** Obviously without reviewing the stoma in person I cannot say if the template is the correct size for your stoma but if it has been measured by the Stoma Care Nurse I would imagine it is correctly cut. You can check the size with the template guide/cut outs (provided in boxes of pouches) to find the one which fits snugly around the

stoma without sitting on the bowel. However many stomas are not round in shape and these template guides/cut outs are only set sizes. The pouch should be cut so that there is approximately 1mm of skin all around the stoma to ensure that the skin does not get sore. I would not suggest leaving the pouch off during the day as you cannot control the stoma output and if this gets onto the skin then this could be the cause of the soreness. A further review by the Stoma Care Nurse should be able to clarify the potential cause and advise with regard to treatment.

**Q:** *I have been suffering from incontinence for sometime now. I had an anal repair two years ago but now need a stoma. I feel I need to prepare for this operation. Can you advise me as to what I can expect next.*

**A:** It is usual that when the surgeon decides to fashion a stoma they refer to the Stoma Care Nurse for pre operative counselling. At this appointment the stoma care nurse will discuss all aspects of stoma formation including diet, exercise, lifestyle, products, help available and all aspects of care. You will be shown the products used and how to use them and all your questions can be answered. If you have certain things you want to discuss it may be worth writing the questions down and taking them with you so that you remember to ask all the questions and that you do not forget anything. You will be provided with written information and may even be taught how to change the stoma appliance and given information to take home on how to do this. You may also get the opportunity to talk to previous patients who will provide a wealth of advice and support. I hope this helps.

**Q:** *The diameter of my stoma opening is quite large approx. 70mm. I have had granulomas and suffer with leakage. Can you advise me as to whether there are any specialist stoma bags available to accommodate a larger stoma opening like mine?*

**A:** There are many different types of pouches, which could help with a larger stoma, as well as accessory products, which may help. I would suggest a review from your local Stoma Care Nurse who will be able to advise and provide or arrange samples of different products, which may be of use. You can then try them and decide on which suit you best. Marlen Healthcare is one supplier.

### 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



# Focus on Stoma Care Nurse Training... Education, Education, Education

The **Salts Healthcare Nursing Academy** is now fully operational and since it opened after Christmas 2013, has had over 60 nurses attend courses. Based in central Birmingham with easy access to the motorway and rail network, the centre consists of a large conference room with the latest audio visual equipment able to accommodate over 100 people, a rest and break out area and two syndicate rooms for the training of nursing professionals in Stoma Care by lecturers from De Montfort University Leicester, supported by Salts Healthcare's senior Stoma Care Nurses.

It is one of the only centres in the UK that teaches the 'Principles of Stoma Care' up to Honours Degree standard and from the end of this year up to Masters Degree level.

Recently, across the UK Stoma Care nursing educational courses have stopped and so Salts Healthcare, a family-owned company founded in 1701 and currently run by the tenth-generation of the Salts family made a strategic decision to invest in the Academy after realising there was a lack of provision for Stoma Care Nurse education. Peter Salt, Salts Healthcare Managing Director said: 'Stoma Care is our industry and we are duty and morally bound to be at the top of our game. Our nurses have to be the best and we realised that together with educational partners we could fill a gap for the betterment of all professionals and providers.'

Salts Healthcare is now not just an innovative designer and manufacturer of world-class products, but through this educational initiative becomes a groundbreaking provider of stoma care education through its association with De Montfort University in Leicester.

Kate Howlett, Salts Nursing Manager supported by Jo Haines, Salts Nursing Manager and Jean Ross, Salts Community Stoma Care Nurse, is responsible for the learning content at the centre and is extremely proud of what is now available. She said: 'There



**Salts Healthcare** – innovative designer and manufacturer of world-class products now groundbreaking providers of stoma care education through its association with De Montfort University, Leicester

are no regular courses in stoma care and so nurses wanting to specialise have to rely on their experience rather than any specific qualifications. We are filling that gap and our courses are validated by De Montfort University, indeed this is the first off-site facility for them, showing how much they think it's a great idea and how successful they hope it will be.'

Kate and Jean work with Penny Harrison from De Montfort University to co-ordinate and deliver the courses, which contribute 30 credits towards nursing degrees – the highest amount that can be awarded. They hope to deliver at least two courses per year to 16 people and there is already a waiting list.

