Spring 2017 | Issue 45

colostomy association

Tidings

Helping **ostomates** since **1967**

Chance to win £2,500 – see page 26

1967-2017

CA Open Day, Sat 16 Sep 2017 – see page 12

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Cover picture
Tracy Smith (see p9) with her husband, Andrew, preparing to take on the zip–wire challenge on Newport Transporter Bridge

How to contact Tidings

Editorial Enquiries
Letters, articles or other submissions

e–mail
editor@colostomyassociation.org.uk
or write to the address below.

Advertising enquiries
For a media pack and advertising rates

e–mail
arvind.anand@colostomyassociation.org.uk
or telephone 0118 918 0500

To request (or cancel) your quarterly copy of Tidings
e–mail cass@colostomyassociation.org.uk
or telephone 0118 939 1537

Postal address
Colostomy Association
Enterprise House 95 London Street
Reading RG1 4QA

dear READERS

April is Bowel Cancer Awareness month. Although colostomies are formed for a variety of different reasons it is estimated that about two thirds are due to cancer. Those of you who were diagnosed following a routine bowel screening will know how important it is to do this test. But there may be others for whom, like Jean, cancer was their Room 101. Alongside her article on page 10 we have details of the symptoms of bowel cancer and the availability of screening. Even if you have a colostomy, part of your large intestine will still be intact so you will still need to do a test. If, however, you are in a follow up screening programme, have recently had or are due to have a colonoscopy, it may be worth consulting your nursing team to check if it is still necessary. Friends and family also need to be aware of the symptoms of bowel cancer and the importance of the screening test, so this month is a good time to remind them.

At 33, Tracy Smith, whose photograph features on our cover, was too young to be included in the routine screening programme. She had to insist that her doctor referred her for further tests to investigate her symptoms. Genetic tests revealed that she has Lynch Syndrome. Tracy tells her story and how she has founded a charity to raise awareness of this condition and support other families affected.

With the holiday season approaching, maybe you are still undecided about whether to go away this year; if so, turn to our centre pages. Many Facebook members have already been inspired to travel by Janey Jane's posts about her trip with Heisenburgh, her unreliable stoma. During her tour of Australia and New Zealand, she was quite open about having a stoma. When people asked why she was wearing a T–shirt with the words THIS GIRL CAN her answer was that she CAN travel with a stoma. Philip has travelled extensively since his stoma was formed in 2007 and takes a different approach. At airports he says nothing but is ready to explain if questioned.

The articles mentioned so far are from people who have had cancer. Rest assured, we have not forgotten the other reasons for stoma formation. We have contributions from two women whose stomas are the result of endometriosis which makes us wonder if this is more common than we think. Approximately 10% of colostomies are thought to be due to diverticulitis; in this issue we have a story from a reader who had a stoma for this reason and had a successful reversal eighteen months later. In the summer issue we are planning to include an article explaining the causes and treatment of diverticular disease and why diverticulitis may sometimes lead to a stoma.

We have received a number of letters about obtaining stoma supplies and in response we have an article outlining the different methods of requesting a prescription. The introduction of the Electronic Prescription Service (EPS) can make the process much quicker. Centralised management of prescribing of stoma products has been introduced by Clinical Commissioning Groups (CCGs) in two areas of England and has the potential to make the prescribing process simpler.

We welcome all suggestions from readers about how we can improve *Tidings*. A recent comment was that it was mainly female orientated. Two thirds of our letters this time are from men, but most of our Real Life experiences are female. This is because over the last six months the submissions we have received have been mainly from women. We would like to encourage men who have a colostomy to write for us so that *Tidings* can provide a similar amount of support for both men and women.

The **Colostomy Association** is holding an Open Day on 16 September 2017 to celebrate 50 years of supporting people with a stoma. The *Tidings* editorial team will all be there and we would be delighted to meet you and hear what you have to say about *Tidings* and your suggestions for future issues of the magazine.

With Best Wishes

Rosemary

Rosemary Brierley
Editor
editor@colostomyassociation.org.uk


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inside this issue

all your regulars & special features

Cover Story

CA News

Living with a Stoma

Holidays and Travel

From Health Professionals

Real Lives

Support

How to get in touch with the Colostomy Association

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

How to become a supporter of the Colostomy Association

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

By telephone:
General Enquiries: 0118 939 1537

Stoma care queries only:
Freephone Helpline: 0800 328 4257

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

Find us on FACEBOOK:

Find us on Facebook

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

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

Don't delay Donate Online today!

