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 Sarah Squire

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 Jackie Dudley

Colostomate & Helpine Volunteer
 Ian Jackson

Stoma Care Nurse Advisor
 Julie Rust RGN, Dip, N MSc

General Manager
 Susan Hale

Products & Services Officer
 Arvind Anand

COVER PICTURE

Colostomy Association's
 10th Anniversary celebrations

How to contact Tidings

By letter write to:

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

By telephone:
0118 918 0500

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

Advertising Enquiries:
 For a media pack and advertising rates.

Contact: Arvind Anand
Telephone:
0118 918 0500

E-mail:
arvind.anand@colostomyassociation.org.uk

Tidings Magazine:

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dear READERS

If you were at the **Colostomy Association's 10th Anniversary Celebrations in July** you will understand why a large proportion of this issue of *Tidings* is devoted to this event. Like our magazine, the weekend's programme included professionals discussing medical topics and other issues which relate to day to day life with a stoma, as well as a wealth of real life stories.

Monty Taylor, Chairman of the **Colostomy Association**, introduced the two days as being topical and fun...and that's what they were. In the opening address our President, Mr Ian Daniels FRCS, Consultant Colorectal and General Surgeon spoke about how surgery today is very different from when he was a junior doctor. Back then the surgeons focused on curing disease and gave little thought to how the patient would cope with the stoma they were creating; they did not consider how it would impact on patients' lives. Today surgeons are listening to patient feedback and considering how they can make stomas better and easier to manage.

Later on the Saturday, Ian Daniels gave a presentation about what is known about the causes of parastomal hernias and emphasised the need for more research into the best form of treatment; a summary of this presentation will be included in a future issue of *Tidings*. Amanda Gunning, Specialist Stoma Care Nurse and **Colostomy Association** Trustee spoke about prescription management; a summary of this presentation can be found on page 26.

The Breakaway and Facebook pages this time are also related to the anniversary celebrations. Sue Blackwell, a trustee of Breakaway, outlines her presentation tracing the growth of this charity from an idea first discussed on New Years' Eve ten years ago. Facebook group members met up on the Friday night before the Open Day

and admin Sally Armstrong tells us how the weekend went for them.

At the fashion show on Sunday morning, I couldn't help thinking that when these models first had their stoma I bet they never thought that one day they would walk confidently down the catwalk in front of an audience of more than two hundred. Short biographies of the models were shown on the screen during the show so we asked if they would like to expand on them and write for *Tidings*. We are delighted to include these stories in this issue.

As many of you will already know, the **Colostomy Association** runs a Helpline which operates even when head office is closed in the evening and at weekends when it is manned by volunteers who themselves have stomas. We are able to offer support to ostomates and answer queries about stoma management. In this issue we ask Julie Rust to answer some of the typical questions we receive on the helpline, in particular those which may require the advice of a nurse specialist. The Beating Bowel Cancer Helpline is there for those whose stoma was created as a result of cancer. Paula Madden, Senior Nurse Advisor, gives examples of the type questions they are asked and details of how patients and their families who have concerns about cancer can contact the Helpline.

We do appreciate your feedback. This is your magazine so we welcome your questions for our nurse advisor, Julie Rust, letters and e-mails for the Readers' Writes page and your real life stories about what it's like to live with a stoma.

Look forward to hearing from you.

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

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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.

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Simply contact us by post:

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An interview with Maria Driffill



When Maria Driffill stands up to speak at charity events it's hard to believe that she is 93 years old. She talks about the people she has met and the experiences she has had during her extraordinary life.

But there is something she doesn't mention, not because she's ashamed of it, but because she doesn't think it is relevant. For the last two years Maria has had a colostomy.

In a telephone interview for *Tidings*, Maria told her story, and described what it feels like to have a stoma in later life.

Tell me about your early life

I was born in July 1922 in the East End of London, close to Petticoat Lane and attended Mile End Central School where I met David, my future husband. We both had a passion for the theatre and joined a local dramatic society. I played major parts in five Shakespearean productions and as a result was awarded a scholarship to the Royal Academy of Dramatic Art. My mother, however, had other ideas, so when I left school I began working six days a week in a hat factory.

We married when I was 18 and David was 20. He had joined the RAF, the year before, at the start of World War II. He warned me, "lots of us boys won't return", but reassured me that if he didn't, I would be OK because I would get a pension of 7/6d a week (around £18.29 in current terms). In fact, throughout our married life he joked that it would never last. As it turned out, we were together for 74 years and were able to celebrate our 70th wedding anniversary with all our family and friends.

So what happened after the war?

I continued acting and played Eliza Dolittle alongside David as Henry Higgins in

Pygmalion at the Stoll Theatre in the West End. Later I began work as a buyer in the props department at the Denham Film Studios. The films I worked on included *Henry V* starring Laurence Olivier, *Great Expectations* starring John Mills and *Caesar & Cleopatra* starring Vivienne Lee. While on the set of *Major Barbara* I also met George Bernard Shaw.

I believe you once worked for Queen Elizabeth II

In the 1950s I went to work for Horrockses Fashions. Being one of the few companies able to obtain fabric after the war, the company held the Royal Warrant. When the Queen required new cotton dresses for her state visit with Haile Selassie, President of Ethiopia, I was sent to Buckingham Palace with sketches and cotton swatches. I was given strict instructions on royal protocol, but, as I curtseyed, I realised my right leg was in front of my left leg, not behind where it should have been! Overcome with embarrassment, I exclaimed: "Oh Ma'am, I've done it all wrong!" The Queen smiled. For the next fifteen years I was sent along to the various palaces when she was choosing new clothes. Every Christmas she sent me a card which featured a photograph of the Royal family and this continued even after I retired.

How did you feel when you first had your stoma?

I had my operation in 2012 when I was ninety. When I asked the doctor how long I had left, he said: "I think you'll last longer than me!" At first I didn't really understand what a colostomy meant and it took a while to get used to. Now, however, it doesn't stop me doing the things I have always done, but I tend not to arrange to go out before 10:30am as my stoma is most active in the morning. I also find that the earlier I

have my evening meal, the better I am with my stoma the next morning.

Not only do I have a colostomy, which has now developed a parastomal hernia, but I also have other health problems; I have had three heart attacks and suffer from spinal stenosis. However, I manage to cope with everyday life, as well as helping other people whenever I can.

Because of my limited mobility, when I go out I need someone to collect me and bring me back, but this doesn't stop me. On Monday I play Bridge, on Tuesday it's the senior citizens' club where I'm the oldest member and enjoy participating in the weekly debate on current affairs, then on Wednesday it's JACS, a Jewish cultural society, and I was responsible for arranging the speakers for many years. On Thursday it's the poetry society, and Friday I spend with the family. Sadly my husband, David, passed away last year. However, I am very close to my daughter, two grandchildren and four great grandchildren. I think family is so important. ■

Maria Driffill is also a volunteer for five charities: Cancer Research, Children with Cancer, NSPCC, Water Aid and The Royal Society of Music. In 2012 she was nominated Volunteer of the Year.

Over the years she has attended meetings and events organised by these charities and other organisations to give more than 150 talks about her experiences. If you live in the Middlesex area and your local stoma support group is looking for a speaker for one of your meetings, why not telephone or e-mail **Colostomy Association's** head office and we will contact Maria to see if she is available.



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Parastomal Hernias

The keynote speech at the 10th Anniversary Open Day was given by the President of the **Colostomy Association**

Mr Ian Daniels FRCS, Consultant Colorectal Surgeon at the Royal Devon & Exeter NHS Foundation Trust.

A full report on Mr Daniels' presentation about **Parastomal hernias: who gets them and why, hernia repair and prevention**, will appear in a future issue of *Tidings*.



A hernia occurs where there is a weakness in the muscle wall of the abdomen which allows the abdominal contents (usually part of the intestine) to bulge out. If this occurs around the stoma it is called a parastomal hernia.

During his presentation Mr Daniels made the point that prevention is better than cure and one of the ways of doing this may be to wear a support garment, especially early on while the healing process is going on.

Colostomy Association Trustee, Sarah Squire, followed on with a demonstration of the support wear available to the ostomate. To make it a bit more fun she drafted in fellow ostomates, Ian Jackson and Steve Clark, to hold a washing line and Pauline Morgan to peg up the underwear as she talked about it.

Sarah said: We constantly hear that we should be looking after our abdominal muscles following stoma surgery to try and avoid the dreaded hernia but support wear can be a bit of a minefield. Should I have light support, heavy support, items from the High Street or on prescription?

To try and prevent a hernia it is a good idea to wear a light support garment but experience tells me it has to be comfy or it will sit at the back of the drawer gathering dust. There is a good range of items in this category both on the High Street and available from specialist companies. On our washing line, we had support knickers from Primark which come in at just £5 and although they are from the ladies section I

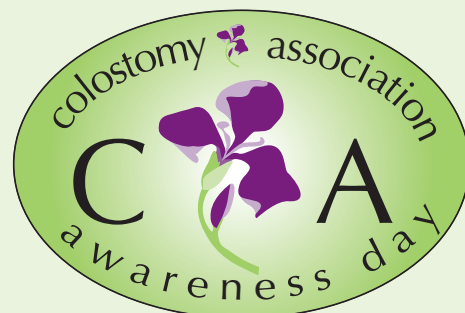
think the boxer style pants would be great for the men too. You MAY be able to get items on prescription from one of the specialist companies although it is at the discretion of your GP and there is no "entitlement" as some people think. But at £5, it may be worth trying high street options first to see how you get on. Light support can be found in the form of knickers, vests and bands (a bit like a boob tube) and can go some way towards hopefully preventing the occurrence of a hernia.

If you already have a hernia, or you take part in activities or exercise which may put strain on your stomach muscles, it is a good idea to get fitted for a stronger support solution, such as a support belt. In this case we advise a visit to your stoma nurse who will be able to advise what might work for you and can measure you accurately for a garment.

Some patients report that support wear has an effect on the output from their bag, and may cause pancaking. This is true for some people but many others find it is not an issue so do give it a try and if you encounter problems speak to your stoma nurse.

We finished the talk by showing a few examples of underwear designed for intimate moments. It is often the ostomate rather than their partner who is bothered by the bag but there are very pretty specialist options available to boost confidence. Covering the bag with a support band, a scarf or vest are also alternatives for those intimate times. ■

Our Annual CA Awareness Day – 3 October 2015



On the first Saturday of October the **Colostomy Association**, volunteers, supporters and businesses will **Go Purple** for CA Awareness Day. This special day was launched in 2014 to complement the existing World Ostomy Day as a way of spreading awareness of the work and support of the **Colostomy Association**.

Last year, supporters organised a range of activities which included: tea parties; mini open days and even wore purple wigs to help spread awareness of the **Colostomy Association** to the general public. This year is going to be even bigger! Dozens of individuals and businesses are getting involved to ensure more people can access the support services of our Charity.

Close to home, we will be turning Reading purple with barber shops wearing purple wigs, cafes serving purple cakes, the local hospital holding a cake sale and other local businesses dressing in purple for the day.

We will also be making our presence known with our purple gazebo on Reading's high street which sees footfall of over 50,000 people each day. If successful, we hope to launch this out to more towns and cities in the future and paint the entire country purple for one day each year!

Across the country our supporters will also be raising awareness of the **Colostomy Association** by going purple. We already have several other businesses interested in having a purple-themed day and some of our volunteers will be holding purple cake sales or digging out their purple fancy dress.

Stay tuned in the next issue of *Tidings* for pictures and updates of what everyone got up to on CA Awareness Day 2015. Perhaps you can help in 2016? ■



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What a difference an operation or two can make!

It all started at the beginning of 2008. Having been a very regular once a day man, I started to find that I was having to go to the toilet more frequently and this kept increasing. I didn't do anything about it or seek medical advice; I just presumed it was part of the ageing process. Then, one day in March, I had a rectal bleed. A visit to the local walk-in centre led to an immediate transfer to the nearest A & E.

After what seemed to be armfuls of blood being taken, an examination by a very young, overworked doctor and a night in a hospital bed I was discharged back to my GP. I was told that my blood results were all over the place. An appointment with a gastroenterologist would be arranged and I would probably need a gastroscopy as it was possible an ulcer had burst and caused the problem.

The doctor thought I had Irritable Bowel Syndrome (IBS), the gastroenterologist said I had a fatty liver and the gastroscopy proved negative. He did say I should have a colonoscopy but didn't write this in his report.

By the end of April my visits were getting more frequent and I requested the colonoscopy that had been suggested. Whilst lying there watching the screen I said to the nurse at my head: "I don't think that should be there" and a voice from behind said: "No, it shouldn't."

I knew then what was wrong with me. I had a tumour in my rectum the size of a golf ball which had grown through the bowel wall. A course of 25 intense shots of radiotherapy combined with a course of chemo helped to shrink the tumour and in December 2008 I finally had an Abdomino Perineal excision of Rectum (APER) and a stoma was formed.

Right from the moment it was diagnosed I vowed to remain positive. I had it and the sooner I got rid of it the sooner I would return to a normal life. I emphasised this even more to myself when the surgeon told me that they had removed the growth fully and cleared the nodes that had been

affected, saying it was a good job they had, as if they hadn't he would have given me less than five years to live.

I slowly regained my strength and returned to work on limited hours, went to the gym, went swimming and took part in my two greatest loves: walking and travel. My wife, Pat, supported me at all times ensuring I didn't overdo it.

I attended a Salts Open day and met a lovely **Colostomy Association** volunteer called Barbara and when I mentioned I would like to join the **Colostomy Association** and help others she grabbed me with both arms. As a result I have been a **Colostomy Association** volunteer and helpline ever since.

Through Sue Hatton's articles in *Tidings* I learnt about colostomy irrigation, but when I discussed it with my stoma nurse was told that due to the way my internal piping had been done it would be inadvisable to use this method of stoma management. Although disappointed, I carried on like everyone else having the odd hiccup and down days but shrugging them off and I continued to enjoy a new life.

Since then I have had two walking holidays on the mountains of Andalusia in Spain, (pictured below right). We have also cruised in the Mediterranean and to Madeira and the Canaries but the highlight was last year when for my 70th birthday Pat and I went to China, Hong Kong and Dubai.

China is not the easiest of places for someone with a stoma but by using common sense and, at times, imagination, it is possible to go anywhere and see everything. We climbed the Great Wall of China (pictured in the background), saw the Terracotta Army, the pandas at Chengdu and cruised the Yangtze river.

I had been having my regular clinic checkups, but the Colonoscopy procedure was proving difficult due to my internal piping. Then I developed a parastomal hernia which grew quite large very quickly and it became almost impossible to be

scoped. The surgeon decided to operate on the hernia and at the same time re-site the piping. This was done at the end of 2014 and three months later I was scoped without any trouble. When I asked about colostomy irrigation I was told: "No problem, as long as you wait until February to let everything settle down again".

I was shown how to irrigate and what a difference it has made to my life. I now feel I have a freedom that I had not experienced in the previous six years. Although I still carry my emergency kit, I have not had to use it, or an accessible toilet, since February. Inwardly I feel so much better as well as having a complete 'detox' every other day.

Activities, walking in particular, have become so much easier. I recently spent seven days walking about 60 miles in the Jura Mountains of France. I only wish that I had been able to irrigate when we were travelling in China. By the time this article is published, Pat and I will have been to Italy and had a walking holiday in Wales.

All my experiences have helped greatly when talking to people on the **Colostomy Association** Helpline, particularly those who are finding it difficult to cope, those who are a little scared about going abroad and those who are about to have an operation and don't know what life is going to be like when they come out of hospital.

As I said at the beginning what a difference not ONE but TWO operations can make...in my case 'life' from the first operation and a 'much improved lifestyle' from the second.

Frank



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From One Ostomate to Another

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

In the last issue of *Tidings* we published the following query on the Readers' Writes page:

I have had a colostomy for four years now and have tried the usual ways of preventing pancaking from happening (lubricating the pouch, covering the filter etc.) to no avail, but wonder if anyone has come up with any other ideas.

Ione Lee

What is Pancaking?

This occurs when, instead of dropping to the bottom of the stoma pouch, the stoma output accumulates around the stoma. It may seep beneath the flange/baseplate which can lead to leakage and sore skin.

Thank you to all our readers who wrote to tell us about their experience of pancaking. Although we are not able to include all your letters and e-mails, below is a selection of the replies we received.

During the day, any form of restriction around the top of the stoma pouch will tend to cause pancaking. Frequent causes are from clothing (waistband/belt/support garment etc.) exerting an 'enclosing'

pressure on the output area, thus preventing the output from falling. Wearing high-waisted garments can move the belt line above the stoma and so relieve the problem of pancaking, but these garments are not currently very fashionable.

At night time, lying on ones back is always a problem for pancaking as gravity is unable to draw output away from the stoma towards the base of the pouch. The problem is aggravated by the weight of bedclothes pressing down on the accumulating output, and further aggravated by any firm or tight clothing. Lying on one side or the other tends to help a bit, and for those who always lie on a particular side then applying the night time pouch at an angle can also help to alleviate the problem.

If you are able and are 'allowed' to do so – take up irrigation. Pancaking becomes history.

A.D.

I have had a colostomy for about a year, and as soon as I got home from hospital I was having a problem with pancaking. I spent three days on the internet trying to find a solution and eventually found three.

