

# Tidings

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

## Cover story

- Get well and be positive

## Inside

- Moving On
- The Colostomy Association's 10th Anniversary
- Colostomy Reversal
- And all our regular features

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## COVER PICTURE

Davina Jowett

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# dear READERS

**With the Colostomy Association anniversary celebrations just a few months away, our theme in this issue is moving on. The first ten years has seen the association reach out to support more ostomates and move into larger premises. In the next decade, as well as building on what we have already achieved, we plan to raise awareness about stomas within the general public, and remove the taboo about poo.**

Our cover illustrates how times are changing. Davina Jowett, who is to be one of our models at the fashion show at the **Colostomy Association** celebrations in Reading, has already appeared in a national magazine and has helped to dispel negative images about having a stoma. Now Davina tells us her story and is very honest about how she feels about having a colostomy and how it has affected her life. She was diagnosed with bowel cancer at 28 which shows cancer is not confined to the older age group. As April is *Bowel Cancer Awareness Month*, we also include Keith Askew's "Cautionary Tale" of how his symptoms too went undiagnosed. To beat bowel cancer we all have the duty to make family and friends aware of the symptoms, and encourage them to take part in the bowel screening programme.

For some moving on may be a reversal. At head office we receive quite a number of telephone calls, e-mails and letters from ex-ostomates saying thank you for the support they have received but now they have had a reversal they no longer need our magazine. We are also contacted by ostomates trying to decide whether or not to go ahead with a reversal. This issue we have articles on this topic from the point of view of a specialist stoma care nurse, Caroline Rudoni, and a consultant surgeon, our president, Ian Daniels. We would also like to thank all those readers who wrote in

with their experiences of reversal and we include Catherine Sommer's account of how she felt both before and after her reversal as well as quotes from other e-mails we received.

These experiences show that for some the path to recovery is not always smooth and in some cases a reversal is not possible because of underlying medical conditions or the amount of bowel that was removed when a stoma was formed. This was the case for Pauline. Her reversal was unsuccessful. So instead, she moved on to managing her colostomy by irrigation and says that since then she sometimes forgets she has a stoma. Noreen also began to irrigate last summer. In this issue she tells us how she is getting on six months later.

Thank you for all your letters and e-mails; please keep them coming so we can raise the issues which concern you on the *Readers' Writes* page. If you have a query about stoma care, do write to us so we can pass your question on to Julie Rust and we can share her answer on the *Dear Nurse* page. The closed CA Facebook group now has a membership of over 3,000 and a team of six fully trained admin volunteers. If you haven't already done so, now might be the time to join this safe, friendly group.

To mark the **Colostomy Association** 10th Anniversary we have a **Tidings Supplement**, eight-page pull out in the centre pages. It outlines the programme for this year's celebrations. We do hope you will be able to join us for the Open Day and Fundraising Gala Dinner on Saturday 11th and Fashion Show on 12th July. Places are going fast.

**Rosemary Brierley**  
on behalf of **The Tidings Editorial Team**

Email:  
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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:  
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2

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all your regulars & special features

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# A Week in the Life of "El Presidente"

From our President  
Mr Ian Daniels, Consultant Colorectal & General Surgeon



**Monday:** the First Lady felt I needed to change foreign policy. Flying in, operating at dawn, and then home for tea and crumpets seemed ideal to me. However, she felt I ought to see some beaches, so evoking the Normandy spirit I obeyed instructions... there is a higher authority than being President!

**Tuesday:** Boarded the plane at Exeter and we're off... unusual experience this, no computer, no talk to write, no papers to read. First Lady gave me a book, so 1990's. Now where is my iDevice? What you haven't packed it! Almost a diplomatic incident! Plane ride boring. No deadlines tomorrow.

**Wednesday:** After an inland recon mission: an Ottoman fort, tails of British (and ANZAC) bravery, I returned to the beach. First Lady attempts impression of Halle Berry. I'm feeling very James Bond in my swimmers! Boat patrolling off-shore looks like a naval vessel. First-Lady informs me it's Green Peace looking to re-float me should I get beached!

**Thursday:** Bored with the beach. It's too hot, sand everywhere, and lots of people lying about doing nothing. Anyhow, decided to put my skills to use and spot the pathology. An hour later I've seen cardiac surgery scars, nephrectomy scars, lots of hernias, laparotomy scars, lots of dodgy swimwear... but not a single stoma. Then out of the blue I see a bottom, but this one is different – only a thin piece of string disappears between the cheeks. Surely someone with no bottom, therefore no need for material to cover it. I feel a breakthrough of enormous social proportions... only for her to turn to reveal equally small string at the front, but no stoma! Now traumatised by the fact that people will show almost everything, and often too much covered by too little, I retire for a G&T to reflect on the fact human nature will show too much... but is embarrassed by a bottom on the tum.

**Friday:** Still no stomas.

**Saturday:** There is only so long you can feel like a deep fried haddock, all oiled up and

cooking, so went for a forage into town. Casually walking along there he was in front of me... a Danish chap with a stoma bag. We talked about the fact that he had been operated on by a mate in Aarhus, Denmark, and how he did not feel out of place with his stoma bag on view. Indeed all those around him seemed not to care.

**Sunday:** Back to Blighty, the grounds of the Cream House needed tending, so a day of reflection on a change in foreign policy... for a week at least. Yet to tell the First Lady that I'm making a quick raid on the Spanish Coast next week to talk about hernias...

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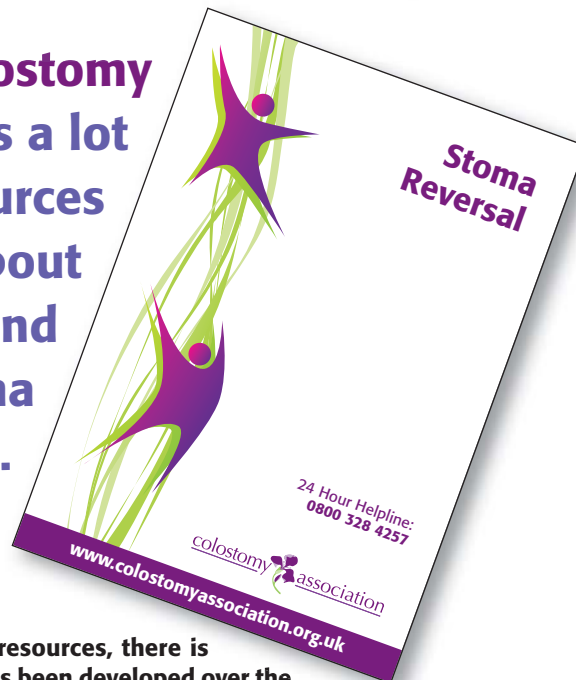
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# Literature

The Colostomy Association has a lot of resources available about colostomies and stoma management.



In addition to DVD and website resources, there is available a lot of literature that has been developed over the years to help people understand and better manage their stoma.

A number of booklets are available to help you; these are added to and updated on a regular basis and can be ordered from our website. From the **Quick links:** drop-down menu of our website, select **Literature and FactSheets**, as show at the bottom of the page, to view the literature available.

Whilst most of the literature is free, large quantities and shipping overseas may be charged for.

Below is the current list of literature available at the time of going to press:

## Factsheets:

These are normally extracts from previous editions of *Tidings*, where the subject matter has been covered in sufficient detail.

The article can be used to provide ample information about stoma management and care.

As with the literature, the Factsheets are constantly updated and added to. A current list of the factsheets can be found on the **Colostomy Association** website where they can either be downloaded or ordered.

The website address appears at the bottom of this page; below is a list of Factsheets at the time of going to press:

- Adhesive removers
- Bed protection
- Deodorants
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- Obtaining prescriptions
- Pancaking
- Pouch/Bag covers
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- Solidifying agents
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- Stoma product suppliers
- Support garments
- Swimwear
- Travel insurance
- Trousers
- Underwear
- Wind/Ballooning/Odour
- Websites for young colostomates

## Title

- Living with a Colostomy
- How will a Colostomy affect me?
- About Stoma Reversal
- Travel Advice
- An Introduction to Irrigation
- Healthy Eating
- Parastomal Hernia
- Colonoscopy through the stoma
- Pain and Discomfort in the Rectum and Perineum
- Caring for Colostomates
- About Rectal Discharge
- Travel Certificate
- Sam has a stoma (Story/Colouring Book)

To order or download any of the above literature or Factsheets, visit our website at:

**www.colostomyassociation.org.uk**

## Quick links:

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- New Products & Services
- Colostomy Association Events
- Open Days
- Read My Story
- Young Ostomates
- Regional Support Groups
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- Literature and FactSheets
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# a CAUTIONARY TALE!!

Looking back I should have done something about it months before. But, as you know, us men think we are invincible and don't like to bother the doctor, especially if it involves toilet habits.



**Ten years ago at the age of 55 my wife, Dorothy, and I decided to start a new life in south west France. We sold our house in the UK, bought a renovation project in a small village near Limoges and rented a cottage nearby.**

Over the next 12 months we spent a lot of time travelling to and from the UK to supervise the renovations and to carry out certain repairs ourselves. It was during this period that I noticed a change in my bowel habits. I found I had to visit the loo with some urgency most days and occasionally there was some blood present which I put down to a possible fissure caused by the regular visits to the loo.

In 2006 I also started to suffer abdominal cramps after food but they were irregular to begin with.

My wife told me to get treatment but I ignored her and in June that year my sister, who is a nurse, badgered me into seeing a doctor. After a chat, with no physical

examination of any kind, the doctor said I was probably suffering from Irritable Bowel Syndrome (IBS). I was prescribed antispasmodic drugs and told that if there was no improvement in two weeks to see him again. There did seem to be some improvement and I now had it in my mind that I had IBS. Nothing more serious ever entered my head and so I didn't go back to the doctors. I read about IBS and decided to change my diet in an effort to identify what was irritating my bowel.

We moved to France permanently in September and at first everything seemed to be fine, but soon the spasms returned and the visits to the loo became more frequent until February the following year when I passed a lot of blood and was in considerable discomfort.

I went to see our local French doctor and after a full examination he said that IBS was unlikely to be the problem and arranged for me to have a colonoscopy at the local hospital.

Unfortunately, at the same time our 31 year old daughter in law was diagnosed with cervical cancer, therefore we travelled back to the UK regularly to support the family and help where we could while she was undergoing treatment.

I delayed my colonoscopy for several weeks until June when I had the examination in our local French hospital. It was performed under general anaesthetic, which is typical in France, and almost as soon as I had recovered the oncologist told me that he had found two large polyps which could not be removed during the procedure because of their location and size, and that they were almost certainly cancerous. Surgery was the only option. As you can imagine this outcome was a shock and a lot to take in. I never thought for one moment that I could have cancer.

As we were living in France I decided to have the surgery there. After all they had a good reputation. I was told that the operation would take about four hours and that I would be allowed home after two weeks. Well, that was the plan.

However, after the operation I developed peritonitis. I was then taken back to theatre for a second laparotomy and when I came to I had an ileostomy. I had never been told that I may have to have a bag and it was difficult to come to terms with it. Over the next few days my condition didn't improve and I started bleeding from the rectum. They decided to operate again, and so to laparotomy number 3. This time when I came to the young surgeon, who undoubtedly saved my life, told me that about 60% of my colon was now missing and that I had a colostomy, as well as an ileostomy. I began to improve after that but still had setbacks as a fistula had formed and the drainage from the wounds was not working properly.

After six weeks in the intensive care unit the surgeon could see that I was becoming depressed and emotional so agreed to allow me to go home to recover. Fortunately the district nurse for our village was excellent and visited me every evening for weeks after and eventually the stitches and drain tube were removed. As I had been fed a high calorie feed intravenously in hospital I had to learn to eat again.

Three months later I was admitted to the same hospital for an operation to remove the ileostomy and activate the colostomy: laparotomy number 4. To say I was apprehensive is an understatement, but all went well and I was allowed home after just six days. Then began two years of recovery. I had a final colonoscopy in July 2011 and was told that it was clear.

Unfortunately we had to sell our lovely touring motorbike as I couldn't sit comfortably for long journeys and didn't have the strength to manoeuvre it at slow speeds. Over the next couple of years we spent more and more time in the UK and in 2011 decided to return full time.

In October 2012, my doctor in the UK decided to carry out his own tests and sent me for a CT scan. Imagine my amazement and horror when I was told there was something suspicious in the bowel again. This was followed up by a colonoscopy and I could see for myself a large tumour in the colon which must have been there for some time. It was stage 3 advanced. I had more surgery to remove the tumour, more of what was left of my colon and some small intestine. As I had a hernia above the site of the tumour, the surgeon went in at that point and repaired the hernia at the same time.

Three of the lymph nodes removed were suspicious so I was offered chemotherapy to mop up any cancerous cells. The chemo lasted six months. I have never felt so weak but I was fortunate in that some of the expected side effects didn't happen. I was also supported by my full time carer, my wife, the Macmillan nurses, and attended the day unit of my local hospice which gave my wife some respite.

Well that all ended in August 2013. Since then I have had a colonoscopy, and a CT scan and all was clear. Monty (my colostomy) is seven years old now and apart from the occasional mishap we get on quite well and it is reassuring to know I can contact my stoma team if I have any problems.

I can only stress that if I had done something sooner and not been fobbed off with an IBS diagnosis I believe I could have saved myself and my family a lot of stress, pain and heartache. I would also encourage anyone receiving a bowel screening pack to use it even if there are no symptoms.

Early detection is the key to survival.

It was only when I spoke to my family about the cancer that I discovered it was possibly hereditary. My grandfather had bowel cancer and had a colostomy bag. This was never discussed in my presence as I was growing up so it came as quite a surprise. I have two sons and three grandsons who are all aware of my situation and know what to look for and what action to take, so hopefully they can avoid the traumas I have been through.

Keith Askew

## Bowel cancer – Symptoms

- **Bleeding from the back passage (rectum) or blood in your stools**
- **A change in normal bowel habits, lasting longer than four to six weeks**
- **A lump that your doctor can feel in your back passage or abdomen (more commonly on the right side)**
- **A feeling of needing to strain in your back passage (as if you needed to pass a bowel motion)**
- **Losing weight**
- **Pain in your abdomen or back passage**

Ref: [www.cancerresearchuk.org](http://www.cancerresearchuk.org)

## Bowel Cancer – Screening

- In England Bowel Cancer Screening is offered every two years to everyone (registered with a GP) aged 60 to 74. People 75 and over may request a screening kit.

**More information: Free phone helpline 0800 707 60 60.**

- In Wales Bowel Cancer Screening is offered every two years to everyone (registered with a GP) aged 60 to 74. You cannot request a kit if you are 75 and over.

**More information: Free phone helpline 0800 294 3370.**

- In Scotland Bowel Cancer Screening is offered every two years to everyone (registered with a GP) between the ages of 50 to 74. People 75 and over may request a kit.

**More information: Free phone helpline 0800 0121 833**

- In Northern Ireland Bowel Cancer Screening is offered every two years to everyone aged 60 to 74. You cannot request a kit if you are 75 and over.

**More information: Free phone helpline 0800 015 2514.**

- In Ireland the BowelScreen programme has now started, on a phased basis starting with men and women aged 60-69. Over time the programme will be extended on a phased basis until the full 55-74 age group is reached.

**More information: Free phone helpline 1800 45 45 55**

**Remember that no screening test is 100% reliable. If you have symptoms of bowel cancer at any age, you should not wait for a screening invitation, but make an appointment with your GP.**

Ref: [www.beatingbowelcancer.org](http://www.beatingbowelcancer.org)



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For a **free sample** of HydroFrame, Hyperseal or HydroFrame Mini with Manuka honey, please complete the coupon and return it to: **CliniMed Ltd., FREEPOST HY241, High Wycombe, Bucks, HP10 8BR (NO STAMP REQUIRED)**, call the CliniMed Careline on **0800 036 0100** or visit **[www.clinimed.co.uk](http://www.clinimed.co.uk)**

**HydroFrame** with Manuka honey

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**Hyperseal** with Manuka honey - small low profile

**Hyperseal** with Manuka honey - small high profile

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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.

# From One Ostomate to Another

The column where ostomates share their experiences and pass on their hints and tips.

**Odour is one of the issues many of us are concerned about when we first have a stoma. Modern appliances, however, mean that, provided our appliance is working well, the only time that an odour is noticeable is while we are changing the pouch, but then everyone, whether they have an ostomy or not, can leave a smell in the bathroom.**

Special deodorants for ostomates are available on prescription. However, with rising costs within the NHS, some GPs may be unwilling to prescribe them. A quick browse on the drug tariff website reveals a variety of aerosols most of them priced between £4 and £5 for a canister containing about 50ml. If you are struggling to obtain an ostomy deodorant on prescription, or perhaps if you feel like saving the health service some expense, you may have tried some of the air fresheners available in the supermarket. If so, which have you found most effective? Perhaps you use solid gel air fresheners which work all the time, or auto air fresheners which can be pressed to give a boost when required.

But what about when we need to change our pouch away from home? How do we make sure there is no lingering odour in someone else's bathroom? This is where small aerosol sprays for ostomates become really useful as they can easily be carried around with a spare pouch in a pocket or handbag. If you are at an Open Day look out for the tiny 5ml sample bottle which can be refilled when it runs out. We often read that striking a match will dispel any odours. Do any of you use this method and would you recommend it?

A deodorizing product inside the pouch can minimise the odour of the pouch contents and can be useful if you regularly need to do a bag-change while out and about, or at work. These are available on prescription

and can be in the form of deodorant drops. Some work by masking, some by neutralising or absorbing the odour, others by eliminating odour-causing microbes within the pouch. Deodorising gels have the added bonus of reducing pancaking, and deodorising sachets are designed to also make the stoma output more solid once inside the bag. You may remember reading in the last issue of *Tidings* that medicinal charcoal tablets which are designed to be swallowed can be placed inside the pouch where they will absorb unpleasant odours. We have also heard that TicTacs inside the pouch work well. Another tip for those of us anxious to keep NHS costs down.

There should be no odour while we are wearing a pouch. An unpleasant smell is usually a sign there is something wrong. Maybe the contents of the pouch are leaking out under the flange. This could be for a number of reasons, perhaps an unsuitable or a badly fitting pouch. If this is the case consult a stoma care nurse who will be able to advise you on product/s to solve the problem. With a drainable pouch, odour can be the result of failing to clean the outlet thoroughly before closing the open end.

Any wind which is passed through the stoma will be released through a filter near the top of the pouch. These filters have a deodorising function but their design and effectiveness varies. So if you are continually having a problem with odour it may be worth trying other pouches produced by different manufacturers. Filters do not work properly if they get wet. This could be on the inside because the liquid contents of the pouch have come into contact with the filter. Or it could be on the outside, so it is worth covering the filter with one of those small sticky patches (that are found inside a box of appliances) while you are taking a bath or shower, or swimming. Remember to take the patch off after you have dried yourself to allow any excess gas to escape again and so prevent ballooning.

So if you think you get a whiff of your stoma, first check there is no leakage, then the filter and if you use a drainable the outlet. Having eliminated all these reasons, stop for a moment and ask yourself: "Is it because I'm so conscious of my stoma that what I think I can smell isn't really there?" The best way to answer this question is to ask someone else, who you can trust to give you an honest answer, to have a sniff and, more often than not, they will say they can't smell anything at all.

**Rosemary Brierley**

**For more information on:**

The Drug tariff:

[www.nhs.uk/924aspx](http://www.nhs.uk/924aspx)

Click on Part IXC Stoma Appliances

Wind:

[www.bsg.org.uk/patients/general/windy-symptoms](http://www.bsg.org.uk/patients/general/windy-symptoms)

## Sharing Hints & Tips

I have just bought from Amazon the most amazing product. It's called *Poo Pourri* and is made in the US. It sounds like a joke but for the first time in seven years since I had my colostomy I have walked away confidently from a toilet after changing my pouch.

You just sprinkle a few drops into the water before you empty the pouch, flush and there is no smell! I have tried so many sprays and they help, but only mask the smell. Therefore, I feel terribly inhibited when using a toilet away from home. The big drawback is that it costs £10 for a 100ml bottle. Have other people found this product and what's the verdict?

**Regards  
J.W.**

If you have an experience or anecdote you'd like to share, or hints and tips to pass on to other ostomates e-mail or write to the editorial team:

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

# NEWS FROM



**Sue Hale, Colostomy Association General Manager, writes:** There are several exciting items to report on this quarter so read on to find out more!

## NEW! Photo Competition and 2016 Calendar

We want your pictures for the **Colostomy Association 2016 Calendar**



For the first time ever, the **Colostomy Association** will be releasing its very own 2016 calendar and we would like you to send us your best scenic holiday snaps. Twelve lucky winners will be picked to feature in the calendar and there's a chance to win a great photographic prize.

Our 2016 calendar will demonstrate that having a stoma is no barrier to living a full and active life. We are looking for stunning landscapes from your travel; whether they are of a Nordic grotto or beaches in Hawaii – whatever the season, whenever they were taken, enter them into the calendar competition.

There is a special prize for 1st place so as well as receiving a certificate, the winner will also receive a wall canvass of their winning photograph approximately 76cm x 50cm (30" x 20") kindly donated by Jessops and worth £70, and a free 2016 **Colostomy Association** calendar. The winning photograph will feature prominently on the front cover of the calendar and for one of the months inside the calendar. Those awarded 2nd and 3rd places will each receive a certificate and a free calendar with their photo included, while the remaining nine selected runner up photographers will each receive a free calendar.