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

①

Visit the **Colostomy Association website** and **simply click** on the **donate panel** on the **home page.**

JustGiving ②

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

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

Bulletin Board

Stoma Friendly Society News

Our Stoma friendly society campaign is gathering momentum. We are working with several large organisations who are planning to make the required changes to their accessible toilets. We are delighted to announce that the following organisations have joined our campaign.

Marks and Spencer have confirmed that a shelf will be available in accessible toilets where the cistern top is not suitable.

Stoke City FC's home ground, The bet365 stadium with a capacity of 27,902, will now display **'Not all disabilities are visible'** #stomafriendly stickers on all of the toilet facilities across the stadium. Stoke City is the first Premier League football club to join the campaign.

Lincoln City Council are making improvements to their public toilets and will be using our stickers, we are also working with several other councils.

Lords cricket ground are now stoma friendly. Ready for the 2017 cricket season, their accessible toilets now have a shelf, hook and disposal bin. You will also find a 'not every disability is visible' sign on the doors.

Super Stomas – Colostomy Day 2017

This year Colostomy Day will continue to focus on fighting the poo taboo by highlighting how super stomas are.

There is still a stigma around stomas but many people would not be here today if they had not had life–saving surgery. **Let's celebrate how super stomas are!**

How can you get involved?

Social Media

We want you to share your **#superstoma** across social media with a 'thumbs up'. If you don't fancy showing your stoma bag, or your friends and relatives want to join in you can just do a clothed thumbs up where the stoma is/would be and share. Let's get **#superstoma** trending and celebrate how super they are.

Share your story

Celebrate your stoma and how it saved your life. We will be featuring stories across our website and social media, or you could share on your blog or let the local paper know. Let's raise awareness of the different issues that lead to stoma surgery and highlight that anybody, any age, any background can have a stoma.

There are many more ways you can get involved. Over the coming months we will be releasing more information about Colostomy Day and our packs will be available in June. Keep an eye on our website and social media. You can register interest now by emailing cass@colostomyassocation.org.uk with the message subject Colostomy Day 2017.

Thanks to Al from Stress Free Outdoors for the great photo.

Waste and rubbish collections

There is concern that ‘belt tightening’ exercises by local councils are having an effect on ostomates. We have recently been made aware of a number of cases where waste collections have been reduced and limitations have been placed on how much and what waste can be collected. In most cases the problem has been easily rectified by additional medical or nappy waste collections being introduced.

To alleviate concern we have written to the Local Government Association to seek their advice on how local councils should be dealing with this matter. We will keep you updated on our progress.

We are also putting together a handy toolkit that you can use to approach your council if you have a problem relating to waste collections.

If you would like further information please contact us cass@colostomyassociation.org.uk

2017 Open Day

Our 2017 Open day takes place on **Saturday 16 September**. With a chance to meet fellow ostomates, find out about the latest products and listen to topical talks it’s a must for all ostomates. Set in beautiful parkland with golf and leisure facilities on site, the day ends with a fashion show and dinner. **Find out more on page 12.**

We need you…

Colostomy Association Blog

You may have noticed the newly launched blog section on our website. This features guest blogs from ostomates, appliance manufactures and more. Are you interested in featuring on our blog? Perhaps you’d like to share your story, have hints and tips to share or have a message for other ostomates. We would like to hear from you. Email our Marketing Officer to find out more. **clare.matthews@colostomyassociation.org.uk**

Young people’s focus groups

We are launching a series of focus groups for young ostomates (18–30) to find out how having a stoma affects you, what issues you have, if any, and how we can better support you. If you are interested in taking part please contact our Development Officer **giovanni.cinque@colostomyassociation.org.uk**

Lynch Syndrome UK

Tracy Smith and Dr Ian Frayling at the 2nd Annual Conference of Lynch Syndrome UK

***Tracy Smith**, founder and trustee of the new charity Lynch Syndrome UK describes how she discovered she had inherited the genetic mutation that causes this condition and the effect it has had on her family. The aim of the charity is, not only to support families affected by Lynch Syndrome, but also to raise awareness of this condition among health professionals and the general public.*

Feeling tired is a side effect of being a busy mum of three, working a full–time job that entailed nights, early mornings and long days. Couple that with a husband that works away for half of the year, I didn't even bat an eyelid!

I had been having trouble with a 'pile'; even during my last pregnancy the midwife commented on it. I tried everything the doc threw at me. I was fobbed off with hemorrhoids and an IBS diagnosis but this persistent little problem wasn't going away.