The best of the three is a product called a *stoma bridge* which is available in two sizes. I use the smaller one which is similar in size to a sugar cube. One of the sides is sticky so you peel off the protective sticker and then insert the foam cube into the bag. I use two, which I stick on either side of the hole. The company that I dealt with is called

Opus Healthcare and they sent me some samples of a product made by *Clearway*.

I also use baby oil, and was advised to smear this inside the bag using my fingers. However, I found that even after doing that and washing my hands, the oil was still on my fingers and was getting onto other surfaces and ruining the adhesion, so now I use the spray bottles of baby oil and spray into the bag maybe three or four times. Since using this method I have had no more problems with pancaking.

I know this information is not new but it might still help.

B.M.

I find the *OakMed M-0320K Microskin Closed Pouch* the answer to pancaking. I suffered in the early years of having a colostomy and, until I found this pouch, nothing really felt safe. Pancaking, and not originally finding a suitable solution, was one of the reasons why I turned to irrigation which I also recommend if Ione hasn't tried it. Of course I do realise that many people are unable to irrigate for various reasons but if she is able to give it a try I can certainly say it changes your life of living with a colostomy. With regard to the *OakMed Microskin Pouch*, I believe they

CONTINUED ON PAGE 14, COLUMN 1

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

LIVING WITH A STOMA FROM OUR READERS

CONTINUED FROM PAGE 13, COLUMN 3

also produce a two-piece with the same microskin flange. It is also worth mentioning the need to be particularly careful when removing the pouch from the skin as the adhesive is so good that it can make the skin sore if you try to remove it too quickly – best to use an adhesive remover and prise it away gently.

Lynda Sargeant

The reason I have pancaking is that just before it performs, my stoma retracts a bit. Because I gained weight after the op it now retracts into a valley. The flange of the bag (all the bags) is a bit rigid and the flange doesn't follow the stoma into the valley; it remains flat, level with the rest of the flange, creating a gap, hence the pancaking.

I tried a gadget which sounded as if it would work. It had a flange with a collar that sticks up into the pouch. You put this on first and apply the pouch over it. The problem was that the flange was rigid and the collar was soft, so the flange behaved like all flanges and stayed up there clear of the stoma when it retracted and the collar collapsed and was unable to keep the bag open. I wrote to the manufacturers to ask why the flange wasn't soft and the collar rigid but they didn't answer the letter.

Peggy Thomas

I have had my colostomy for seven years. For the first two years or so I was a martyr to pancaking. The over-efficient activity of the filters resulted in a powerful vacuum forming which effectively prevented any matter getting into the pouch and everything leaked under the flange. Sealing the filters gave some relief but did not always work, and could also result in troublesome ballooning.

I read a feature (maybe in *Tidings* but am not sure) by a stoma nurse who had found that some of her patients had benefitted by changing to OakMed pouches. On the basis that I had nothing to lose, I sent for samples and did find some improvement. I have used OakMed ever since, and while I cannot claim that I am trouble-free, on the whole life is much easier. There are still occasional leakages, and I have had the odd disaster (fortunately rare), but I would certainly recommend a trial of OakMed. Apparently the filters are unusual in some way – I think they allow the pressure to build up slightly before activating so the vacuum effect is avoided.

JD Wright

Pancaking is a subject often talked about on the Facebook group so I asked the question: "As it's a big problem for many, what helps you with pancaking?"

I had a good response with the top answers being:

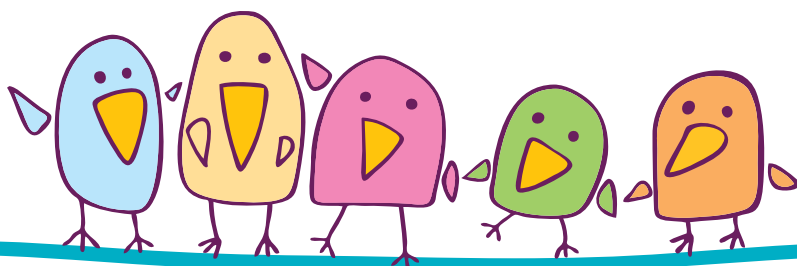
- 1 cover the filters to inflate the bag a little;
- 2 add a little lubricant to the bag (baby oil is most popular);
- 3 irrigation works well for those that can;
- 4 changing diet or drinking more; and
- 5 changing the type of bag you wear (mostly to a convex bag).

Sadly though, the most common reply (over a third of those that replied) was that they had never found a solution that works and they just have to put up with it!

So come on all you product designers there must be a fortune to be made by the one who solves this problem for all.

Ian Jackson

Facebook Administrator



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2016 Calendar order yours today

Many people believe that having a stoma means you can no longer live a full or active life. For some that means putting an end to sports and activities they enjoy while others fear they can no longer travel or journey abroad.

The **Colostomy Association** is committed to showing that having an ostomy is no barrier to living life to the full, and we'll be showing off some of our supporters' adventures around the world in our 2016 calendar.

The **Colostomy Association's** 2016 calendar showcases some of the journeys that our supporters have made. From treks up mountains to the striking scenery of Zion National Park in Utah; each month of our calendar shows that having a stoma should not stop anyone from being able to travel the world and enjoy life.

Our 2016 calendar has been carefully designed and curated so that it can take pride of place on your wall. All money raised from sales of the calendar will go towards supporting the services that the **Colostomy Association** provides to thousands of people with a stoma each year.

Each image was submitted by a **Colostomy Association** supporter and it proved difficult to short-list them down to the final 12 due to the high quality of all the entries. The winning photo of *Rubjerg Knude Lighthouse in Jutland*, northern Denmark by Kevin Young features proudly on the front cover and as the picture for August. There are also 11 other fantastic entries each perfectly suited for every month of the year.

Tick off some of your Christmas presents early with our 2016 calendar as it makes an

ideal gift for anyone. Our calendar is high quality, ring-bound and glossy, with each page measuring A4 (21.0cm x 29.7cm), which doubles in size when hung on the wall. The calendar contains 12 high-quality scenic images from all corners of the world. To purchase your calendar/s please fill out the order form below.

If this new **Colostomy Association** product proves to be a success, this will become an annual photographic competition so please support us by buying your 2016 calendar today!

Orders for the beautiful **Colostomy Association** 2016 calendar are now being taken, **in plenty of time to reach you for Christmas gifts.**

To order your calendar/s, simply fill in the form to the below. Make your cheque payable to **CA Commercial Ltd** and return the form and cheque to: **Colostomy Association, Enterprise House, 95 London Street, Reading, Berkshire RG1 4QA.**

Or, for credit card sales, contact us on the following number:

Tel: **0118 939 1537** during office hours.

Alternatively, place your order online at:

www.colostomyassociation.org.uk/shop

Last orders need to be received at the office by 1st December 2015, in order to process them so they reach you before the last posting times for Christmas 2015.

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What's next for Stoma Aid?

Which would you choose: a stoma bag or a tin can? Each day, tens of thousands of people don't have a choice and are forced to use a tin can, bin bags or other unsuitable items. For many ostomates in developing countries, stoma supplies are either unaffordable or unobtainable. The Colostomy Association wants to put an end to this terrible injustice by launching Stoma Aid.

Earlier this year we began asking for donations for Stoma Aid – a proposed new service to collect unused and unneeded supplies in the UK and distribute them to people in need abroad. Our online fundraising campaign has already raised almost **£3,000** and thankfully we've also received hundreds of pounds in donations since our last article in *Tidings*.

The response has been overwhelming with dozens of our supporters helping our campaign through donations or just spreading the word. Although we are still a long way off our goal of raising **£150,000** to run Stoma Aid for three years – we are committed to running this new project.

To show our commitment to Stoma Aid, the **Colostomy Association** has pledged £10,000 towards the start-up costs of the project as well as 50% of ongoing costs year-on-year. This commitment will help ensure that Stoma Aid can be made a reality quicker than ever and that thousands of people across the world will soon be able to access much-needed stoma supplies.

The **Colostomy Association** is currently waiting to hear back from various Trusts about potential funding for Stoma Aid. Additionally, we will soon be launching a series of presentations to Rotary Clubs across the UK to try to secure further funding from them for this worthwhile project.

Every day the **Colostomy Association** receives telephone calls from people wanting to donate stoma appliances but we currently have to turn them away.

Meanwhile, the **Colostomy Association** has developed links with various UK charities who will collect the sorted items

and ensure they reach the people who need them. These relationships are already in place and there are thousands of potential recipients urgently need our help. Please help us make this invaluable project a reality so that we can give these people back their dignity and a feeling of self-worth.

The money raised will go towards funding warehouse facilities for Stoma Aid, staff to run the service, packaging materials and general overheads, as well as potential travel costs for the volunteers who will be responsible for sorting out the donated items and repackaging them ready to be collected.

We would still welcome any contributions you could make towards getting Stoma Aid off the ground – any money donated will be specifically earmarked for the Stoma Aid project and could help make a difference to thousands of people across the world. Email our Marketing Communications Officer to find out more – niall.norbury@colostomyassociation.org.uk

A Hard Lesson Learnt

In July I realised that my priorities needed a serious re-shuffle. I was going to Scotland, from Devon, stopping off for the night at a cousin's house in Rochdale.

My husband drove all the way as it would have been Christmas if I had driven. We enjoyed a warm welcome, a lovely evening, and good food then went to bed. So far so good.

I irrigate, so imagine my utter horror the next morning when I looked for my kit-bag and couldn't find it anywhere. I had diligently counted out all my pouches, sleeves and accessories, making sure I had plenty of everything. Into my suitcase went the larger items: water bag and tubes, plastic jug plus a few extras. Oh! and some more pouches, wipes, and other bits... just in case. Well, you never know! I know now!

Those priorities I mentioned? Before setting off, I was busy sorting out the cat dish, litter tray and persuading her into her basket –

she hates going to the cattery. Water plants, switch off whatever, as you do. My husband put the cases etc. in the car and we were ready to rock... which is how my kit-bag came to be left in the bathroom.

You need three things to irrigate: jug; water; bag; and sleeves. The first two were in my case but the latter were neatly stowed in my kit-bag... in Devon! Then the stress kicked in, in a big way. Three pouches and one clothes change later and we were talking about going home. I had rung all the big chemists in the area, got loads of sympathy but no luck. Then I had an idea. I rang a local stoma support group in Rochdale and spoke to a very nice lady who advised me to try the stoma department at the local hospital.

In the meantime my husband had found Ainsworth Surgical Suppliers on my iPad. He then rang them and Hallelujah! They had Dansac sleeves and would let me have

some free samples as I only really needed three, thus dispensing with having to get a prescription. Problem solved. Scotland was great and so were Ainsworth. I have since written to them to say a huge Thank You as they saved the day.

And those priorities once again...No.1:

Forget everything else, sort Mr Strawberry out first. It's kit before cat. Thank heaven this all happened on a Friday. I dread to think what difficulties I would have had if it had been the weekend. What an Olympic-sized wally! I have been irrigating for seven years so should have known better.

Is there any other advice for anyone caught out in a similar situation?

From a very chastened
Donna Ashbrook



Ainsworth Surgical Supplies is an independent family-run business specialising in stoma care since 1981.

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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

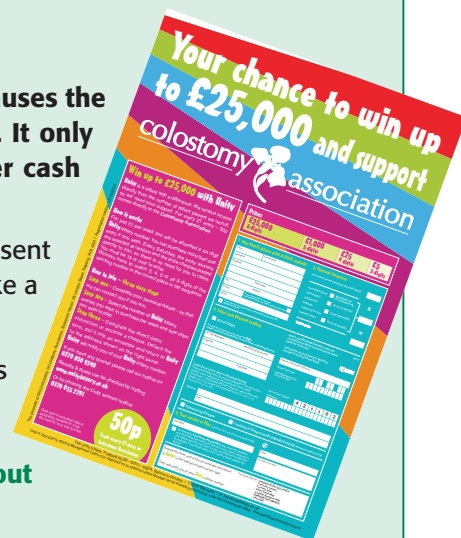
All of us at the **Colostomy Association** are constantly surprised and humbled by the various ways our supporters fundraise for us. As an independent Charity, every penny raised helps fund our work supporting ostomates across the UK and raising awareness of life with a stoma.

NEW! Unity Lottery

Unity is described as the nation's fundraising lottery. It's designed to give good causes the chance to gain support and raise valuable funds through a weekly lottery draw. It only costs **£1 per week** for chance to **win £25,000** each and every week, plus other cash prizes!

Every Saturday, the lucky winners are selected at random and prize cheques are then sent by post to the recipients, so there is no need to check your winning numbers and make a claim.

Participants will be allocated a six digit Unity Lottery number, which will remain theirs for as long as they keep playing. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence. More than one six digit number can be purchased and players have to be 16 or over to enter. **Further information about this opportunity including a registration form can be found on page 12.**



Special Thanks

We're always grateful to everyone who donate or fundraise for us each year. In this edition of *Tidings*, we'd specifically like to thank a few individuals who have made special donations towards the **Colostomy Association**:

- ❖ **Hilda Foster** A long-time receiver of *Tidings* magazine, sadly passed away recently. However, her daughter, Susan, decided to give **£50** towards the **Colostomy Association** for all the help and support Hilda received over the years.
- ❖ **Peter Platt** while Peter no longer receives *Tidings* magazine after undergoing surgery for a reversal a few months ago, Peter decided to give **£100** towards the **Colostomy Association** to help others receive the same amount of support that he had.
- ❖ **The Pheasant Inn** Charlotte Jones and her mother who run The Pheasant Inn in Allithwaite recently managed to raise over **£1,000** for the **Colostomy Association** at their pub!

Many thanks to you all, as well as to those not specially mentioned here! ■

London to Brighton for the Colostomy Association

This autumn, a team of four cyclists will make the journey from London to Brighton in aid of the Colostomy Association.

Starting in South London, the team – *Smurfits Unchained* – will join thousands of other cyclists on a 54 mile journey through Mitcham, Bandstead, Haywards Heath, Ditchling Beacon and finally Brighton.

The team members forming *Smurfits Unchained* are: Ian Jackson; Nigel Goodger; Dave Paxman; and Duncan Taylor. Speaking about why they decided to cycle in aid of the **Colostomy Association**, Ian Jackson said: "I've always enjoyed cycling and after my colostomy wasn't sure if I'd ever get back to it. When I finally did, I and a couple of work colleagues decided to do a challenge ride for the **Colostomy Association** on their 10 year anniversary. It been a tough journey but I'm now sure I'm fitter than I've been for years. With the correct advice and support a colostomy doesn't have to stop you achieving your goals."

So far, the team has managed to raise over **£700** for the charity and we all hope their ride goes well! ■

Finally and sadly...



One of our very own, much loved dedicated volunteers, Doug Haywood, who sadly passed away earlier in 2015 kindly donated **£3,000** to the **Colostomy Association** in his Will.

Doug had been struggling with an ongoing illness for several years and finally succumbed in June 2015. Doug's work for the **Colostomy Association** has helped improve the lives of many people living with a stoma and his enthusiasm and support will be sorely missed.

R.I.P. DOUG

NEW
Extended Hours

Out-of-hours Nurse Support Line

Amcare™ Group Nurses are now available to help stoma and rectal irrigation patients with any issues they might have. All our specialist nurses are Care Quality Commission (CQC) registered and hold relevant stoma care qualifications.

The Out-of-hours nurse support line is available
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to speak directly to a
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via Telephone, FaceTime
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Making life *easier* for you



PAIN AND PLEASURE

Each summer residents of the Exmoor villages of Bridgetown and Exton are invited to join the exclusive Exton Hill Club by completing a walk which includes the infamous Exton Hill – a mile-long stretch of tarmac with gradients of 1 in 6 to 1 in 4!

Club badges are handed out to first-timers at the Badger's Holt pub after a gentler downhill leg through fields and woodland.

Walkers pay for membership not just with pain and suffering, but by subscribing to the chosen charity for the year and non-walkers are welcome to join them in that as they cheer them in for a slap-up tea. **Colostomy Association** volunteer (and Club member since 2013) Mary Le Coyte was quite unable to comment at the end of the walk but later told *Tidings*: "it's always great fun...when it's all over – and I was delighted that Club members chose the **Colostomy Association** as beneficiary in its 10th Anniversary year." The traditional top-of-the-hill photograph includes three new members.

This tiny village helped raise **£145.50** for the **Colostomy Association**, Thank you.



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Withdrawal of 500 Club

As you can see from page 12, in this issue of *Tidings* magazine we have recently joined Unity Lottery which gives our supporters the opportunity to give to the **Colostomy Association** and be in with the chance of winning up to £25,000 each week.

With the introduction of this new external lottery, we are sorry to announce that our own **500 Club** will be ceasing at the end of the year. This is due to lack of interest and the time taken to administer it behind the scenes.

All existing paid up participants will automatically be included in the final draw with a **top prize of £1,000** this December, but everyone has been written to, requesting they cancel their standing orders direct with their bank (as we are unable to cancel these six monthly/annual payments on your behalf).

However, the new Unity Lottery is a fantastic chance to win big cash prizes, as well as helping support the vital services the **Colostomy Association** provides to thousands of people with a stoma each year.

Thank you for your support of our 500 Club over the years. However, we do hope you will now transfer (or join) and benefit from our new Unity Lottery! Good luck everyone!

Winners of the June 2015 draw can be found on page 41.

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Reference: 1. Stephen-Haynes, J. 2008. Skin integrity and silicone: Appeel® 'no-sting' medical adhesive remover. British Journal of Nursing, 17(12), pp.792-795.