When the Academy isn't being used to teach nurses about Stoma Care, it's a training hub for Salts employees to ensure their teams are up to date with the latest developments in the industry. Training and professional qualifications are paramount according to Jean Ross, Salts Community Stoma Care Nurse. 'Every industry, not just Stoma Care nursing methods are constantly changing

and thankfully improving due to innovations in technology and surgical procedures.

As an industry we must understand the changing nature of our work to ensure we deliver the best possible service for patients. Also the service providers and their needs are constantly changing so as nurses we must be able to deliver the best possible provision in any situation. I also think patients are demanding more and quite rightly so. We must manage and deliver their needs and wants.'

The Academy is also being used by patient ostomy groups including the BreakAway Foundation for member Information Days and meetings. The facilities are provided free of charge by Salts.



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**SALTS**  
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# Readers' writes

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

## Dear Editor

Many thanks for sending me the quarterly 'Tidings' magazine. Recently, I needed information regarding my colostomy and (as I keep all the mags) I browsed through them all, sent for numerous free samples, from various firms, and received lots of helpful additions for use with my closed bags. I was not satisfied with the help I was getting from my supply/delivery company, so I contacted 'Fittleworth' regarding their delivery service. They were outstanding, a pleasant helpful receptionist greeted me, excellent customer service, careful assistance, timely delivery and extra products to try. What a difference from the service I've had for 25 years from my previous supplier. Thanks to your magazine for all the helpful adverts from firms offering samples and delivery support.

Yours faithfully,  
M.M (Mrs)

## Dear Editor

I am a colostomate and have tried very recently to apply for a renewal of my disabled badge. On telephoning the office for an appointment I was asked if I would answer a few questions, which I agreed to. The first question was could I walk the length of a football pitch. After a little consideration I said Yes, I could. And was immediately told I did not qualify due to the fact that the Welsh Government have instructed that anyone who can walk that distance does not qualify and colostomy is no longer classed as a disability. I think that this is totally wrong. Colostomates need facilities such as disabled toilets to carry out a pouch change and disposable bins etc. To me this is totally wrong and is discrimination, which should not be allowed. I would be most grateful if you could throw your weight, or offer any advice to me

on this matter. I am a senior citizen of 87 years who likes to get out and about, but now I feel somewhat restricted by this ruling.

Yours faithfully,  
S.E.H

**From Ed:** I understand your frustration but being a colostomate is not considered a 'disability' – so they are correct in what they are saying. To qualify for a blue badge a successful application MUST be on the basis of limited mobility i.e. a person must be unable to walk or have very considerable difficulty in walking. For more information obtain the leaflet entitled 'Can I get a Blue Badge?' which is available from the Department of Transport by phoning: 0300 123 1102 or visit their website at: [www.mobility-unit.dft.gov.uk](http://www.mobility-unit.dft.gov.uk).

In relation to disabled toilets – all ostomates are entitled to a key which will open approximately 9,000 locked toilets around the UK under the Disabled Toilets National Key Scheme. Some local councils will provide this key free or for a small charge. Keys can also be obtained from CA at a cost of £3.50 see the application form on Page 8.

The Welsh Government – The Minister with responsibility for Transport, Carl Sargeant, has laid the Regulations that will extend the eligibility criteria for Blue Badges.

These changes will mean that automatic entitlement for a Blue Badge will now be linked to the new Personal Independence Payments (PIP) that will replace Disability Living Allowance (DLA) for people of working age, 16 to 64.

These changes to the Blue Badge scheme in Wales will reflect changes in the UK welfare benefits system.

The Welsh Government is extending automatic eligibility for a Blue Badge to people who can stand and then move but no more than 50 metres and to those who cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. This includes people with sensory impairments and those with cognitive impairments.

Work is also underway to explore how local authorities can identify those people who face the same difficulties in travelling, but are not automatically eligible for a Blue Badge, as they are not of working age and cannot apply for PIP. This is a complex area that needs further research.

The Welsh Government  
Contact Tel: 0300 0603300

<http://wales.gov.uk/newsroom/transport/2013/130304-blue-badge-regs/?lang=en>

I do hope you find this information helpful please write and let me know if I can be of any of further assistance.