The **Colostomy Association** calendar will be available to order from October 2015 so keep a space on your mantelpiece or buy several as a Christmas present for friends and family! Further details on how to order your 2016 **Colostomy Association** calendar will follow in the autumn edition of *Tidings*,

along with a special feature on the winning photographs.

The deadline for photographic entries is **7th August 2015** so get snapping! Please note we will only accept landscape and scenic photos and all photos must be high resolution digital as this means they will successfully print in the highest quality at larger scale (300dpi about 10Mb) photographs are required for print in magazines, so some mobile phones are not suitable. To whet your taste buds, some splendid examples are given above, and these were taken by our Chairman, Monty Taylor on his previous travels.

Please email your photograph along with your contact details (name, address, postcode and phone number) to [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

A consent form will then be sent to you for signature, if short listed, giving your permission for the photograph to be used with your full name for publicity purposes to promote the **Colostomy Association**; including but not exclusively the 2016 calendar, on our website and in *Tidings* to name a few. We hope to hear from you soon!

# THE OFFICE



## Survey Results Announced

A big thank you goes to the 150 supporters who responded to the survey mentioned in our last edition of *Tidings* about whether they would be willing to pay an annual fee for *Tidings*. The results were incredibly interesting and there were many great suggestions and comments sent in too.

80% of respondents said they would be happy to pay an annual fee with a charge of £20 being the most popular figure. Rightly, many people raised concerns that those on a low income might be unable to pay the fee and suggested alternative models of financing the magazine.

Following a discussion made at our Trustee Board meeting in February it was agreed that *Tidings* would remain free of charge and that an annual fee would not be put in place. Our Trustees felt that the **Colostomy Association's** services should remain free to everyone who needs our support, so that we can help as many ostomates as possible.

However, any donation made not only helps fund future issues of *Tidings* but

enables the **Colostomy Association** to continue to support thousands of ostomates across the UK. Currently only 25% of *Tidings* readers have ever made a donation so please consider making a contribution when you can, regardless of the amount, to help us ensure more ostomates can access our free vital services into the future.

## NEW! E-newsletter



**There is now yet another way to stay up to date with the Colostomy Association and stoma-related news – by signing up for our new monthly e-newsletter.**

Going out electronically by email at the end of each month, the **Colostomy Association** e-newsletter is a great way to keep up to date with the latest ostomy and stoma

news. Our e-newsletter contains information on upcoming events, fundraising activities by our supporters, updates from the **Colostomy Association** as well as information on stoma and ostomy products.

The e-newsletter is completely free to receive. To sign up, all you need to do is go to this online link and enter your details: <http://eepurl.com/baYDq1>

## NEW! Car Raffle

As part of our 10th Anniversary celebrations we are holding a special raffle which gives the chance for one lucky winner to walk away with their own car.

Raffle tickets are included in this edition of *Tidings* and everyone has the chance to win a New Vauxhall Corsa and other cash prizes.

Each ticket costs just £1 and will help raise vital funds for the **Colostomy Association**.

Please support us by buying as many tickets as you can or by selling them to family and friends. See centre page pull-out feature and note that more raffle tickets are available on request.





# Soft Convex Skin Barrier

## Designed with the Individual in Mind

Introducing the new range of **Moderma Flex** closed one-piece pouches with a new diamond shaped Soft Convex SoftFlex skin barrier. Designed especially for individuals that will benefit from the flexibility and conformability that Hollister soft convexity offers.

### SoftFlex skin barrier formulation

Gentle on the skin, the SoftFlex skin barrier is thin and flexible

### Diamond shaped barrier

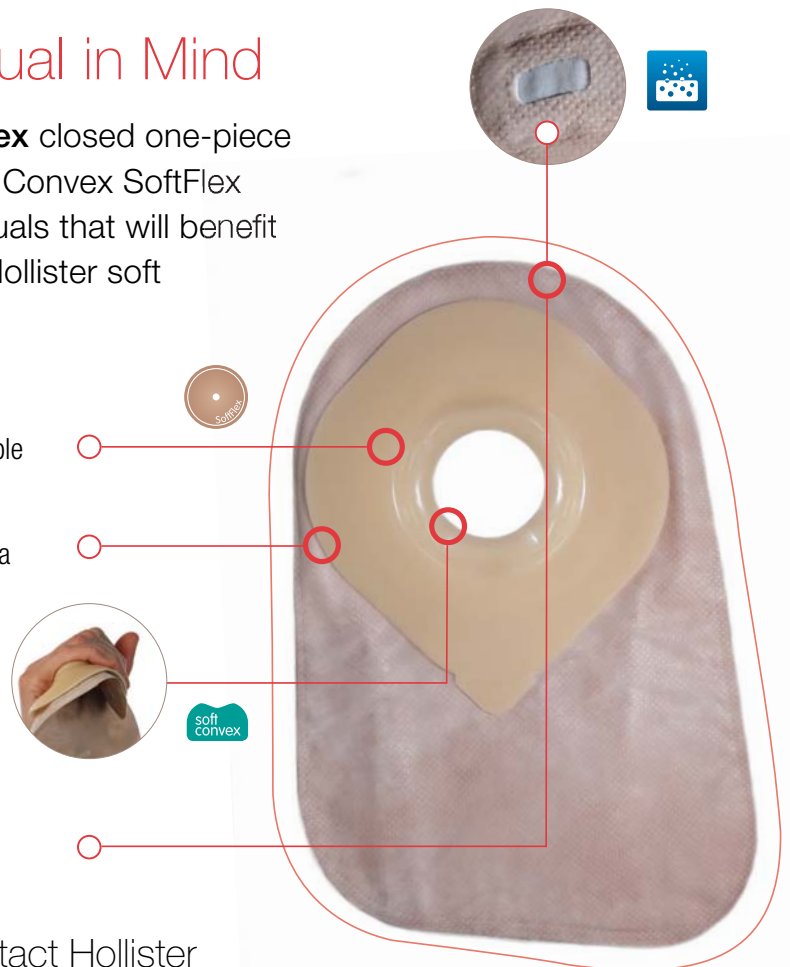
Offers greater adhesive coverage on either side of the stoma for added security

### Soft and flexible convexity

Designed to conform to each individuals body shape for comfort and security

### AF300 filter

Generous air flow, coupled with an odour-eliminating carbon element, help reduce pouch ballooning and odour.



To request FREE samples, please contact Hollister at **0800 521 377** or email [samples.uk@hollister.com](mailto:samples.uk@hollister.com)

**Hollister Ostomy. Details Matter.**



**We need YOU! Fundraising is an immensely important source of income for the Colostomy Association as we rely heavily on donations. Help us continue to provide support to ostomates and their families 24 hours a day, 365 days a year.**

**Donations**  
When sending your donations please don't forget to include your contact details.  
Thank you!

## Fundraising Focus

All of us at the **Colostomy Association** are constantly surprised and humbled by the various ways our supporters fundraise for us. As an independent Charity, every penny raised helps fund our work supporting ostomates across the UK and raising awareness of life with a stoma.

## Special Thanks

Each month we receive lots of kind donations from our supporters. Sadly, we can't publicly acknowledge everyone, but here's one particular example that deserves a special mention:

Helen Robbins and her family who raised **£510** at a coffee morning and raffle in January. Their event was a huge success with homemade food, gifts and cards on sale.

As a keen quilter, Helen's mum kindly crafted a beautiful patchwork quilt, bag and cushion as special prizes for the raffle. Our deepest thanks go to Helen and all her friends for raising such an amazing amount of money for us and especially to Helen's mum for donating such a gorgeous handmade quilt! Thank you all!



## Raffle Prize Draw

Don't miss your opportunity to win a Vauxhall Corsa and other exciting prizes in our raffle draw this July.

Tickets are enclosed with this edition of *Tidings* and the raffle is explained in more detail on **Tidings Supplement page 7** in our centre—spread 10th anniversary article.



## Not for the faint-hearted – skydive for the Colostomy Association

The **Colostomy Association** has teamed up with Skyline to bring our supporters an exciting new way to fundraise.

If you've ever wanted to tick skydiving or parachuting off your bucket list then now you can. Through Skyline, there are five skydiving fundraising activities you can register for including: tandem skydives; solo skydives; and parachute jumps. Alternatively, you could register for the annual London to Brighton cycle ride.

Full details can be found on the Do It for Charity website by following this link: <http://www.doitforcharity.com/uk-events.aspx?set=choice#summarytab>

## London to Brighton

In September 2015, Ian Jackson and his team, *Smurfits Unchained* will be cycling over 50 miles from London to Brighton in aid of the **Colostomy Association** through Skyline.

The team is hoping to raise £500 for the **Colostomy Association** and any donations you can make will help make the 50 mile ride a little easier. Visit their JustGiving page to find out more about their story and to help them reach their target [https://www.justgiving.com/Ian-Jackson13/?utm\\_source=email&utm\\_medium=emails-from-eua&utm\\_content=shorturl&utm\\_campaign=eua-email-sponsorshprequest](https://www.justgiving.com/Ian-Jackson13/?utm_source=email&utm_medium=emails-from-eua&utm_content=shorturl&utm_campaign=eua-email-sponsorshprequest)

## London Marathon

Since undergoing stoma surgery three years ago, Siobhan Grist has had to face many of the challenges that come with living with a colostomy. Every step of the way, Siobhan's husband, Liam, has supported her. Now you can help support Liam as he undertakes one of his biggest challenges yet – the London Marathon in April 2015.

Liam is running to raise awareness of life with a stoma and to help ensure thousands of ostomates in the UK get the support they deserve. You can help make the weeks of training and twenty-six mile slog a little easier by visiting his online fundraising page and making a donation via:

<http://uk.virginmoneygiving.com/LiamGrist>

## Lasting Legacy

In this edition, there's a feature about leaving a legacy to charity. Without appearing to focus too highly on the end of our lives in recent editions of *Tidings*, please bear in mind that this way of giving does benefit a worthwhile cause after you've gone. Even a legacy of a set amount of say £1,000 in your Will would help us continue to provide our free services in the years ahead! Please remember to let your next of kin know about your wishes in advance so this won't come as a surprise!

CONTINUED ON PAGE 18, COLUMN 1

CONTINUED FROM PAGE 17, COLUMN 3

## Ways to Donate!

There are now two new ways you can help support the work of the **Colostomy Association**: clothing donations and jewellery/foreign currency.

## NEW! Clothing Collection

Do you have any spare clothes? Whether they're shirts that no longer fit or skirts from last season, your unwanted clothes can help raise much-needed funds.

We have teamed up with iCollectClothes who provide a clothing collection service in the South East of England. If you live in London, Essex, Kent, Hertfordshire or Suffolk then you are able to donate old and unwanted clothes in aid of the **Colostomy Association**.

To donate: collect up your clothes in boxes or black sacks, and book an appointment to collect the clothes from a place and a time that suits you by visiting the website at: [www.icollectclothes.co.uk](http://www.icollectclothes.co.uk) be sure to select **Colostomy Association** as the recipient of the donations. Or, telephone Freephone **0800 879 4417** to arrange a collection. They will take adults' and

children's clothing, woollens, paired shoes, handbags and belts so start saving up your unwanted items now. No bric-a-brac.

## NEW! Jewellery and Foreign Currency Donations

Do you have any unwanted items of jewellery or foreign currency?

Help change the lives of ostomates across the UK and send them to the **Colostomy Association**.

Sending a donation is easy and free – in this issue of *Tidings* you will find an envelope in which you can put any unwanted or old jewellery, as well as gold, silver, costume jewellery, watches and foreign banknotes.

Even broken and damaged jewellery will help – dig out your mismatched earrings and broken necklaces and donate them towards a good cause.

For more information:

Telephone: **0800 633 5323** or visit: [www.recyclingforgoodcauses.org](http://www.recyclingforgoodcauses.org)

## Used Stamps needed

Do you have any used stamps you can donate? People are refunded their postage in full as long as they mark the envelope for the "CA" when sent direct to this company (and use commemorative stamps as they become part of the fundraising).

Any stamps are taken but the commemorative stamps are the most valuable because they relate to special events. £10 per kilo is paid including the weight of the envelope.

### Instructions to stamp donors:

- No more than 1cm of envelope left around each stamp (as per photo).
- Not trimmed too close so that the perforations are damaged.
- Use special commemorative stamps on the envelope when sending.



Please send your used stamps to: 'CA', c/o Fundraising Stamps Ltd, 59 Mitre Copse, Bishopstoke, Eastleigh, SO50 8QE

Don't forget our Recycling Appeal



Recycling Appeal is a multi-product technology appeal to raise funds for **Colostomy Association**.

Freepost envelopes are available or collections can be organised, simply visit:

<http://www.recycle4charity.co.uk/Register/C60511>

# LEAVING A LEGACY



**Rachel Fuller**

Royce & Co, Solicitors

**Charitable gifts in wills bring in approximately £10.4 billion per year for UK Charities. This figure could be so much more if the solicitor or will writer actually reminded you that including a charitable legacy in your will was possible and the benefits it would bring not only to the charity but also to you, your loved ones and your inheritance tax bill.**

Many of us regularly donate to our favourite charities to support their more than worthy causes during our lifetimes. However, once we have fallen off our perch such payments cease and whilst we endeavour to ensure that our loved ones are remembered with a small memento in our wills, it would seem the Charities that we have so fastidiously supported during our lifetimes suddenly get forgotten.

Charities cannot function without donations from the public but why should we include a charitable legacy in our wills?

- 1 Every little helps. Many people rely on charitable organisations to assist not only them but also their families and loved ones and what better way to acknowledge the work these organisations do than to leave them a legacy, however small, in your will. If you have relied heavily on a particular charitable organisation for whatever reason just imagine if it had not been there for you; if it had insufficient funding to provide you with the care and advice when you needed it most.
- 2 Doesn't it make you feel good? Many people feel they want to give simply because it feels like the right thing to do; a sense of giving back to society in a positive way and making a difference to others after your death.

- 3 Death and taxes. We all know that inheritance tax is levied at 40% over the exempt amount of £325,000 (or £650,000 in some cases). Gifts to registered charitable organisations are currently exempt from Inheritance Tax so they would be taken off the value of your estate before the Inheritance Tax is calculated or, your estate could pay Inheritance Tax at a reduced rate of 36% on some assets if 10% or more of the net value of the estate is left to registered charities. These are the current UK tax rules and can be subject to change.

For the tax relief to apply however, the charity must be a registered charity or organisation so make sure that the name of the charity is correct together with the charity's registered charity number and registered address. You can either check this on the charity's website or on the Charity Commission website.

- 4 Windfall. Many charities work hard to raise the profiles of the good work that they do. Fundraising and lifetime charitable giving allows the charities to budget, but an unexpected windfall gives them that bit extra to make a real difference.
- 5 You can request that the legacy you leave is put towards a specific charitable purpose. This could leave a lasting reminder of your support for your favoured charity.

## How can you make a charitable gift in your will?

It's easy - where there's a will there's a way. In order to make a charitable gift in your

will, you do of course have to make a will. The intestacy rules (that apply in the absence of a valid will) do not provide for charitable legacies.

If you already have a will then you don't have to make a new one. Just ask your solicitor to prepare a codicil for you. A codicil is a document that amends rather than replaces an executed will. The codicil must conform to the same legal requirements as the original will i.e it must be signed by the testator in the presence of two independent witnesses which is why it is better to be done properly by a solicitor otherwise it could be invalid. But it would only be a short document if all you are doing is inserting a charitable legacy. The original codicil must be kept with the original will.

You could leave a fixed amount to your favoured charity, an item or you could leave the charity a proportion of what is left after other gifts have been deducted.

## How could the beneficiaries of your will make a charitable gift after your death?

Provided all of the residuary beneficiaries under your will agree (and are old enough to agree), the beneficiaries could change your will by way of a deed of variation to make or increase a donation to charity so that the estate meets the 10% test. If it is your wish to include a charitable legacy then you should change the will yourself during your lifetime rather than rely on your beneficiaries to carry out your wishes later on.

**Rachel Fuller**

Lift Plus

# An adhesive remover that's gentle on the skin



**Lift Plus, a highly effective adhesive remover, reduces the pain associated with the removal of stoma pouch adhesives:**

- Breaks down the adhesive bonds that flanges and pouches form with the skin
- Lift Plus Citrus also available for those worried about odour
- Available on prescription as a handy spray or disposable wipe

*For a free sample, via our  
next day delivery service:*

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*- visit [opus-healthcare.co.uk](http://opus-healthcare.co.uk)*

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# Irrigation and you

Sarah Squire, Trustee writes: Tidings readers will remember Noreen writing about her experiences shortly after she began irrigating last year. Six months on Noreen has kindly written an update to let us know how she's getting on and how she has modified her technique. Also, following on from Brian's cycling adventures in the last *Tidings*, we have had enquiries into the **Colostomy Association** office about how to make his telescopic irrigation pole, so, Brian has written some simple instructions for anyone who would like to make use of a similar pole.

## My Colon, My Stoma and Me – Six months on

**A lot of water has gone under the bridge, or, more accurately, up and down My Colon – since I wrote six months ago about my introduction to colostomy irrigation. I think it is fair to say that I have learnt a lot and I'm still learning and experimenting.**

So what have I discovered in the last six months? Well, in my previous article I referred to irrigation as a procedure, which indeed it is. However I had somehow ignored the fact that it was a procedure that was dealing with something alive – i.e. me. I had assumed that every irrigation would be the same and of course they are not. I had forgotten the very obvious fact that what I ate was going to have an effect on the output. Looking back now I realise how silly this was but I think I was so carried away with the freedom of irrigating that I had forgotten I am not some sort of robot!

Irrigating every 24 hours is different from doing so every 48 hours. It's a bit quicker, taking about 40 minutes, and I do not always have a 'poo plug' just inside My Stoma, something that is always there when I leave irrigating for 48 hours.

I no longer get cramps when introducing the water. I was infusing it a bit too quickly initially and slowing the speed solved that problem. Regardless of how often I irrigate I no longer keep 500ml of water for a final flush out. For some very silly reason I had assumed I was aiming at almost clear, 'colonoscopy ready' output at the end. This is, of course, ridiculous; all I'm aiming for is a poo-free colon for the desired period of time.

Irrigation is a method of colostomy management which involves using specialist equipment to introduce warm water into the bowel via the stoma. The water causes muscular contractions (peristalsis) within the bowel which in turn cause expulsion of its contents. Many Ostomates prefer this method of colostomy management as it gives them a sense of control. If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. Also have a look at the **Colostomy Association** website for more information on irrigation and how to purchase the *Irrigation and you* DVD.

All the equipment lasts well. Manufacturers' guidelines say to change equipment three monthly but I find it can last longer than this. I have found that I need to flush Milton solution through the water bag and tubing every couple of months or so to stop them becoming mouldy. I think I will need a new water bag in a few months as the regulator is getting slightly loose. The cone lasted well and I have just replaced it.

The mantra 'we are all different' is mentioned very often in *Tidings* and it is as true of irrigation as of any other aspect of our problems. To that should be added 'it doesn't matter'. The amount of water you use, the length of time the procedure takes, the number of times you infuse more water – none of these things actually matter. If it works for you, it's fine, so long as you stay within guidelines discussed with your stoma nurse.

I briefly mentioned in my previous article the fact that I can now wear support underwear to give protection against a parastomal hernia. Now I think about it, I realise that this is probably the most important advantage of irrigation – a medical one rather than one of convenience. I had tried wearing a support garment with bags but it just didn't work for me. Now I use a variety of products, from the pants and belt supplied on prescription when I go to the gym, to an M&S firm support all-in-one garment when I want a good shape.

The flexibility of irrigating makes my life so much easier. If I have consecutive days of needing no stoma noise I will irrigate every morning. If I have nothing planned I will leave it for 48 hours. If I have a very early start one morning I will irrigate at 36 hours in the evening. I am in control.

Irrigation was also a huge benefit when I went into hospital again this year for lung surgery. I irrigated the night before admission and put on a bag. I did not feel like eating much post operatively and effectively I forgot all about my stoma for six days. By then I was well enough to irrigate again.

I do hope the above will encourage you to try irrigating if you are medically able to do so. Buy the excellent DVD of Judy irrigating or watch the video on YouTube of Brian in New Zealand. Dansac also have a good video and Coloplast an animation. All are slightly different but between them they give you a good idea of how irrigation works. It's not a one-way street and you can always go back to bags if you find irrigation is not for you. Good luck and go for it!

**Noreen**

Before Noreen managed her stoma by irrigation she found it hard to wear support garments as they tended to cause pancaking. Many people are able to successfully wear support underwear/belts with an active stoma, but irrigation may be beneficial to those who have problems, like Noreen did.

it's time to  
**CHANGE**

**John's Story...**

I have been using the Trio Silicone products that were sent to me and Siltac 3 is amazing! I can't believe the difference they have made. I have been able to keep my pouch on for two and a half days the first time in 18 years! For all the sores and pain I have been through over the past years, I cannot believe how in just a short time the Trio products have changed my life. I just can't thank you enough.

**Like John you could share your experience with other ostomates and make a change to someones lifestyle for the better.**

Go to [www.TrioOstomyCare.com/actsofkindness](http://www.TrioOstomyCare.com/actsofkindness)



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[www.TrioOstomyCare.com](http://www.TrioOstomyCare.com)

# How to make Brian's telescopic irrigation pole



The typical bathroom set up

In the last edition of *Tidings*, Brian talked about irrigating while on a cycling holiday.