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Irrigation and you

Sarah Squire, Trustee writes: Following on from our fantastic 10th Anniversary weekend in July we've been talking to some of our fashion show models who use irrigation as a way to manage their colostomy.

Our wonderful models (pictured here in their glamorous fashion show attire) explain below how they came to have a stoma and what led them to irrigation:

Janet writes: In 1997 I was diagnosed with bowel cancer and surgery took place just a few days later. A week after the operation I didn't feel well and the next thing I knew, 10 days had passed and I was in intensive care with my sister sitting by my bedside.



The join in my intestine had burst and I'd had an emergency Hartmann's procedure. Once I was eating again, I was shown how to attach and remove a see-through pouch by my stoma nurse and told I could order more through my GP. She also told me there was a procedure called *irrigation* but that I wouldn't want to do it as it was quite unpleasant. I carried on like this for a few years in total ignorance that there was any other kind of bag, wipes etc. let alone irrigation.

One day, I was handing in my prescription at the surgery, and the receptionist asked me why I didn't irrigate. Her husband did and she was sure he would tell me about it. He very kindly did so over a cup of coffee. I was really excited about this development, so off I went to a new stoma nurse. We sat behind a locked door in a small office, with a washbasin and a bucket and an irrigation

set. Not ideal, I hear you say. I persevered and soon got the hang of it. Fortunately, I have a tiled floor in my bathroom which was very friendly to the odd splash or spill as I was not very adept as pouring water from a jug into the sleeve to rinse it out. I now use the water container and the nozzle to rinse the sleeve.

I cannot say just how much freedom irrigation has given me. I have far less wind, no pancaking, never worry about a bulge or where the next loo is. Although I have the odd problem with my insides, I forget I have a stoma most of the time. I irrigate every day and it takes me about 30 minutes. After about 10 minutes, I peg up the sleeve and either read, start preparing my evening meal, go into the garden etc. Then I forget about it for 24 hours. There is nothing I cannot do now that I would be doing if I didn't have a stoma. Let's face it, at 77 I wouldn't be wearing a bikini anyway!

I have travelled to Australia, Tasmania, Singapore, Japan, U.S.A. and various places in Europe. All these countries with my irrigation set in my hand luggage. I can truly say "anywhere I can hang my hook is home", for my stoma at least.

My next big stroke of luck was walking past a doorway with the sign "The British Colostomy Association". Up the stairs I went to be greeted by the smiling faces of Jo and Beryl, a whole new world opened up. I am very fortunate that I live not far from Reading, or just think what I would have missed. I can't remember when I first became a volunteer, but it must be ten years now. I have had such good times and

will be forever grateful that I didn't just pass that doorway by.

My third stroke of luck after discovering irrigation and **Colostomy Association**, was 15 years ago, meeting and then marrying, a man who didn't care that I had a stoma and christened me his Bag Lady.

Ron writes: I'm now aged 77 and living in the village of Lympe near Hythe in Kent with my wife Maureen. We have been married for 56 years; have three children and six Grandchildren.



Retiring in 2000 after spending my working life in the food industry, both retail and manufacturing we were able to extend our caravanning holidays to include spending several months a year touring France and Spain.

CONTINUED ON PAGE 24, COLUMN 1

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.

CONTINUED FROM PAGE 23, COLUMN 3

Having always kept fit exercising both at home and at the gym (I was often the 'token male' in the mixed aerobics classes!), it was a surprise to be told I needed heart surgery. This was in 2003, I was convinced they had made a mistake but they hadn't and a double bypass was the result. From this I made a full recovery and was able to take my annual ski holiday – hooray – and continue with our extended holidays.

In 2008 a further surprise when on returning from holiday I mentioned to my GP that I had noticed blood spotting on toilet tissue on just two occasions. Fortunately my GP took this more seriously than I did and after the run of tests Bowel Cancer was diagnosed. In the September I had an APeR procedure resulting of course in having a Stoma. This time convalescence was longer, in fact three months of twice daily visits from the wonderful District Nurses.

But that is now all in the past and fortunately we continue to enjoy all the things we did previously, still long stay caravanning holidays, still skiing and now long haul flights to Australia to visit our son and his family with long stop overs in Singapore, Bangkok and Kuala Lumpur.

One of the most significant things I did after my operation was to attend the **Colostomy Association** open day in the West Midlands. There I met, in addition to many dedicated **Colostomy Association** volunteers, Sue Hatton **Colostomy Association** Trustee and champion of Irrigation as a means of stoma management.

Talking to Sue and others convinced me that irrigation was well worth trying, there was nothing to lose, if it didn't work out I could always revert back my previous way of managing. The event also led me to apply to become a **Colostomy Association** volunteer and to also get more involved with our local stoma support group.

The great thing about Irrigating is the freedom it gives when planning trips out whether it's a meal out, a weekend away or longer trips.

On all our travels, Irrigation has been a godsend. Being able to adjust the day/time of irrigating means a trouble and stress free journey no matter what means of travel.

Spending, as we do, long periods of time away does sometimes bring challenges and I certainly have experienced the extremes of disabled facilities, from what you might call five star standard to one in Spain that was a converted deep sea container. No windows, no ventilation but it satisfied the requirement for disabled facilities – just – but gosh was it hot!

One topic that often crops up regarding travel and irrigation is water quality. It's

something that has never worried me, I work on the principle that if it's drinkable it's ok, if not boil it or use bottled. In Spain where a lot of areas have desalinated water I always use bottled which is very cheap.

But my 'water story' is of a trip to the outback in Western Australia where we stayed overnight at a homestead. The water on the farm came from a pond, complete with an assortment of wild life. Having explained my need for pure water I was assured they would provide triple filtered water which would be no problem. In the morning the triple filtered water had a lovely green film floating on it, yes I skipped irrigating that day!

I guess the point is if you are enjoying reasonable health there need not be any changes to your life style.

Fortunately I am able to do all the things that I was able to do before my 'op' – and I still can't play the piano!

But thanks to having a stoma I have been able to walk the catwalk and can now change my passport occupation from 'retired' to 'Male Model'.

Every cloud has a silver lining.

Gillian writes: I awoke after my seventh back operation to be told that a nerve that led to my bowel and bladder had been severed so I would be doubly incontinent.



As you can imagine, life changed considerably. I had no feeling *down there* and had one or two embarrassing accidents. Eventually I opted for a colostomy, and also using a catheter to 'spend a penny'. I then discovered that my husband was having an affair with my best friend. After our divorce was finalised I wondered what to do with my life.

I had spent a couple of holidays in Turkey and decided to go and live there. The doctor

nearly had a fit but said I should 'go for it'. My three daughters were very supportive so off I went into the unknown at the age of 61.

I rented a lovely two-bedroomed flat overlooking the beach. By then I had discovered irrigation, which was a godsend in Turkey, and arranged to get a regular delivery of bottled water. I also got a job with Thomas Cook as a Transfer Rep to and from the airport and their hotel. It was a lovely interesting job and I went white water rafting, para gliding and on jeep safaris. We had picnics on the beach and lots of parties.

Eventually I had to leave Turkey and return home as I had a large hernia. I was very lucky to live in Devon and be referred to Mr Ian Daniels who re-sited my stoma and all was well. He then asked me if I would be a model in the forthcoming **Colostomy Association** fashion show.

My eldest daughter then persuaded me to move to Wales and bought me a bungalow to live in. I was having awful trouble with my bladder and ended up by having two more operations and now have Botox injections into the bladder at regular intervals. No matter how much I tried to persuade them they would not give me some for my face! Since then I have had more trouble with my bowel and two more operations.

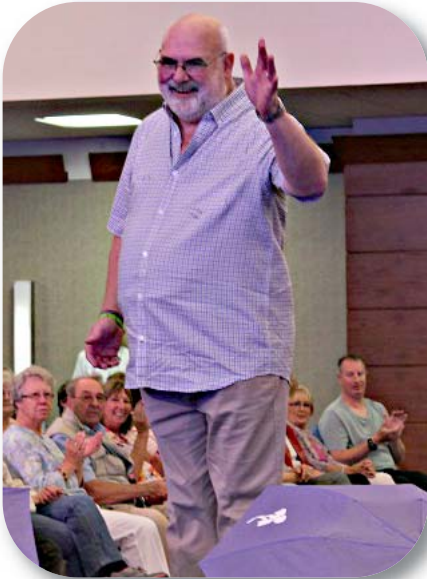
I am still living on my own but have a man 15 years younger than me and I am frequently on his Harley Davidson motorcycle, much to the amusement of my grandchildren, one of whom gave me a crash helmet!

So after 37 operations I am still kicking up my heels and despite what life has thrown at me I am enjoying myself. It has not all been happy times; when my marriage ended it was one of the worst times of my life. I suffered deep depression and without the support of my children and friends I would not be here.

Life is precious. When dealt with something that feels completely alien, at first you think you cannot cope anymore, but we find a hidden strength from deep within ourselves and we will get through it all.



Steve Clark writes: Around 14th February 2011, a familiar pain returned. Despite drastic dietary precautions, it wouldn't disappear. I should have gone to the doctor but we had a commitment in a couple of days to tow a trailer down to Toulouse in France, to help our son and daughter-in-law relocate to the UK.



The voyage back to Portsmouth on Friday was a nightmare. It was on a 'conventional' ship and took about three hours longer than the outward passage. I found a comfortable seat in a quiet area of the ship and planted myself there for the whole passage. I couldn't move for the pain; I was getting worse and worse.

Although I still had the pain over the weekend, I still didn't consult a doctor. On Monday when my wife, Cherry, insisted on making an appointment with the GP the doctor examined me and immediately telephoned Queen Alexandra Hospital, Portsmouth for a bed. I was admitted to the surgical assessment ward and found myself on the operating table that afternoon. I don't know what time I awoke but I was taken into intensive care and have a vague

recollection of seeing all the family gathered round the bed. It was at this point the shocking news was broken to me: I had a colostomy bag...A what? I didn't have a clue what I was being told and, probably due to the drugs, I couldn't really be bothered to ask questions and find out!

After complications, further surgery and general recuperation, I was able to buy a new taxi and get back on the road about the middle of August, 2012, a full 18 months after all the fun had started! This was a major step; I was still not very fit, physically, and I was unaware of any other people in my position. I felt depressed and alone.

A great improvement to my psychological state came when we found the **Colostomy Association**. Their website pointed me towards the CA closed Facebook group which I joined. Wow! All these people on Facebook with stomas! Suddenly, I was not alone; I had someone else to talk to, who knew my situation.

Then came the blockbuster: The Facebook group were organising a get together in Birmingham. After a brief discussion with Cherry, I told her we were going! There were about 30–35 of us for the weekend and we had a wonderful time. I met loads of people who, quite honestly, were beyond inspirational; they were awesome. That's the wonder of the **Colostomy Association** closed Facebook group!

A major change to my stoma management was made as a direct result of the Facebook group. It introduced me to the concept of irrigation. I can now get 24 hours without a change of bag although some people are lucky enough to go 48 hours or even longer. The procedure has allowed me to forget about my bag and get on with a normal life.

I have irrigated in numerous hotel rooms but, probably the most unusual irrigation was in Silloth, Cumbria. We had travelled to

visit son and daughter-in-law but, due to space, stayed in a caravan on a holiday site. There was a tiny shower room containing the loo and I have strong recollections of wedging myself into the space to irrigate with a full storm underway outside. The caravan was rocking violently and the water bag was hanging quite precariously on a window catch. I still don't understand to this day how I didn't end up with a bag full of warm water crashing down on me!

So, where am I now?

Well, the **Colostomy Association** have trained me up as a volunteer and I am an administrator on the Facebook group as well as providing background support to a local group that has been started by two lovely ladies in South Hampshire.

Last year, I dressed in a purple wig and spent a weekend in my taxi, raising money for **Colostomy Association** awareness.

Oh, and I somehow found myself volunteering to appear in the **Colostomy Association's** Gala Weekend fashion show. Daft? Me? Yep, as a brush but, as a result of the **Colostomy Association**, I am thoroughly enjoying life with a colostomy. ■

Many *Tidings* readers will now hopefully have seen the *Irrigation and you* DVD produced by **Colostomy Association** which is a brilliant tool for explaining the irrigation process.

Colostomy Association volunteer Judy Colston received an award at the 10th Anniversary event in July for her contribution to the DVD. We are extremely grateful to Judy who volunteered to be filmed while irrigating. It makes such a difference to be able to see someone actually performing the procedure, but we appreciate it is not an easy thing to do in front of a film crew.



Prescription Review



L-R: Amanda Gunning, **Colostomy Association** trustee and Clinical nurse manager for Hollister Ltd and her colleague Julie Oxenham, Clinical Nurse Specialist in stoma care

Amanda Gunning, **Colostomy Association** trustee and Clinical nurse manager for Hollister Ltd spoke at our 10th anniversary event about how we, as patients could potentially help save our NHS money but more importantly ensure we are using the best product to suit our needs. She has kindly expanded on her talk and from the work that she and her colleague Julie Oxenham, Clinical Nurse Specialist in stoma care, have undertaken in the field of prescription review, they have given an overview for *Tidings* readers.

Amanda and Julie write: As many of you are aware, the NHS is tasked with making efficiency savings in order to deliver the level of care needed for this country and £30 billion cost savings need to be made by the NHS by 2017¹.

Evidence has shown the cost of overall prescriptions are down by 5%, but in stoma care there appears to be a 21% increase². With a £248 million spent on stoma appliances and additional products throughout England in 2013³, the cost from additional products alone has risen from £12.7 million in 2000 to £53.1 million in 2012⁴. What can we do as stoma nurses and ostomates to help reduce these costs?

Incorporating prescription review into routine follow up may safeguard against increased and incorrect usage of stoma products. Prescription review is a process whereby the stoma nurse in partnership with the ostomate looks over an individual's stoma products on their prescription to check that they are current for clinical need. By ensuring that the prescription remains appropriate unnecessary costs to the GP who picks up the cost of stoma products is avoided.

Prescription review work is undertaken by stoma nurses working closely with CCGs (Clinical Commissioning Groups) and medicines managers. CCGs are the organisations that co-ordinate the delivery of NHS services in England specifically the services that GPs offer. Medicines Managers are individuals who are tasked with ensuring that people make the best possible use of their medicines and appliances (stoma products) so waste is

avoided. Any money released from the process of prescription review will go back directly into the GP's budget which will benefit the care of that patient at their GP practice.

The **Colostomy Association**, IA and Urostomy Association have worked closely with the stoma industry and stoma care nurses at the Patients Industry Professionals (PIPs) Forum to produce the Stoma Prescribing Guidelines (*Fig 1*). A copy is available from the **Colostomy Association** office and our website. GPs and medicines' managers have found this useful as a baseline to help in their understanding of how stoma products should be prescribed. However as stoma nurses we are aware that our patients are individuals and product usage will vary according to the clinical need of that person and this is taken into account when prescribing stoma products. As stoma nurses we can often use prescription review to champion the needs of our patients to ensure that the level of

products agreed with the GP is adequate so in this way it is just not about cost-savings it is acting as the patient's advocate also.

In the process of prescription review, communication between the stoma nurse, GP and the individual patient is imperative so any changes to the current prescription are clearly understood and patient's needs are met. As stoma nurses we often see items on the prescription that are not used but continue to be prescribed and these require deleting but they can always be ordered if needed in the future. As already indicated, your stoma nurse is your advocate and if your needs change or you require alternative products the stoma nurse will assist you to liaise with your GP in order for them to understand your requirements.

Annual prescription reviews are important in preventing the continued rise in stoma prescription costs as over time the stoma requirements for ostomates may change and items may no longer be needed if the

STOMA PRESCRIBING GUIDELINES		
Type	Average wear time	Average quantity per month
COLOSTOMY		
One-piece pouches closed pouch	Pouch changed 1 - 3 times a day	30 - 90 pouches
Two-piece baseplates closed pouch	Baseplate changed 2 - 3 times a week	8 - 12 baseplates
	Pouch changed 1 - 3 times a day	30 - 90 pouches
<i>Because colostomates have differing amounts of large bowel, their stomas behave differently and the number of changes they need to make each day varies enormously. At one end of the scale certain colostomates may manage their stoma by using a drainable pouch while at the other end certain colostomates may be able to irrigate. In between there will be a wide variety of one and two piece appliances and additional products used and a wide variety of changes required each day.</i>		
ILEOSTOMY		
One-piece drainable pouch	Pouch changed every 1 - 3 days	10 - 30 pouches
Two-piece drainable pouch	Baseplate changed 2 - 3 times a week	8 - 12 baseplates
	Pouch changed every 1 - 3 days	10 - 30 pouches
UROSTOMY		
One-piece urostomy pouch	Pouch changed every 1 - 3 days	10 - 30 pouches
Two-piece urostomy pouch	Baseplate changed 2 - 3 times a week	8 - 12 baseplates
	Pouch changed every 1 - 3 days	10 - 30 pouches
Open night drainage bag	Bag changed weekly	4 bags
Single use drainage bag	Bag changed daily	30 bags

Fig 1: PIPs Forum – Stoma prescribing guidelines

initial problem no longer exists, a pattern of habitual usage may develop which may lead to waste and unnecessary costs to the patient's GP (Fig 2: Examples of over ordering/inappropriate use of stoma products). Amongst some individuals there may be a misunderstanding of how additional products should be used in practice; misunderstanding of how skin barrier wipes are used has been shown to be particularly commonplace. Many of you may not have been reviewed by a stoma care specialist for some considerable time and what you were told about how your stoma products work may have been forgotten especially if it was at the beginning of your stoma experience; education around product use is essential to avoid inappropriate usage and this may have to be on an annual basis. A recent example of a case study in prescription review (Fig. 3) highlights some of the issues discussed above.