## Dear Editor

I was a hospital social worker in the 1980's when a 'colostomy bag' was considered dreadful news. In 1985 I was diagnosed with advanced cancer of the colon, and the fear of a colostomy was almost my major concern. However it was not necessary. Move on 28 years to February 2013. I had felt unwell for a few days when suddenly I had a raging temperature and constant vomiting and severe stomach pains. I was rushed into hospital where they eventually found that I had adhesions from the cancer op. They had stuck my lower bowel to my spine and pelvic





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# Readers' writes

floor and the small bowel had something like a strangulated herniation. Urgent surgery followed and a colostomy was not thought likely. When I was awake in CCU the nurse asked how long I had had my colostomy. I was horrified and said he had just told me my worst nightmare. I hated the whole business of a colostomy and wanted to be free of it. A reversal was a possibility but it could create new problems and no guarantee of success.

However, luckily I had joined your Association where I read a letter about flushable bags and irrigation. Amazingly I am no longer concerned about carrying around a bag of poo when visiting friends and now spend nights away from home. Basically I lead a normal life. My great concern is that the hospital stoma care nurses never spoke of any alternatives (to the usual bags) which they must have known about. In my experience they sign you up while in hospital to a product and delivery company but do not mention any alternative types of product from other companies.

So without your magazine I would still be continuously struggling with a bag of poo and how to deal with it whilst lunching at a friend's house.

I cannot thank you enough and Welland and the people who took the trouble to talk about their flushable bag experiences within the pages of Tidings. With true appreciation.

A.R

## Dear Editor

Twenty years into having my colostomy, one would hope that I would have no problem with the supply of various ostomy products? Why then am I now sitting here, anxiously counting my few remaining pouches wondering if I will have enough to last until my next delivery? Let me explain. Up until a few weeks

ago my method of ordering was simplicity itself. I would phone my delivery company, dictate my order and suggest a delivery date when I would be in to receive the parcel. This would be within two or three days of phoning and they never, ever, were late (but on one or two occasions a disconcerting but welcome day early). Meanwhile, while they were putting my order together and sending it, I would contact the GP's surgery and ask for the prescription for that order. As soon as I could, the prescription was collected by me and posted to my delivery company and thus the whole transaction was completed within three or four days!

But NOT anymore! A few weeks ago my delivery company phoned me, apologetically, to tell me this system was no longer being allowed by the NHS. They can no longer start dispensing until my prescription is in their hands. 'It will mean you will need to order your prescription a couple of days earlier'. 'More like a couple of weeks!' The prescription has to be ordered during the week, no weekend surgery here! Inevitably this means the prescription will probably land at my delivery company just prior to the weekend. They do not process prescriptions at the weekend! So, more delays. It seems the prescriptions can take a couple of days to shuffle from their post box to a desk...which then have to be sent to 'Despatch'. (The bottleneck is growing!) Eventually, they will send the order...via the courier, who may, if we are not in, take it back, or they may leave it with next door....who go to bed around 6pm, working odd shifts.

Now just WHY did the NHS have to change the regulations? The system wasn't bust so why fix it? We had such a simple, efficient, verbal system that ran to my knowledge like clockwork for minimally 20 years and now we have a system that is full of delays, full of uncertainties and incredibly wasteful on the patient's time. Without the certainty of a delivery date, it means we have to wait in two, three or more days on the off-chance that maybe everything has come together and we can take

delivery of our very necessary items.

Now, my voice, loud and persuasive though it might be, is just a little voice in the wilderness, easily ignored. I simply do not accept that 'it's got to be like this...' For my part I am more than happy to supply 'a patient's perspective' if it will help to influence a return to 'sensible times' once more.

Yours sincerely,

A.B

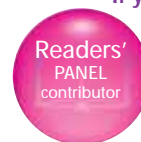
**From Ed:** Thank you A. B. for your letter. The CA advises the following:- Always allow up to three weeks from placing the order with a Supply Company until it is delivered to your home. The Editor would like to hear from you so please write in with your experiences.