Regular travellers know that the first thing an irrigator will look for in an unfamiliar bathroom is somewhere to hang the water reservoir. Many people carry an adhesive hook which can be stuck on most flat surfaces, but Brian has gone one step further to ensure he will never encounter a problem. He has designed and made a telescopic pole which fits into his rucksack for travelling.

**Brian writes:** The water bag can be suspended from anything above shoulder height such as: doors; shower screens; windows; coat hooks; or, whatever will support its weight. Then you are on holiday in a strange bathroom where the toilet is situated next to the hand basin but too far from the door or shower and the walls are artexed. Oops, you have a problem.

In situations like this I use my telescopic irrigation pole. I made it from a clothes line prop sold by Wilkinsons which I then cut into pieces about 30cm (12") long. The basic material is 20mm square hollow steel and I fitted a male plug into one end of each piece to facilitate re-assembly.

Each section is about 30cm (12") long to facilitate packing into a rucksack or pannier

**Brian Kirby**



The device ready for packing

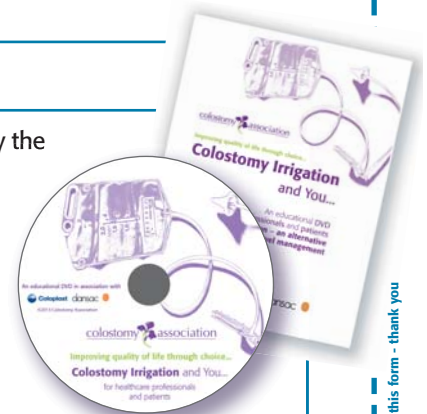
## Colostomy Irrigation and You DVD

### 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 a method of bowel management**. **Note:** 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 return it with your cheque made payable to the **Colostomy Association**, to:

**Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA**



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

Name: \_\_\_\_\_

Address: \_\_\_\_\_

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

Tel: \_\_\_\_\_

Email: \_\_\_\_\_

**Please allow 30 days for delivery.**

**Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA Charity No. 1113471 VAT No. 917079312**



Carolyn Stammers speaking with Petronela Mavropol during an observation session

occasioned by lack of appliances. In these early days many UK patients, manufacturers and stoma care nurses offered surplus appliances sending in excess of 1,000 parcels of appliances; for so many a lifeline, all were received with enormous gratitude and thanks. As the Romanian health department developed, and after pressure from the project team, ostomy patients are now thankfully receiving bags by prescription, although the choice is limited.

The original project grew out of IA's 40th anniversary celebration at the suggestion of Professor Sir Miles Irving FRCS. As the project developed so it became necessary in 2000 to form a separate charity that continues today – the Romanian Ostomy Patients' Support Foundation (ROPSF). It is run by seven trustees, drawn from **Colostomy Association**, IA, together with our surgical president, Mr Robert Lane, two highly experienced nurses and of late a Romanian psychologist who currently works in the UK but has been closely associated with patient research in Romania.

ROPSF's aims follow closely those of the original project: training nurses in stoma care; the development of patient support groups; and research into good practice. All are still seen as highly relevant as we move forward. For the trustee team it is important to remember that there are a huge number of people in the country with colostomies as cancer of the bowel is prevalent in so many parts of the country.

Over the years ROPSF has been fortunate with its close connections to many of the major Romanian hospitals, to highly skilled surgeons and very devoted nursing staff. Throughout the years ROPSF has been able to run conferences for doctors, nurses and patients and has also been instrumental in offering teaching of stoma care at various levels. In 2012 ROPSF ran its first Romanian *Train-the-Trainer* course in the UK when eleven previously trained stoma care nurses were invited back to the UK for a week's training and work observation at major hospitals. What was especially pleasing is that all of these nurse-trainers have returned to their mother country and are passing on their knowledge and skills to their colleagues; this is most rewarding for all concerned.

Although the project has been in existence for twenty years, 2015 promises to be an important year with three major, costly and very different projects; all are in the development stages, with the ultimate aim of offering help to the patient. ROPSF is embarking on a paediatric stoma care training exercise. Nursing staff caring for neonates, babies and very young children together with the parents at three of the

CONTINUED ON PAGE 26, COLUMN 1

# In the face of challenge

**What must life have been like feeling desperately ill but virtually unable to give up work for want of depriving the family of a basic living wage? Or, having a stoma and not having a bag? Or, being stigmatised by one's work colleagues? Would one ever be able to live a normal life again in the knowledge that the prognosis was far from favourable.**

These were a few of the many personal issues that confronted and challenged the three UK stoma associations in 1995 when asked to explore whether they could give support to helping ostomy patients in Romania; to people who were slowly emerging from the despotic regime of Nicolae Ceauşescu already disadvantaged and now carrying the burden of life with a stoma.

After travelling to Romania, meeting doctors, nurses and of course patients and realising the patients' plight, strenuous efforts were made in the first place to offer surplus ostomy equipment to try in a small way to alleviate some of the suffering



Picture from Romania – one of the many painted churches in North East Romania



# experience freedom



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CONTINUED FROM PAGE 24, COLUMN 3

principal children's hospitals will be supported with an intensive week of training. This will be undertaken by a specialist paediatric stoma care nurse from the UK together with support from ROPSF's nurse trustees.

Later in the year there will be a seminar at the children's hospital in Bucharest for surgeons at which the trained nurses will take an involvement as well as parents. Having a stoma at such a young age is both traumatic for the infant and distressing for the mother and all too often impacts on the whole family. Until now this area of support has not been featured but it is most necessary and ROPSF has been kindly invited by some of the leading Romanian surgeons to help in this area of care.

Alongside this work attention is also being given to enhancing the knowledge of those nurses who become involved with urostomy patients and their particular needs. Here again it is anticipated that a group of Romanian nurses will undertake a week's experience in stoma care at a UK hospital where urology is to the fore.

And for the patients, while patient support groups are developing there is a need to bring the existing groups together to share ideas and information and also to demonstrate what can be achieved if they work collectively.



The project director, Bob Bailey being introduced by Professor Cristian Dragomir the chief colorectal surgeon at a Romanian surgeon's conference

There are a few good examples of patient groups around Romania some run by ostomy manufacturers and suppliers whilst others are patient led. But as the trustees know only too well patients talking to one another, sharing thoughts and ideas is all part of the healing process; the same holds true for Romanians just as for Brits.

There is little doubt that over the years the lot of the Romanian ostomy patient has

changed dramatically; better care, conventional appliances and a greater chance to return to a near normal lifestyle. All of this is clear to see but there are still challenges that require ROPSF's attention if the standards which we uphold are to be fully replicated in Romania.

For more and current information please view us on [www.ropsf.co.uk](http://www.ropsf.co.uk)

**Bob Bailey**

## Your Travel Checklist

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

The ostomate needs to remember to:

- take sufficient supplies for your stay;
- take all supplies and travel stoma kit as hand luggage;
- ask the airline in advance if you need extra hand baggage for your supplies;
- 'check in' online 24 hours before departure to secure your preferred seat;
- avoid food and drink the day before you are to travel that are likely to cause upset or excessive wind;
- take medication to firm up or loosen output;
- carry your Travel Certificate with you especially when passing through immigration or security areas;
- take some form of electrolyte replacement solution in case you become dehydrated;
- drink bottled water in foreign countries, avoid ice in drinks and use bottled or boiled water to clean around your stoma area; and
- store your supplies in a cool place, out of direct sunlight.

CA Booklets, Leaflets and Factsheets are available



Simply contact:

**General Enquiries:**

0118 939 1537

Monday to Thursday

9am – 5pm and

Friday 9am – 3pm

or

**E-mail:**

[cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

or download from our

**Website:**

[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)



# Home Delivery

## Making life easier

At Pelican we understand you want a fast and reliable home delivery service, and we are dedicated to providing just that. We offer stoma products from all manufacturers, so **whatever products you're using, if it's available on prescription, we'll deliver it!**

- A personal, discreet and independent service delivered direct to your door
- Nurse support and advice whenever you need it
- One hour delivery slot with a text notification service
- Repeat prescription service
- Expert advice from our fully trained BHTA customer services team
- Complimentary wash bag with your first order

**Sold? Then join us today! Call Freephone 0800 318 282**

# Update on stoma care products and services

*Tidings* is always interested to learn about new stoma care products and services from manufacturers and suppliers. 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 others.



## New OakMED Primo Pouches

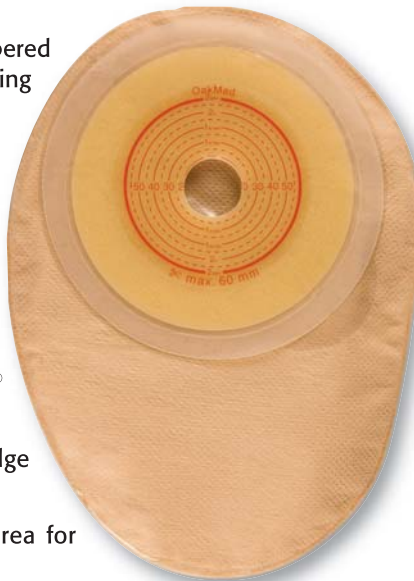
The perfect hydrocolloid tapered edge adhesive for outstanding adhesion and security

Primo's new anatomical shape has been designed to fit around body contours faultlessly, providing you with increased protection and confidence.

The unique features and benefits of the new Primo® range also include:

- Unique tapered edge hydrocolloid adhesive
- Generous adhesive area for added security
- High tack adhesive which can be re-positioned
- New, thicker, superior split fabric cover
- Moisture protective filter system

For free samples please call **0800 592 786** or visit [www.oakmed.co.uk](http://www.oakmed.co.uk)



## New OakMED Easylease spray – on prescription

It is a silicone based no sting medical adhesive remover used to help remove the pouch or to clean any adhesive residue or paste from the skin after removing the pouch.

The silicone works by rapidly penetrating the adhesive–skin bond on the peristomal skin surface to form an interposing layer. This is the type of adhesive remover is the product of choice by many Health Care Professionals.

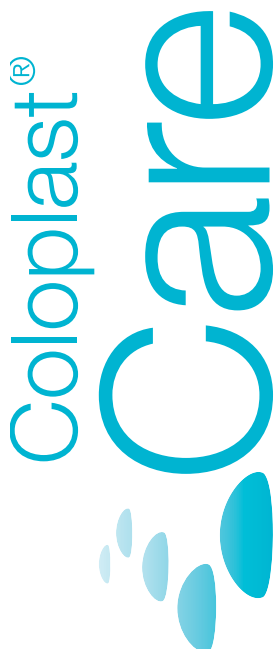
The spray contains:

- Tea tree oil for antiseptic properties
- Silicone for a gentle, no sting removal of the adhesive

The spray can has 'Bag on Valve' technology which means:

- No propellants required
- No 'chill' feeling when sprayed onto the skin
- No sting
- 100% product in the can (room not taken up with propellants)
- No waste
- Use any way up

Call **0800 592 786** or for free samples, visit [www.oakmed.co.uk](http://www.oakmed.co.uk)



**Coloplast care is a new, tailor-made support programme that is designed to meet the needs of people due to have the formation of a Colostomy or who are living with a colostomy.**

This new email programme provides you with a reliable source of lifestyle and stoma related advice, on the topics you want, when you want them.

We have also introduced a new stoma self-check, for you to take control of your own personal stoma health. We understand that

it is easy to accept small problems with your skin or appliance, but this shouldn't be the case!

If you identify issues, you can read relevant articles or request a call back from our Coloplast care advisory team. Our specialist team can offer relevant advice and support or refer you to our clinical nurse specialist for a phone or skype consultation.

Everything we do is tailor-made to meet your needs.

Sign up today: [www.coloplast.co.uk/care](http://www.coloplast.co.uk/care)



## Gellymate Absorption Tablets & Capsules With Odour Neutraliser

Are you experiencing leakage problems or embarrassing odours with your current system because of loose stool? Then why not try **Peak Medical's Gellymate absorption tablets or capsules** which binds the loose stool into a gel helping to reduce leakage, skin irritation and embarrassing odours.

**Now available on prescription** from your GP and can be obtained from your usual supplier.

For more information about Peak Medical's new **Gellymate absorption tablets & capsules** simply call **Freephone 0800 652 0424** or email: **info@peakmedical.co.uk** and quote **M83** to receive your **FREE samples**. Visit Peak Medical's website: **www.peakmedical.co.uk** for more information.



## New True Oval Soft Convexity Wear time unsatisfactory? Skin suffering? Losing confidence?

Then try Peak Medical's **New True Oval Soft Convexity Closed Pouch.**

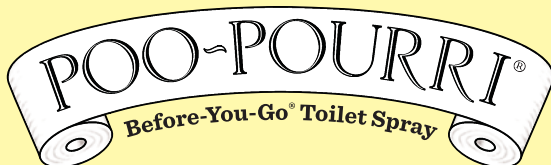
Available in two cut to fit options:  
**13-44 x 29mm and 13-54 x 37mm.**

Designed for a more accurate fit for non-round, irregular shaped stomas, and those in skin folds and creases, the unique, soft, flexible oval insert provides noticeable comfort when moving and bending.

Optimum depth and oval profile for maximum benefit, providing gentle oval pressure where needed. May help to improve pouch wear time and reduce the need for additional accessory items.

For more information and to order your **FREE samples** please call **Freephone 0800 652 0424** or email: **info@peakmedical.co.uk**

See our advert on page **42**.



from



**Biggest Little Gift Co**

**Poo~Pourri® the 'before you go' toilet spray has been a real hit with many readers of Tidings and is a new concept in home fragrance.**

It's one of the most practical products on the market and already boasts sales in excess of 4 million bottles. The whole range is attractively packaged and what's more it really works!

There are four fragrances to choose from, *Original, Deja-poo, Number 2* and *Royal Flush* for men.

To use you simply spritz the bowl three or four times before you use the toilet, and all odours are trapped in their porcelain prison; all that remains is the subtle blend of Poo~Pourri's aromatherapy oils and secret ingredients.

Two sizes are available in the UK: a 4oz bottle (200 uses); and a very handy 2oz bottle (100

uses) that is great for travel, fitting discreetly away in your handbag or pocket.

This is not a chemical cover up; there are no harsh chemicals, it's safe to use and really effective. The product is also well reviewed and raved about on colostomy websites throughout the USA.

The Biggest Little Gift Company already sells Poo~Pourri® below the recommended retail price but they have put together an **EXCLUSIVE offer for Tidings** readers, these will give further savings of up to 24% off their already low regular price.

You can see details of the offer on **page 8**.

For more information, Email:

**orders@biggestlittlegiftco.com**

or visit

**www.biggestlittlegiftco.com**

alternatively call

**01925 453 031**

*Poo~Pourri®, the 'Before-You-Go' Toilet Spray*



# Starting my life

**At the age of 28 I started passing blood from my back passage. I remember feeling scared, but at the same time I convinced myself it was just piles, as I was only passing small drops. But after six weeks the bleeding started to get much worse, I became very constipated and extremely bloated, so I decided to go to the GP.**

The GP felt my tummy and advised me that I was suffering from severe constipation and gave me some laxatives. But after weeks of taking them, my bowel motions became much worse so I went back to my GP but this time I saw someone else who suggested I try some enemas. However, they only caused pain, worsened my motions and made me feel generally unwell.

It was a very worrying time: I was in and out of the GP surgery for over eleven months. Then the GP examined my back passage, advised me that I may have a fissure which was causing me to bleed and he wanted to refer me to a

consultant at Kingsmill Hospital. The waiting period would normally be seven weeks but I felt so unwell that I asked him to refer me to a private consultant.

On examination, my consultant said she could feel a large ulcer inside my bowel. She said it could be serious and sent me for an urgent biopsy, which later confirmed that I had bowel cancer. I was sent for both CT and MRI scans and a week later they told me the tumour was on a nerve inside my bowel and that I would have to have a permanent colostomy.

I can remember the devastating feeling, the shock and the disgust. My exact words were: "I would rather die, than have to live with a colostomy." My whole world had fallen apart – how would I ever feel sexy or attractive again? What would my husband think of me? Could he possibly look at me in the same way? I wanted to curl up and die. Everything felt so surreal. I started a week of intensive radiotherapy, which I was told would make me infertile, and that I would have to go on HRT. There was so much to take in. I went into hospital frightened to death, not wanting to

wake up from the surgery and see a bag stuck to my body. Inside I was hoping I would die on the table.

I remember waking up and not wanting to look; I couldn't bear to see what they had given me and, although it was possible my stoma had saved my life, I could not come to the terms with being stuck with it for the rest of my life. When the nurse came to dress my wound, I felt disgusted, unattractive and alone. I broke down and fell to pieces. The thought of having to clean it, touch it, look at it made me feel sick. How could I be so young and have to go through this?

It was on the 10th day that I first passed a motion through my stoma. I was wearing a huge bag and, so the staff could monitor my motions, it was clear and you could see everything. I broke down; I just wanted them to take it off, I didn't want to look at it, I felt so dirty. I remember locking myself in the toilet and ripping off my bag I didn't even know how to clean it, as I had paid no attention. I guess I was in denial.

After two weeks I went home, but my stoma stopped working – deep down I was glad because it meant I didn't have to clean it. Over the next six weeks I became extremely unwell – crying in pain. My marriage was breaking down at this point. I felt so alone, but I felt too ill to go out of the house. Every day it was a struggle to get up, the pain was getting unbearable, I started vomiting, sweating and my weight was falling rapidly.

I rang my colorectal nurse and I explained my bowels had not moved for six weeks and that I was vomiting severely, I thought I was going to die. She told me to come to the hospital and there would be a bed for me. When I arrived I threw up so badly they had to put a tube up my nose and I was told I would have to go to theatre again as they suspected I had an obstruction.

I woke up in intensive care unit and spent about a week there before being moved to a ward where it was explained that I had nearly died on the table. My bowel had fallen into my pelvis, double-knotted, rotted and everything had been building up. I felt too ill to care; I only weighed four stone, I had clostridium difficile and a blood clot. I had given up. I was just existing, stuck in the bed not talking. It was as if I had died inside – I didn't want to get better, I had had enough. I would lie there day after day like a zombie.



# e all over again

As the weeks went on I started to feel more human, still not great and far from being myself, but I somehow got it in my head to start gaining weight so I could go home. I began to make progress and I was discharged when I weighed around five stone. My chemotherapy had been put on hold as they wanted me to gain more weight so my body would be stronger. My stomach had shrunk so much it was hard to eat, but I knew I had to try, to have any chance of getting better. I didn't dare leave the house as people used to stare, I felt skinny and ugly. The fact that I had to change my bag was more than devastating. I couldn't look at myself in the mirror or even undress in front of my husband and only wore baggy clothes. It was the lowest time of my life. I remember looking at my morphine bottle and thinking I could just drink it, go to sleep and it would all be over.

I knew I had hit my lowest point, the day I looked into my mum's eyes and seeing her pain, I just knew I had to try, even if it wasn't for myself, then at least I had to do it for my family. They had been there by my bedside, through all of it and I couldn't put them through any more pain. So I decided I needed to turn all my emotions around and get my mind focussed to get well again, and that was my turning point. To get well and be positive.

As I started to gain weight and feel more like myself, I started to look at my illness in a different light and feel like I was actually lucky to come through it. When I got to six stone I started six months of chemotherapy. It was a very tough period; the chemo made my output runny and sometimes I would be out in public and my bag would leak or even come off. I felt embarrassed. I hated it and would sit in my room alone and cry.

Half way through my treatment I left my husband as my marriage had gone past saving. I had to look at my life and turn it around for the better, because the alternative would be to lie down and give up. I finished my chemo and after four weeks I decided to look for a new job. I started work caring in the community and without even realising I began to pick myself up. I was laughing again and I started meeting friends. I never let on to anyone how I felt about my stoma, how I couldn't get used to it.

I had to start my life all over again, single, and with this thing stuck to my stomach. The thought of ever meeting anyone again and undressing twisted my insides as I knew that if I couldn't accept it, then who else would? I had to try and build up some confidence again – it was a long battle. As

time went by my confidence grew, I never hid the fact that I had a stoma, talking about it and telling people is what got me through.

The reactions I got from men surprised me, as they would tell me how beautiful I was, and before long I started going out in my lovely old clothes, feeling more myself. As time went on I started to date again and never once had a negative reaction from anyone. I am now in a new relationship, with a very healthy sex life.

I went back to the gym and started loving myself again – realising that my stoma (who I now call Petal) is part of me. She saved my life and there is not one single day that I wake up sad, depressed or negative; I am happy and very confident with my body. I show my bag off on the beach and I am proud of the way I came through this as I have a happy and healthy life. Although Petal plays up at times I never let her get me down, even though there have been times when I have been admitted back into hospital. So now I am careful; I drink plenty of water and eat lots of vegetables. I am just so thankful to be alive and well. Petal is there for life and for that I am truly grateful.