It is thought that skin problems affect around a third of colostomates and over two thirds of those with an ileostomy or urostomy. Some people may regularly self prescribe by ordering alternative additional products that they may see advertised which may not be appropriate if it is not at the advice of a stoma nurse. Products can be used to protect the skin around the stoma for those at risk of skin breakdown and as you are aware there is a wide choice of barrier products available, packaged as a wipe, spray or an applicator stick. These products vary in cost and an individual assessment is required to ensure the most appropriate one is prescribed. A study undertaken by Rudoni and Dennis (2009) indicated that 73% of stoma nurses recommended that patient's should seek their advice before using an additional

product, particularly in the case of red and broken peristomal skin. However, in contrast, 64% of patients reported that they do not contact their stoma nurse prior to trying an additional product and 51% of patients reported using an additional product, not recommended by their stoma nurse. However, it has been noted that some patients may have experienced difficulties contacting their stoma nurse or believe that they are too busy (anecdotal evidence from the **Colostomy Association**). Ostomates that have an understanding of their individual prescription requirements and are proactive in accessing stoma nurse provision are central in supporting cost effective prescribing.

Peristomal skin conditions or sore skin around the stoma may present as red, itchy and broken skin due to leaking or ill fitting appliances which may become the 'norm' for some ostomates. Although this seems shocking it reflects what we see in practice as SCNs, as it appears that because a person has a stoma they expect to put up with problems and do not like to bother their stoma nurse. As SCNs we do not want sore skin to become the 'norm' for our patients and want them to approach us not just so that the products prescribed are appropriate but more that our patient's quality of life is improved. At the same time we are aware that many established patients want to make decisions about their own care without the intervention of the SCN. Boyles (2010) comments that as stoma nurses we need to remain mindful of a patient's right to independence, but need to work with them to give them the skills and confidence to make the choices most appropriate for them.

Stoma nurses do not want to be seen as the 'prescription police' however they are central

to sensible stoma prescribing and cost reduction. Patient education in the correct use of stoma appliances and additional products may assist in reducing prescription costs. Ostomates that take a proactive approach in contacting their stoma care nurse with stoma management problems will impact on the spending reduction required by the NHS, which at the same time will ensure that their stoma prescription is most appropriate for them contributing to an improved quality of life. ■

Case Study

- Mrs X, 80 year old lady who had a colostomy formed 8 years ago. Not seen a SCN for 6 years.
- Using a convex drainable pouch (£40.15 for a box of 10) never drains this pouch, swapped to a closed equivalent pouch (£27.98 for a box of 10). **£623 cost savings over a year.**
- Using a thickening agent in the pouch which she thought was a deodorant. Deleted off script. **£232 cost savings over a year.**
- Changed adhesive remover to a cost-effective alternative, using 5 sprays a month. **£132 cost savings over a year.**

Total cost savings over a year = £987

Fig 3: Case study to illustrate the cost-savings made when undertaking prescription review.

¹Health Foundation 2014

²You and Yours 2013.

³Health and Social Care Information Centre 2014.

⁴NHS Business Services Authority 2012.



Patient with a rolling monthly order: 80 boxes of 30 pouches per box and equivalent flange extender found in a spare bedroom (£8,500)



100 adhesive removers found in the bottom drawer of a bed (£900)



A gentleman using 10 boxes of 30 barrier wipe cloths monthly to clean his stoma (£240 a month or £2,880 a year)

Fig 2: Examples of over ordering/inappropriate use of stoma products

OPEN ALL HOURS

www.colostomyassociation.org.uk/shop

NEW! Colostomy Association Online Shop

Many of our readers and supporters have been telling us for some time about how they would like to purchase **Colostomy Association** branded merchandise. So, we are very proud to announce that the **Colostomy Association** online shop is now open.

Our shop features a range of **Colostomy Association** merchandise that you have been asking for such as: pens, wristbands, umbrellas, coasters, T-shirts, running vests, lapel pins, colostomy irrigation DVDs and more. Buying **Colostomy Association** products is a great way to give to our Charity with 'retail therapy' as an added bonus.

The **Colostomy Association** Products & Services Officer, Arvind Anand, said: "Come and visit us at colostomyassociation.org.uk/shop or complete the order form below to treat yourself or shop for a gift. Some of these items will also help raise our profile nationally – and what's more, an umbrella will make a very pretty Christmas stocking filler!"

of the facilities being in a usable state.

Product

(prices inclusive of VAT & p+p)

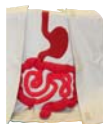
Unit Price

Quantity Required

Sub Total

Anatomy Aprons

£157.50



A fantastic teaching tool for educating people about the various kinds of stomas. These aprons can help explain a variety of different surgical procedures including colostomy, loop colostomy, transverse colostomy, ileostomy, colectomy and hemicolectomy.

Lapel Pins

£3.00



A simple and elegant way of showing your support for the **Colostomy Association** with our pretty and discreet lapel pins. Hard enamel lapel pins of purple Iris, produced in four colours. Supplied with butterfly clutch pin. Measuring 25mm high.

Irrigation and You DVD

£4.99



Colostomy Irrigation and You is an educational DVD aimed at patients, it has been produced to raise awareness about colostomy Irrigation as a method of bowel management. Sold individually.

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.

CA Wristband

£2.00



Show your support for the **Colostomy Association** with our bright and bold wristbands. Silicone debossed wristbands, available in green or purple infilled with contrasting coloured text.

202mm x 12mm x 2mm. Sold individually

Coasters

£3.50



These durable plastic coasters are easy to wipe and they feature **Colostomy Association** branding as well as our website address and helpline number. Ideal for home or office. Sold individually.

Pens

£1.50



Ideal for handbags or jacket pockets. White pens with black ink and the **Colostomy Association** logo. Sold individually.

NKS – RADAR Key

£3.50



Access 9,000+ locked toilets around the UK where the RADAR logo is displayed. The National Key Scheme (NKS) aims to provide disabled key holders with independent access to the toilets provided for them and increases the likelihood

Product

(prices inclusive of VAT & p+p)

Unit Price

Quantity Required

Sub Total

CA Umbrella

£11.50



Shield yourself from the rain and look good at the same time. Ideal for your handbag.

Manual folding polyester umbrella in purple with white Iris logo on four panels. Supplied in a nylon sleeve with a Velcro fastening. Size: 90cm x 35cm. Sold individually.

Running Vest

£12.49



Joined a running club, running a marathon or just want to take up jogging? Purple sleeveless running vest printed on the front and back with the **Colostomy Association** logo in white.

Cool Vest from Just Cool by Awdis. 100% polyester, 140gms.

Sizes available (inches):

S (34), M (38), L (41), XL (44), 2XL (47)

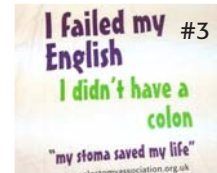
T-shirt



Three designs to choose from, all T-shirts are printed on Fruit of the Loom quality cotton. Printed on one side with the selected design and in **Colostomy Association** colours.

T-shirt designs with the following words:

- #1 Living life (with a colostomy) and proud of it
- #2 Living life (with a stoma) and proud of it
- #3 I failed my English I didn't have a colon – my stoma saved my life



T-shirt size	Unit cost	Design #	Size	Colour	Quantity	Sub total
S (35-37), M (38-40), L (41-43), XL (44-46)	£17.49					
2XL (47-49), 3XL (50-52)	£18.49					
5XL (56-58)	£19.49					

Colours available – not exact colours – colours shown for guidance only:

Sizes S-3XL only: Ash ☐ White ☐ Light pink ☐ Sky ☐ Natural ☐

Sizes 5XL only: Black ☐ White ☐ Heather grey ☐ Navy ☐

Women's size guide:

S 10 M 12-14 L 16 XL 18

All products sold individually and prices are per item and inclusive of VAT & p+p. Please allow 28 days for delivery.

Please send me the above marked items. I enclose a cheque for

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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! Independence Products Ltd

Independence Products Ltd and SpiroTect™ contact information is now integrated.

Independence Products Ltd contact email has changed to: **enquiries@ipl.uk.com** To avoid missing any news please mark this email address as not 'spam' if it is in your junk mail box.

Our website details have remained the same:

www.IndependenceProducts.co.uk

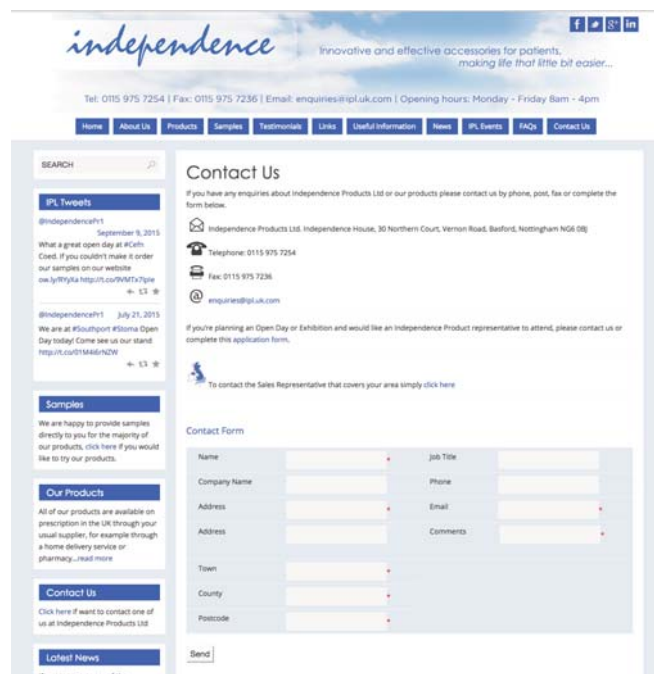
The mailboxes which you could be familiar with, are now:

- **Info@ipl.uk.com**
- **enquiries@ipl.uk.com**
- **sales@ipl.uk.com**
- **samples@ipl.uk.com**

If you do use the email address of **...@independenceproducts.co.uk** then these emails will still reach us in the interim.

If you have any further questions or queries please feel free to contact Independence Products Ltd on:

0844 800 2236 or **enquiries@ipl.uk.com**



New
It's time to
make life better

respond
making life better

We know the difference that the right stoma care can make to your quality of life. That's why we will do so much more than simply deliver to your door.

Through our BHTA-trained support team, community nurses, website and social media pages we also provide a network of friendly support, information and expert advice. Our aim is for you to feel supported and connected, with a personal, caring local service that puts your wellbeing first.

We are part of the family-run Eakin Group – specialists in ostomy care since 1974. We champion quality of life for people living with stoma, putting your care at the heart of what we do.

Our service is independent and we value our relationship with you and we'll always listen to what you need so we can help to make your life better.

Whatever stoma care product you need, as long as it's available on prescription you can rely on us to deliver it quickly and with absolute discretion.

Our friendly, customer support teams will always take the time to get to know you and talk through the kind of help you need. They're all BHTA-trained, discreet and friendly – and committed to building a personal relationship that you can rely on for support, advice and guidance.

Our local community nurse teams are there to help you make the move from hospital to home and provide ongoing support should you need it. Their support complements the care you receive from your hospital stoma nurses and healthcare professionals. Our nurses can visit you at home, provide expert support and advise on how best to live with a stoma.

Our promise to you

Your quality of life and wellbeing is important to us. As part of our commitment to offering a service that makes life better, we will:

- Be independent, honest and informative

- Be trustworthy, personal and discreet
- Exceed our customers' expectations
- Build lasting relationships.

It's simple step 1

Simply call our friendly support team, send us an email or visit our website.

Make sure you have your full name, address, phone number, GP details and the prescription items that you'd like to order to hand. We will also provide the complimentary extras you might need, like moist wipes, dry wipes or disposal bags.

step 2

We'll contact your GP directly where possible to get your prescription. As soon as this is received, we will send your order out and we will be in touch.

step 3

Now you can sit back, relax and look forward to your parcel arriving. All our orders are sent in discreet, unbranded packaging.

Call us now on **0800 220 300** or visit **respond.co.uk**

The CA Fashion Show

Models share their stories



L-R: Monty Taylor, Chairman – Colostomy Association; Maureen Ford; Dean Armstrong (back); Ms N; Marlene Ellis (back); Faye Jones; Ron Huckstep (back); Sarah Hacker, Mayor of Reading; Aled Griffiths; Janet (back); Davina; Gillian Rawson; Steve Clark; Yvonne Frost, Image-On

An audience of more than two hundred applauded and cheered as eleven models walked down the catwalk on Sunday 12th July. Models were male and female, ranging in age from 11 to 70 plus. Anyone present who hadn't realised they were at the **Colostomy Association** Open Day, would never have guessed that every one of them had a stoma.

Each model wore three outfits: Cool & Casual, Smart & Sophisticated and Glamorous & Gorgeous. Six of the models share their stories here. Another four describe their pathway to a stoma and then on to irrigation on page 23.

Marlene writes: I worked as a doctor's receptionist for 18 years where I came across the full spectrum of illnesses and medical conditions. Little did I suspect that one day I would be the subject of the correspondence between the surgery and hospital consultants.



I was diagnosed with bowel cancer in 2013 soon after my 50th birthday and was told I would need a permanent colostomy. I met such devastating news with an absolute determination to face it all head-on and to embark on the long and hard road to recovery with a positive attitude.

Early on I made the decision to be open about having a colostomy, telling my close friends and family soon after the operation. To my delight all my friends and family were extremely understanding and supportive and I feel that level of support helped me come to terms with matters. It was a great pleasure to take part in the fashion show to mark the **Colostomy Association's** 10th anniversary celebration. It was absolutely brilliant – especially bearing in mind that a year previously I was in the middle of six gruelling sessions of chemotherapy.

In February of this year I had to undergo an operation to correct a hernia that had developed around my stoma. This interrupted the process leading to me adopting irrigation. Whilst I have not yet done so I am keen to irrigate as soon as practical.

Being a model strutting my stuff along the catwalk, though initially nerve-wracking, was one of the greatest moments of my life. Uplifting. Reassuring. Outstanding. All my friends and family who attended the fashion show were impressed by its professional delivery and organisation and were touched by the models' stories, clothing and sheer style. My friends were so happy for me being a (super) model that they marked the occasion by having a summer tea party.

CONTINUED ON PAGE 32, COLUMN 1

The CA Fashion Show M

CONTINUED FROM PAGE 31, COLUMN 3

Whilst it was a great honour and pleasure to be a model, for me the most satisfying aspect was when, after the show, I was approached by a lady who told me that her mother's concerns and anxieties about having a stoma were greatly reduced when she saw us and was inspired by all the models, of all ages, proving that such a procedure does not prevent you from enjoying life and looking absolutely fabulous.

Three cheers for the **Colostomy Association!**

.....

Dean writes: It all started in 2012 with a scorpion. This arachnid had been brought back from Greece and taken to a local pet store in Walthamstow, London. With only one claw it had no pet value so they contacted me. I'm an arachnophile, and I named my new friend Sue.



Sue had difficulty catching and keeping hold of her food. She ate crickets so I tried to help by holding them. I got stung and became paralyzed all down my right side. Fortunately, the surgeons at Whipps Cross Hospital managed to stop the poison before the incident became fatal. The poison did, however, significantly damage my pancreas and three months later I had an acute attack of pancreatitis.

A year later, in September 2013 I had another attack; this time it was chronic. I was taken to York University Hospital. When I insisted on knowing the truth, I was told I was going to die. I didn't die, but when I came round after the operation, I had no stomach, gall bladder or spleen, only half a

pancreas and had lost some of my intestines. I now had a transverse colostomy and a bag attached to my right side. My surgeon, Mr Glen Miller – easy to remember – was great. He told me the news and, being so happy to be alive, I can honestly say I have never given a second thought to my physical condition, not once, that's the truth.

My pain and what I never talk about is in my heart: it's broken. Sue stung me because she is a scorpion and that is their nature, that's what they do. My heart was broken by Mandy. She's not a scorpion, Mandy is Mandy, and that is her nature, that's just what she does!

Occasionally I have to go to the bathroom in the middle of the night, but on the whole, my bag goes unnoticed by myself and others. It's not a problem really; a bit of preparation is needed when I go out: my RADAR key, a spare bag, adhesive remover and wipes. I sometimes carry a small bottle of water to clean the opening, and a hand sanitizing spray... oh and doggie-type disposal bags.

I've had a couple of embarrassing moments and when they happen I repeat in my head an old mantra, "this will pass". It always does. I once got caught behind a skip and a furious lady asked: "What on earth are you up to, my young man?" That was outside York Minster. Sorry God, I couldn't help it; damn thing blew up like a barrage balloon!

Please, if you are new to having a bag of some type let me give you some advice: join the **Colostomy Association**. You will, I promise on my heart, find all the hope, help, love and support you rightly deserve. You can, and will, have a great life if you just reach out your hand. Believe me, if you join the association all that you will ever need will be there.

Lastly, I used to be a children's entertainer called Mr Bubbles. I had to stop doing that when I became ill, but that's OK because, thanks to the **Colostomy Association**, I am now a super-model!

.....

Maureen writes: It was back in 1979 that my partner dropped me at St Pancras hospital for an appointment to get the results of a biopsy.