**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](mailto:editor@colostomyassociation.org.uk)

or write to:  
**The Editor**  
**Colostomy Association**  
**Enterprise House**  
**95 London Street**  
**Reading RG1 4QA**

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

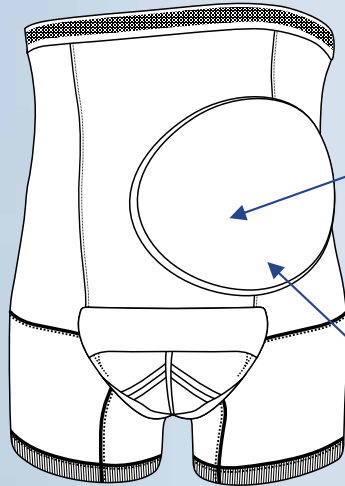


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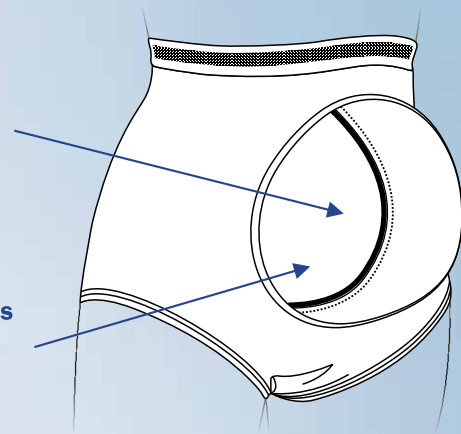
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- UA Urostomy Association  
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www.urostomyassociation.org.uk
- IOA International Ostomy Association  
www.ostomyinternational.org
- Stomadata & Stomafr  
www.stomadata.com  
www.stoma.fr
- Macmillan 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 (B&BF)  
Formerly Incontact and Continence Foundation  
General enquiries: 01536 533255  
Web: www.bladderandbowelfoundation.org
- Bowel Cancer UK  
Tel: 020 7381 9711  
Email: admin@bowelcanceruk.org.uk  
Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK  
Tel: 08450 719300 (Lo Call rate)  
Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)  
(The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)  
Web: www.glo-uoa.org
- Ostomy Lifestyle  
Tel: 0118 324 0069  
Email: admin@ostomylifestyle.org  
Web: www.ostomylifestyle.org

## Stoma Care Patient Open Day event dates...

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

Listings are updated throughout year.

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

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

# SASH

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## Ladies Big Op Group...

The meetings are for ladies who have had a pelvic exenteration and require one or two permanent stomas.

The group meets on the **2nd Tuesday of every month** at the **Maggie's Centre**, The Lodge, College Baths Road, Cheltenham GL53 7QB

**Time:** 10.30am – 12.00 Noon

**Next meetings:-**

• May 13th • June 10th

To **book** please contact:

**Sam Richardson** at Maggie's  
email: [Samantha.Richards@maggiescentres.org](mailto:Samantha.Richards@maggiescentres.org)

**Gill Hopkins** Stoma Care CNS Direct line office 03004 224363 Stoma Care Office, Cheltenham General Hospital

Meetings are supported by **Gill Hopkins Stoma Care CNS, Gynaecological Nurse Specialist and Cancer Support Specialist from Maggie's.**

There is also access to a dietician, benefits advisor and physiologist should attendees require any extra help.

## POUCH COVERS

Designed by Ursula Naish

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

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



**For further information please contact:**

**Ursula Naish, 9 Oast Meadow, Willesborough, Ashford, Kent TN24 0AS**  
Tel: 01233 640 863 Email: [ursulanaish620@btinternet.com](mailto:ursulanaish620@btinternet.com)



Made by an Ostomate  
for Ostomates

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Thank you for your support

## Regular donation

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

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

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

**My Details:** Title: \_\_\_\_\_ Name: \_\_\_\_\_ Surname: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Postcode: \_\_\_\_\_  
 Telephone (home): \_\_\_\_\_ Mobile: \_\_\_\_\_  
 Email: \_\_\_\_\_

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

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

To the Manager: (Bank or Building Society)

Bank Address: \_\_\_\_\_ Postcode: \_\_\_\_\_

Name(s) of Account holder(s): \_\_\_\_\_

Account number: \_\_\_\_\_ Sort code: \_\_\_\_\_

I would like to make a **regular donation\*** of  £15  £20  £25  £50 or other amount (please state) £ monthly  quarterly  annually starting on the  1st  15th  25th of month: \_\_\_\_\_ year: \_\_\_\_\_