Fast forward to two years later and the 'pile' was still there! Enough was enough so I visited the GP and demanded to be referred to have it banded. We had a long conversation and I refused to move until he called them. I had tried everything he had suggested but nothing was working and I needed to be seen. I sat and watched him dial and make the appointment which would be in four to six weeks. As I left, I asked for the number so I could see if I could be put on the cancellation list as well. I called them when I got home and was lucky enough to get a cancelled appointment a few days later.

After the hospital visit, a trip to the day unit and several tests later, I was told I had cancer. The 'pile' was in fact the tumor protruding outside of my bottom. I was 33 years old.

Things moved pretty quickly; my permanent stoma (Quasimodo) was formed. I started on a clinical trial of chemo and radiotherapy as my odds weren't too good and my oncologist said that it would be my best fighting chance. Whilst I was going through my treatment, my little sister was diagnosed with bowel cancer and had an ileostomy formed; so was my aunty, who underwent surgery and had a resection.

Life with a stoma doesn't prevent me from doing anything! I'm quite pigheaded (as my husband can contest to) and I was determined that my life wouldn't change. The stoma would have to adapt to my lifestyle, not the other way around.

My oncologist and consultant wanted me to undergo genetic testing because of my age and I was diagnosed with Lynch Syndrome with a MSH2 alteration.

Lynch Syndrome (LS) is an inherited genetic mutation, which gives patients a predisposition to some cancers. It was previously known as HNPCC or hereditary non–polyposis colorectal cancer.

Cancers associated with LS include colorectal, endometrial, ovarian, stomach, hepatobiliary (liver and bile), urinary and kidney, small bowel, brain/central nervous system and sebaceous cancers, pancreas, breast and prostate.

Twenty–nine members of my close family have been tested so far. Fifteen have LS and there are close family members still to be tested so only time will tell how many more will be affected. Lots of extended family members have also been tested and have been found to be positive too. The number keeps growing and the true extent is still uncertain.

The good thing is now we are aware and now we have the chance to hit the ground running and get one up on LS because we know about it. Unfortunately, there are lots of families out there that know nothing about LS and I want to change that.

Three years ago, I met a group of like–minded people and am proud to say that I'm a founding member and trustee of a new charity called Lynch Syndrome UK.

Lynch Syndrome UK aims to ensure that for the public benefit, people and their families affected by LS are provided with support in the form of information, signposting and listening. The charity also aims to increase public awareness of the syndrome by educating members of the general public and health professionals.

Our vision is that all people affected by Lynch Syndrome in the UK have access to standardized screening, thus enabling prevention of the development of cancer and early diagnosis enabling survival.

It is so important to me to give people the chance to fight back and take care of their health, as we know that early detection saves lives. We sadly lost my sister at the age of 23 and my first cousin at age of 20. I don't want to see another family go through this and lose people that they love and care about. If sharing my story prevents this, I'm happy to share.

You can find more information about LS at **www.lynch-syndrome-uk.org**

Room 101

Quote from George Orwell's novel, 1984:

> *‘You asked me once, what was in Room 101. I told you that you knew the answer already. Everyone knows it. The thing that is in Room 101 is the worst thing in the world.’*

As far back as I can remember, I had a dread of the word Cancer. My mother and both her parents died of cancer and I became convinced in my twenties that I would too.

I remember telling friends: “If I ever get anything nasty, I don't want to know. They can tell me I've got a nasty cold or a tummy bug or something, and will feel better soon. None of this ‘The Patient Must Be Told The Truth’ nonsense for me thank you.” I really did not want to know.

It was my Room 101. In the novel *1984*, Room 101 contained the ‘worst thing in the world.’ For Winston Smith that worst thing was rats. He envisaged them as vicious, smelly creatures, squeaking and clambering all over him, gnawing his flesh. For me it was the Big C word. I imagined it in very similar fashion.

I reached the age of 75 without incident. Then I started to notice that my bowel habits were changing, frequency and urgency increasing. I knew something was seriously wrong, and I knew I was being silly, but I did nothing about it. Everywhere I looked, newspapers, magazines, television, I saw dire warnings that even slight changes should be investigated, but that door to Room 101 was too scary to open.

It was perhaps as long as a year before I mentioned it to my husband. I remember my understatement, “I'm becoming a little concerned about…” A *little concerned* indeed! True to form he acted fast, telephoned for an urgent doctor's appointment, told me to get in the car and drove me to the surgery. There would be no backing out now.