We had been to a concert at the Royal Albert Hall the previous evening so were feeling happy. What a terrible shock it was

to be told I had cancer (the C word was never spoken of then). The operation to remove the cancer resulted in a colostomy.



At the time there were no specialist stoma care nurses, so I was just given a bag and the nurses expected me to get on with it. I left hospital with two appliances – the district nurse came the next day and left more – all different shapes and sizes, mostly old and perished! Whilst I was in hospital my partner moved our home to a new neighbourhood on the other side of London where I knew no one. I struggled – they were difficult days. My weight had dropped from nine and a half stone to six and a half stone and walking was difficult. There was no physiotherapy, so each day I walked a few more steps and gradually became stronger.

Seven months later my partner and I were married in a very simple ceremony; life was good, I was so happy just to be alive. Sometime later while we were on holiday in Menorca, I met a lady who also had a colostomy. She told me about a stoma care nurse at St Thomas' Hospital in London. On returning home I immediately made an appointment to see her. How wonderful it was to talk through all the problems I was having, with somebody who could understand and help. I realised then how important it is to talk about cancer and stomas.

Together with a number of other cancer patients I started a support group in North London. First we went for counselling training and then had an article about our group published in the local paper. Over the

Models share their stories

years I have been involved in setting up other groups and fifteen years ago, on retiring to Norfolk, helped start a stoma care group in Kings Lynn. There is so much wonderful help now that nobody should have to go through the difficulties that I experienced.

At 54 I found a lump and was diagnosed with breast cancer; again I was shocked. Ten years later it was back and resulted in a mastectomy. Now all I get is low grade skin cancers. Yes I have become the proverbial creaking gate; my saving grace is my sense of humour.

I have been volunteering for the **Colostomy Association** for many years and help to man the telephone helpline. This is a lifeline for so many; there is always somebody to speak to. I thoroughly enjoyed the tenth anniversary of the **Colostomy Association** and it gave me great pleasure to be included in the fashion show. A big thank you to all at **Colostomy Association** head office.

.....
Three of our models have already featured in Tidings. For new readers we include a short summary of how they came to have a stoma, followed by an update on what's been happening to them since their stories appeared in the magazine.

Faye first told her story in the 2011 winter issue of Tidings. She was born with Hirschsprung's disease, a condition where nerve cells are absent in part of the bowel, which results in chronic constipation, pain and blockage.

During her childhood she had several operations to remove sections of bowel, but at 13 years old she was still suffering from incontinence so opted to have a colostomy.

Faye takes up the story: I celebrate my stoma's birthday on the 7th April every year. It changed my life for the better. I was a completely different person; my parents couldn't keep me in. I went from being in nappies at the age of 12 – as a kid that's pretty horrible – to not having to worry about where I would find the next available toilet.

I have tried irrigation as I heard it lets you have so much more freedom, but it wasn't the answer for me. Despite trying all different speeds, times etc, I still suffered the same pain and nausea. Never mind, it's not meant to be. I gave it a go but my

bowel wasn't happy about it. Truthfully it is a bit disappointing but I think the bowel is a major part of your body and you have to listen to it. However, my colostomy never stops me doing the things I want to do, including sky-diving, holidays abroad and wearing a bikini.



In my early twenties I developed a strangulated hernia which required emergency surgery. Due to a post-operative infection my abdomen didn't heal as well as I would have liked. However, in March 2014 plastic surgeons performed a miracle which gave me the confidence to wander around Egypt wearing a bikini for the first time in my life. I thought if by doing this I could help just one other person with a stoma then it was worth it.

My partner, Neil, and I first met at work in 2012. He always used to criticise my nail varnish or wind me up over something. Then once we were in team meeting and my bag let off a huge noise; I wanted the ground to swallow me up but Neil didn't flinch. After the 'works do' that Christmas, we went to a local pub for a drink, then on to his house where we ended up chatting until the early hours. The friendship grew and grew over the next few months, and after I left that job – I now work for an NHS children's disability team in the community – we kept in touch. We booked our holiday to Egypt together 'as friends'... you can guess the rest! It wasn't until March this year that we made it official. Neil is so accepting and understanding of my colostomy and helps me change my pouch if needs be. We are currently attending the

genetics clinic and awaiting a further appointment to see the consultant to find out about the risk of any children I might have being born with Hirschsprung's. Neil was at the fashion show, where I, once again, wore a bikini, and he did surprise me with that kiss at the end of the catwalk.

.....
Regular readers will remember Davina. Her photograph appeared on the front cover of the Spring 2015 issue of Tidings and inside was her very moving story, which had also featured in Take a Break magazine.

Davina was diagnosed with bowel cancer at the age of 28 and found it very hard to come to terms with a permanent colostomy. Added to this, two months after her stoma was formed she had further surgery for a bowel obstruction and woke up in intensive care. Her weight had fallen to four stone. This was her lowest point. However, seeing the pain in her mother's eyes made her determined to get better for the family who has been at her bedside throughout. When her weight reached six stone she began six months of chemotherapy and it was during that time that she left her husband as she says that her marriage had gone past saving. Four weeks after finishing her chemo she began to look for a new job and soon after started work caring in the community.

The title Davina gave her story was Starting my life all over again. It was a long battle, but her confidence grew. She has never hid the fact that she has a stoma and says that talking about it and telling people is what got her through.



CONTINUED ON PAGE 35, COLUMN 1

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CONTINUED FROM PAGE 33, COLUMN 3

Davina takes up the story: I now work in my local hospital, on a care of the elderly ward and absolutely love my job. My main hobby is weight training in the gym and occasionally I like to go boxing and mountain biking. I love my sports, and try to have a very active and healthy life style.

It was a great experience to be part of the **Colostomy Association's** 10th anniversary, and although it landed on my 40th birthday, I was more than happy to postpone my own plans so that I could be a part of it; I thoroughly enjoyed the whole weekend. It really was amazing. Now I plan a belated celebration for my 40th birthday by going abroad with my boyfriend for a week's holiday in a five star hotel in the Algarve.

So I am pushing it in the gym and ready to go bikini shopping so I can strut my stuff on the beach. Although I don't choose to irrigate my stoma, I am lucky enough to be able to use a plug for up to 12 hours a day and, although I rarely do this, it's great for going on the beach, if I choose not to wear a bag.

.....

Aled: After his story was featured in Issue 36 of *Tidings* Magazine, 11 year old Aled received the Rotary Great Britain and Ireland Young Citizen Award.



Aled was born in 2003 with VACTERL association. Some of his anomalies include a hole in the heart, imperforate anus, one kidney, spinal defects as well as hand and arm issues. He spent the first eight weeks of his life in hospital where he had a colostomy formed at two days old followed by open heart surgery at six weeks.

He kept the colostomy for a year before having it reversed. Since then he has had numerous operations on his bowel and bladder, and four years ago had two conduit stomas formed. The first was an ACE (Antegrade Colonic Enema) procedure

where a section of bowel was brought out through the skin to form a channel which can be catheterised to introduce water to stimulate the bowel to empty. The other was a Mitrofanoff procedure where a small section of bowel was used to create a channel which is catheterised to drain urine from the bladder.

This hasn't stopped Aled. He loves to talk to others about his issues and this energy and determination has been recognised. At the age of eight he was invited to speak at a continence nurse study day where he was declared guest of honour. This led a year later to an invitation to the Association of Stoma Care Nurses conference where his presentation received a standing ovation. Aled has also been awarded the Diana award for his volunteer work.

At the fashion show finale Aled wore a dinner jacket and bow-tie and walked down the catwalk to the theme tune of Superman.

Not only did Aled appear in the fashion show, he also gave a presentation at the **Colostomy Association** Open Day on Saturday about VACTERL association and how it has affected him. He was a guest of honour at the Gala Dinner that evening where he was the first to get up and dance. A dance with Aled was an impromptu item that he kindly offered at the auction thus raising **£90** for the **Colostomy Association**, in addition to the **£250** Aled donated earlier in the day from part of the prize money he received for his BBC Award.

.....

During the intervals while the models changed their outfits, some background information about each of the models was projected onto an overhead screen.

.....

Our next model underwent radical surgery for a pelvic tumour in 1999 which resulted in a permanent colostomy.



She enjoys time spent with friends and family, travelling, learning, music and history.

She says: "I've learnt that if you reach for the stars you can actually just about touch them...and live your dreams...Life has no limits, the only failure is to never try."

The **Colostomy Association** would like to thank all the models who agreed to take part in the fashion show which many people in the audience have said was the highlight of the 10th Anniversary Celebrations. ■

.....

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10th Anniversary Celebrations



In July this year, the **Colostomy Association** celebrated 10 years of supporting people with a stoma, at a weekend of special celebrations in Reading. Over the course of the events hundreds of people were able to find additional support, meet other ostomates and celebrate the fact that having a stoma is not a barrier to living a full and active life.

Open Day

The weekend started with our Open Day and feedback from attendees has been incredibly positive with many people saying they found the help they needed and answers to questions and queries.



Supporters and exhibitors at the 2015 Open Day

There were plenty of opportunities to find some support at our Open Day. Our exhibition hall was filled with over 25 stalls from charities, manufacturers and other companies, displaying their wares which ranged from stoma products to legal advice. Throughout the day attendees also had the chance to book one-to-one appointments with two Dansac stoma care nurses for any medical queries. These proved to be very popular!

The main highlight of our Open Day were the talks covering a variety of useful topics such as support garments, prescription management and hernias, as well as guest talks from The Breakaway Foundation and our junior ambassador representing our Junior Ostomy Support Helpline (JOSH),

Aled Griffiths, aged only 11. More details on some of the Open Day talks can be found in this issue of *Tidings*, while there will be a special feature on support garments in a future edition of our magazine.

One exhibitor said: "Not only was the weekend inspirational it was very enjoyable and the balance the **Colostomy Association** team created, made it a joy for us to attend and be welcomed as a part of! The hard work I know that goes into organising such events was really evident in yours as the whole weekend flowed seamlessly, which is testament to the planning and efforts of the **Colostomy Association** staff."

Fundraising Gala Dinner

In the evening, past and present supporters of the **Colostomy Association** came together to celebrate the last 10 years at our special gala dinner.



Colostomy Association supporters dancing to House of Beau with Aled front-and-centre

In addition to a delicious three-course meal at the Royal Berkshire Conference Centre, guests were able to enjoy an evening of entertainment courtesy of the House of Beau, kindly sponsored by Dansac. A variety of cabaret acts kept the audience entertained throughout the night with the awe-inspiring hand balancer, the hula-hoop troupe and the vintage Rockabellas getting everyone onto the dance floor.

The gala dinner was also an opportunity to raise much-needed funds for **Colostomy Association** services. Our auction saw guests bid on fantastic prizes such as a weekend away in a country cottage in Norfolk, a portrait sitting from a professional artist and a dance with the weekend's stand-out star, Aled Griffiths.

Additionally, we also announced the winner of our hugely popular car raffle at the end of the gala dinner and £19,922 worth of raffle tickets were sold, with almost 1,000 tickets purchased during the open day alone. The lucky winner who got to drive away with a Vauxhall Corsa for just £1 was Mr C Stead from Yorkshire who came down to Sonning Common Garage near Reading to collect the car and meet our chairman, Monty Taylor.



Mr Stead, left, receiving his prize from Monty Taylor

The cash prize winners included:

- Mrs O Jackson£500
with a £20 donation back
to the **Colostomy Association**
- Mrs L Barrett£250
- Mr F Parr£50
- Mr J Price£50
- Anonymous£50
x 2 people

The evening also gave us the ideal opportunity to officially present several

CONTINUED ON PAGE 39, COLUMN 1



Whether you need to create a snugger fit around your stoma, soothe itchy skin or make doubly sure you don't leak there is a Trio silicone product just for you.



10th Anniversary Celebrations

CONTINUED FROM PAGE 37, COLUMN 3

special people with well deserved awards in recognition of their contributions to the **Colostomy Association** over the past decade and beyond. These included two *Volunteer Lifetime Achievement Awards* for Roger Barrett and Pat Ottley as well as separate special award for **Colostomy Association** Volunteer, Judy Colston.



Roger Barrett receiving his Volunteer Lifetime Achievement Award

Roger Barrett – Roger joined the Colostomy Welfare Group back in 1985 and since that time he has been vital in developing links with hospitals and Stoma Care Nurses as well as allaying people's fears and concerns of living with a stoma.



Pat Ottley's Volunteer Lifetime Achievement Award being received by her granddaughter, Clare

Pat Ottley – A volunteer for over 30 years, Pat's incredible enthusiasm and dedication helped ensure that vital services such as our 24-hour helpline were able to run smoothly. Pat was willing to get involved in any way despite juggling her support for the **Colostomy Association** with two busy jobs. Pat was unable to collect the award in person so her granddaughter, Clare, received the award on her behalf.



Judy Colston receiving her surprise award from Alfred Levy who collected it on the night, on Judy's behalf

Judy Colston – Judy received a surprise award for her involvement in the production of our *Colostomy Irrigation DVD*. Judy has given her time and energy to the **Colostomy Association** for years and allowed herself to be filmed irrigating in her own bathroom in her underwear. Thanks to Judy's courage, our DVD has been a huge success and has helped transform the lives of many people with a stoma.

And finally, **Julie Rust** who is featured separately on our *Dear Nurse* page 50 for her contribution to *Tidings* magazine.

Fashion Show

Our weekend of celebrations came to a close on the Sunday morning with our Fashion Show which saw 11 wonderful models, each with a colostomy, take to the catwalk to demonstrate that having a stoma shouldn't stop you from looking and feeling good.

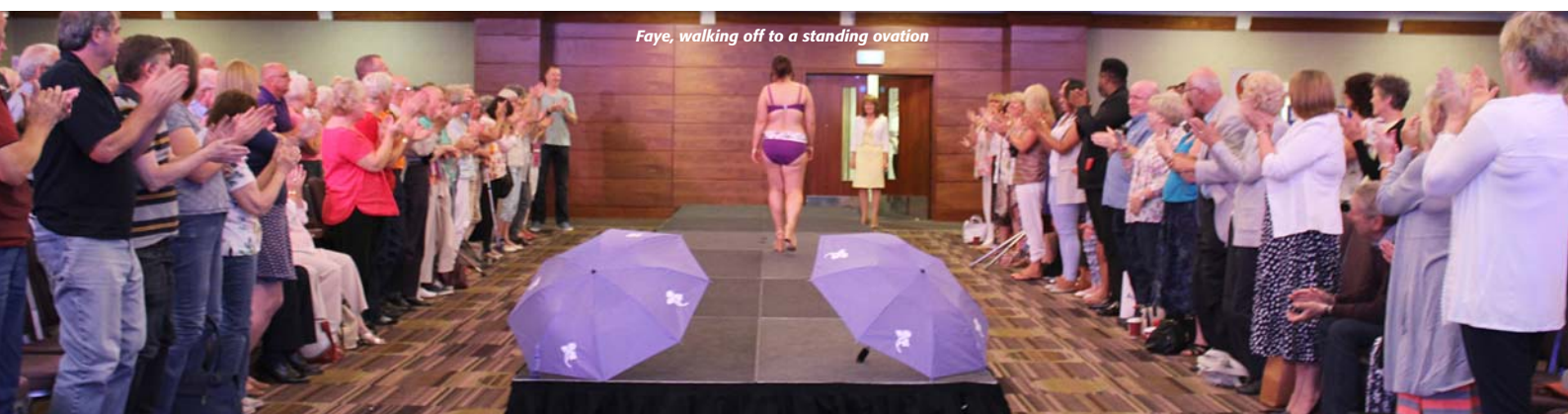
The mood at the Fashion show was electric with everyone in attendance incredibly supportive of our wonderful models and to the cause. Our brave models (aging from 11 years old upwards) showed off a range of clothing from comfy and casualwear, to formal and fancy clothes from both John Lewis and *Damsel in a Dress* and Debenhams and *Jacques Verte*. One of our models, Faye Jones, received a standing ovation for walking down the catwalk in only a bikini!

Another of the models who took part, Davina who featured on the front cover of *Tidings* issue 37, said: "I was really honoured that I was invited to be a part of the **Colostomy Association's** 10th anniversary, to be able to strut my stuff on the catwalk and show others that you can have a stoma and look and feel amazing. I feel proud to have overcome the fears of living with a stoma and I hope it will help others facing the poo taboo!"

Alongside our Fashion Show was our incredibly successful handbag shwap. Guests were able to donate their old handbags and pick up an as-new one – some for as little as £5. A few lucky attendees managed to scoop themselves designer handbags from Luis Vitton, Osprey and X. All proceeds from the shwap went towards the **Colostomy Association** with over **£650** raised in the space of just a few hours, while the CA Facebook group raffle raised **£348.50** and a further **£212** worth of **Colostomy Association** Merchandise was sold.

The Fashion Show event, sponsored by ConvaTec, was an inspirational example of why having a stoma is no barrier to living a full and active life. It was the perfect ending to a weekend celebrating the support and services the **Colostomy Association** provides each year to thousands of people affected by stoma surgery.