**Davina Jowett**



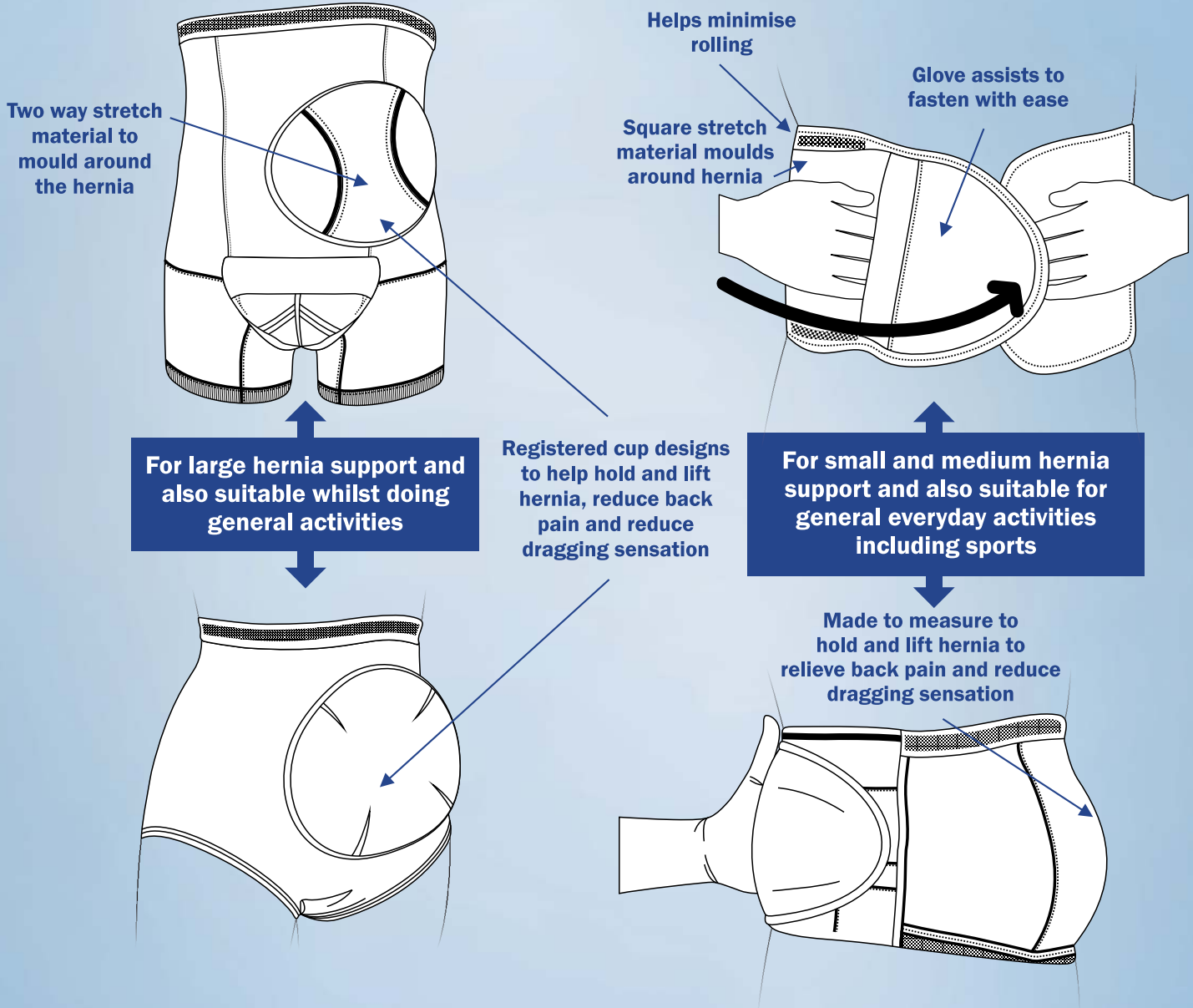
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- By working closely with stoma nurses, CUI ensures that your hernia support device will be the most appropriate product for your requirement.



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# 10th Anniversary Supplement

Tickets are selling fast for our fun-filled weekend of events celebrating 10 years of the **Colostomy Association** this summer.

To be held at the Royal Berkshire Conference Centre in Reading on 11th–12th July 2015, we will be looking back at 10 years of success and looking to the future as well. It promises to be a very special weekend and will provide some wonderful opportunities to share in our celebration, as well as to find out about the latest stoma products, make an appointment with a stoma care nurse and to network with fellow ostomates. Please book your place now to avoid disappointment!

Kicking off the weekend is the **Colostomy Association's** Open Day event where members of the public, ostomates, carers and healthcare professionals are able to find out about the work of the **Colostomy Association** and other organisations.

There will be over 20 exhibitors at the open day, individual manufacturers' prize draws, a range of stoma-related talks, stoma care nurse appointments through Dansac and free refreshments. Additionally, it will be an ideal opportunity to meet and speak with our local volunteers, staff, trustees and president.



## Testimonials

Read what people have said about previous open days, what they thought and how they benefited from coming along. The quotations listed below are taken from the evaluation forms collated on the day:



## Book Now!

Please complete the booking form on the reverse of this page and return it to the office by **11th June 2015**. Over 100 people have already registered for these events so please hurry to avoid disappointment! Hope to see you there!

## Can't make it to the celebrations?

You can still help the **Colostomy Association** by donating any 'as new' handbags for our handbag swap and by spreading the word to others about our special 10th Anniversary events this year.

### List of Sponsors

Our grateful thanks go to the following manufacturers who have part sponsored some of these special activities (to date). Their generosity is very much appreciated as these financial contributions will make our 10th anniversary a very special celebration and will also help to keep costs down to a minimum.

Amount	Sponsor
£4,000	Dansac
£3,000	ConvaTec
£1,150	Salts
£500	Trio Healthcare
£400	CliniMed/Securicare
£100	Ostomart

### Your chance to sponsor

Would you like to sponsor part of the cost of our celebrations? If so, here are a few opportunities for you to consider (prices available on request):

- Light refreshments at various intervals throughout
- Lunch at the Open Day
- Sparkling wine for the After Dinner Toast
- Fundraising Gala Dinner Table Décor/Centrepieces
- Audio/Visual Equipment Costs for presentations and speeches

# 10th Anniversary Open Day 2015 & Fashion Show

Royal Berkshire Conference Centre | Madejski Stadium | Reading



## Booking Form



I would like to attend the following **Colostomy Association** events (*please insert the number of places required*).

**Quantity**

**Open Day on Saturday 11th July 2015** ..... *free of charge*

**Fundraising Gala Dinner on Saturday 11th July 2015** ..... *£45 per person*

**Fashion Show on Sunday 12th July 2015** ..... *free of charge*

**I enclose a cheque made payable to CA Ltd totalling** .....

 . 

————— **PLACES ARE LIMITED SO PLEASE BOOK EARLY TO AVOID DISAPPOINTMENT** —————

<b>Details:</b>	Title:	Name:	Surname:
Address:			
			Postcode:
Telephone (home):		Mobile:	
Email:			
Dietary requirements:			
<b>Stoma Information:</b>	Year of Birth:	Stoma Type:	Colostomy <input type="checkbox"/>
	Year of operation:	(Please tick)	Ileostomy <input type="checkbox"/>
	Reason for your stoma:		Urostomy <input type="checkbox"/>

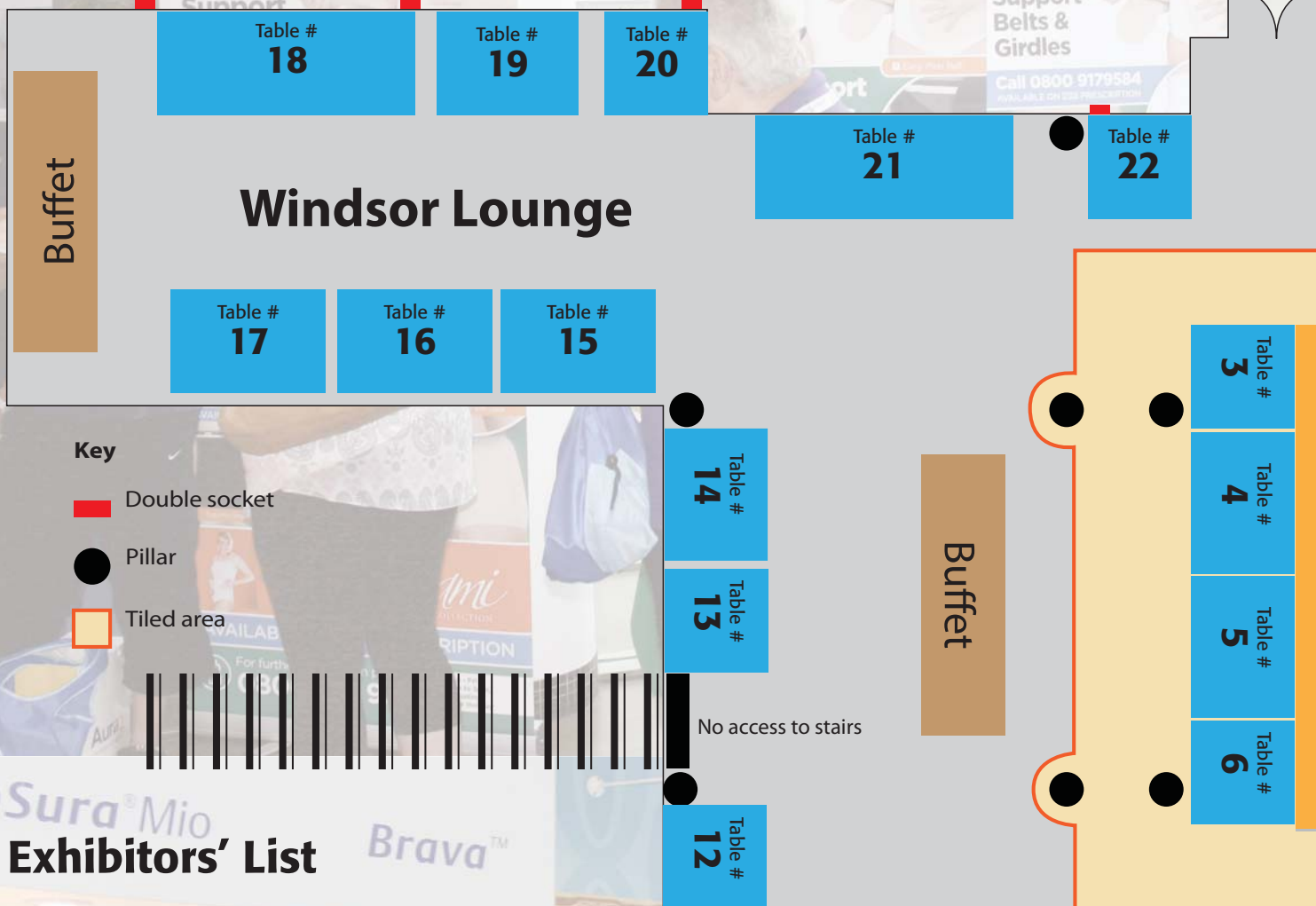
(This information will help the Colostomy Association learn more about you and how we can help – it will not be passed on to third parties)

Please return this form to: **Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA** by **11 June 2015**

Tickets for the fundraising Gala Dinner will be sent to you later in the Spring.

Look out for more information about our 2015 celebrations in the coming months!





**Exhibitors' List**

**Windsor Lounge**

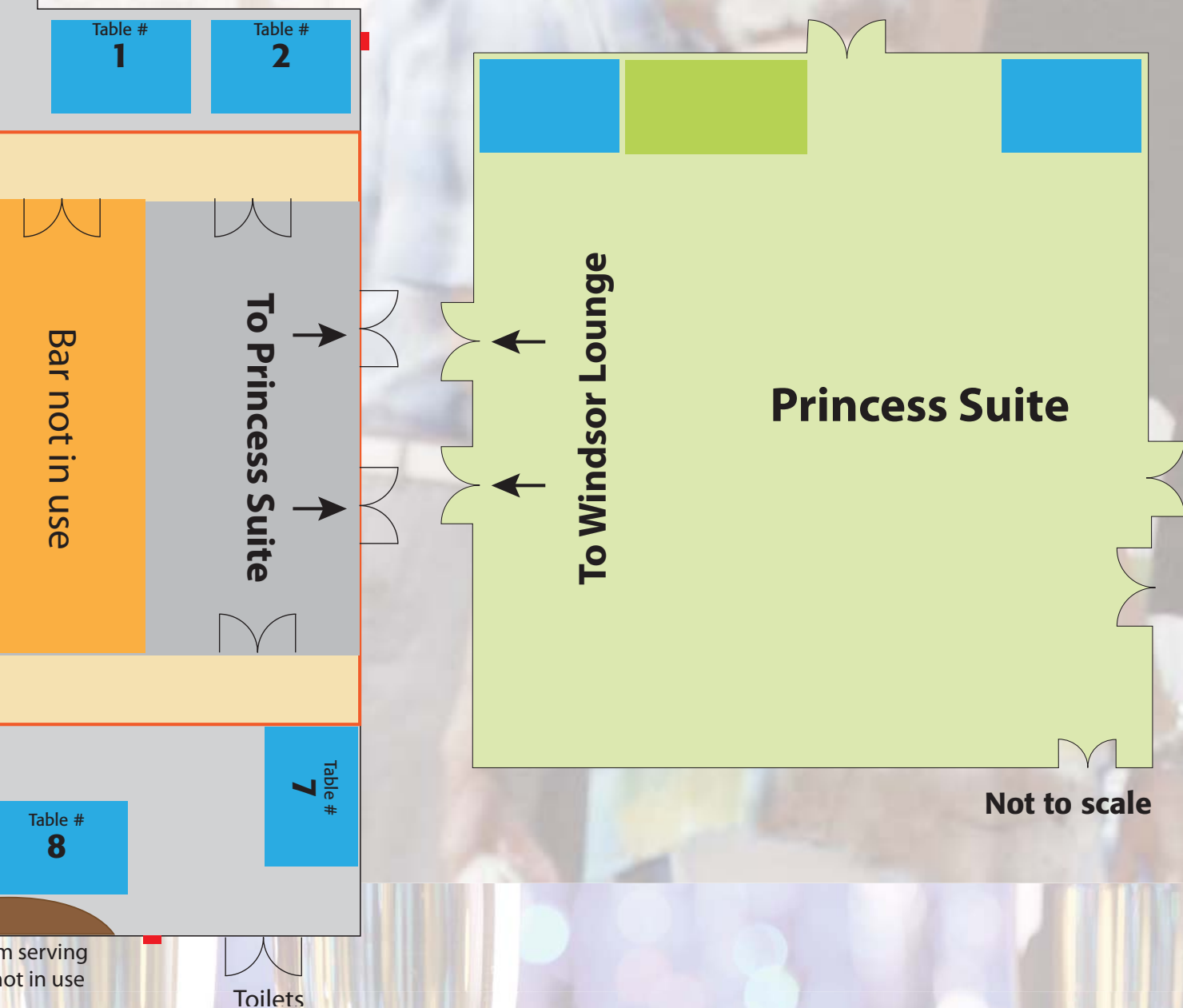
Table	Exhibitor
1	ConvaTec
2	Provisional booking
3	B Braun
4	Provisional booking
5	Bullens Healthcare
6	Bournemouth Insurance
7	Provisional booking
8	Provisional booking
9	Alliance Pharma
10	Fittleworth Medical
11	Coloplast
12	Rapidcare
13	Dansac
14	Dansac
15	Ostomart
16	Trio Healthcareform
17	AMI Medical Ltd/Suportx

**Windsor Lounge**

Table #	Exhibitor
9	
10	
11	
18	Salts
19	ClinIMed
20	ClinIMed
21	Pelican Healthcare
22	Oakmed
	Princess Suite
	Princess Suite IA
	Princess Suite UA
	Princess Suite Breakaway
	Princess Suite
	Princess Suite

# EXHIBITORS' STANDS

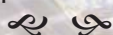
Main entrance



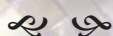
## *Fundraising Gala Dinner*

**Saturday 11th July 2015**

6:30pm to 12:30am



6:30pm – Public bar opens



7:00pm – Three Course Dinner including some wine

Cabaret Style Entertainment Acts

After Dinner Toast

After Dinner Speech

Special Awards Presentations

Car Raffle Prize Draw

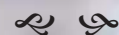
Dancing

12:30pm – Close

## *Fashion Show*

**Sunday 12th July | 10.00am to 1.00pm**

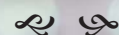
10:00am to 1:00pm



10.00am – Registration and Tea/Coffee and Biscuits

Handbag Swap

Time to view Exhibitors' stands



11.00am – Fashion Show

12.00 noon – Final Time to view Exhibitors' stands

1.00pm – Event Close

# Fundraising Gala Dinner

**Saturday 11th July 2015**

6:30pm to 12:30am – see previous page for programme

Our fundraising Gala Dinner promises to be a night of good food, great entertainment and plenty of opportunities to dance the night away. The evening starts with a delicious three-course meal, followed by a presentation ceremony for several awards including volunteers' lifetime achievement and our Purple Iris stoma care department award.

There will also be a fun photo booth for the latter part of the evening, as well as a variety of cabaret entertainment provided by *House of Beau* in between the courses. This includes the Halo Hoop Trio, Hand Balancer and the Rockabelles! Also look out for our wonderful car raffle as tickets will be sold throughout the day and the prize draw will take place during the evening. This is a 'jacket and tie' event with tickets for the fundraising dinner costing £45 per person (tables of 10).

The delicious three course dinner menu will be revealed on the night, but if you have any special dietary requirements please let us know at least two weeks' before the event.

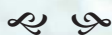


## Accommodation

A hotel is on site at the Madejski Millennium Hotel, Reading Football Club Stadium Complex if overnight accommodation is required that weekend.

Reduced rates are offered for **Friday 10th July 2015** and **Saturday 11th July 2015**. Double room, with single occupancy including breakfast at **£72 inc VAT** or double room, with double occupancy including breakfast at **£84 inc VAT**.

To book, please contact the **Hotel Reservations Team** direct on **0118 925 3500** and quote **Col 110715** to obtain the discounted prices. (Note: cancellation of room/s must be made before 2:00pm on the day of your stay.)



## Post Event Publicity

Photographs will be taken during the event by our Marketing Communications Officer and representatives from the press may be present as we hope to feature in the local newspapers. It's also planned that video footage will be taken this year to provide a record of special sections which can then go live on our YouTube account or via our website.

# Fashion Show

**Sunday 12th July | 10.00am to 1.00pm**

10:00am to 1:00pm – see previous page for programme

On Sunday morning we will be challenging perceptions of ostomates at our free fashion show. Doors open at 10.00am with refreshments and a handbag shwap activity where people are encouraged to donate any 'as new' handbags and buy another one, raising funds for the **Colostomy Association**.

There will be a chance to meet exhibitors again before the fashion show begins at 11.00am. Colostomates of all ages (one as young as 11 years of age) will be modelling a range of clothes on the catwalk and the University of Buckingham will be selling their unique eco-shade sunglasses range. The fashion show is sponsored by ConvaTec with Yvonne Frost (Image-On) acting as image consultant and the clothes are being kindly loaned by John Lewis.

Davina Jowett (front cover story) will be one of the models on our catwalk so you'll have the opportunity to meet Davina in person if you come along, as well as Aled who featured in the previous edition of Tidings!



## As-New Handbags Wanted for 'Shwap'

**Please dig out any good quality as-new handbags you no longer use and keep them on one side for the handbag shwap activity on the Sunday morning.**

It should be fun! We're hoping to raise extra funds through this unusual activity – not to mention publicity in the local papers!

If you're not able to attend, but have some clean and attractive as-new handbags that might be suitable for the stall, please bring them with you to the event or post them to the office in advance if you are not attending.

Perhaps your family and friends have suitable as-new handbags to donate too. All donations will be welcomed and will help make the bag shwap a huge success! Many thanks.

# 10th Anniversary Prize Draw

Your chance to win a New Vauxhall Corsa 1.2 Sting

# for just £1

## Even Poundland can't do that!

In this edition of *Tidings*, you'll find tickets for our special car raffle and other cash prizes. Each ticket costs **just £1** and will help raise vital funds for us. Please support us by buying as many tickets you can or by selling them onto family, friends and work colleagues. (If you'd like more stocks please contact the office and we'll be happy to despatch more!)



The car is sourced from Sonning Common Vauxhall Garage near Reading and it can be upgraded to a higher specification at the winner's discretion.

The draw will take place at the fundraising gala dinner on **Saturday 11th July 2015** so make sure you buy your tickets now or more tickets on the day itself!

To be considered for the draw submit your ticket stubs and payment by **Wednesday 8th July 2015**. Cheques must have cleared by that date. **Late entries will be considered as donations.**

Minimum transaction charge for credit card payments is £10.00. Do not send credit card details in the post – send your contact details and the office will call you to take payment over the telephone.

The car comes\* with: a CD/MP3 player and iPod control; power steering; heated windscreen; a tyre pressure monitoring system; 16" alloy wheels; tax for one year; cruise control; electric door mirrors and more.

**There are also several cash prizes on offer.**

Picture for illustration purposes only.

\*Car specifications subject to change without notice.

Charity No: 1113471  
Lottery Licence no: LOT000141

# 10th Anniversary Prize Draw

Your chance to win a car for £1

Three door hatchback • 16" alloy wheels • Taxed for 12 months  
Cruise control • Heated windscreen • Airbag • Can be upgraded

<b>CASH PRIZES • CASH PRIZES • CASH PRIZES</b>		
<b>2nd</b> <b>£500</b>	<b>3rd prize</b> <b>£250</b>	<b>4th prizes</b> <b>£50 x 5 prizes</b>

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**£1**  
Ticket  
10 per book

**1st prize**  
New Vauxhall  
Corsa



Draw date: **Saturday 11 July 2015** during the Gala Dinner event in the evening at **Royal Berkshire Conference Centre, Madejski Stadium, Reading RG2 0FL**

No tickets may be sold by or to anyone under 16 years. No tickets may be sold on the street.