After his examination my doctor gently told me that there was indeed a growth there and he would arrange for further investigation. To my surprise, I felt nothing.

“I'm just numb,” I thought. “I haven't taken it in yet.”

I waited for my inevitable disintegration, but it never happened. Throughout the following few months of investigations, radiotherapy, chemotherapy, surgery (including the formation of my stoma) I felt no fear, no anger – just acceptance.

I had been told pre–operatively that my colostomy might later be reversible, but it was found that the tumour was too low down in my rectum for that to be possible. This was a great disappointment at the time, but six months later I felt relieved not to have to face further surgery to reverse the procedure.

The months passed. The operation and the therapy faded into memory. I went to the hospital for my annual check–ups and all remained well. Finally, five years on, I was discharged.

Amazingly, at no time did I feel threatened. I had entered my own Room 101, full of my fears. I had faced up to those fears and they had proved infinitely less fearsome than I had imagined.

Jean Wright

Bowel cancer – Symptoms

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

Ref: **www.cancerresearchuk.org**

Bowel Cancer Screening

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

More information is available by calling the free phone helpline **0800 707 60 60**.

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

More information is available by calling the free phone helpline **0800 294 3370**.

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

More information is available by calling the free phone helpline **0800 0121 833**.

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

More information is available by calling the free phone helpline **0800 015 2514**.

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

More information is available by calling the free phone helpline **1800 45 45 55**.

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

Ref: **www.beatingbowelcancer.org**

The NEW Brava® Protective Seal improves your appliance fit. It is designed to protect against leakage and protect your skin.

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Address
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By providing your personal information on this form, you are consenting to Coloplast using it for administration and analysis purposes and to process your sample order. We may share this information with healthcare professionals and other companies required for the delivery of your products or as required by law. We may also contact you to ask you to clarify your sample requirements and to ask you to complete customer satisfaction surveys. From time to time we do let our customers know of new products or services which may be of interest by phone, email or post. By submitting your information to us, you consent to us contacting you in this way unless you have indicated that you would prefer for us not to contact you by ticking the box below.
Please do not contact me by: Email ☐ Phone ☐ Post ☐

50th Anniversary
Open Day 2017 and Fashion Show

Saturday 16 September 2017

Booking Form

I would like to attend the following **Colostomy Association** events at

Wokefield Park
Goodboys Lane
Mortimer
Reading
RG7 3AE

(please insert the number of places required):

		Quantity
Open Day only	*Free of charge*	☐
Open Day, Fashion Show and Evening Meal	*£25 per person*	☐
Fashion Show and Evening Meal only	*£25 per person*	☐

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

Details: Title: First Name: Surname:
Address:

Postcode:
Telephone (home): Mobile:
Email:
Dietary requirements:

NOTE: Please remember to book your own overnight accommodation if needed.

Please return this form to: **Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA** no later than **31 August 2017**, but bear in mind places are strictly limited so it will be best to book early to avoid disappointment.

Official tickets for the Fashion Show and Dinner will be sent to you nearer the time.

50th Anniversary Open Day and Fashion Show 2017

Join us for our open day and fashion show on **Saturday 16 September at Wokefield Park, Berkshire**. Our open day will feature exhibitions from stoma product suppliers, topical talks and presentations, SCN appointments and more. In the evening we hope you'll stay for our fashion show and dinner. Colostomates of all ages will be gracing the catwalk and modelling a range of outfits proving that you can have a stoma and still look and feel great.

The dinner will be followed by a presentation ceremony, including volunteers' contributions and our beautiful Purple Iris stoma care department award. (So please remember to nominate your team if you feel they have given you exemplary stoma care.)

Accommodation – To book rooms please contact the hotel direct on **0118 933 4100** quoting **COLO150717**.

Book Now!