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

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

Please pay: **NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP**Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS) \_\_\_\_\_

Signature: \_\_\_\_\_ Date: / / 2014

giftaid it

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

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

Thank you for your gift

Signature: \_\_\_\_\_ Date: / / 2014

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

Stoma Type: (Please tick) Colostomy  Ileostomy  Urostomy 

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

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





## Single donation

### Thank you for your support

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

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

<p><b>Note:</b> Please ensure that we have your correct contact details: full name, address and postal code telephone number thank you</p>	My Details: Title: _____ Name: _____ Surname: _____	
	Address: _____	
	Postcode: _____	
	Telephone (home): _____	Mobile: _____
	Email: _____	
	Optional Information: Date of Birth: _____ Reason for your stoma: _____	

Stoma Type: (Please tick) Colostomy  Ileostomy  Urostomy

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

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

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

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

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

Yes, I require a receipt  (Please tick.)

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

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

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

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

Signature: \_\_\_\_\_ Date: / / 2014

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



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



## Sussex: Colonaid

Colonaid is a self-help support group for Bowel Cancer patients, supporters and families who have attended Worthing Hospital. It was started in 2008 by a group of ex-patients and staff from the Colorectal Department at Worthing Hospital. The group offers support, advice and raises awareness of Bowel Cancer. Members meet at 11.30am on the first Tuesday of each month at the John Selden Public House, Salvington on the outskirts of Worthing. After the meeting most members retire to the bar for a sandwich and drink.

Several of our members are volunteers at Albion in the Community part of the Brighton & Hove Albion Football club. It promotes awareness of Cancer in the community by bringing Cancer symptoms to the attention of the community, as early detection is very important for successful treatment. For more information visit the website [www.albionsbecanceraware.com](http://www.albionsbecanceraware.com) and Facebook page: [albionsbecanceraware](https://www.facebook.com/albionsbecanceraware).

Some members also take part in Worthing Hospital Cancer Patients Forum organised by a lead Macmillian nurse. The group meets regularly at the Hospital to improve the processes, care and awareness of Cancer patients entering the Hospital. One of the members has been Wing Walking and is about to do a Parachute jump to raise money for Cancer charities.



The group owns a smoothy bike, a normal bike fitted with a liquidiser operated by pedal power. The group uses the bike to promote exercise and healthy eating. We ask members of the public to ride the bike and offer small samples of the smoothy drinks of fresh fruit and fruit juice produced by the bike.

Finally, several members volunteer to attend various functions to give presentations/talks to raise awareness about Bowel Cancer.

New member quote: 'having attended a sociable, cheerful and fun meeting of Colonaid it gave me confidence and support to cope with the future'.

All together we are a very active group of people.

For more information about Colonaid visit the group's Facebook page: [Colonaid Worthing](https://www.facebook.com/colonaidworthing) or contact Andrew Fletcher via e-mail: [colonaidworthing@yahoo.co.uk](mailto:colonaidworthing@yahoo.co.uk).

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



**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...



### Scotland

- **Ayrshire:**  
Ayrshire and Arran Stoma Support  
Contact: Jim 01292 220945
  
- Stoma Care and Recovery (S.C.A.R)  
Contact: Maggie 01294 271060/  
0781 7736147/maggie13@sky.com  
Rhona 01294 557 478
  
- **Fife:**  
Fife Ostomy Support Group  
Contact: Ishbel Barr 01592 772 200
  
- **Glasgow:**  
Glasgow Stoma Support Group  
Contact: Maureen O'Donnel  
01236 436479
  
- **Midlothian:**  
Maggie's Edinburgh  
Contact: Maggie 0131 537 3131
  
- **Scottish Borders:**  
Stoma Support Group  
Contact: Nancy 01450  
374012/nancyfraser@talktalk.net  
Fiona 01450 371063/  
r.gentleman@sky.com
  
- **West Lothian:**  
GOSH  
Contact: Scott Pattison: 07502163644



### England – North

- **Cheshire:**  
Stockport Support Group  
Contact: Angela Simpson  
0161 320 9400/0800 652 6667
  