Our special thanks go to all of our wonderful volunteers for their help and to the sponsors which included ConvaTec, Dansac, Salts Healthcare, Trio Healthcare, CliniMed/SecuriCare and OstoMART who gave very generously to make the events such a huge success. For more photographs, visit our website or Facebook page and stay tuned for video footage coming out later this year, which may also be adapted for a future TV programme. Whether you came to our weekend of celebrations or couldn't make it – we hope to see you at our next national event in 2017! ■

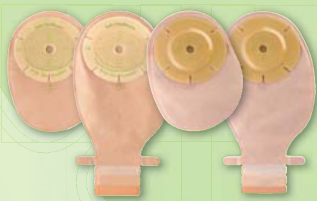


Faye, walking off to a standing ovation

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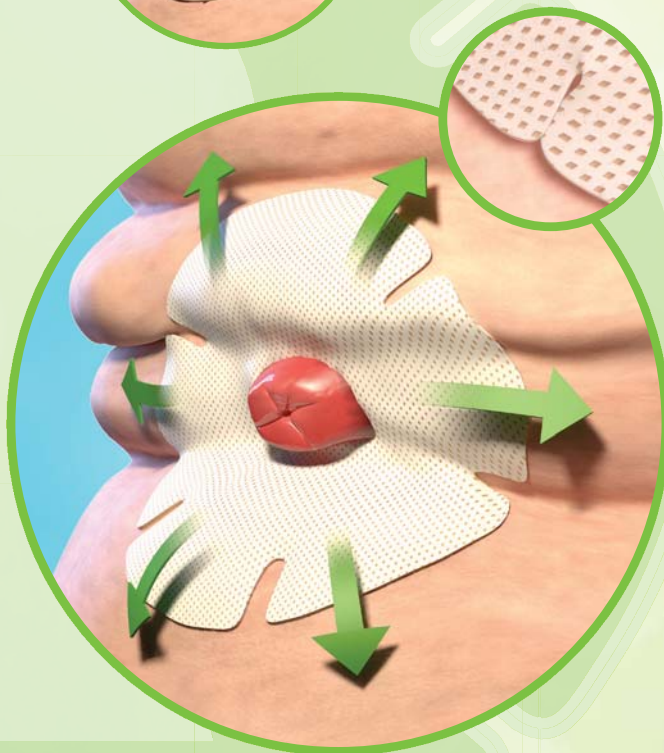
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News From the Office

Readership Survey

It's been several years since we last conducted a survey in *Tidings*, asking your views about the magazine and our other services – your wait is now over!

The feedback you give is important to us so do take part; you might even **win a £50** Debenhams voucher. It's a chance to have your say on a variety of topics, as well as to put forward ideas for the future direction of our Charity. Not only will your comments help us to improve our magazine and develop our range of services, it will also provide us with vital evidence for:

- **fundraising** to prove the need for potential new projects such as those not currently provided by the NHS or local Councils;
- **marketing** to produce up-to-date statistics for use in press releases on how a stoma may have affected your quality of life and the positive impact our Charity may have had on you and/or your family's personal wellbeing; and
- **campaigning** to effectively champion issues of concern and to be a stronger voice in the political arena.

As an incentive to encourage everyone's participation, each survey completed giving personal contact details will be included in a prize draw for an opportunity to **win a £50** Debenhams voucher.

To save money on printing, postage and staff resources, we've produced an online version which helps us quickly analyse the results, so please visit: <http://goo.gl/forms/Wu88CmE5ic> to complete the survey. For those who are not online, a limited number of surveys can be

sent by post on request so hurry and ask for a copy soon in order to return it by the submission deadline date.

Please complete the survey by **7th November 2015** in order to have a chance of **winning this £50** prize, kindly donated by Debenhams. Surveys completed or returned after that date will still be analysed and will provide vital evidence for our ongoing fundraising, marketing and campaigning efforts. Your support would be very much appreciated. Thank you so much!

Fundraising Standards Board



There has been some bad press in recent months regarding the high volume of charity appeals letters, mostly relating to the bigger charities which seem to send out regular communications to their supporters seeking donations.

This has never been our policy and we have only ever once sent out an appeal letter to test the water. We appreciate people have limited funds which is why our services are offered **free of charge** to anyone who needs our help or support.

Our limited resources are carefully budgeted each year as we simply don't have access to vast sums of money, such as those available to other charities.

We know that when you make a donation – whichever charity you support – you would like assurance that the organisation

is committed to best practice. That they are responsible in the way they fundraise; dedicated to honesty and accountability.

That is why the **Colostomy Association** has signed up to fundraising regulation through the Fundraising Standards Board (FRSB). Membership is a commitment to the highest standards of fundraising. Should

CONTINUED ON PAGE 42, COLUMN 1

500 Club June 2015 Draw Winners!

Mr Baker	£ 358.00
Ms Rowland	£ 179.00
Mrs Duffy	£ 71.60
Mr Gilbert	£ 71.60
Mr McMinn	£ 71.60
Anonymous	£ 35.80
Anonymous	£ 35.80
Anonymous	£ 17.90
Anonymous	£ 17.90
Anonymous	£ 17.90

NOTE:

The following people also kindly donated all or part of their winnings back to the Colostomy Association: Mr Baker donated £58; Anonymous donated £17.90; Anonymous donated £17.90; Mrs Duffy donated £15.00; Mr Gilbert donated £11.60.

Win up to £25,000 with the new Unity Lottery – see page 12 for details.

CONTINUED FROM PAGE 41, COLUMN 3

there be any concerns about the way we fundraise, we have a robust complaints process in place, notifying the FRSB of any issues raised. It is about being accountable for our actions and ensuring that we put you – our supporters – first.

From now on, you may see the *Give with Confidence* tick logo on our website and appeals, reminding you of our commitment to best practice in fundraising. We hope that our membership of the FRSB will give you added confidence in our fundraising and, ultimately, encourage more people to provide vital support for the tens of thousands of people living with a stoma in the UK.

If you have any concerns about the way we fundraise, please get in touch by calling: **0118 939 1537** or emailing:

cass@colostomyassociation.org.uk

For more information about the FRSB, and what our membership means in practice, please refer to:

www.givewithconfidence.org.uk

Meanwhile, from time to time you may receive a mailing from us about manufacturer or hospital open days in your area. If you'd like to unsubscribe from this type of marketing, please let us know.

Vital Statistics

In 2014 our admin team **answered 2,431** of your telephone calls and **replied to 1,892** of your emails. Outside of office hours, our volunteers also **answered 498** more of your calls.

Our dedicated team of volunteers also **attended 201** open days to help ensure more people across the country are able to access our services. Additionally, our Charity continues to grow with **over 1,000** people signing up with the **Colostomy Association** over the course of 2014.

Volunteer Sponsorship

CliniMed

CliniMed have kindly agreed to fund several events for our wonderful volunteers in the next few months.

This autumn CliniMed have organised an interesting neurolinguistic programming weekend event for our Trustees and staff, along with representatives from the IA and Urostomy Association and they have also arranged a special overnight stay in the Midlands as a social gathering for up to 25

of our dedicated volunteers. Additionally, CliniMed are now planning to arrange a similar volunteer event for us in the Spring.

Without sponsorship of this nature, we would find it difficult to fund refresher training courses or social gatherings for our fantastic volunteers. Thank you so much CliniMed – this is very much appreciated by us all.

It is important for us to invest in our highly valued team of dedicated volunteers, as the **Colostomy Association** simply would not exist without them. Our volunteers are instrumental in the success of our Charity as they man our 24 hour helpline, represent the **Colostomy Association** at hospital and manufacturer open days, distribute leaflets to stoma care nurses, offer home or hospital visits, deal with hundreds of ad-hoc calls each year on specific topics of concern, administrate our closed Facebook group, help us produce *Tidings* magazine, assist with admin in the office and sit on our Trustee Board. A special thank you goes to them all! ■



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.

Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA Registered Charity No: 1113471



Junior Ostomy Support Helpline (JOSH)



L-R: Aled Griffiths; Sasha Kelly (JOSH helpline); and Wendy Hetherington, **Colostomy Association** Trustee, on the JOSH stand that weekend.

In the last issue of *Tidings*, we announced the news that we had received a £10,000 donation for JOSH. Since then we have also received another £2,000 from CHK Charities and we've already started putting the money to good use.

In the past few months, we have been updating and improving our JOSH literature and marketing materials to help spread awareness of the helpline and to ensure that more families are able to find the support they need. Our new leaflets – designed by our Products & Services Officer, Arvind Anand – were ready in time for the **Colostomy Association's** 10th anniversary weekend and as the newest addition to JOSH, made a big splash.

Anyone in attendance at our weekend of celebrations would have left impressed by the bravery and courage of 11-year-old, Aled Griffiths. During the Open Day, he spoke about his experiences growing up with VACTERL Association – a condition which has caused him to have 12 operations during his life. VACTERL Association is a series of birth defects including Vertebral anomalies, Anal Atresia, Cardiac defects, Tracheoesophageal fistula, Esophageal atresia, Renal & Radial anomalies and Limb defects.

In addition to speaking at the 10th anniversary event, in the past year Aled has received the Rotary Young Citizen Award after a Rotary Club member read his story in a previous edition of *Tidings*. It is no understatement to say that we're incredibly pleased to announce that Aled Griffiths has been appointed as the Junior Ambassador for JOSH.

As Junior Ambassador, Aled will be a powerful voice for JOSH and will help show what young people with bowel and bladder dysfunctions are capable of when they have support. There is no better example of this than Aled being the youngest model at the **Colostomy Association's** fashion show who confidently showed off outfits to a room of several hundred people.

Speaking about being chosen as Junior Ambassador for JOSH, Aled Griffiths said: "It felt like an honour to be asked to be the Junior ambassador."

If you'd like to speak to a parent who has experience of raising a child with a stoma or other bowel diversion and dysfunction, please call the **Colostomy Association's** 24 hour helpline: **0800 328 4257** – and ask for a JOSH helpline to give you a call back. You will then be matched with an individual JOSH volunteer who will be able to talk to you about your child's bladder or bowel problems and they will help you deal with any specific concerns. ■



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Facebook Group

10th anniversary celebrations – Reading



After months of planning, the big day finally arrived and a large number of excited CA Facebook group members set off from all around the country, heading to the Millennium Madejski Hotel in Reading.

Gradually everyone appeared at the hotel, some having had very long journeys but nonetheless looking forward to the weekend. New members and 'old' ones soon got chatting in the bar (where else?) and Denize's dog, Xenia, was, as usual, the star attraction – he was very well-behaved for the whole weekend and even wore a bow tie on Saturday night!

Our table in the conference hall was set up, with displays of group merchandise and of course Tomas bear waiting to be a raffle prize. Then to price up a large number of handbags which had kindly been donated, ready for the 'Shwap' on Sunday morning.

We had pre-booked a table at the local Pizza Hut for our Friday evening meal, so

later on we all set off, some on foot, others driving. I think more people came than expected, and we took up a good chunk of the restaurant, but the staff there did a wonderful job sorting out the orders for nearly 30 people and the evening went well.

After breakfast on Saturday everyone had a chance to visit the trade and charity stands, and later on to listen to some very interesting and informative talks on a variety of topics. We had a lot of visitors to our Facebook group stand – many of them members of the group who were at a meeting for the first time. A large number of raffle tickets were sold, orders for merchandise taken – and quite a lot of chatting as well! We all hope that meeting others 'in the flesh' will encourage newer members to post on the group, and encourage yet more friendships to be formed.

After lunch we were able to listen to more speakers, including our own Sarah Squire

and her very entertaining talk on underwear – ably assisted by Ian Jackson, Steve Clark and Pauline Morgan. Yet more raffle tickets were sold and we ended up making £348.50 for the **Colostomy Association**. Tomas was won by Margaret Smith and he will be going to live in Scotland now.

Judging by the feedback since everyone has gone home, I am sure the whole weekend was enjoyed by all who attended and we will all be looking forward to getting together again before too long.

If you would like to join the 'closed' CA Facebook group, search for '**Colostomy Association Support Group (UK)**' 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!

Sally Armstrong



Colomate



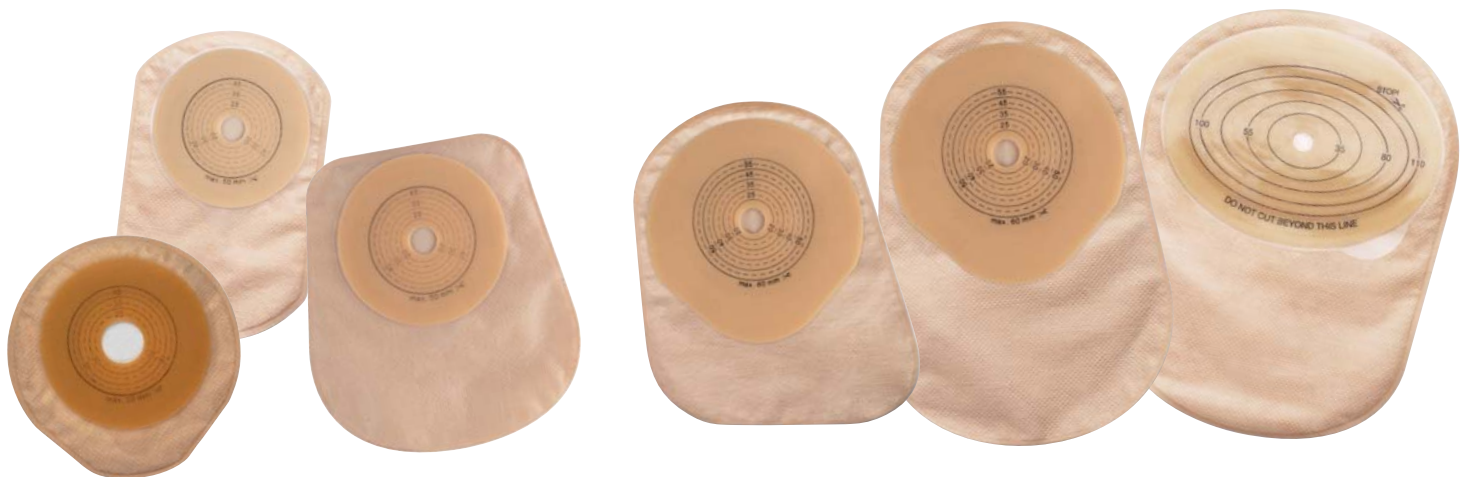
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We were delighted to be invited to attend the Colostomy Association's 10th anniversary celebrations and present about the work of Breakaway. It was a great weekend and lovely to meet so many people, especially those from the CA Facebook group. I particularly enjoyed the hula-hoop lady and the hand balancer acts that were part of the Colostomy Association's Gala Dinner entertainment, I wonder what makes someone decide to become a hand balancer?

For those of you that weren't there we've been asked to write up our presentation for this edition of *Tidings*. This has involved much wracking of brains as we tend not to practice presentations, just stand up and talk. It's made much easier when the subject matter is something you really believe in, so here goes...

Breakaway is the only UK wide charity offering support to children with bladder and/or bowel diversions/dysfunction and their families. You all know that Breakaway was set up by Julie Bastin after her daughter Hannah was born with complex anorectal malformations.



Hannah, after birth

Julie was 25 at the time Hannah was born; there was no indication that anything was wrong at any scan. Julie was faced with the words that no parent wants to hear: "Your daughter needs surgery today to save her life". Hannah was just one day old when her colostomy was formed. When Hannah was four Julie decided that no other family should ever feel as alone as they did, so Breakaway was born.

In 2006, thirty nervous people attended the first ever Breakaway weekend, wondering if

it would be all 'American' with people sat round talking about stomas, or indeed what it would be like. That first weekend was a huge success and since then we have gone on to hold 27 family weekend residential, activity weekends, welcoming around 1,700 people. We have watched them zip wire from a 40ft tower, canoe on the river, build bridges, hold a critter, occasionally push someone in the river and much more!

Since 2006 we've helped almost 400 families, taking them out of isolation and helping them to realise that they are not on their journey alone. Our families have children who have either had a congenital birth defect, developed inflammatory bowel disease, have severe constipation, or have no diagnosis at all. They have ACEs, Mitrofanoffs, ileostomies, colostomies, internal pouches, or a combination, the most common being an ACE and a Mitrofanoff. Some have continence issues and use rectal washouts or self-catheterise. Peristeen is becoming popular amongst specialist centres as a first line treatment for severe constipation and we've a number of families that have had great success with it.

All our families have one thing in common: once they discover Breakaway they know they are not alone. As well as our activity weekends we have closed Facebook groups for parents and family members (the Breakaway Foundation Family Support Group) and one for the under 18s (the Breakaway Foundation Under 18s Support Group) and regional support groups in London & the South East, Wales and Scotland that meet up on a regular basis. We hold regular information days in different parts of the country to help put families in touch with others near them, as well as spreading the word about Breakaway. We've had a helpline since the very start of Breakaway, but the need for it has dropped off since the Facebook groups were set up, as people can get the immediate support and advice that they need at any time day or night.

We've got a network of trained volunteers, we've presented at the ASCN (Association

of Stoma Care Nurses) conference and even been invited to write up our research for publication in Gastro Intestinal Nursing magazine. Recently we have partnered with a Bear Named Buttony, who make bears with stomas to send to children pre and post op. The Breakaway Buttony Bear is a wonderful new project that we know will bring huge joy and comfort to a lot of children.

Breakaway is 10 next year, something that Julie could never have imagined back in 2006 on that cold and wet first weekend in Wales. We've lots of exciting things planned, so do keep checking the website and Facebook page for more details.