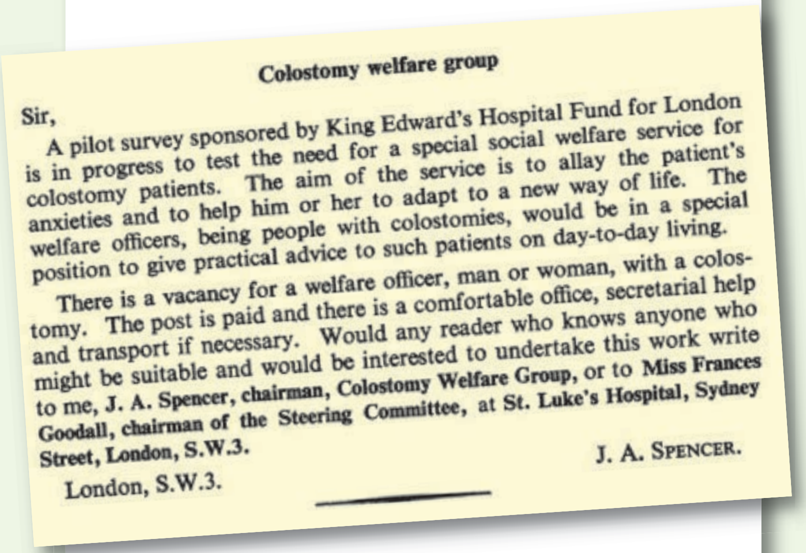
Please complete the booking form and return it to the office no later than 31st August 2017, but the earlier the better to guarantee your place(s). The open day is free to attend and dinner and fashion show tickets are £25 pp We look forward to seeing you there.

To find out more visit our website.

Colostomy Association 50 years… where it all began

With 2017 marking the Association's 50th year we've been delving into the archives and are learning some fascinating facts about our past. The historic feature that we're putting together will make interesting reading. An appetiser of what's to come is included here.

One of our first successes has been to track down the recruitment advertisement that started it all off…



Colostomy welfare group

Sir,

A pilot survey sponsored by King Edward's Hospital Fund for London is in progress to test the need for a special social welfare service for colostomy patients. The aim of the service is to allay the patient's anxieties and to help him or her to adapt to a new way of life. The welfare officers, being people with colostomies, would be in a special position to give practical advice to such patients on day-to-day living.

There is a vacancy for a welfare officer, man or woman, with a colostomy. The post is paid and there is a comfortable office, secretarial help and transport if necessary. Would any reader who knows anyone who might be suitable and would be interested to undertake this work write to me, **J. A. Spencer, chairman, Colostomy Welfare Group**, or to **Miss Frances Goodall, chairman of the Steering Committee**, at **St. Luke's Hospital, Sydney Street, London, S.W.3.**

J. A. SPENCER.

London, S.W.3.

This advert appeared in the November 1966 edition of the *Journal of the College of General Practitioners*. Perhaps most striking is how the aims it sets out are just as relevant today as they were half a century ago. If nothing else, the advert tells us that while medicine may advance, people still experience surgery in the same ways and have the same 'human' needs before and afterwards. Thankfully, an appointment was made shortly after the advert was placed and the rest as they say is history.

To find out who got the job and what happened in the years and decades that followed, look out for the next edition of *Tidings*…

Colostomy Association Purple Iris Stoma Care Award

The Purple Iris is awarded for outstanding stoma care and exemplary service within a stoma care department or community setting and nominations are now being sought. This beautiful award will be presented to the winner during our Open Day this year as part of our special celebrations.

The last recipients of the **Purple Iris Award** were the stoma care team at **Maidstone Hospital** (pictured left) who were presented with the award at our Open Day fundraising gala dinner in Reading in July 2015.

Judy Mallett and Kirsty Craven from Maidstone Hospital said at that time:

> *'We are delighted and honoured to have received the Purple Iris Award. We feel it is a very special achievement as the nomination has come from patients we have looked after. We believe passionately about providing a high standard of care for patients, their families and carers that we have had the privilege to look after'.*

Nominations are now open for the 2017 award, so if your team has gone above and beyond in their care for you or a family member please complete the form below and return it to us by **30 April 2017**.

We welcome nominations for stoma care teams who:

- **Deliver an exceptional level of care**
- **Lead an excellent co–ordinated care package with other agencies and across a variety of health issues**
- **Are innovative with their ideas to deliver outstanding patient support**

A representative from the winning stoma care department will be invited to attend our **Open Day dinner at Wokefield Park** on Saturday 16 September 2017 when an official presentation will be made by our President.

We look forward to receiving your nominations and to hearing about the wonderful work being carried out by stoma care teams across the UK. Careful consideration will be given to all entries and we will feed back comments anonymously to all nominated teams in recognition of their invaluable efforts.

Purple Iris Stoma Care Award – Nomination Form

Your details

First Name: **Surname:**

Address:

Post code:

Telephone Number: **Email:**

Nomination details

Name of team/department:

Name of hospital/community setting:

Reasons for nomination:

In two brief sentences, please describe what impact this team's support has had on your life or that of a family member (maximum 50 words) here:

Additional Information

On a separate sheet please explain why your stoma care team/department deserve this accolade (maximum 500 words). Please remember to head this up with your name and that of your nominee.