- 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
  
- **Cumbria:**  
Grange Cancer Support Group  
Contact: Marie 015395 33279
  
- **Lancashire:**  
Oldham Stoma Support  
Contact: June Wilde 0161  
312 5538
  
- Tameside Ostomistics  
Contact: Paul Seavers 0777  
1359046
  
- Trafford Bowel Care  
Contact: Jackie Carey (Secretary)  
0161 7489 659/Doreen 0161 9627  
818/John 0161 7484 655
  
- North Manchester and Bury  
Support Group  
Contact: Julie Meadows (SCN)  
0161 720 2815/07841206910
  
- **Merseyside:**  
I.C.U.P.S  
Contact: Stoma Care Nurse  
0151 604 7399
  
- **Northumberland:**  
Berwick Ostomy Support Group  
Contact: Bobbie Minshull 07714  
479320
  
- Hexham Ostomy Group  
Contact: Judith 0796 792 7286
  
- Northumberland Cancer Support  
Contact: members@northumberland  
cancersupportgroup.co.uk
  
- **Tyneside:**  
NHS Molineaux Walk-in Centre  
Contact: Lesley Brown 0191 282  
6308

## Royal Victoria Infirmary Support Group

Contact: Gordon Weatherburn  
0191 234 1109

### • Yorkshire:

Acorn Ostomy Support Group  
Michelle Hurrell on 07580693155  
(after 6pm).

Airedale Stoma Support Group  
Contact: Sue Hall 01535 210483

Barnsley-Bottoms Up  
Stoma Support Group  
Contact: Stoma Nurses 01226  
432528 or Celia Utley (Chairman)  
01226 284262

Behind You (Calderdale &  
Huddersfield Bowel Cancer Support  
Group)  
Contact: Stoma Care Nurse  
01484 355 062

Dales & Vale Ostomy  
Support Group  
Contact: Carol 01677988150/pcw-  
agw@tiscali.co.uk

Dewsbury & District Ostomy  
Contact: Janet/Eileen 0844 8118110

Leeds Bowel Cancer  
Support Group  
Contact: Lynda Castle (Colorectal  
Nurse) 01132065535

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  
Pete Rennard 07939518642/  
01482 793966/Rosanna Grimsby  
01482 801575

### • Isle of Man:

Stoma Support Group  
Contact: Carole Cringle (SCN)  
01624 650212



## England – Central

• **Buckinghamshire:**  
Milton Keynes Stoma Association  
Contact: Mrs Joanne Dixon 01908  
318262

• **Leicestershire:**  
Kirby Ostomy Support Group  
Colostomy, Ileostomy & Urostomy  
in Leicestershire  
Contact: Janet 0116 239  
2844/kosg2013@btinternet.com

• **Nottinghamshire:**  
Nottingham Colostomy, Ileostomy &  
Urostomy Support Group  
Contact: Rosemary Brierley  
0115 982 6691

Nottingham Stoma Support  
Contact: Jenny or Michaela 0115  
9627736/Mrs B Heath 0115 966  
3073

North Notts Stoma Support Group  
(Sutton-in-Ashfield)  
Contact: Tore and Nicky Norman  
01773 715460

• **Shropshire:**  
B.O.T.S (Bums on Tums)  
Contact: Irene Constable 01691  
238357

• **Staffordshire:**  
Outlook  
Contact: Moira Hammond 01782  
627551

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

• **East Midlands:**  
Newhall Stoma Support Group  
Contact: Diana Manning 01283  
541311 or Helena 07932 331850

• **West Midlands:**  
Coventry Stoma Support  
Contact: Martin Robbins  
07947 385 643

**Note:** Information about stoma support groups is regularly updated in Tidings magazine and on the Colostomy Association website.

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 support group the CA would be pleased to assist.

Contact the CA office:  
**0118 939 1537**

or E-mail: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)



## 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: Brian Waller (Secretary)  
01206 540449

Optimistic Ostomates  
Contact: Angela Taylor/Carol Booth  
01702 385509 or 01702 385510

STEPS  
Contact: Jackie Coleman

## SUPPORT GROUPS IN YOUR REGION

01268 451937

### Redbridge Ostomists Club

Contact: Stoma Nurses: Chris/Lisa  
020 8970 8321

### • Hertfordshire:

#### Colonise

Contact: Anastasia  
01727 760 981

#### Hertford Stoma Support Group

Contact: Ralda 01992 535311

#### Stevenage Ostomistics

Contact: Alfred Levy 01767 316958/  
Judy Colston 01438 354018

### • 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 (SCN) 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:

#### 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: 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 769679/07827997424