Promoter: Mr Monty Taylor, Colostomy Association,  
Enterprise House, 95 London Street, Reading, RG1 4QA

all be notified by telephone, email or post and announced in the Autumn 2015 edition of *Tidings*

Registered in England and Wales No: 1113471  
Car specifications subject to change without notice. Sourced from Sonning Common Vauxhall, RG4 9PN

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First name \_\_\_\_\_  
Surname \_\_\_\_\_  
Address \_\_\_\_\_  
Postcode \_\_\_\_\_  
Tel no \_\_\_\_\_

# By way of history



**1963** A lady called Gertrude Swithenbank (herself a colostomate) is approached by a Registrar within her hospital, asking if she would be interested in making regular visits to other colostomy patients.

Gertrude's visits encourage patients' recovery as they realise she is leading a full and active life. Conversations between Frances Goodall (who was the then General Secretary of the Royal College of Nursing, and who later became Vice-President) and Gertrude Swithenbank begin. From these conversations the idea of a National Service for Colostomates is born. Frances Goodall takes up the torch and consults with surgeons, medical social workers and nurses.

**1966** The King Edwards Hospital Fund for London provides funds to conduct a pilot survey to find out if there is a need for a National Service for Colostomates and 29 hospitals take part.

**1967** The survey's findings are published and as a result the Colostomy Welfare Group (CWG) is formed and becomes a registered charity. The charity is based in two rooms at St Luke's Hospital, Chelsea. Emily Brain, responsible for conducting the survey is appointed secretary and welfare officer. Barbara Saunders becomes the first trainer of Stoma Care Nurses at St. Bartholomew's Hospital. CWG's Trust Deeds state the purpose of its service: 'To relieve suffering by providing, throughout Great Britain and Northern Ireland, a welfare service for patients who have had or are about to undergo colostomy surgery'.

**1969** The service is free to all members, and every member receives an annual letter.

**1972** The CWG move offices to Ecclestone Square, London and become an Associated Charity financed by the National Society for Cancer Relief (now known as Macmillan Cancer Support). The CWG expands with the help of a growing number of volunteers and extends support to the rest of the world by founding the International Ostomy Association.

**1987** The CWG establishes a network of area organisers and visiting volunteers, all with a colostomy.

**1989** The CWG rebrands and is now known as the 'British Colostomy Association' (BCA).

**1990** The BCA headquarters move to Station Street in Reading.. The association builds an impressive portfolio of supportive literature and runs a helpline manned by volunteers (who are all colostomates).

**1998** A BCA newsletter is introduced and distributed every six months.

**2000** The helpline becomes a 24 hour service.

**2004** Macmillan Cancer Support eventually withdraws its financial support because it is recognised that not all colostomies were formed due to cancer. However, Macmillan remains incredibly supportive by allowing the use of the existing rent free premises and office equipment. New trustees are sought.

**2005** The BCA is replaced by the **Colostomy Association**, a UK registered charity now completely self-funding, with an enthusiastic Board of Trustees at its helm. Macmillan also enables the transfer of the database, as well as rights for the BCA magazine name and literature.

**2006** Issue 1 of the association's (now quarterly) magazine *Tidings* is launched and distributed to its supporters.

**2007** A website launches to reinforce the message of the **Colostomy Association**, to provide online support, reassurance and practical information.

**2008** The **Colostomy Association** moves to new premises at London Court in Reading.

**2010** The Website is relaunched to allow easier access to the latest news and literature, together with links to travel, insurance and stoma suppliers.

**2013** The **Colostomy Association** moves to larger second floor premises at Enterprise House, 95, London Street in Reading. (Pic right)

**2014** The **Colostomy Association** launches its very own annual CA Awareness Day on the first Saturday of October.

**2015** The **Colostomy Association** celebrates 10 years in its current form and is going from strength to strength – do join us at some of the special events if you can!





# Happy Stomaversary

**“It may not have been the day she was born, but it was the day she started living.”**

**Having a stoma can be difficult but growing up with one brings its own set of challenges. As a parent of a child with a stoma your main goal is trying to make your child's life as normal and trouble-free as possible. For those looking for an example to follow, they could not find many better than Emma Boyce.**

At six years old, Beth has faced more challenges and obstacles than most adults. As a young child she faced constant problems with constipation, wore nappies 50% of the time and had frequent ‘accidents’. As a result, she was only able to attend school half the time and was missing out on both her education and many of the activities most children take for granted.

In December 2013, Great Ormond Street Hospital told Emma that after many tests they were still unable to tell what was wrong with her daughter and, to give her a better quality of life, they suggested giving her a stoma.

After a few tough months, Beth underwent stoma surgery in January 2014 and has since seen huge improvements in her quality of life; her attendance at school has improved dramatically as has her school work and she is now able to take part in activities such as swimming which she wasn't able to before.

However, there still remained the challenge of ensuring that Emma's daughter lived a normal life. The surgery enabled her to take part in school and other activities in a way she was never able to before, but what could be done to overcome the stigma of having a stoma? Ostomate children often encounter bullying, embarrassment and isolation. However, Emma has been

working hard to ensure that her daughter never faces these issues.

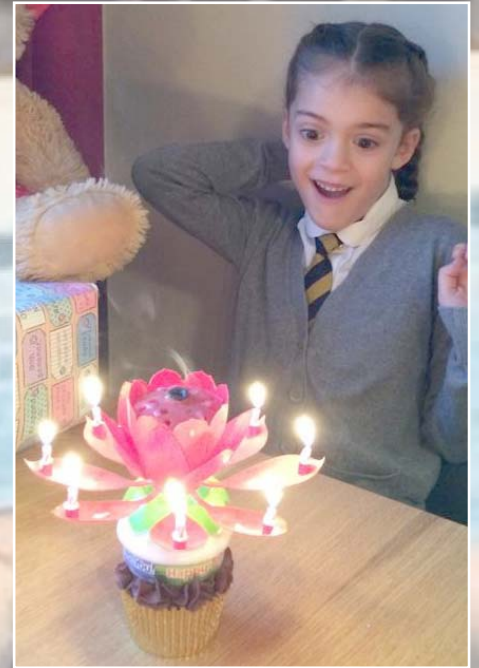
Emma met with her daughter's school to discuss how they could best accommodate Beth. She decided that it would be best to be as open and honest as possible, and in response the school was extremely supportive. Before the surgery, Beth's class had a question and answer session with her to help answer any misconceptions or questions they might have. After the surgery, Beth received cards from everyone in her class wishing her well.

Beth is now able to take part in school swimming lessons alongside her friends and, following encouragement from her school, Beth has learned how to empty her stoma bag without any supervision. The support from Beth's school and classmates has hugely increased her confidence and as a result her school work has been getting better and better.

Outside of the classroom, Beth has received an incredible amount of love and support. Although she lives with her mother, she has regular contact with her dad who attends every hospital appointment.

As a family, they now celebrate Beth's *Stomaversary* each year, Emma saying: “it may not have been the day she was born, but it was the day she started living.” The support Beth has received from her friends, family and school has given her a newfound confidence.

Speaking about what can be done to help children with a stoma, Emma said: “I think It's important for schools and parents to always speak positively about stomas. Children pick up on your emotions regarding their bag and they need positive



encouragement in order to accept and come to terms with the changes.

“We have found honesty and openness and school has really helped boost Beth's confidence, but each child is different and it's important to involve the child in any decision making regarding their care. Beth was included in meetings with the teachers, teacher's assistants and her Stoma Nurse before returning to school and had some very valuable input regarding how her Stoma was managed.”

Looking at Beth you would now not be able to distinguish her from any other happy six year old. This is thanks to the incredible hard work, love and support from her parents and school.



# Colostomy Reversal



Caroline Rudoni,  
AmCare Nurse Manager

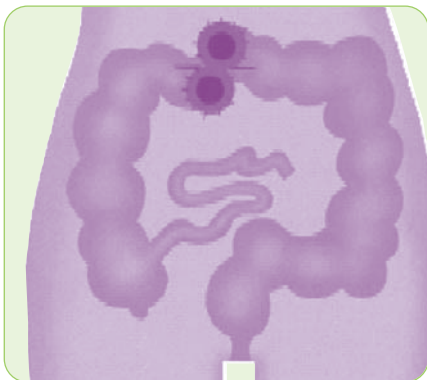
There are many conditions that can result in surgery that leads to the formation of a colostomy, and depending on the type of surgery performed you may have either a loop colostomy or an end colostomy.

**Caroline Rudoni, AmCare Nurse Manager writes:**

## Loop Colostomy

A loop colostomy is usually formed in the sigmoid colon (lower large bowel) to divert faeces away from the rectum or anus in cases of obstruction, or poor function/control. A loop colostomy may also possibly be formed in the transverse region of the colon if you have had part of the lower bowel or rectum removed. It is usually situated on the left of the lower abdomen, but depending on the area of bowel used to form the loop colostomy, it may be sited on the right side (some transverse colostomies).

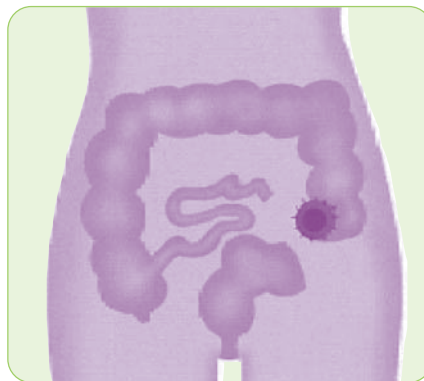
A loop colostomy is formed by bringing a loop of colon (large bowel) out through the abdominal wall and cutting half way through the bowel so it can be opened to create two sides to the colostomy – a proximal (top) loop which links to the stomach and is where faeces is expelled, and a distal (lower) loop which leads down to the anus.



Loop Colostomy

to the stomach out as a colostomy. The distal (lower) end of the bowel can be over-sewn and left inside the abdomen or can sometimes be brought out as a mucous fistula and attached to the lower end of the wound.

This type of colostomy is often formed in an emergency, particularly for problems from diverticulitis. The end colostomy may also be formed for cancer of the lower rectum and anus and has a single end as all the bowel downstream is removed.



Hartmann's Procedure

## Can the colostomy be reversed?

This is something you will need to discuss with your surgeon. Potentially it is possible to have a reversal as long as you still have some of your rectum and anus in situ, and the nerves are still intact. Your surgeon may suggest you undergo some tests on your rectum prior to deciding on a reversal. However, there may be other reasons why your surgeon would feel reluctant to reverse your colostomy, such as anaesthetic risks.

## What does the operation involve?

A loop colostomy is much easier to reverse. The surgeon will loosen the colostomy from

the edge of the skin and join the two loops of bowel back together before the intact bowel is secured back inside the abdominal cavity. The procedure will take place through the colostomy site and the skin may be closed using staples or sutures once the procedure is completed or the wound may be allowed to heal by itself. No abdominal incision will be required.

An end colostomy is more difficult to reverse. The end colostomy will be loosened from the edge of the skin and usually a small margin of bowel (1–2cm) is removed. The surgeon will then need to locate the distal end of the bowel, usually through an abdominal incision and free that part of the bowel from any adhesions which may have resulted following the initial surgery. Usually the incision is made through the same incision as your initial surgery (old scar). Once the distal part of the bowel is accessed and mobilised, a small margin of bowel will be removed so that two healthy ends of the colon can be joined together. Often due to the difficult nature of joining the colon back together a temporary loop ileostomy (a stoma from the small bowel) will be formed for 2–3 months to allow the join in the colon to heal properly and without risk of leakage. Some surgeons will offer the choice of laparoscopic (keyhole) surgery for reversal of an end colostomy. It is, however, more difficult to perform using keyhole surgery due to the adhesions from previous surgery. Whilst the operation may be started with keyhole surgery there is often the need to convert to an open operation.

## Following Surgery

Procedures following reversal differ for each surgeon and they will explain what you should expect to happen while in hospital. Typically following reversal of a loop colostomy, the surgeon will allow you to start eating and drinking as part of an enhanced recovery programme.

## End Colostomy

An end colostomy is usually formed in the sigmoid region and situated on the left side of the body. It is formed by cutting the colon all the way through creating two ends, and bringing the proximal (top) end which links

Occasionally the bowel goes into ileus following surgery, where it 'goes to sleep' and does not absorb or move the food through the gut as it should. If this happens you will not feel like eating and may require a drip to give you fluids until the bowel restarts. The function of the bowel may be a little disturbed until the anus has 'remembered what to do!' This is a temporary effect.

The wounds at the site of the old colostomy and on the abdomen (if present) will be checked to ensure they are healthy and healing well. Length of stay following reversal of a loop colostomy is around 2–5 days. For an end colostomy it is longer and can be 5–10 days. Some surgeons will wait until you have had your bowels open before you are discharged, but this is often not routine practice now.

## What to expect from your bowel function

Having your bowels open following reversal can be a different experience for everyone!

It can take a few days for your bowels to start working following surgery, and some people can experience uncomfortable wind pain during this time. If this occurs, drinking peppermint tea, fruit juice and prune juice will usually help, but occasionally laxatives are required. Sometimes traces of blood may be passed when you have your bowels open initially – this is not uncommon and should clear after a few bowel actions.

In general most people do find that their bowel habit will differ from how it was prior to having a colostomy formed. Your bowel habit can be unpredictable initially following surgery but this does usually improve within 3–6 months. However, if you have had a segment of lower bowel removed, thus making your bowel shorter in length, or if you have had chemotherapy or radiotherapy you may find that your bowel takes longer to settle and you may adopt a different bowel pattern. Patients who have had a significant section of their rectum removed can develop symptoms of Low Anterior Resection Syndrome (LARS). If you have received chemotherapy and/or radiotherapy as part of your treatment, this can also affect the ability of the anal sphincter to work correctly.

## Changes in bowel habit

You may experience one or more of the following changes to your bowel habit following reversal of your colostomy:

- Change in frequency - the number of times you have your bowels open during the day
- Urgency to open your bowels - a sudden need to go to the toilet to have your bowels open
- Diarrhoea – a much looser or watery stool than you previously passed

- Constipation – a harder stool which may be difficult to pass. This can be due to a narrowing of the join (anastomosis) where the colostomy was reversed. Sometimes scarring occurs at the join and this can cause the bowel to be less flexible and quite rigid, which causes tightening and narrowing of the bowel and can in some cases result in partial or full obstruction of the bowel.
- Fragmentation – where you only pass a small amount of stool but do not feel you have completely emptied your bowel. This can result in a number of visits to the toilet during the day to have your bowels open. This often happens if part of the rectum has been removed and is referred to as clustering, where you may return to the toilet a number of times in a short period.
- Leakage of stool from your anus – it is important to do pelvic floor exercises to ensure the sphincter muscle at the anus have good control.
- Difficulty in distinguishing whether you need to pass wind or stool.

## Diarrhoea

If you do experience diarrhoea or soft stool following reversal, you may find you get sore around your back passage where the loose stool irritates the skin. Following each bowel action it is important to wash the area well with water or use a moist toilet wipe which can be flushed away. Once you have cleaned the area gently, dry and apply a barrier cream or barrier skin protective wipe.

Some people (both male and female) chose to wear a small pad (panty liner/sanitary towel) in their underwear if they are anxious about any leakage.

## Diet

Generally you will be encouraged to return to your usual diet. However, if you experience problems with your bowels post reversal you may be given dietary and fluid advice to help with your problems.

Foods containing fibre can have an effect on your bowel action.

Fibre can be used to bulk your stool if you have diarrhoea/soft stool; but if taken with lots of fluid the fibre can cause your bowels to work more frequently. Fibre should be adjusted, depending on your bowel action.

Some people find that drinking lots of caffeine will also make their stool looser or lead to urgency. If this occurs you may wish to reduce the amount of tea and coffee you drink, or use decaffeinated versions.

As with any operation, some people will have a great experience following reversal of their colostomy whilst others may experience a number of difficulties. If you do experience problems do contact your stoma care or colorectal nurse who will be able to give you advice.

## The Surgeon's Perspective



Ian Daniels FRCS

**If a colostomy has been formed as part of an emergency operation, or to remove a cancer of the lower bowel, when I am discussing the potential of 'putting someone back together' I ask them about the issues of a 'controllable mess' (stoma) versus 'an uncontrollable bottom' (re-connected). These views of course represent the extremes of the spectrum for patients.**

Life with a well-formed, secure colostomy can lead to improvements in quality of life, an independence that may be reversed by an operation to connect the bowel back together. This is, of course, contrasted by patients with poorly constructed stomas who have difficulty in securing an appliance, concern about body image and a desire to be 'normal'. Outcome is greatly influenced by function before the surgery and the condition that led to the colostomy... No two people are the same.

There is also no clear definition as to when a colostomy should be reversed as it depends upon other aspects of health and any other treatment, such as chemotherapy etc. Indeed, a colostomy may be reversed many years down the line, but only after careful assessment.

Any patient considering surgery to reverse a colostomy should seek advice from their surgical team, not just about the immediate surgery, but also the potential complications from surgery, such as anastomotic leakage, hernia formation and the need for a temporary ileostomy, as well as the risks and the changes in function they may experience in the short and longer term.



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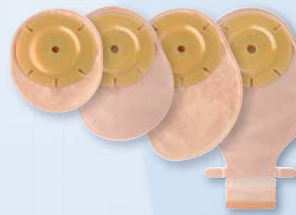
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<sup>Δ</sup>Data on file at Salts Healthcare Ltd.

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# To reverse or not to reverse?

Thank you to everyone who responded to our request for experiences of stoma reversal. We are not able to include them all and will be holding some over for future editions of *Tidings*.

In this issue we are publishing Catherine's article about how she felt as she waited for a reversal and whether she made the right decision. We have also selected quotes from other articles to illustrate the fact that ostomates have different medical and surgical histories which means that the outcome of reversal surgery will vary.



Catherine Sommer

**As for so many other ostomates, my colostomy was an unwelcome surprise. A slight dull ache in the lower abdomen in June 2012 led to an ultrasound scan in July, then in August severe pain, sickness, and brief hospitalisation with a diagnosis of diverticulitis, followed by a sigh of relief, as the antibiotics appeared to have worked.**

Violent pain at the end of September took me back to hospital with a perforated bowel, and on 4 October 2012 I woke up after a Hartmann's procedure, with a bag and a row of 40 staples down my tummy. I had been very lucky. I was still alive.

A stoma seemed like the knell of doom, but the surgeon comforted me by saying that it was probably reversible, quoting 6 to 12 months. The stoma nurse provided plenty of information – possibly too much in the early days, when I couldn't take it all in – but she did recommend that I contact the **Colostomy Association**. This was excellent advice, and I greatly appreciated the brochures they sent me, *Tidings* magazine with its valuable free samples, and the online information I found. I discovered YouTube videos of how other people coped with their stomas, and felt less alone.

Best of all was the discovery of the **Colostomy Association's** closed Facebook group; other people dealing with the same problems and questions I had. Helpful tips and hints from these new friends made living with a colostomy very much easier, and I realised how fortunate I was; most of these wonderful people were suffering far worse than me, but their cheerfulness, humour, love and general empathy was incredibly uplifting.

As the days lengthened into months, I quickly grew used to my new condition, and discovered I could eat and drink virtually anything, including curry and fish, which can be difficult for some people. A glass of champagne turned my bag into a balloon, but drainable bags solved that problem (and others). Mushrooms or sweet corn emerged in much the same state as they had gone in, but I had no digestive issues at all. The only negative thing was that I developed a hernia that soon grew to the size of a melon.

My routine consultation with the surgeon after six months showed that I was making good progress, but wasn't yet ready for reversal. I was a little disappointed, but I'd adjusted to living with a stoma, and it made very little difference to my everyday life. At the next consultation, almost a year after my operation, I was sent for a colonoscopy through the stoma. Unlike the previous rectal colonoscopy, excruciating in spite of gas and air, this colonoscopy was only slightly uncomfortable and it showed that I was suitable for reversal.

Of course, I took that as good news.

I personally knew two people who had had a reversal, and they both assured me that they were fine and 'back to normal'. But I am in my seventies, and they were both younger than me when they had the procedure. Then I started to read up on the

subject, and noticed the comments that were being made on **Colostomy Association** Facebook by those who had been reversed, known jokingly as 'Dysons' because they were now bagless. These 'Dysons' had mixed reports – some had gone back to normal life pretty quickly, but others were suffering from cramps and complaining of pain months afterwards or had had complications due to infections. Some had no sphincter control and were faecally incontinent, others even went so far as to have their reversal reversed, and were relieved to get a new stoma. Disaster after disaster popped up on the Internet.

I found all of this disconcerting and unsettling. I read the leaflet from the hospital, which listed the possible risks. Of course, the hospital has to inform patients of all risks involved in surgery, but when you read '4% chance of death' it does give you pause for thought.

To reverse or not to reverse? That was the question.

My next visit to the consultant was in February 2014, and at that point I had to give my answer. I weighed all the horror stories against the advantages of being bagless, and decided that nothing ventured, nothing gained. My name went onto the list, and I felt committed to my decision.