Hannah now

If you've got a child with a stoma and you've not yet been to a Breakaway weekend, then have a look at our weekends for 2016. They are the 27th–30th May 2016 at the Belmont Outdoor Centre, Meigle, near Blairgowrie, Scotland, and the 26th–29th August 2016 at the YHA National Forest in Moira, Derbyshire. If you are interested in attending email us at info@breakawayfoundation.org.uk for a booking form.

Sue Blackwell
Breakaway Trustee

More information about Breakaway Foundation.

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<http://www.justgiving.com/breakawayvisits>

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Telephone:
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Email:
info@breakawayfoundation.org.uk
Web:
www.breakawayfoundation.org.uk

Beating Bowel Cancer's Specialist Nurse Helpline is there for patients

Beating Bowel Cancer is the support and campaigning charity for everyone affected by bowel cancer.

We help patients to access the treatment they need and provide emotional and practical support to improve their lives.

When bowel cancer hits, it can be hard to know where to turn and it's natural to have lots of questions and concerns.

That's why the charity runs the UK's only nurse-led specialist helpline for bowel cancer. Patients call it a 'lifeline' and often build up long term relationships with our nurses over many years.

The helpline is open from 9:00am until 5:30pm Monday – Thursday and 9:00am until 4:00pm on Friday on **020 8973 0011** or by email: **nurse@beatingbowelcancer.org**

Patients and their families tell us they are grateful for the opportunity to go through questions and issues they have and to explore their own feelings on what is happening during this difficult time.

The aim of our helpline is to complement the work of the NHS bowel cancer teams across the UK.

Here are some examples of the types of questions we are asked on the helpline and their answers:

Q: *My CEA tumour markers are high and rising despite being on chemotherapy. I have read many oncologists don't use CEA markers during chemo as they can cause so much anxiety. I also read that CEA can rise even if chemo is working, as*

the tumours break down and therefore the proteins are higher. Is this true?

A: CEA (carcinoembryonic antigen) measures a protein that may appear in the blood of some people who have certain kinds of cancers, especially bowel cancer. Several factors can cause your CEA level to rise, including smoking, an infection, inflammatory bowel disease, pancreatitis, liver cirrhosis and other cancers. Chemotherapy and radiotherapy can also cause a temporary rise in CEA levels, so this could be what is causing a rise in your levels.

Your CEA level fluctuates over time, just like your blood sugar level, blood pressure and heart rate. So levels can vary greatly between individuals.

CEA markers can be used by health professionals to monitor a patient's response to chemotherapy, and can often be used in the follow-up period when treatment ends. A rising CEA level in the months and years following your operation could be an indicator of recurrence, and if this was the case usually a CT scan of chest, abdomen and pelvis would be requested for you.

Q: *I was diagnosed with bowel cancer at 42, had treatment and am fine. My children are aged 20 and 22 and I wonder what information I should be telling them about family history (I never told them I had bowel cancer). My grandfather died of bowel cancer at 70.*

A: I am sorry to hear you had a cancer diagnosis at such a young age, but pleased to hear you are doing well now.

Have you been to a regional genetics or family history clinic yourself? When it comes to working out the best screening for your children, and your siblings, as they are both first degree relatives to you, the health professional involved needs to see you first to work backwards, forwards and sideways in terms of your family history. They may also need further information about the test results of the biopsies of your cancer. If you haven't been seen in a family history clinic, your GP can refer you there, or to the hospital team who did your surgery (if you are still under their care).

I think you are doing the right thing in collecting all the evidence and information together before talking this through with your children, as they need answers when this type of difficult conversation is opened up.

I really hope this helps. Do let us let us know how you get on.

Q: *I had a reversal of my ileostomy for rectal cancer four months ago and am practically housebound. I can go to the toilet up to 10–15 times a day and my bottom gets really sore. If I go out I have to wear women's pads to save me embarrassing myself. Is there any advice you can offer me?*



Paula Madden, Senior Nurse Adviser at Beating Bowel Cancer, talks about the charity and its unique support for bowel cancer patients and their families.



A: Thank you for your e-mail. I am sorry to hear that you are having such distressing symptoms following the ileostomy reversal.

Firstly, it is important to know that your bowel habit will never be exactly as it was prior to your surgery and people must adjust to a 'new normal'. That is not to say there aren't things one can do to effectively manage the symptoms you describe and get back a decent quality of life.

It is possible that the symptoms you are describing may be a manifestation of 'Anterior Resection Syndrome'. This is a group of symptoms which some people experience following surgery for rectal cancer. These symptoms include clustering, frequency, urgency, incontinence of faeces, incontinence of wind, alternating diarrhoea/constipation and incomplete emptying.

A combination of diet, medication and exercise may help your bowel function. The best approach to diet is to try and identify those foods that make your motions too fast, then remove them or restrict them and try them again at a later date. Try small frequent meals (skipping meals makes establishing the 'new normal' difficult) and aim to drink eight cups of water a day. It might be worth following a low residue, low fibre diet for a period of weeks until things settle down. Foods like mashed potato, eggs, white bread, ripe bananas, gelatine (jelly babies/marshmallows) and

smooth peanut butter can all help firm up your stool, initially, until it becomes more manageable.

For more information about diet you can download our 'Eating Well' booklet from our website.

It is also worth considering taking anti-diarrhoea medication. It sounds like the frequency of your visits to the toilet is making your skin sore; this must be very uncomfortable. When possible, washing with warm water after each bowel motion and drying thoroughly can be helpful. Avoid any perfumed soaps or wipes that contain alcohol as they can irritate the skin. Have you tried any of the zinc-based barrier creams? Apply a thin layer over the sore area once the skin is properly dry. This can help create a barrier to protect your skin.

If your skin is persistently sore or broken it may be that you have an infection which will need a different type of management. You should speak to colorectal nurse specialist or GP if this is the case.

Q: *I have completed treatment and been told I am now clear of cancer but I can't seem to move on, I am so frightened the cancer will come back. I feel guilty because my family are so happy and think that everything is ok now. Is this a normal reaction?*

A: This is all a very normal reaction. The feelings that a person can experience

after cancer treatment is completed can be just as complex and as distressing as those that you may experience at diagnosis. The expectation from family and friends that life will settle back down and go back to what it was before can be challenging too.

Concerns about cancer coming back, is a very common fear. When you are having treatment it feels like something is being done to stop or treat the cancer but when it's over it may feel that nothing is being done and the cancer could return. This is a very natural reaction. This fear and anxiety usually settles over time; not only does the worry usually lessen but also the actual risk.

For some reading that may help reassure you that you are not alone and that your feelings and reactions are normal, go to **www.beatingbowelcancer.org/forum**

If you are finding that your fear and anxieties are not improving you can get help from your GP who may refer you for some counselling or cognitive behavioural therapy (CBT). CBT cannot remove your problems but can help you manage them in more positive ways.

If you have any concerns related to bowel cancer, you can contact the Beating Bowel Cancer helpline on **020 8973 0011** or email **nurse@beatingbowelcancer.org**. You can speak to other people affected on the charity's online forum at **www.beatingbowelcancer.org/forum**

Dear Nurse

**Julie Rust RGN. Dip, N. MSc.
Clinical Nurse Specialist
Stoma/Colorectal
Royal Stoke University Hospital
University Hospitals of
North Midlands NHS Trust**



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 Colostomy Association are passed to Julie Rust RGN. Dip, N. MSc. CNS Stoma/Colorectal to review and answer. Answers are published in the next issue of *Tidings*.

Q: *I am writing this letter because I know there are lots of people like me that suffer from adhesions of the bowel. About two years ago I had to go to hospital because of the pain and sickness that I was experiencing. The doctors there asked me if I had tried morphine patches and I replied no, but on coming home I asked my doctor for them. Since then my life has changed so much for the better, they start to work about two hours after putting them on and stop the pain and, more often than not, the sickness. For anyone that has adhesions they stop so much misery. I hope that I have helped someone at least.*

A: Pain and sickness can be caused by many different things and they should always be assessed by a medical practitioner such as your GP before taking long term medication so that the actual cause can be identified and the correct treatment given. However, you are correct in that this sort of pain relief can be very effective. Pain can be very debilitating and should be managed well to enable patients to continue to lead an active lifestyle. I am pleased that this was successful for you and thank you for sharing your experience.

Q: *In 2010 my husband was diagnosed with bowel cancer at the age of 52. After months of treatment followed by surgery then by chemo he now has a permanent colostomy. However, recovery has been far from easy. It took exactly a year for his wounds to heal, only to have abdominal adhesions. It's these that are now a big problem. My husband will frequently go without eating (he can't afford to lose any weight as it is). This is because of stomach cramps and feeling sick, sometimes actually being sick. Once this subsides the stoma will actually start to work, resulting in liquid stools that quickly fill up his colostomy bag. He quite often now has to have time off work because of this. Medication does nothing to help and we*

now feel completely alone with this situation.

We'd be glad of any advice to help ease my husband's discomfort. It would be much appreciated.

A: I am sorry to hear that your husband is struggling and feeling abandoned by the health care system. I would suggest a review by the consultant if he continues under follow up at the hospital, otherwise a review by the GP and a new referral to a consultant may be needed so that he can be assessed and the cause of the problem identified. Once this has been done then treatment options can be discussed and hopefully he will be able to continue with a healthy lifestyle without the worry of pain and sickness.

Questions frequently asked on the Helpline

Q: *What is the best thing to do if the skin around the stoma becomes sore at the weekend and it is not possible to contact an SCN until Monday?*

A: If your skin becomes sore or irritated at the weekend you need to ensure that the size of the aperture in the bag is fitting correctly to the stoma, as a hole which is too large will allow stool to come into contact with the skin and therefore burn it. Also if the hole is too small the pouch may leak again leading to stool contaminating the skin. There are many areas now where the stoma care nurse works throughout the weekend and it may be worth contacting them in case your area has a seven day service. Alternatively you could contact the Out of Hours district nurse for advice. If the skin is red but dry and intact, Calamine Lotion can be used but if the skin is broken and wet then something more complex is required and it is a matter of contacting the district nurse or stoma care nurse as soon as possible.

Q: *What are the reasons a stoma bag may leak and how can this be prevented?*

A: There are many reasons a stoma appliance can leak including incorrect template size, allergy to the adhesive, shape of the abdomen/stoma, sore skin and many more. It is important to identify the cause of the problem to enable the correct solution to be found and your stoma care nurse is the best person to do this.



Julie Rust receiving her award from Ian Daniels, **Colostomy Association** President, at the Gala Dinner

Special Award for Julie Rust

As the **Colostomy Association** celebrates 10 years as a charity, the opportunity was taken to acknowledge the commitment of one of our dedicated contributors who has been helping make *Tidings* a vital read for over a decade.

Over the past ten years, the *Dear Nurse* section in *Tidings* has been an integral and popular feature for thousands of readers. However, it would be nothing without the hard work and enthusiasm of Julie Rust.

Over the years, Julie has helped many people come to terms with their stoma, resolving their concerns, helping them to regain their confidence so that they feel able to leave their homes and return to live life to the full.

Julie is an incredibly kind person who has an acute understanding of the needs of ostomates and always deals with the enquiries in a prompt, helpful and personable way. Julie embraces the variety of topics which need to be addressed and relishes being able to respond fully to readers' concerns.

It is for these reasons that Julie was presented with a special surprise award at our 10th anniversary gala dinner, formally acknowledging the huge impact her work has had not only on the magazine, but on the lives of thousands of people.

The **Colostomy Association** is exceptionally lucky to have Julie on the team for the production of *Tidings* magazine and we hope Julie will continue to support us in this way for many years to come. ■

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

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 in or e-mail us today. The editorial team looks forward to hearing from you.

Rosemary Brierley

Dear Editor

I wish to thank you all at the **Colostomy Association** for your wonderful issues of *Tidings*. I have received copies since my brush with bowel cancer in 2006 and have found the articles enormously helpful, informative and friendly in coming to terms with a stoma.

The articles on having a reversal were more than helpful in my decision whether to have one or not. I have decided not to go for a reversal, being quite happy to manage the stoma procedure, having had much practice and being the wrong side of 70 years old, I feel that with a stoma it could be easier in the long run to remain tidy and in control!

Congratulations on your 10th Anniversary. I have seen the issues grow over the years to a very professional, yet friendly, publication.

Yours very sincerely
P.F.

Dear Editor

I had a letter published in your January 2015 magazine asking for help regarding my friend Paul's unfortunate rectal stump discharge issue at Christmas 2014. A lady called Elizabeth responded via your office and was able to give him some advice.

Just to update you on the situation: in April this year Paul attended the spinal

unit at our local hospital for a routine procedure and mentioned to his consultant about the stump issue. The consultant examined the stump and cleared out some discharge that was present. He suggested a clear-out every six to nine months, probably to be done at the outpatients department in the spinal unit. We have yet to see how this works out, but at least we have a point of contact via Paul's spinal consultant.

I read your *Tidings* magazine on Paul's behalf and we have found some very useful advice and information in your articles and readers' letters. Thank you again for your help.

Regards
Denise Harper

Dear Editor

When I had my colostomy five years ago I was told I was entitled to a RADAR Key which I have rarely needed to use as the disabled loos are usually open. Today I went to Ascot races where I did need to use my radar key but it did not fit the door! I had to ask an official who came with a completely different key. He said that my key would probably fit in their other disabled loo! What good was that!

I was told my key would fit any loo in the UK so perhaps *Tidings* readers would like to know that they might need two different RADAR keys.

Congratulations on your wonderful magazine – it never fails in quality and information.

Regards
Joy Harrison

Unfortunately, this can sometimes be the case. We are aware that the NKS – RADAR key will not open every UK accessible toilet. Only toilets which display the NKS – RADAR key sign can be operated with that particular key.

Dear Editor

I am writing to you regarding Mr Woodman's letter and your response in the 'Your Letters' section of the recent edition of *Tidings*.

I have been a wheelchair user for nearly 30 years due to paraplegia; I also have a colostomy. I would like to point out that accessible toilets are not just designed for wheelchair users, but for varying types of disability thus making them multi-functional. They are not specific to one type of disability so they are not perfect for everyone.

Yes it is wrong that some people will give sarcastic comments or glares of anger, but the use of accessible toilets has been abused for many years, so it is understandable that the comments and glares, even if not warranted, take place.

Readers' writes

May I also point out that even if not ideal, many ambulant disabled people still have the option of using non-accessible toilets if accessible toilets are not available. For me as a wheelchair user if there is no accessible toilet then I either have to avoid these venues or limit the time I am there! So just a thought for your campaign...how about making it so there are better facilities for all users of accessible toilets?

Yours sincerely
Mark Price

The Colostomy Association is aware that accessible toilets are multi-functional and the needs of some users take priority over others. However, we believe the requirements for ostomates are small: the simple addition of a hook to the back of a toilet door can make the world of difference for someone with a stoma and the inclusion of a shelf is also beneficial. Ideally, these improvements should be made to all toilets, not just those that are accessible. We have already corresponded with the UK wide network of train providers about these requirements and plan to work with other organisations such as Changing Places so that any improvements made for ostomates are part of larger changes to widen accessibility across disabilities and conditions.

Dear Editor

I think it would be an idea to put a notice in disabled loos explaining why they are used by people not in wheelchairs. It's educational to google "who is entitled to a radar key". I intend to suggest this the next time I'm challenged.

Apart from coat hooks the other critical thing is a shelf. It would be great if this could be included in the specification for these loos. The disabled loo in Bristol Temple Meads has a great shelf, which is actually part of the fabric of the building. Very handy.

Yours sincerely
Peggy Thomas

Dear Editor

In the early weeks and months following my colostomy operation six years ago I was mystified as to the potential uses of those little plastic, self-adhesive patches supplied with closed pouches with filters.

The professional stoma-care advisers handling my induction to pouch management explained that they were useful to use when swimming or taking a bath in order to minimise the entry of water into the pouch. An alternative function, they suggested, was to avoid the potentially embarrassing escape of gases on social occasions. Since I don't swim these days and abandoned the long bath in favour of showering long ago, I could see no really useful purpose for them (except, of course, the social one).

How wrong I was! I was to discover, with time, after trying numerous brands of pouch, that filters for the most part do not function spontaneously. In consequence, in my ignorance, I found myself having to change pouches initially several times a day on account of the accumulation of gas.

Eventually I hit on a solution to the problem by sticking a pin through the middle of the filter, then expelling the gas by gentle manual pressure. To avoid the possible escape of more than just gas, I use the plastic seals to reseal the pouch. This can be done several times a day, if necessary, just using the one seal. As a result I have managed, over the years, to reduce my average pouch use to one a day.

It took me five years to discover a brand of pouch whose filter did operate spontaneously. But this discovery disclosed another problem – the risk of pancaking. The absence of content in the pouch, when first mounted, tends to cause the front and back walls of the pouch to stick together, thereby causing leakage under the flange.

The answer here was to use the provided stickers to seal the filter before putting the pouch on. No need for the professionals' advice to put crumpled or rolled 'cigars' of toilet paper in the bag to fill it out, or to use those fiddly little adhesive 'stoma bridges' to keep the walls apart; the gases generated soon see to that!

I share this experience with those of your readers who choose to use the one-piece filtered bag so that they may enjoy the advantages that I have of:

- i. a relatively simple and trouble-free routine for dealing with the problems of excess gas and leakage;
- ii. the comfort of being able to enjoy a menu unrestricted by the need to

exclude items of a gas-generating tendency; and

- iii. the satisfaction that, apart from saving myself the tedium of unnecessary pouch changes, my routine is saving the NHS and the Exchequer (at roughly £3.00 a pouch) at least £1,000.00 a year.