#### Dover & District Stoma Support

Contact: Maria Culleton (SCN)  
01227 769679

#### Dover Stoma Friends Group Support

Contact: Julie Bell & Ros Marshall  
07771345701/01304822696

#### Maidstone Stoma Support Group

Contact: Judy or Kirsty  
01622 224305

#### Medway Ostomy Group Support (MOGS)

Contact: Helen or Tracey  
07773 605534

#### Thanet Stoma Buddies Support Group

Contact: Phil (Secretary)  
01843 587769

### • London:

#### Homerton Hospital Bowel & Stoma Support Group

Contact: Angela Davy 0208 510 5318

#### South Woodford Support Group

Contact: Christina 0208 5356563

#### Surrey & South London Bowel Cancer Support Group

Contact: Sue Berry: 01737 553134 or  
John Amos: 0208 668 0796

### • Middlesex:

#### Inside Out

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

#### Semi-Colon Club

Contact: Pat Black/Katheryn Foskett  
01895 279391

### • Oxfordshire:

#### Oxfordshire Ostomy Fellowship

Contact: Pat Longworth  
01235 524163

### • Surrey:

#### Epsom & District Stoma Support Group

Contact: Lindsay, Trevor or Sheena  
01372 735925

### • Sussex:

#### Colonaid

#### Colorectal Dept at Worthing Hospital

Contact: Andrew Fletcher e-mail:  
colonaidworthing@yahoo.co.uk

#### (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: Rob 01179 668021/Janet  
01934 248114
  - **Cornwall:**  
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
  - **Dorset:**  
CUPID Colostomy, Urostomy, Pouch, &  
Ileostomy of Dorset  
Contact: Beryl Andrews  
01202 483303

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

- **Wiltshire:**  
Swindon IA  
www.swindon-ia.org.uk

Wessex Stoma Support Group  
Contact: Michael Slater 01722  
741233



## Wales

- **Gwent:**  
Blaenau Gwent Self Help  
Contact: Celia McKelvie  
01873 852672

- **Bridgend:**  
Bridgend Ostomy Patients  
Support Group  
Contact: Anita Brankley (Secretary)  
01656 645602 or Pat Jones 01656  
786103

- **Newport:**  
COSG (Cwmbran Ostomy Support  
Group) Contact: Pippa Lewis 01633  
791 339/07504713069

- **Mid Glamorgan:**  
Royal Glamorgan Stoma Care  
Support Group  
Contact: Domenica Lear  
01443 443053

- **Swansea:**  
Swansea Ostomy Self Help Group  
Contact: Glynis Jenkins 01792  
418245



## Northern Ireland

- **County Antrim:**  
Antrim Area Stoma  
Support Group  
Contact: Chris Wright  
07720 717771

Mater Infirmorum Hospital – Belfast  
Contact: Karen Boyd  
028 90741211 Ext 2329

Royal Victoria Hospital – Belfast  
Contact: Sarah Haughey/  
Audrey Steele 02890 240503  
Ext 3483

- **County Armagh:**  
Craigavon Community Hospital  
Contact: Mary Jo/Bernie  
028 38612721

- **County Down:**  
Daisy Hill Hospital – Newry  
Contact: Bernie Trainor  
028 3883500 Ext 2222

North Down Stoma  
Support Group  
Contact: Adrian Ewing 07850 741511

Ulster Hospital  
Contact: Hazel/Martina  
028 90 550498

- **County Londonderry & Derry City:**  
Causeway Patient  
Support Group  
Contact: Mary Kane 028 70 346264



## The Channel Islands

- **Guernsey:**  
Guernsey Ostomates  
Contact: Luci Deane 01481 236077/  
lucideane58@gmail.com



## Eire

- **Bowel Cancer Support Group  
(Irish Cancer Society)**  
National Cancer Helpline  
Freefone: (00 353)1 800 200 700  
Contact: Olwyn Ryan  
(00 353) 1 231 0500

- **Mayo Stoma Support  
(Castle Bar Hospital)**  
Contact: Marion Martyn  
094 902 1733

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