The colorectal department was obviously very busy. Although I was supposed to have surgery within 18 weeks, I heard nothing. Spring turned into summer, and summer into autumn. I didn't mind, my colostomy was not a huge disadvantage. By late September I was on the point of phoning to say they should take me off the list as I could live quite happily as an ostomate for the rest of my life, when the hospital rang me and said that my surgery was scheduled for the following Friday, 3 October 2014. I

CONTINUED ON PAGE 39, COLUMN 1

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CONTINUED FROM PAGE 37, COLUMN 3

dithered frantically for two days, but eventually decided to go ahead. It was exactly two years since my Hartmann's; same surgeon, same ward, even some of the same nursing staff, who remembered me. I had been prepared to experience a similar sequence of events as before, but this time I had a pleasant surprise. Firstly, the operation took only three and a half hours as compared to seven the first time. Secondly, this time round I was in much better physical shape, healthy and relatively fit, so my recovery was correspondingly quicker. In fact, convalescence time was more than halved. Thirdly, I had only 34 staples down my tummy, starting at the waist, so I could actually bend! And my hernia had gone.

To my great joy, I passed wind 30 hours after leaving theatre, and five days after the operation my bowels were working, meaning I could go home. By the end of October I was able to resume my normal routine and needed no extra help. The district nurse came in regularly to pack the wound where my stoma had been, and on 23 December this too had completed healed and I was discharged. A great Christmas present!

It was hard to believe that, after all my misgivings and apprehension, the surgery had been such a complete and utter success. I kept waiting for something to go wrong; surely, it can't be as simple as this! But it is. My intestines are reconnected. Everything works perfectly, including sphincter control. I'm careful not to lift or carry anything heavy that could cause another hernia, but to be perfectly honest if it weren't for the scars on my tummy, which are now also fading, I would think it had all been a dream and I had never had a colostomy at all.

Of course, every one of us is different and some have better chances than others. You can live a perfectly normal life with a colostomy, and I am grateful that I had this experience, which has been enriching in many ways and made me so much more aware of invisible disabilities. But if you have the option of a reversal, I would say: "Take it!" Especially if, like me, you have recovered from the condition that caused you to have the stoma in the first place and are otherwise in good health.

Yes, there are risks and you hear tales of failed reversals, but I am sure that the success rate is greater. And why should you not be one of the successes? As I said before, nothing ventured, nothing gained. Thank you to my surgeon who persuaded me to say yes. I am so glad I overcame my fears and had the reversal.

Other readers wrote to tell us that their experience following a stoma reversal wasn't quite as they'd expected. Here are some quotes from their stories.

## Ken Drake

**"I was originally diagnosed with bowel cancer in June 2000 and was told that I would probably have an ileostomy... the operation was carried out shortly afterwards. It was only later that I recall being told that I could have it reversed and naturally this seemed a good thing to have done although I do not recall any discussion about the possible outcomes of this reversal operation, so we went ahead with it in March 2001.**

"It was great not to have the bag there anymore and although I initially struggled with managing without the bag I was assured that in time I would get used to it and that my sphincter muscles would start working as they had previously. However, in my case they didn't... I continued like this for over a year but still made no progress. My surgeon said that he felt that in my circumstances the only solution was to give me a colostomy. That was the last thing I wanted. Nevertheless I could not continue as I was. On the other hand, to be fair, there were some periods when life was great and I could stray from the toilet without fear of an accident. Nevertheless the bad periods were such that we decided to go ahead with the surgeon's advice. In the days leading up to that operation I was enjoying one of my good spells... Perhaps I didn't need this operation after all. Then the hospital informed me that my operation had to be cancelled as there were no beds available. What a relief! Shortly after that I had one of those bad spells again. That was just what I wanted. I now knew that next time I was due for this colostomy operation I would have no more doubts. I have now had a permanent colostomy for 12 years and... I have been able to carry on with living my life to the full and am thoroughly enjoying it."

## Pauline Morgan

**"In January 2008 I was diagnosed with cancer of the rectum. I underwent radiotherapy, followed by seven hours of surgery. A loop ileostomy was formed to give the area where the cancer had been removed a chance to 'rest'. My recovery was hampered by seepage into my pelvis, which caused sepsis and a large abscess. After my operation I had six months of chemotherapy treatment, then in March 2009, following a CT scan and colonoscopy via my rectum, I was told all was clear and I was put on the waiting list for a reversal.**

"I had my operation in July 2009. The actual reversal operation wasn't painful, and my scar, which was closed using glue externally, can now hardly be seen. After a day I was allowed to slowly introduce food, then after two days I passed a motion from my bottom. A week later I was told I had to have another stoma because the reversal hadn't worked, and I again had sepsis. This time it was a colostomy... I was unlucky in that the reversal failed, but this was due to radiotherapy treatment I had received. I think the initial reason for the stoma, and treatment received had some bearing on the result.

"In May 2013 I spoke with my stoma nurse about irrigation and saw my surgeon who agreed I could try. He also said after five years I might now be suitable for a reversal. He did a colonoscopy, but told me right away that in his opinion it would not work. I would be left incontinent. I was obviously disappointed, but I cope well with my bag and, since irrigating, I sometimes forget I have a stoma."

## Chris Moore

**"In February 2007 I had a Hartmann's procedure which removed 25cm of bowel, closed off the rectum and formed an end stoma. It gave me very little trouble. I did however find it annoying at times. In June 2008, I asked about the possibility of reversal. I was given a colonoscopy through the stoma and a CT scan and, after some discussion, the consultant agreed to do it.**

"In September 2008 the surgeon opened me up along the line of the original operation and reconnected my bowel. In doing this, however, he got into difficulty with adhesions and had to remove part of the small intestine to free space for doing the reconnection. I was in hospital for about a week. Eventually with the help of laxatives the bowel started working again, but there were problems with my urinary system and I needed a catheter. It was good to return home, but I had problems controlling my bowels. I was referred to the incontinence nurse, who was a great help and gave me exercises to strengthen my pelvic floor muscles. So by about the end of January 2009 everything was getting under control.

"Over the next two years I was able to get up to speed again. Then towards the end of 2010 I started to suffer from bloating

CONTINUED ON PAGE 40, COLUMN 1

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and abdominal pain. This was due to a stricture at the join in the bowel and it took about six months of repeated and painful visits to the hospital to get it under control. Since then, it has required balloon dilation every two years, but I have been able to lead a normal life, with a few limitations – daily use of lactulose, and other softeners when needed, to ensure that there is a good flow through the stricture, and avoidance of foods that may not reduce to a mushy form such as some fruit skins and sweetcorn.

“Despite the hassle of the last few years, I am pleased that my stoma was reversed. However, if I needed a stoma again, then it would not worry me too much.”

*Maybe you feel the quotes above focus on the problems that can occur. However, do remember that the majority of ostomates who have had reversals no longer read Tidings. They have moved on with their lives and do not feel the need to share their experiences through the pages of the magazine, or on the internet.*

As well as volunteers who are ostomates, **The Colostomy Association**, also has those who are ex-ostomates. We asked two of them to tell us about their reversals:

## Dennis Pilmoor

“In January 2011 I was diagnosed with cancer of the bowel and within two weeks I had an operation. I was told that it had all gone well and I was sent home from a private hospital three days later. Unfortunately after three days at home I became very poorly and my wife phoned the hospital who then told her to bring me back to hospital. After various tests I was told that I had peritonitis caused by the joint leaking inside after the bowel resection. I had another operation and woke up with a colostomy.

“Fourteen month later I was told that I could have a reversal which would involve me having an ileostomy while my bowel healed, so the surgeon was sure that the join in the bowel was sound. After three months I had an operation to reverse the ileostomy. All went well and I was then able to use my bowel once more. I feel I made the right decision to have the reversal even though it was a painful operation and took a while to recover. I still have problems with soreness around the rectum. I need to take Loperamide every day and I can’t eat big meals then leave the house, but my toileting habits are regular and I am happy.”

## Muriel Findlay

“I had bowel cancer and required emergency surgery for a perforated bowel in March 2003. A colostomy wasn’t that bad; I accepted I would have it for the rest of my life. Two and a half years later my surgeon told me he’d like to try a reversal. However, he warned me that when he operated he might find he couldn’t do it after all. I told myself if that happened I’d just carry on. I’d be disappointed but it wouldn’t be the end of the world.

“The reversal was in July 2007. They went in through the same scar and re-joined my bowel, and to allow the join to heal they formed a temporary ileostomy. The ileostomy was closed four months later. I felt a bit apprehensive as after two and a half years with a stoma I would be opening my bowels in the normal way. At first I was passing motions more frequently and did have a couple of mishaps. However, once I got home and returned to my normal diet I found that my bowels behaved better than they had before I had my stoma; then, I had alternating bouts of constipation and diarrhoea – now I went every day at the same time.”

Of the calls, letters and e-mails received to cancel *Tidings* (Jan 2011 – Jan 2015) 243 gave reversal as the reason. Many of these ex-ostomates told us of the success of their operation.

At head office we receive a number of calls from ostomates trying to decide whether to go ahead with a reversal. Muriel and Dennis are happy to speak to those facing a reversal and also to anyone with concerns in the early stages after surgery.

# Legacy donation

## A gift in your Will

If you are about to make a Will, or are considering making a change to your current Will, please consider leaving a legacy to the **Colostomy Association**. Your legacy could secure the Association’s future and provide continued support to all those ‘living with a colostomy’ present and in the future.

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Draws will take place at the end of March, June, September and December and winners will be notified shortly thereafter.

Membership is restricted to the first 500 applicants so don't delay.



For more information contact us on **0118 939 1537** or download the form: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

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Anonymous	£ 34.00
Ms Ferridge	£ 17.00
Anonymous	£ 17.00
Anonymous	£ 17.00

**NOTE:**

The following people kindly donated all or part of their winnings back to the Colostomy Association: Mr Omar donated £50; Mrs Harrington donated £34; Mr Salt donated £68.

### Get your chance to win with the 500 Club

Simply complete and cut out this standing order mandate, as soon as possible and return it to:

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

**Colostomy Association:**  
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### 500 Club entry form

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# Junior Ostomy Support Helpline (JOSH)



**Building on our existing team of JOSH parents, several more new helpliners were trained in late January 2015.**

Pictured here are some of the newest recruits with presenters and **Colostomy Association** Trustees, Wendy Hetherington and Amanda Gunning at the training session at our offices in Reading. (Presentations were also given by Helen Bracey, Trainer, Ostomy Lifestyle.) Wendy works for CliniMed and she has been the leading light in setting up this vital new helpline for parents and carers of children with a bowel or bladder dysfunction while Amanda is the Team Leader in Clinical Nursing Services with Hollister.

Wendy says: "It's been great to launch this much needed helpline as it is estimated 1,500 children are born every year with a bowel or bladder disorder – that's four babies each day. It's so important that parents or carers have somebody to turn to who can relate to their own situation and can help them through any emotional difficulties they are facing themselves or to help them developing coping strategies to support their children from birth right up to their teenage years."

Fundraising is underway to cover the cost of a further training session planned for

Birmingham in the Spring and for a range of other resources.

To reach a JOSH volunteer, please call the 24 hour **Colostomy Association** helpline on **0800 328 4257** and ask for a JOSH helpliner to ring you back. You will then be matched to a specific JOSH volunteer who will be able to relate to your situation and help you deal with any specific concerns. The JOSH helpliner will then ring you back at a time convenient to you both and this could be an evening or a weekend for instance. Do get in touch!



## Photo ID Card

The **Colostomy Association** 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 **Colostomy Association** 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 can be downloaded from our website: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

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

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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 **Colostomy Association** office via the following methods:

Telephone: **0118 939 1537** or Email: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk))

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**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: \_\_\_\_\_



Please **tick** 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 a charge of **£6.50** (including postage and packing) and enclose a passport photograph.

**NOTE:** Please send a copy of your prescription/recent delivery note as proof of eligibility and make the cheque payable to: **Colostomy Association**.

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# Facebook Group

## Three years on



Photo: Ian Jackson

L-R: Michael McCaughey, Sarah Squire, Natalie Slow, Steve Clark, Sally Armstrong, Ian Jackson

**Sarah Squire writes:** Just three years after changing the CA Facebook group to a "Closed" group, we are very proud to say we have a hugely successful support group with a membership of over 3,000!

Changing the privacy setting to make the group closed meant that members could post on the group, safe in the knowledge that their other Facebook friends could not see what was being said. Let's face it, I don't necessarily want my old school friends to see me talking about an issue I might be having with poo!

New members are warmly welcomed and some choose to sit quietly for a while which is fine of course. Others arrive with a particular issue and group members are on it within minutes, advising from their own experiences.

Over and over again we see someone arrive in tatters and feel their relief on finding others who have walked a mile in their shoes. It isn't all problems and sadness though – we have a lot of laughs along the way and I have met friends for life on the group.

As the group has grown, the job of the Admin has become more time consuming. I am certainly not complaining – I love being an admin on the group but as numbers increased we felt the team needed to grow too.

Last year I introduced three new admins to *Tidings* readers: Ian Jackson; Natalie Slow; and Steve Clark. They have been brilliant

additions to the team and are a huge help. As we approached 3,000 members though, we felt a couple more admins would be helpful. It didn't take long to come up with some names and I am delighted to say that Michael McCaughey and Sally Armstrong are now part of Team Admin. They have fitted right in with the team and we are all working really well together.

**Sally writes:** Hi, I'm 62, married with two grown-up sons, and looking forward to the arrival of my first grandchild very soon. I live near Watford, Hertfordshire, and my main hobbies are gardening and photography.

I have a permanent colostomy after being diagnosed with bowel cancer five years ago. I recently learnt to irrigate, with lots of encouragement and advice from group members, and it has been life-changing! I was so pleased to be invited to join the admin team of our Facebook Group, which has been a huge support to me, and am looking forward to helping out in any way I can.

**Michael writes:** Hi I'm 64 and have been married to Audrey for 45 years. We have a son and daughter, one grandson aged 3 and another due soon.

I started work aged 15 years and had my own business by the time I was 26. I retired in 2006 and now we enjoy holidays plus I love gardening and am a good cook! In 2013, I woke in hospital with a perforated bowel. I had no idea what a colostomy or a stoma was but with Audrey's help and

support we did well. I was lucky enough to be reversed in 2014 but decided to stay with the group and do my best to help others. I was surprised and honoured to be asked to join our admin team and I'm enjoying it very much.

With the expanded admin team, we felt this was a good time to build on training too, and on a Saturday in January this year we all met at the **Colostomy Association** office in Reading to go over a number of Facebook related subjects but also to refresh everyone on **Colostomy Association** Volunteer training. We are very grateful to **Colostomy Association** Trustee and stoma nurse Mandy Gunning who joined us for the day and helped by presenting part of the session. So we are proud to say that all CA Facebook Admins have completed an up to date Volunteer training course. Plus I must admit, just to be able to get everyone in one room together for the first time was brilliant, and made me realise what a great team we have. We are all different ages, from different backgrounds and different parts of the country but we all agree that the CA Facebook group should be a happy, safe, friendly place for members to offer and receive support.

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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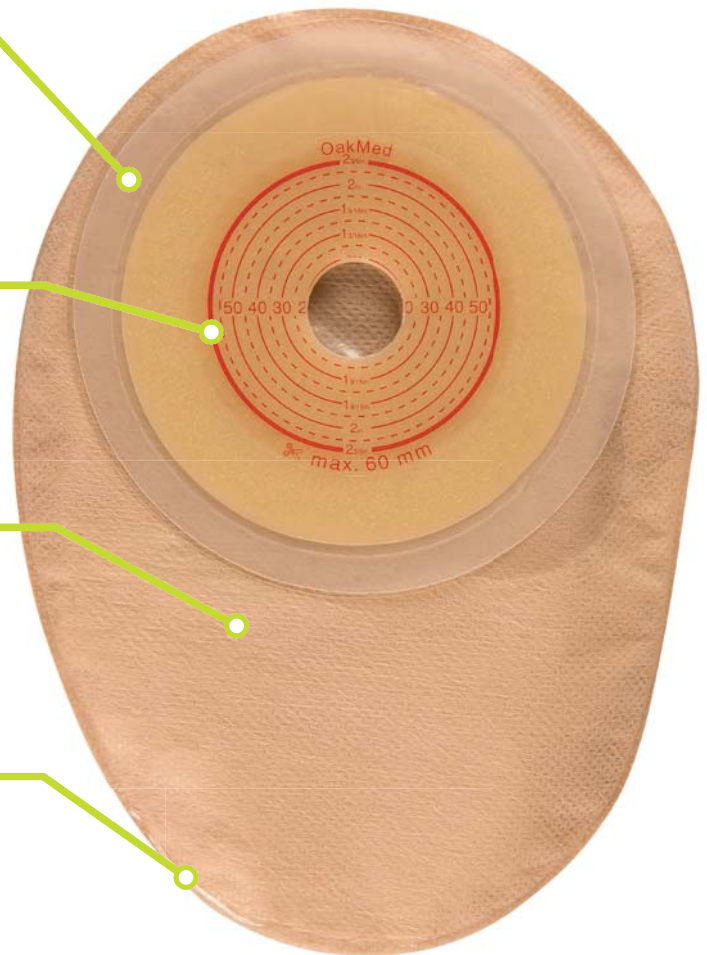


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**"This was a very difficult time and was a lot to take in"**

It's the start of another busy year for Breakaway. As well as organising our two family activity weekends this year, and a number of regional Information days to help spread the word about Breakaway, we have also started planning for 2016 as Breakaway will be ten years old next year.

So only a year younger than the **Colostomy Association**, but a long way to go to reach the dizzy heights of IA who turn sixty next year. By the time that Breakaway is sixty, we'll have retired, well actually we'll be dead! Even Hannah, the inspiration for Breakaway will have retired! We have got some amazing children out there, and who knows which one of them will be running Breakaway in sixty years time?

We've also been delighted to announce the appointment of two new trustees, joining Julie Bastin, Ron Bastin and Sue Blackwell. Beverley Stacey and Jason Somers. Bev is a long time reader of *Tidings* as her son Max has had a colostomy since just after he was



born, he's now a cheeky six year old, with some cracking dance moves, it's a pity *Tidings* isn't video enabled, you'd love him! Bev's been involved with Breakaway for a few years now, and we were delighted to ask her (and her notebook!) to join the trustees. Jason is a newer recruit to Breakaway, but he's already raised thousands of pounds for us, his son Toby is also six and has an Ileostomy due to Hirschsprungs, Toby could give Max a run for his money in the dancing stakes! It's great to have some new people with lots of good ideas, and enthusiasm.

We're planning another volunteer training session later in the year, as we've had some fantastic new parent volunteers wanting to join us. We're delighted that Anne Demick has agreed to run our training once again, our last training day was really well received. Our volunteers are such a diverse bunch, between them they have experience of every kind of Stoma, as well as the conditions that lead to them, from the very common to the very rare. You'd be hard pushed to contact us and us not be able to put you in contact with someone who really does understand from first-hand experience.

Our two family weekends are the 1st-5th May at the YHA National Forest in Moira, Derbyshire, and the 28th-31st of August at Woodrow High House in Amersham, Buckinghamshire. The weekends are a wonderful opportunity for families to get together, for parents to talk to other parents who really understand what they are going through, and for the children to not only have a great time, but to realise that they are not the only child with a Stoma. It's not too late to book, though by the time you read this there will be limited availability for

May. Check out the details on the website or Facebook and email us for a booking form. We'll leave you with the words of a family who came last year for the first time: "I really wanted my son to meet other kids with a Stoma as he was starting to feel really different to all his class mates, and apart from when we were in hospital we'd not met anyone else with a bag. We were all so nervous, but that soon disappeared. You couldn't help but be inspired by all the kids running around having fun together, and talking so openly about their bags and different conditions. As parents it was so brilliant to be able to sit and relax over a beer and talk to people who understood. It can be so hard when your friends don't understand what it's like to have a child with a Stoma, but since going to Breakaway we have a whole bunch of new friends who do understand, and who we can keep in touch with via Facebook. Breakaway has made such a difference to our lives, I don't know where we'd be without it."



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- Can be sprayed at any angle
- Conveniently sized 50ml spray



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# What Should I Eat?

**Sophie Medlin, registered dietitian and lecturer in dietetics at Plymouth University answers some of the questions that are frequently asked on the Colostomy Association Helpline.**



**Q:** *Do people with a colostomy have to follow a special diet?*

**A:** There is no special diet for people with stomas despite what others might tell you. In the first four to six weeks after your surgery, you may still be a little swollen and for this time it would be worth being careful of foods with skins, peels and pips. When you have fully recovered from your surgery you should get back to enjoying a normal, healthy balanced diet.

**Q:** *How can I work out which foods affect my stoma?*

**A:** The best way to do this is to keep a record of what you are eating and drinking and what your output has been like, to identify any patterns. If you are struggling to pinpoint the problem show it to your stoma nurse or dietitian.

**Q:** *Why are some foods more likely to cause wind than others?*

**A:** Some of the things we eat such as the skins of peas and sweetcorn, the peel in marmalade and pips in tomatoes, are not digested in the small bowel at all; this is why ileostomates will see them whole in their bag. These foods travel into the large bowel where bacteria ferment them. This fermentation process, in the same way that fermented beer becomes gassy, creates gases in our bowel which need to come out. There has been some new research showing that certain sugars we get from many

different foods can add to this problem. These are called FODMAPs. If you find you have a particular problem with gas and you can't work out which foods are causing it ask your GP to refer you to a dietitian for advice.