Dare I hope that my experience might be of some influence on the kind of advice given by stoma support teams when introducing newcomers to stoma management? It would also be a bonus if suppliers of one-piece pouches could be persuaded to include a note with their products offering hints on this particular use of the enclosed seals, though I realise this is probably a vain hope in that it would be a tacit admission that their filters cannot be expected to activate spontaneously!

Yours sincerely
Michael Ward

Dear Editor

In the run up to the General Election I became extremely concerned about the future of the NHS. It seems we all want the benefits of the NHS, but rarely stop to think where the money comes from or really where it all goes.

A friend has recently come back from working in Somalia where in rural areas, if ostomates survive the operation, they manage their stomas with plastic bags and Sellotape. I feel enormously grateful for my wonderful free bags. I'm told that I am allowed up to 90 colostomy bags per month. This seems ludicrous. A few people with particular medical conditions may need to change a bag three times a day, but then why not use drainable ones? My drainable bags are changed sometimes every day, sometimes every two or three days. I use about 30 per month, at most.

A box of my bags costs my GP surgery nearly £90. So I can cost the NHS nearly a thousand pounds a year! What can be done to try to reduce this whacking great cost to the NHS? I might try irrigating!

With best wishes
K.G.

CONTINUED ON PAGE 55, COLUMN 1

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.uk
- 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

Freephone
0800 389 3111



Ref. No. HB102

Stoma Support & Hernia Belt Ref. No. HB102

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

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

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

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

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



Ref. No. SR103

"The ring of confidence"



Ref. No. SS104

Stoma Shield Ref. No. SS104

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

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

Sash Medical Ltd.

Woodhouse, Woodside Road, Hockley, Essex SS5 4RU Tel: 0044 (0)1702 206502

Web: www.sashstomabelts.com



Security & Leakage Belt

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

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

Readers' writes

CONTINUED FROM PAGE 53, COLUMN 3

Dear Editor

I have had a colostomy for 21 years, which fortunately has caused me little or no problems. In the past we have taken many long-haul flights, but because of my husband's ill health have not done so since the body X-ray machines were introduced at the large airports.

I recall that when the machines were about to be installed, there was a lot of talk of full body searches, once the bag showed up on the screen.

As I am planning to fly from Heathrow in the not too distant future, I wondered if any of my fellow readers have had experience of this equipment, as I admit to being a little apprehensive and forewarned is forearmed.

Regards
V.B.

I too have a colostomy and since 2002 have travelled abroad every year, on most occasions flying from Heathrow. I have never experienced any problems at airports. If my hand luggage has been searched it has always been carried out very discreetly. I always change my pouch at the airport just prior to going through security to ensure it is empty or the contents are minimal.

At most airports the scanner has been the metal detecting archway and I have never been stopped. On my last trip there was a body X-ray machine at a South American airport and after passing through it I was stopped and asked if I minded if a female security officer patted me down at the front. I agreed and, rather than mention my colostomy, decided to wait and see what happened. I was just waved through. I did have my Colostomy Association travel certificate in my pocket in case there was a problem, but in the end it wasn't needed. Obviously, this is just my personal experience. We do occasionally hear of a problem, but this is very rare considering the number of ostomates who travel abroad every year.

In the Winter Issue of Tidings (No 36) on Page 19 we published an article on Travel and the Security Inspection. If you don't have a copy you will find it on the website. Click on Information and then scroll down to Tidings Magazine.

Dear Editor

My husband recently had a colostomy formed. Unfortunately he also has a disc

problem and needs to wear a back support. We have spoken to three physiotherapists who cannot help, as most supports would cut across the stoma and bag. I wondered if any *Tidings* readers know of any company that can provide a back support that can be worn by a person with a stoma.

Thank you
Muriel

If any readers are aware of any support which can be worn by ostomates with back problems, without affecting the functioning of the stoma, please contact Colostomy Association Head Office and we will pass the details on to Muriel.

The Editor

I am writing to you and your team expressing my deepest gratitude for all the devoted work by you and all your colleagues in the past and at the present time.

In March 2009, I became an ostomate, after two years of struggle with two primary cancers. I was unable to manage my colostomy satisfactorily as I am gluten and lactose intolerant. My stoma had problems right from the beginning: lots of painful episodes, which developed into days in bed with hot water bottles. Finally, my surgeon told me I had a considerable hernia, but the vague promise for a repair never materialised.

Saturday 20th July 2013 was the day that changed my life. At the Colostomy Association Patient Open Day at Royal Berkshire Conference Centre I listened to, the outgoing president, Professor Bill Heald's superb address and then to a speech given by Mr Ian Daniels who was to become our *El Presidente*.

On March 26th Wednesday 2014 Mr I Daniels and Mr A M Watts gave me back my quality of life. It was a long operation, recovery was steady. I believe, not only did I have the best surgical expertise from both a colorectal and a plastic surgery consultant, but also the best care from the whole team of nurses, nursing assistants, tea ladies and cleaners. My stay at the Royal Devon and Exeter Hospital was the best hospital experience I have had in my whole life.

More than a year has elapsed since my hernia repair. Not all my problems have disappeared but my life has improved immeasurably. Unfortunately I missed Mr Daniels' talk, Hernias – so many

problems – so few solutions, on 11th July 2015.

Kind Regards
L.I.M.

A summary of Mr Daniels' talk at the Colostomy Association Open Day will appear in a future issue of Tidings. ■

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

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.

Your badge of honour – wear with pride.



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Marketplace

advertise your events • messages • services here

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



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FREEPOST SWB11095, Bridgwater Somerset, TA5 1ZA

Neville Hall Hospital, Stoma Care – Open Day

Neville Hall Hospital Conference Centre, Abergavenny
Oct 31st 2015 – 9:30am – 12:00noon
Contact: Stoma Care Team

Ipswich Hospital, Stoma Care – Open Day

Kesgrave Community Centre, Twelve Acre Approach, IP5 1JF
Nov 4th 2015 – 10:00am – 3:00pm
Contact: Stoma Care Team

Salts Healthcare, Glasgow Open Day

Holiday Inn, East Kilbride, Stewartfield Way, G74 5LA
Nov 5th 2015 – 11:00am – 2:00pm
Contact: Trevor Donald at Salts

Blackpool Victorial Hospital, Stoma Care – Open Day

Health Professional Education Centre (HPEC), Blackpool FY3 8NR
Nov 7th 2015 – 10:00am – 2:00pm
Contact: Gill Towers – Stoma Care Team

Salts Coffee Morning

Loughborough Town Hall, Council Chamber, Market Place, Loughborough, Leicestershire, LE11 8EB
Nov 20th 2015 – 10:00am – 12:00noon
Contact: Helen Sale

North Devon

Bowel Cancer Support Group
Henry Williamson Room, Barnstaple Library, Barnstaple
Nov 26th 2015 – 2:30pm–4:30pm
Tel: Karen Day 01271 322 464

Stevenage Ostomistics

Oval Community Centre, 27 Vardon Road, Stevenage, SG1 5RD
Nov 28th 2015 – 10:30am–1:00pm
Tel: Judy Colston 01438 354 018
Email: neilcolston@btinternet.com



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Royal Glemorgan Hospital Stoma Care Support Group – Coffee Morning

Heritage Park Hotel, CF37 2NP
Oct 2nd 2015
Tel: Theresa Hall 01443 443 053

Northern General Hospital/Royal Hallamshire Hospital, Sheffield Annual Stoma Exhibition/Open Day

Hillsborough Arena, Middlewood Road, Sheffield, S6 4HA
Oct 5th 2015 – 10:00am – 3:00pm
Tel: 0114 271 4015

Sherwood Forest Hospital – Open Day

The Towers, Botany Avenue, Mansfield, NG18 5NG
Oct 13th 2015 – 10:30am – 2:30pm
Contact: Stoma Care Department

Musgrove Park Hospital, Stoma Care Department – Open Day

Somerset County Cricket Club (Priory Bridge Road Entrance), Taunton, Somerset, TA1 1JT
Oct 14th 2015 – 11:00am – 2:30pm
Contact: Stoma Care Department

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



Thank you for your support

Regular donation

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

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

Note:

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

My Details: Title:

Name:

Surname:

Address:

Postcode:

Telephone (home):

Mobile:

Email:

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

Instruction to your Bank/Building Society to pay by Banker's Standing Order**To the Manager:** (Bank or Building Society)

Bank Address:

Postcode:

Name(s) of Account holder(s):

Account number:

Sort code:

I would like to make a **regular donation*** of ☐ £15 ☐ £20 ☐ £25 ☐ £50 or other amount (please state) £
☐ **monthly** ☐ **quarterly** ☐ **annually starting on the** ☐ **1st** ☐ **15th** ☐ **25th of month:** **year:**
thereafter until further notice. *Please state your donation amount in words:

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

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

Name: (IN CAPITALS)

Signature:**Date:** / / 2015


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**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)

FREE lapel pin - with all new Regular donations of £15 or more

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.

Note:

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

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



DOGS in Dartford

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.

On 20th May 2015 a new support group held its first meeting in Dartford, Kent. We are calling ourselves Dartford Ostomy Group Support (DOGS) because the inspiration came from another Kent Group, the Medway Ostomy Group Support (MOGS) and, following that; we obviously had to call ourselves DOGS.

The meeting was held at St. Anselm's Parish Centre, 89 West Hill, Dartford, DA1 2HJ and 23 people attended. We really had no idea how many to expect and were very encouraged at the turnout. There is obviously a need in the area but with just three of us, Tracey, Sue and myself, organizing the group, only one of whom is retired, we are struggling with getting the existence of the group to the attention of those whom we could help. There are a huge number of doctors' surgeries for instance and while we get an encouraging welcome when we call we will not be able to visit them all for some time. Any suggestions and offers of help will be most welcome.

I expect all support groups have a crisis from time to time but we did not expect one at our first meeting. Our speaker, representing one of the firms that supply stoma appliances, failed to turn up! However, one of our wonderful stoma nurses stepped into the breach and all was well. It did reveal to those present that despite the glossy adverts this supply company obviously has a fairly chaotic back office.

It was a testing moment when we gathered for our second meeting a month later on 17th June. Who would come again and who would not? Would enough people think it worthwhile? Happily most of the people who came to our first meeting turned up again together with several new faces and we in fact had more present than at our first meeting. What a relief.

The occasion was not without incident. When Sue and I turned up early to set up the room we could not get into the church centre. I had been given a code to key in to



L-R: John Brown, Tracey Bryant, Mayor Ian Armit and Susan Norris

release the door that only opened it at certain times so I had not been able to try it out. It was not clear how this worked and I was obviously doing it wrong. Also there was a funeral service in the church. We gained access eventually and managed to have everything ready when people started turning up.

When most people had gathered and had some refreshments Sue gave a talk about irrigation. This was quite an eye-opener for me as I had only read some general articles about the process.

Before the meeting I had written to the Mayor of Dartford telling him about the group and inviting him to a meeting and to my surprise he accepted. The mayor turned up during Sue's talk and sat very quietly while she continued explaining how it all worked. Afterwards he thanked us very much and said it had been quite an experience and I believe him!

And so we go on. July came round and this time there were no difficulties in getting into the church hall. It turned out that I had been given the wrong code and, as it is both day and time sensitive, you can only try it out on the day and time that you need to use it. Experienced Ostomy Support Group organisers are, I am sure, well

acquainted with the unexpected difficulties that arise but we are very much novices.

The talk was given by a supplier of 'sports' support wear. It was a good presentation but I expected special swimwear and maybe cycling stuff in inspired Lycra. However, there was really nothing that the good lady showed us that helped for swimming or cycling over and above that which was available elsewhere.

Now for August. We are going to have something very different. A barbecue! But first we have a nutritionist who will, perhaps, tell us to avoid all those traditional BBQ foods. I hope she stays and enjoys what will be, I am sure, a fine spread.

In September we have invited a local expert bee keeper to come and explain the medicinal qualities of honey.

We will continue to meet on the third Wednesday of each month from 1:00pm to 3:00pm. We will of course be pleased to see any readers of *Tidings* particularly if you live in our area.

Contacts Tracey, Sue or John on
Tel: **07948 974 350** or
e-mail: **Dogs-uk@hotmail.com**

John Brown

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

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 on 01934 248 114 or Rob on 0117 966 8021

Buckinghamshire

Milton Keynes Stoma Association
Dee Stobie 0190 867 2918 or mksa@mail.com

C

Cambridgeshire

Connections Cancer & Colostomy Group
Bev or Sue Scott 0135 386 0356 / 07766 958 811 or Barbara Hunt 01353 862 133
Peterborough Stoma Support Group - Ostomistics
Alan Wright
01354 653 290 / 07836 661 102

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: 0147 753 5071
Warrington Ostomy Support Group
Jane Shaw: 0192 566 2103

Cleveland

Oops Group
Julie Morrisroe/Carol Younger: 0128 728 4113

Co. Durham

Bishop 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
Keith Anderson: 0182 225 8618, cbcsinfo@gmail.com or website www.cornwall-bowel-cancer-support-group.co

Optimists
Sue Hatton: 0132 634 0058

Ostomist and Carers Support Group
Christine Davey: T: 016370 850 895
E: chris.davey28@gmail.com or Mandy Rowe: 01726 832 642

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 jdkelly234@gmail.com
North Devon Bowel Cancer Support Group
Karen Day: 01271 322 464

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Jenny Pipe: 01202 740 440
Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Beryl Andrews 01202 483 303
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: 07932 331 850

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

Amanda Rowe: 0172 334 2446

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 07941 827 393

H

Hampshire

Solent Ostomates Support Group (New Forest Branch)
Ron Lever 023 8089 3949 / rdlever@sky.com

Solent Ostomates Support Group (S.O.S.)
Carole Summer: 07527 707 069

Southern Ostomy Group
Caroline or Karen on: 07756 819 291 southernostomygroup@hotmail.com

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
Heather Norman: 07624 480 973

Stoma Support Group
Carole Cringle stoma nurse: 0162 465 0212

Isle of Wight

Optimistics
CNS's 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
Carole Hobbs: 0130 381 4014 or Margaret Webb 0123 362 8807

Atoms Support Group
Maria Culleton, SCN: 0122 776 9679 or 07827 997 424

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 07948 974 350 or dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Julie Bell: 07771 345 703 or Ros Marshall: 0130 482 2696 or June Golding (Organiser): 0130 482 2696

M.O.G.S (Medway Ostomy Group Support)
Helen Or Tracey: 07773 605 534

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 Ostomisticks
Paul Seavers on 07771 359 046

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, Sheila: 0120 536 4493

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

March Group
Sharon Palmer: 07414 828 867 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: 07717 335 884

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

Rectangle - Colorectal Cancer Support Group
Regina Raymond 020 7472 6299

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: 01737 553 134 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 on 0189 527 9391

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: 07714 479 320

Hexham Ostomy Group
Judith on 07967 927 286

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
Moiria Hammond 07788 402 195

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

T**Tyne & Wear**

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com
NHS Molineaux Centre
Gordon Weatherburn: 0191 234 1109
Royal Victoria Infirmary Support Group
Gordon Weatherburn: 0191 234 1109

W**West Midlands**

Coventry Stoma Support
Martin: 07947 385 643

Wiltshire

Swindon IA
www.swindon-ia.org.uk
Wessex Stoma Support Group
Michael Slater:
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: 07580 693 155 (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 Edmond: 01924 512 041 or
01924 512 072
Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse
Specialist) 0113 206 5535
Rotherham Ostomates Caring Support
Karen Kilford: 07880 575 758
Scarborough Stoma Support Group
Sister Jean Campbell: 0172 334 2388
The Hull and East Riding Colostomy
Support Group
Pete Smith: 07989 565 335 or Pete
Rennard: 07939 518 642 / 0148 279
3966 or Rosanna Grimsby: 0148 280
1575. 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 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

Scottish Borders

Moray Ostomates Support Group
Maggie 01343 552 449 / Kathleen
07789 684 285

Stoma Support Group

Nancy Fraser: nancyfraser@talktalk.net
or 0145 037 4012. Fiona Gentleman:
r.gentleman@sky.com or 0145 037
1063

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales**Bridgend**

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

Denbighshire

North Wales Ostomy Support Group
Debi Devine 07876 762 503 / Hazel
Duke 07976 817 246 / Email:
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

Powys

The Bracken Trust Cancer Support
Centre
Helen Davies: 01597 823646

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

Channel Islands**Guernsey**

Guernsey Ostomates
Luci Deane 0148 123 6077 /
lucideane58@gmail.com

Northern Ireland**Co. Antrim**

Colostomy Association Volunteers
Northern Ireland
Chris Wright: 07720 717 771
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: 028 3861 2721
Daisy Hill Hospital Support Group
Bernie Trainor: 028 3083 5000 Ext
2222

Co. Down

North Down Stoma Support Group
Adrian Ewing on 07850 741 511
Ulster Hospital
Hazel/Martina: 028 9055 0498

Co. Fermanagh

Erne Hospital
To be confirmed

Londonderry

Causeway Support Group
Mary Kane: 028 7034 6264

Republic of Ireland**Co. Mayo**

Mayo Stoma Support
Marion Martyn: 094 902 1733

Dublin

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

France**Provence**

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

Kosovo**Kosovo**

Kosovo Ostomy
Arta Uka: kosovoostomy@gmail.com

Spain**Alicante**

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

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