**Q:** *How is it best to treat a short episode of diarrhoea?*

**A:** It is best to treat a short episode of diarrhoea (24–48 hours) in the same way as you normally would by sipping at least 2 litres of fluids throughout the day. If you have an ileostomy you will be losing a lot of salt so make sure you use fluids that contain salt such as rehydration sachets or sports recovery drinks with a little added salt; drinking plain water or non-salty drinks will make you more dehydrated and thirsty. During this time you may well tolerate plain foods better than rich foods but there is nothing in particular to avoid. If the diarrhoea goes on for longer than 48 hours or you are very thirsty and lethargic it is worth contacting your doctor as you may need more help in managing dehydration.

**Q:** *What advice would you give to an ostomate who always has a fairly liquid output from their stoma?*

**A:** As long as your output is less than 1,000ml per day, be reassured that your body will be able to cope with this liquid output. If it is bothering you, you could try some of these simple dietary measures:

- include arrowroot biscuits which thicken the stool;
- separate out food and fluid so you aren't drinking at the same time as eating;
- avoid drinking large amounts of fruit juice;
- switch to decaffeinated tea and coffee; and
- avoid artificial sweeteners.

If you find it is troublesome and unmanageable you may wish to discuss the possibility of using sachets from your stoma nurse, or anti-diarrhoeal medication from your GP. It is also worth getting your GP to check that none of your medications cause diarrhoea.

**Q:** *After my reversal will I be able to go back to eating as I did before I had my stoma?*

**A:** Initially the join in your bowel might be swollen. It would be sensible for the first month to avoid skins, peels and pips and slowly introduce them back into your diet when you feel you have recovered from your surgery. In the long term you should get back to eating and drinking a normal diet and enjoying your food.

## In the next issue

Sophie answers questions on eating abroad, vitamins and probiotics.

# 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 am 64 and have had a colostomy for 20 years due to colon cancer. For 18 years or so I had little or no problems in dealing with my stoma as long as I ate a good amount of fibre with plenty fruit and vegetables and avoided constipation. I also have had a stomach acidity problem on and off throughout this time and have been on various strengths of Omeprazole.*

*Within the last two years or so my output has gradually changed. It seems that I can no longer eat much fruit, vegetables or fruit juice without it resulting in very soft stools and sometimes diarrhoea. Fruit was always a favourite part of my diet and I really miss it and wonder if I am getting enough vitamins without this part of my diet.*

*I am told by my GP that Omeprazole can cause diarrhoea but considering I have been on it for many years and had no problem in the past, I am not sure that this is the answer. It certainly makes managing my stoma a lot more tricky and I worry about odour now whereas I never really had a problem with it before. I find I have to change my bag (the Coloplast Assura/Sensura two-piece system) a lot more frequently due to odour.*

*I am losing my confidence a bit and would really appreciate your views as to why this is happening. I am wondering if you have heard of this problem from other ostomates*

**A:** Obviously as we age our appetites change and we may find that our bodies cope differently with foods we previously had no issue with. However, your situation does sound quite extreme. I don't have a complete answer for you

but I would suggest you keep a food/drink diary and include how often you change your pouch and the consistency of the motion. Once you have done this for several weeks, I would make an appointment to see your stoma care nurse to see if there is anything she can offer. Also ask for a review with your GP to see if a referral to a dietitian would be appropriate. I would also say that if you have any other signs and symptoms such as blood in the stool or loss of weight then seek an early appointment with your doctor as this change in bowel habit appears to have been present for a while.

**Q:** *I had a colostomy in January last year to help deal with incontinence due to a combination of childbirth damage and sclerosis of the digestive system. Things*

*were fine for seven weeks, then it suddenly prolapsed. When I discovered it, I was in the toilet at a busy railway station, had no idea what it was and whether I should rush to A&E or try to cope. In the end, of course, it was the latter and somehow I survived the journey home.*

*My stoma nurse and surgeon agreed I couldn't really live with it, partly due to the risk of damage, the difficulty of changing pouches and the stress it was causing. I had more surgery in May to 'repair' it – what a relief – for a while. But eight months after the 'repair' it is starting to peek out again. It's not too bad and perfectly manageable at the moment but very gradually getting worse. It is aggravated by any kind of bending, even just tying shoelaces, and bending and lifting together are a definite no, no. It prefers me to sit around and do nothing which is tempting but probably not the long term answer, especially as my gorgeous two year old grandson just has to be played with and my garden is beginning to let out strong hints that it will soon be spring!*

*I have been advised that putting on weight would help to hold it in but my sclerosis makes eating difficult. The surgeon who did the repair commented that if it's happened once it will almost certainly happen again and unfortunately he seems to be right. I hoped it wouldn't be so soon though.*

*I would be so grateful for any advice or experience you, or other ostomates, may have to offer. I really don't want more surgery and I feel like I've already cost the NHS too much.*

**A:** Cost to the NHS should not be at the forefront of your mind. If you have this sort of problem then you need to listen to the advice of the surgeon and if he suggests surgery then you need to consider it. If you are managing a prolapse at the moment then you need to continue with what you are doing. You are correct in that lifting and bending will aggravate the issue and really other than avoiding lifting and bending there is not a great deal else you can do. The surgeon is correct; the fact that you have had one prolapse increases the chances that it will happen again. I believe there is a specialist prolapse belt available, although I have never had to use it on a patient but your own stoma care nurse may be able to find out about it. I'm sorry I cannot give you any definitive advice but I think you are doing all the correct things at the moment.

**Q:** *I love long hot bubbly baths. As I irrigate, I could obviously leave my stoma bare, with no risk of output. I am sure the skin around my stoma would benefit from a nice warm soak but are there any potential problems for the stoma itself?*

**A:** It is alright to have a bath when you are not wearing a pouch. It won't cause any problems with the stoma. You may find, however, that any fragrant bubble bath may cause irritation so I would suggest avoiding too much use of bathing products. Obviously the main concern is the stoma acting whilst the pouch is not in situ. You state that as you irrigate you should not have any output from the stoma and if you are confident with this then enjoy your soak!

**Q:** *I have a poorly sited stoma due to an emergency operation. I tried having a reversal and it went wrong, so now I have a stoma and I can't cope with it. It leaks and now my skin is really bad and I want another operation to change position but they won't consider it till I put weight on, but this is impossible for me because as soon as I eat it goes straight in my bag. Any advice or help would be appreciated.*

**A:** You do not state what sort of stoma you have or what is was performed for. The skin excoriation is likely due to the leaks and there are many reasons why it should leak. I would suggest a review with your local stoma care nurse as she will be able to assess the stoma and condition of the skin and suggest a treatment plan to try to solve the issues. It may be that the stoma has changed size and shape and therefore a new template may help or the stoma may be in a skin crease and therefore a different product, such as a convex pouch would be beneficial. The skin, if it is excoriated,

will need treating and again if you request a review your stoma care nurse will be able to advise. It may also be a good idea to be referred to a dietitian as they will be able to investigate what foods affect you and can advise accordingly to try to support you with your diet. I hope this helps and you get sorted in the future so that you can take control of the stoma and return to your own lifestyle.

**Q:** *I was diagnosed with bowel cancer towards the end of 2010 and had a permanent colostomy on 30th December of that year. As a result of a recent check-up, I am having to have a colonoscopy very soon. The thought of facing Moviprep is a bit daunting (I am in my eighties and live alone). I would be most grateful for any suggestions or tips from you how to deal with this preparation day. I use a convex closed pouch.*

**A:** Obviously the bowel preparation for the colonoscopy is important but it will cause a loose output from your colostomy. I would therefore suggest that you obtain some drainable convex pouches to use whilst you are taking the preparation. I would also suggest that you do not arrange to go anywhere too far from the bathroom on the day you take it and possibly see if there is a family member who can stay with you during the preparation and after the procedure.

**Q:** *I had a colostomy two years ago due to diverticular disease. For most part my stoma functions normally, but on three occasions the discharge has been in the nature of a voluminous slurry which easily fills four or five closed bags. Due to the quantity of material produced my blood pressure falls significantly and I collapse.*

*These episodes appear to be unconnected with my diet and a recent colonoscopy has produced a normal result.*

*What is causing such large volumes of slurry to be produced and what, if anything, can be done to prevent these incidents from happening, please?*

**A:** This is difficult to answer and the best person to speak to is probably your consultant whom I would have thought would have arranged to follow you up in clinic after your recent colonoscopy. It does sound as if you really have a bad time when this happens, especially as it causes your blood pressure to drop and you to pass out, but a normal colonoscopy is reassuring. However, I do feel that as it is causing so much trouble for you that further investigations may be the way forward.

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

# Readers' writes



Do you have a story to tell, experiences or concerns to share with other ostomates, issues to raise? Maybe you have comments and suggestions about Tidings. Write or e-mail us today. The editorial team looks forward to hearing from you.

**Rosemary Brierley**

## Dear Editor

I had surgery 11 years ago in 2003 after a tumour was found in my rectum. The tumour was very low so the surgery wasn't reversible but, I'm pleased to say, I haven't found living with my "blow hole" a problem. It doesn't stop me from doing anything at all. I have been a recipient of *Tidings* from the start and have found lots of useful information and I sincerely hope other people subscribe, as I do, to assist others.

In the latest issue I read a letter to the nurse about the ostomist who is worried about swimming with a stoma. This person could ask their stoma nurse if it is possible for them to use a *plug*. I have been doing this for years and have never had a problem with it. I swim before eating so my stoma isn't active. It is not painful to insert and isn't visible. I have a large parastomal hernia but even that isn't prohibitive to using the plug. This is a "doable" option for either sex.

Another letter made the enquiry about using bath oils. Again, as long as your pouch is on, it should be OK. I've never experienced any problems. It is very important to an ostomist to feel as "normal" as possible.

The other thing I would mention is that if any new ostomists want to do any heavy lifting or gardening please do make sure that firm support garments are worn. I was unaware of this, which is how I ended up with the hernia. I do,

sometimes, mentor patients who are about to undergo colorectal surgery and give this advice before the problem occurs. Prevention is better than cure!

Due to my hernia, irrigation isn't an option for me but using flushable pouches has been a wonderful solution. It saves the problem of disposing of the full pouches and the outer casing can be thrown in the normal waste. There have been very few places where I haven't been able to flush them away, and they are usually places like the Greek Islands (their waste pipes don't even take toilet paper).

I hope my experiences will be of help to others.

Good luck with getting more subscribers and, above all, keep up the excellent work.

Best wishes

**Marijke Williams (Mrs)**

*There is no reason why ostomates cannot go swimming while wearing a pouch. However, if the filter becomes wet, this can make it less effective and lead to ballooning later on. Therefore, while in the water, it is advisable to cover the filter with one of the filter cover stickers that are supplied in the box with the pouches.*

## Dear Editorial Team of Tidings

I have been reading *Tidings* for more years than I care to remember, but the last issue (No. 36) you really excelled yourselves. There were so many interesting articles and the writers are an inspiration to us all.

I had a similar experience to Trevor (Sex in Pouch City), as I met my husband when I was sixty-two. We got on so well I was very soon faced with the problem of explaining that I had a stoma as a result of bowel cancer. I took him to a coffee shop to explain. He just didn't seem to understand at all and seemed to think there was something terribly wrong. When I finally managed to get him to understand, he said only: "Well, that's alright then" and the matter was settled. We married two years later and me having a stoma, including all the little accidents along the way, have never been a problem. In private, he even sometimes refers to me as his "bag lady".

I am very much looking forward to the celebrations in July and I am certain it will be a great week-end.

With best wishes

**Janet Bradley**

## Dear Editor

I was intrigued to see the photo from Ann Carruthers in *Tidings* No. 34, showing the sign in Tokyo airport for a toilet equipped with ostomate facilities.

My wife and I had a holiday in Japan in 2010 – before I had a stoma – and visited the tourist town of Takayama. Looking through our souvenirs recently I came across a map from the Tourist Office and to my surprise and delight saw that many of the toilets in the town are labelled as 'Ostomy/Stoma friendly'.

# Readers' writes

Being aware of the **Colostomy Association's** campaign for better toilet facilities for ostomates, I emailed the Tourist Office asking what facilities a toilet must have for it to qualify as stoma friendly. The reply came the same day, with a photo of a typical multi-purpose toilet, in this case in Poppo Park, just left of the railway station. I can only look in amazement and envy at the facilities – although the photo does not show if there is a coat hook on the back of the door!

David Jack

## Dear Editor

Cancer of the rectum meant a stoma seven years ago. I have 'progressed' from a flat closed bag to a convex maxi drainable. I am told that my colostomy acts like an ileostomy. It is completely erratic. I never know when it will erupt. I drain my bag about five times a day.

My big problem is odour. I don't take holidays anymore as I could not expect anyone to share a bathroom. I don't like having to use public or other people's toilets. I know I have a supersensitive nose where smell is concerned, but I'm not paranoid. I have heard remarks about the smell when I've been in a toilet and felt compelled to remain in the cubicle until everyone has left.

Having tried all kinds of sprays etc., either in the bag or out, I would be grateful for any readers' tips.

Yours sincerely  
J.P.

**PS** On the subject of paying for *Tidings*, £12 was suggested when I first got it. Since then I have increased the amount to £20 yearly. Despite all the voluntary work it must still cost quite a lot to produce.

*If you haven't tried it already it may be worth considering a pouch deodorant which works by eliminating odour-causing microbes within the pouch, rather than by masking or neutralizing the odour. The only ostomy drops that work this way that we are aware of at present are Na' Scent, distributed by Bullen and available on the drug tariff. For more information visit:*

[www.nascent4u.com](http://www.nascent4u.com)

See also From **One ostomate to Another** on Page 13.

## Dear Editor

Re: Rectal stump problems

My friend had been paraplegic for over 50 years when he opted to have a colostomy

to make life easier. He had the Hartmann's procedure eight years ago in September 2006 and has had no problems adjusting to the new way of life, and in fact his quality of life has improved considerably.

At the time he was advised about potential issues regarding the rectal stump discharge, but had only ever had minor stains on his underwear so thought he had no problems. Just before Christmas he experienced a copious discharge from the stump. Living alone with no carers, he was in somewhat of a mess – wheelchair, bed, floor, himself – and when he asked for help and advice, he was passed from pillar to post.

Apart from immediately post-operatively when he had stoma nurses to call on for advice, he has no defined nurse or contact, and on contacting the stoma department, was told they couldn't help as they only deal with the stoma itself, not the rectal stump. The GP was arranging for a district nurse to come out to do a clear-out on the second day of this problem, but that got cancelled as they erroneously thought he was going into hospital for the treatment.

Finally on Christmas Eve, after three days of trying to cope with this situation, the district nurse came out to do a clear-out by suppositories, by which time most of the discharge had already cleared by itself. The district nurse was not familiar with this situation and said my friend needed to be seen by the surgeon as she thought faeces were present. This was not helpful as he was already upset and frustrated at how he had (not!) been treated.

On reading your *Tidings* magazine, it seems that colostomates are always advised to contact their stoma nurse for help and advice. Is anyone else in the position of not having a named nurse to call on, or is it just in this area?

Denise Harper

## Dear Editor

I have just received my latest copy of *Tidings* which I look forward to each quarter, thank you for such a helpful and informative publication.

I thought I would write to you about an experience I encountered a couple of weeks before Christmas. I was sitting watching TV one evening when I started getting what I thought were indigestion pains. As the evening progressed they became more severe so I decided to go to bed. About 2am the pain was really intense

and I was violently sick. I hoped that would ease the pain but it didn't. As I live on my own and am a comparatively new colostomate, I was getting frightened. I dialled 111. About 20 minutes later two very nice lady paramedics arrived and asked questions, took my blood pressure and did an ECG as I have angina. They couldn't work out what was wrong and asked if I would like to go to A&E which I declined as I was feeling slightly better.

The paramedics stayed with me for a while and took me back to bed and settled me down with instructions to see my GP the next day as they seemed to think it was a virus. When I saw my GP she examined my tummy and said I had adhesions for which she prescribed rest with plenty of fluids to drink, gradually progressing to more solid intake.

The point I am trying to get across is that if the paramedics had some idea of the problems that colostomates have and how to deal with them, it would have been easy for me to accept the reason for all the pain and vomiting. I don't know if adhesions have been dealt with in your publication but as I said I have not had my stoma very long it was something I had no knowledge of.

Once again thank you for a wonderful magazine, keep up the good work.

Yours sincerely  
Margaret

*We published an article on adhesions back in the summer of 2013 so we will certainly look into including one in a future edition. In the meantime we will send you a copy of this and another article on adhesions which has appeared in *Tidings*.*

*Anyone with severe, unexplained abdominal pain and vomiting is advised to seek medical advice.*

## Dear Editor

Six years ago in September 2008 I was diagnosed with rectal cancer and three liver secondaries. This was deemed inoperable. My oncologist offered intensive radiotherapy and chemotherapy. When I was given a consent form I asked: "What's the alternative?" He replied in two words: "Six months". I promptly signed up.

The radiotherapy was for 25 sessions over five weeks starting in October 2008. After liberal applications of aqueous cream, I

CONTINUED ON PAGE 55, COLUMN 1



## NOTEBOOK HELPFUL OSTOMY SUPPORT GROUPS & ORGANISATIONS

### Helpful Ostomy Support Groups & Organisations

- IA The Ileostomy and Internal Pouch Support Group  
Freephone: 0800 0184 724  
www.iasupport.org
- UA Urostomy Association  
Tel: 01889 563 191  
www.urostomyassociation.org.uk
- IOA International Ostomy Association  
www.ostomyinternational.org
- Junior Ostomy Support Helpline (JOSH)  
24 Hour Helpline: 0800 328 4257  
Email:  
josh@colostomyassociation.org.uk
- Stomadata  
www.stomadata.com
- Macmillan Cancer Support  
Tel: 0808 808 00 00  
Mon - Fri: 9am - 8pm  
www.macmillan.org.uk
- Mitrofanoff Support  
Tel: 01202 937 530  
Email: info@mitrofanoffsupport.org.uk  
www.mitrofanoffsupport.co.uk
- Crohn's and Colitis UK  
Tel: 0845 130 3344  
(Mon-Fri 13:00-15:30 and 18:30-21:00)  
www.crohnsandcolitis.org.uk
- IBS Network (formerly: The Gut Trust)  
Tel: 0114 272 3253  
www.theibsnetwork.org
- Bladder and Bowel Foundation (B&BF)  
Formerly Incontact and Continence Foundation  
General enquiries: 01536 533 255  
Web:  
www.bladderandbowelfoundation.org
- Bowel Cancer UK  
Tel: 020 7940 1760  
Email: admin@bowelcanceruk.org.uk  
Web: www.bowelcanceruk.org
- Beating Bowel Cancer UK  
Tel: 08450 719 301 (Lo Call rate)  
Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)  
formerly The United Ostomy Association  
Web: www.glo-uoa.org
- Ostomy Lifestyle  
Tel: 0800 731 4264  
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 5.

## SASH

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#### Stoma Support & Hernia Belt Ref. No. HB102

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

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

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

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



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

Ref. No. SS104



# Readers' writes

CONTINUED FROM PAGE 53, COLUMN 3

was confronted by a very large machine that worked all around my pelvic area. I paid a painfully sore price for the private areas where I had missed applying cream.

The chemotherapy was from January to May 2009 at three weekly intervals. It involved *Capecitabine* tablets and *Irinotecan* intravenous injections into the back of my hand over two hours each time. I was led to expect that I'd lose my hair, which actually only thinned. These were difficult days – loss of appetite and energy, sore mouth and constantly feeling sick as well as various other side effects.

The large rectal tumour proved to be responsive to these oncology treatments and after various blood tests and scans it was decided that an operation was possible. On 3rd September 2009 I underwent bowel surgery in which my rectum was removed and a stoma formed. I was in hospital for six days and during this time I was taught how to apply my colostomy bag. There are still the

occasional accidents but, by and large, changing the one piece bag after breakfast and before bed at night works well for me. Having a colostomy which can discharge anytime takes some getting used to and I do have a parastomal hernia, but I know my stoma is my life saver.

Following further tests, it was decided that a liver resection in three places could be undertaken. The operation took place about 15 weeks after the bowel surgery. This involved a further six days in hospital, and anxious times wondering if the problem would return. My recovery was slow but sure. However, at 76 I cannot do all I used to do, for example we now employ a gardener and order groceries online.

It is now just over five years since the first surgery. Since then I have not needed any medication for cancer, although I now have a restricted diet and occasional stomach upsets. One cannot be more thankful and full of praise for consultants, surgeons, oncologists and many other healthcare

professionals in Nottingham for excellent treatment at every stage.

Three cheers for the NHS which has kept me alive.

**Ken Morey**

**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. Space permitting, we will print your contribution in the next issue of Tidings or we may hold it over for a future issue.**

**To contribute to the Readers' Writes page:**

e-mail:  
[editor@colostomyassociation.org.uk](mailto:editor@colostomyassociation.org.uk)

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

Please indicate if you are willing for us to print your full name (or just your first name). In the interest of confidentiality, if you do not give us permission we will publish only your initials.

Editing may be required for reasons of clarity or space.

## Help Colostomy Association raise funds

**For your FREE donation box  
simply contact the office**

Telephone:  
**0118 939 1537**

or email:  
**[cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)**

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# Marketplace

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



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FREEPOST SWB11095, Bridgwater Somerset, TA5 1ZA

### Stoma Care Patient Open Day

John Radcliffe Hospital, Level 3,  
Academic Street, Oxford  
Apr 25th 2015 – 10:00am–1:30pm  
JR Office: 01865 221 839 or  
Churchill Office: 01865 235 367

### Bath Hospital

**Stoma Care Open Day**  
Bath Racecourse & Conference Centre,  
Lansdown, Bath, BA1 9BU  
Apr 28th 2015 – 10:00am–2:30pm  
Contact: Stomatherapy Secretary

### Westland Conference & Leisure Complex Stoma Care Open Day

Carling & Wessex Suites, Westland  
Conference & Leisure Complex, Yeovil,  
BA20 2DD  
Apr 30th 2015 – 11:00am–2:00pm  
Yeovil Stoma Care Department Secretary

### ConvaTec Event – Miskin Manor Hotel

Pendoylan Road, Groesfaen,  
Pontyclun, CF72 8ND  
Apr 30th 2015 – 10:00am–12:00noon  
Tel: 0800 834 822

### ConvaTec Event – Crowne Plaza Ealing Hotel

Western Avenue, Hanger Lane, W5 1HG  
Apr 30th 2015 – 10:00am–12:30pm  
Tel: 0800 282 254

### ConvaTec Event – Connaught Room

Cranmere Park, Cranmore Avenue,  
Shirley, Solihull B90  
May 11th 2015 – 11:00am–1:30pm  
Tel: 0800 834 822

### HeSRU (Consultants, Trainees and Healthcare professionals only)

#### Problem Stoma Course

Exeter Castle, Castle St., Exeter, EX4 3PU  
May 12th 2015 – 8:30am–5:00pm  
Jessica Semmens: 01392 408 944



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- Most colours•
- Cotton or lace•

Phone 01205 723327

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### ConvaTec Open Day

The Main Hall,  
The Pavillion Conference & Events Centre,  
Spa Road, Llandrindod Wells, LD1 5EY  
Apr 20th 2015 – 11:00am – 1:30pm  
Tel: 0800 834 822

### ConvaTec Coffee Morning

The Barns Hotel,  
Cardington Road,  
Bedford, MK44 3SA  
Apr 21st 2015  
Tel: 0800 828 254

### Royal Devon & Exeter

#### Open Stoma Meeting

in collaboration with Devon IA  
Royal Devon & Exeter Hospital,  
Seminar Room 1, RILD Building  
Apr 21st 2015 – 5:30pm – 7:30pm  
Jessica: 01392 408 944

### Walsall Manor Colorectal Open Day

Coffee morning for patients  
Manor Learning & Conference Centre  
(Room 301)  
Apr 23rd 2015 – 10:00am – 12:00noon  
Contact: Stomacare Team, Walsall Manor  
Hospital



**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)**





Thank you for your support

## Regular donation

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

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

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

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

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

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

**To the Manager:** (Bank or Building Society)

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

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

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

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

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

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

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

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

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

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

Signature: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / 2015

*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 this donation and any eligible donations that I have made in the last four years 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, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

Signature: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / 2015

**Optional Information:** Date of Birth: \_\_\_\_\_ Stoma Type: Colostomy   
 Reason for your stoma: \_\_\_\_\_ (Please tick) Ileostomy   
 Year of operation: \_\_\_\_\_ 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

DONATIONS HELP US MAKE A DIFFERENCE



Thank you for your support

## Single donation

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.

<b>Note:</b> Please ensure that we have your correct contact details: full name, address, postal code and telephone number. Thank you.	<b>My Details:</b> Title: _____	Name: _____	Surname: _____
	Address: _____		
	Telephone (home): _____		Postcode: _____
	Email: _____		Mobile: _____
	<b>Optional Information:</b> Date of Birth: _____		Stoma Type: Colostomy <input type="checkbox"/>
Reason for your stoma: _____		(Please tick) Ileostomy <input type="checkbox"/>	
Year of operation: _____		Urostomy <input type="checkbox"/>	

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

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

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

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

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

**Yes, I require a receipt**  (Please tick).

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

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

*giftaid it*

**Thank you for your gift**

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

I would like the tax to be reclaimed on this donation and any eligible donations that I have made in the last four years 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, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

**Signature:** \_\_\_\_\_

**Date:** / / 2015

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.



## STEPS turns 10!

**STEPS (SToma Essex Patient Support) was set up 10 years ago by the stoma nurses of Basildon Hospital, to be a support group for patients run by patients.**

The initial meeting was held at Townsgate Theatre in Basildon on the 24th November 2004 and was attended by 40 people. A competition was held to decide on a name for the group and Peter Pavesi, one of the first committee members, came up with the name *STEPS* and that is how it has been known ever since. Today there are 220 members on the mailing list.

The driving force behind the group is its long-standing, tireless chairperson, Maxine Lockwood. Meetings are held at St. Catherine's church in Wickford on the last Tuesday evening of every month and at St. Margaret's Church in Stanford-le-Hope on the second Saturday morning each month. New and existing members are always welcome. For information please email: [stepsessex@gmail.com](mailto:stepsessex@gmail.com)

On Saturday 8th of November 2014, over

70 people attended the 10th birthday celebrations.

The Mayor and Deputy Mayor of Thurrock were in attendance as were the MPs for Thurrock, Ms. Jackie Doyle-Price, and for Basildon and East Thurrock, Mr. Stephen Metcalf. Those who attended were entertained by the choir Fairlights and had a sumptuous afternoon tea prepared by the STEPS committee.

All three stoma nurses from Basildon Hospital joined in the celebrations together with a representative from Dansac, one of the stoma product manufacturers.

A Raffle was held and included prizes graciously donated by Intu Lakeside Shopping Centre, Tesco Extra at West Thurrock, ASDA Living and Sainsbury at Chafford Hundred. In total on the day STEPS raised £249.



**If you would like to see your support group featured here, please telephone the Editor on: 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 IN YOUR COUNTY

**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 county

### England

#### B

##### Bedfordshire

Saturday Social Club  
Karen Richards: 0123 479 2278

##### Berkshire

E.B.O.C (East Berkshire Ostomy Club)  
Jackie Dudley: 0134 442 6652

Reading Bowel Cancer Support Group  
Ted Wingrove: 0118 961 8297 or  
07974 790 558

W.B.O.C (West Berkshire Ostomy Club)  
Jackie Dudley: 0134 442 6652

##### Bristol

Bristol Ostomy Self Support (BOSS)  
Janet: 01934 248 114 or  
Rob: on 0117 966 8021

##### Buckinghamshire

Milton Keynes Stoma Association  
Joanne Dickson: 0190 831 8262

#### C

##### Cambridgeshire

Connections Cancer & Colostomy  
Group  
Bev or Sue Scott: 0135 386 0356/  
0776 695 8811 or  
Barbara Hunt: 0135 386 2133

Peterborough Stoma Support Group -  
Ostomistics  
Alan Wright: 0135 465 3290 / 0783  
666 1102

##### Cheshire

Countess of Chester Hospital Stoma  
Support Group  
Danielle Kirkham: 0124 436 6170

Stockport Support Group  
Angela Simpson: 0161 320 9400 /  
0800 652 6667

Stoma Support Group  
Catherine McIntosh:  
Crewe 01270 666 985

Warrington Ostomy Support Group  
Jane Shaw: 0192 566 2103

##### Cleveland

Oops Group  
Julie Morrisroe/Carol Younger: 0128  
728 4113

##### Co. Durham

OzBishop Auckland Stoma Care Group  
Betty: 0138 881 4535

Darlington Support Group  
Sister Jacqui Atkinson: 01325 743005

##### Cornwall

Carnon Downs Ostomy Support Group  
Ken Jones: 0187 286 3106 or  
www.cornwallostomysupport.org.uk

Cornwall Bowel Cancer Support Group  
Peter Yorke: 01726 821 280 or email  
quillpusha@gmail.com or  
website www.cornwall-bowel-cancer-  
support-gro

##### Optimists

Sue Hatton: 0132 634 0058

Ostomist and Carers Support Group  
Christine Davey: 0120 883 1471

##### Cumbria

Grange Cancer Support Drop in  
Marie: 0153 953 3279

#### D

##### Derbyshire

Diverted Local Stoma Support Group  
Diane Manning: 0128 354 1311

##### Devon

Mid Devon Ostomy Support Group  
Janice: 0136 377 6417 or  
janicedianeparkyn@yahoo.com

##### Dorset

Colostomy Urostomy Pouch Ileostomy  
of Dorset (CUPID)  
Jenny Pipe: 0120 274 0440

Colostomy Urostomy Pouch Ileostomy  
of Dorset (CUPID)  
Beryl Andrews: 0120 248 3303

Colostomy, Urostomy, Pouch &  
Ileostomy of Dorset - CUPID (West  
Dorset)  
Colin Clare - 0130 585 3238

#### E

##### East Midlands

Newhall Stoma Support Group  
Diana Manning: 0128 354 1311 or  
Helena: 0793 233 1850

##### Essex

Connect  
Lin Hart 0127 950 5273

Mid Essex Stoma Support Group  
Paul Foulger: 0124 522 4374, Jeanette  
Johnson: 0137 651 1862

N.E.S.S (North Essex Stoma Support)  
Secretary:  
Brian Waller: 0120 654 0449

Optimistic Ostomates  
Carol Booth: 0170 238 5510 or  
Angela Taylor: 0170 238 5509

Redbridge Ostomists Club  
Stoma Nurses –  
Chris/Lisa: 020 8970 8321

##### STEPS

Jackie: 0126 845 1937

#### G

##### Gloucestershire

Ladies Big Op Group  
Gill Hopkins: 0300 422 4363  
Please Note: For ladies with one or  
two permanent stomas

Vale Stoma Support Group  
jfn.dursley@gmail.com or text 0794  
182 7393

#### H

##### Hampshire

Solent Ostomates Support Group  
(New Forest Branch)  
Carole Summer: 0752 770 7069

Solent Ostomates Support Group  
(S.O.S.)  
Carole Summer: 0752 770 7069

Wessex Urology Support Group  
Adrian Kuczynski: 07910 786 978

##### Herefordshire

Bums on Tums - Herefordshire  
Ostomies Support Group  
Carol Steele 0143 288 0656 /  
carolsteeleglo@gmail.com

##### Hertfordshire

Colonise  
Anastasia 0172 776 0981

Hertford Stoma Support Group  
Ralda: 0199 253 5311

Stevenage Ostomistics  
Judy Colston: 0143 835 4018 /  
neilcolston@btinternet.com or Alfred:  
0176 731 6958

**I****Isle of Man**

IOM Bowel Cancer Patient and Carer Group  
P Caine: 0762 448 0973

Stoma Support Group  
Carole Cringle stoma nurse: 0162 465 0212

**Isle of Wight**

Optimistics  
CNSs Andie Coates & Amanda  
Broadbridge 0198 353 4009

Semi-Colon Club  
Tony Crowson on 0198 355 9326 or  
CNS Helen Fulford 0198 353 4180

**K****Kent**

Ashford Stoma Support Group  
Ron Huckstep: 0794 131 0681 or  
Margaret Webb 0123 362 8807

Atoms Support Group  
Maria Culleton, SCN: 0122 776 9679  
or 0782 799 7424

Dover Stoma Friends Group Support  
Julie Bell: 0777 134 5703 or  
Ros Marshall: 0130 482 2696 or  
June Golding (Organiser): 0130 482 2696

M.O.G.S (Medway Ostomy Group Support)  
Helen Or Tracey: 0777 360 5534

Maidstone Stoma Support Group  
Judy/Kirsty: 0162 222 4305

Royal Tunbridge Bowel Cancer Support Group  
Bronwen Tetley CNS: 0189 252 6111 x 2287

Thanet Stoma Buddies Support Group  
Phil (Secretary): 0184 358 7769

**L****Lancashire**

North Manchester and Bury Stoma Support Group  
Julie Meadows (SCN): 0161 720 2815  
or 0784 120 6910

Oldham Stoma Support  
June Wilde: 0161 312 5538

Tameside Ostomistcles  
Paul Seavers: 0777 135 9046

Trafford Bowel Care  
Jackie Carey Secretary: 0161 748 9659,  
Doreen: 0161 962 7818,  
John: 0161 748 4655

**Leicestershire**

Kirby Ostomy Support Group.  
Colostomy, Ileostomy and Urostomy in Leicestershire  
Janet Cooper: 0116 239 2844 /  
kosg2013@btinternet.com

**Lincolnshire**

Friends East Coast Support Group  
Betty: 0120 572 4120 or  
Sheila: 0120 536 4493

Grantham Support Group  
Bobbie/Amanda: 0147 646 4822 or  
grantham.colorectal@ulh.nhs

March Group  
Sharon Palmer: 0741 482 8867 or  
sharonpalmer44sp@gmail.com

Sutton Bridge and Long Sutton Ostomy Group  
0140 635 1617

**London**

Bowel Cancer Newham  
Scyana: 020 8553 5366  
scyana@tiscali.co.uk

ESSence (Ealing Stoma Support Group)  
Wendy Hetherington: 0771 733 5884

Homerton Hospital Bowel & Stoma Support Group  
Angela Davy: 020 8510 5318 or  
020 8510 7599

South Woodford Support Group  
Nurse Christina and Lisa: 020 8535 6563

St. Thomas' Hospital  
CNS: 020 7188 5918

Surrey & South London Bowel Cancer Support Group  
Sue Berry: 0173 755 3134 or  
John Amos: 020 8668 0796

**M****Merseyside**

I.C.U.P.S  
SCN: 0151 604 7399

St Helens Cancer Support Group  
Office: 01744 21831,  
Denys Floyd: 01744 884097 or email:  
contact@sthelenscancersupportgroup.org

**Middlesex**

Inside Out  
Sarah Varma: 020 8235 4110  
Bob (chairman): 020 8428 4242

Semi-Colon Club  
Pat Black or  
Kathryn Foskett: 0189 527 9391

**Newcastle**

NHS Molineaux Walk In Centre  
Lesley Brown: 0191 282 6308

Royal Victoria Infirmary Support Group  
Gordon Weatherburn: 0191 234 1109

**N****Norfolk**

Kings Lynn Ostomy Friendship Support Group  
For more info please call 0155 369 1370 / 768271 / 775698

**Stars**

Anne Browne: 0160 366 1751

**Northumberland**

Berwick Ostomy Support Group  
Bobbie Minshull: 0771 447 9320

Hexham Ostomy Group  
Judith: 0796 792 7286

Northumberland Cancer Support members@northumberlandcancersupportgroup.co.uk

**Nottinghamshire**

North Notts Stoma Support Group  
Tore and  
Nicky Norman: 0177 371 5460

Nottingham Colostomy, Ileostomy & Urostomy support group  
Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support  
Jenny or Kate: 0115 962 7736/ Mrs B Heath: 0115 966 3073

**O****Oxfordshire**

Oxfordshire Ostomy Fellowship  
Pat Longworth: 0123 552 4163

**S****Shropshire**

B.O.T.S. (Bums on Tums)  
Irene Constable on 0169 123 8357

**Somerset**

Devon IA  
Martin Hornby: 01458 251 095 or  
email: devon@iasupport.org

**Staffordshire**

Outlook  
Moira Hammond 0778 840 2195

**Suffolk**

East Suffolk Ostomy Group  
Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group  
Sandra Hutchings: 0150 258 5955

West Suffolk & District Stoma Group  
Jessica Pitt stoma nurse:  
0163 851 5525

**Surrey**

Epsom and District Stoma Support Group  
Lindsay, Trevor or  
Sheena: 0137 273 5925

**Sussex**

Brighton & District Support after Stomas (SAS)  
Sylvia Bottomley: 0127 355 4407  
Chichester Stoma support Group  
The Stoma Care Team 0124 383 1527  
The Ostomy Friends Group  
Jane Quigley: 0132 341 7400 ext 4552  
West Sussex Princess Royal Stoma Support  
Tina Walker: 0144 444 1881 ext 8318

## SUPPORT GROUPS IN YOUR COUNTY

## T

**Tyne & Wear**

Gateshead Stoma Patient and Carer Support Group  
Stoma Care Nurses: 0191 445 3152 or email [stuart.sutcliffe81@yahoo.com](mailto:stuart.sutcliffe81@yahoo.com)

## W

**West Midlands**

Coventry Stoma Support  
Martin: 0794 738 5643

**Wiltshire**

Swindon IA  
[www.swindon-ia.org.uk](http://www.swindon-ia.org.uk)  
Wessex Stoma Support Group  
Michael Slater:  
[wessex.stoma@yahoo.co.uk](mailto:wessex.stoma@yahoo.co.uk) or on 0172 274 1233

**Worcestershire**

Kidderminster & District Collossus Support Group  
Brendon Drew: 0129 940 0843

## Y

**Yorkshire**

Acorn Ostomy Support Group  
Michelle: 0758 069 3155 (After 6:00pm)  
Airedale Stoma Support  
Sue Hall: 0153 521 0483  
Barnsley Bottoms Up Stoma Support Group  
Stoma Nurses: 0122 643 2528 or Celia Utley (Chairman): 0122 628 4262  
Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)  
Stoma Care Nurses: 0148 435 5062  
Dewsbury & District Ostomy  
Janet/Eileen: 0844 811 8110  
Leeds Bowel Cancer Support Group  
Lynda Castle (Colorectal Nurse Specialist): 0113 206 5535  
Rotherham Ostomates Caring Support  
Karen Kilford: 0788 057 5758  
Scarborough Stoma Support Group  
Sister Jean Campbell: 0172 334 2388, Amanda Rowe: 0172 334 2446  
The Hull and East Riding Colostomy Support Group  
Pete Smith: 0798 956 5335 or Pete Rennard: 0793 951 8642 / 0148 279 3966 or Rosanna Grimsby: 0148 280 1575.  
[www.hercosg.org.uk](http://www.hercosg.org.uk)

## Scotland

**Ayrshire**

Ayrshire & Arran Stoma Support Group  
Jim Krasewitz: 0129 222 0945  
Stoma Care And Recovery (SCAR)  
Maggie: 0129 427 1060/ 0781 773 6147 [maggie13@sky.com](mailto:maggie13@sky.com) or Rhona: 0129 455 7478

**Fife**

Fife Ostomy Support Group  
Ishbel Barr: 0159 277 2200

**Lanarkshire**

G66 Support Group  
Les Ireland: 0141 776 3866  
Glasgow Stoma Support group  
Chairperson: Maureen O'Donnell: 0123 643 6479

**Midlothian**

GOSH (West Lothian)  
Scott Pattison: 0750 216 3644

**Scottish Borders**

Stoma Support Group  
Nancy Fraser: [nancyfraser@talktalk.net](mailto:nancyfraser@talktalk.net) or 0145 037 4012. Fiona Gentleman: [r.gentleman@sky.com](mailto:r.gentleman@sky.com) or 0145 037 1063

## Wales

**Bridgend**

Bridgend Ostomy Patients Support Group  
Anita Brankley (Secretary) 0165 664 5602 or Pat Jones 0165 678 6103

**Denbighshire**

Conwy & Denbighshire Ostomy Support Group  
Debi Devine 0787 676 2503 / Hazel Duke 0797 681 7246 / Email: [devinetherapies@btinternet.com](mailto:devinetherapies@btinternet.com)

**Gwent**

Blaenau Gwent Self Help  
Celia McKelvie: 0187 385 2672 After 6pm  
Cwmbran Ostomy Support Group (COSG)  
Philippa Lewis: 01633 791 339 / 07504 713 069

**Mid Glamorgan**

C.A.S.S Colorectal and Stoma Support Group  
Colorectal Nurse Team on 0168 572 8205

**Pembrokeshire**

PSA (Pembrokeshire Stoma Association)  
Roy Whitfield 0143 776 0701

**Rhondda Cynon Taf**

Royal Glamorgan Stoma Care Support Group  
Domenica Lear 0144 344 3053

**Swansea**

Swansea Ostomy Self Help Group  
Glynis Jenkins: 0179 241 8245

## Northern Ireland

**Co. Antrim**

Colostomy Association Volunteers Northern Ireland  
Chris Wright: 0772 071 7771  
Mater Hospital  
Karen Boyd - Stoma Nurse: 028 9074 1211 Ext 2329  
Royal Victoria Hospital - Belfast  
Sarah Haughey/Audrey Steele: 028 9024 0503 Ext 3483

**Co. Armagh**

Craigavon Area Hospital  
Mary Jo/Bernie: 0283 861 2721  
Daisy Hill Hospital Support Group  
Bernie Trainor: 0283 083 5000 Ext 2222

**Co. Down**

North Down Stoma Support Group  
Adrian Ewing on 0785 074 1511  
Ulster Hospital  
Hazel/Martina: 028 9055 0498

**Co. Fermanagh**

Erne Hospital  
To be confirmed

**Londonderry**

Causeway Support Group  
Mary Kane: 028 7034 6264

## Channel Islands

**Guernsey**

Guernsey Ostomates  
Luci Deane 0148 123 6077 / [lucideane58@gmail.com](mailto:lucideane58@gmail.com)

## Republic of Ireland

**Co. Mayo**

Mayo Stoma Support  
Marion 2Martyn: 094 902 1733

**Dublin**

Bowel Cancer Support Group (ICS)  
National Cancer Helpline:  
(00 353) 1 800 200 700 or  
Olwyn Ryan: (00 353) 1 231 0500

## France

**Provence**

Stoma France  
Adrian March:+33(0)49 450 1136 or email [info@stoma.fr](mailto:info@stoma.fr)

## Kosovo

**Kosovo**

Kosovo Ostomy  
Arta Uka: [kosovoostomy@gmail.com](mailto:kosovoostomy@gmail.com)

## Spain

**Alicante**

Costa Brava  
<http://www.ostomyinspain.org/>

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