I give my permission for **Colostomy Association** to inform the stoma care team about this nomination including what has been written on this form.

Signed: **Name:** **Date:**

Please return this nomination form to: **Giovanni Cinque, Colostomy Association, Enterprise House,**
95 London Street, Reading, RG1 4QA by 30 April 2017.

A colostomy due to Endometriosis

I have suffered from endometriosis for the last 20 years. In 2008 I had a hysterectomy which was supposed to stop further problems and indeed it did until March 2015, when I started to suffer painful spasms in my left groin area. I had recently given up work and planned to take six months off then get a part time job. It would mean I could do some work on the house and we could also get a dog, something my husband and I had wanted for a long time.

My GP suggested that it may be scar tissue from my hysterectomy which was causing this pain and prescribed painkillers. Over the next few weeks, the pains didn't subside and I then started to suffer with constipation. I purchased over the counter remedies, which worked initially and I felt a bit better but then after a few days began to feel nauseous and ended up being violently sick. There was blood in the vomit so my husband took me to A&E. We spent a Saturday in A&E having X–rays etc. They couldn't find a blockage, so gave me an enema and, as this worked a bit, sent me home. Things did not improve during the next week and I still couldn't go to the loo. I was sick again, this time it was mainly bile. It was a weekend again; the out of hours GP suggested I go back to A&E. So off we go again.

More scans, a CT this time; it showed a narrowing in my bowel, but the doctors weren't sure why. The following morning a consultant looked at my scan in more detail and found that my bowel was completely blocked. After a few days in hospital, I was booked in for an operation. Although I felt pleased that a problem had been found, I was scared to death what they would find – would it be cancer?

The consultant explained the various kinds of stomas, saying that they wouldn't know exactly what they would be able to do, until I was on the operating table. To be honest, I was more worried about having a bag than I was about the actual operation. I've always been a bit squeamish about poo and didn't think I would be able to cope. A lovely stoma nurse came and spoke to me in more detail, measured me up and drew a black circle on my stomach where the stoma would be. Although she put my mind at rest about a few things, I was still really frightened. I was also distraught as we were supposed to be picking up our puppy at the weekend.

The operation took six hours. The next morning the consultant told me that they had done a Hartmann's procedure. They were pretty certain that the blockage was due to endometriosis, not cancer, although to be certain they would have to send a sample off for analysis. What a relief, no cancer! Although I still had this bag.

I was in hospital for two and half weeks in total because the wound became infected. As the wound and the stoma were close together the wound had to be dressed and the bag changed at the same time. When I got home the district nurses came in to do this. I didn't really get to change my bag completely on my own for about a month. The first time I did it, I felt such a sense of achievement. My stoma, by this time named Stanley, did misbehave for a while and I had quite a few leaks and for a time didn't go out, but slowly things began to settle down and I started to get back to normal. We picked up our puppy, called Murphy, who settled in really well. Life seemed OK but I put off looking for a part time job until 2016 to give myself time to get properly better.

Things were going well until February 2016 when I started to get pains in my groin again and then my left leg swelled up; a CT scan showed that a lump was pushing on the main blood vessels into my leg restricting the blood flow. The medical team were pretty sure that the lump was endometriosis again. Apparently, it is possible, although very uncommon, for endometriosis to still be active even after a hysterectomy.

I was referred back to the gynaecological team. My consultant said that I am somewhat unique and he hadn't seen this amount of endometriosis before. I am now on strong painkillers, which allow me to carry on a fairly normal life, although I can't drink alcohol! It is uncertain if an operation will be of any benefit, due to the amount of endometriosis I have, and the surgical team are worried that it will cause more problems that it will fix. I am having scans every six months to see what is happening: the last one confirmed it hadn't got any worse, but also hadn't got any better. I am looking at this as a positive.

It is unlikely that I will be able to have my stoma reversed and I am OK with that now. Stanley has become my friend and most of the time we get along fine. We have the odd bad day, but they are now few and far between. My husband, the dog and I have been on holiday. I was worried being away from the comfort of my own bathroom, but although it wasn't perfect, I managed.

I hope that things have finally settled down now and my life has some normality to it. I am enjoying walking Murphy, something I wasn't able to do a few months ago due to the pain, and have also taken up cycling – although I am taking this slowly!

Karen Cracknell

Medical Terms Explained

Endometriosis is a disorder where tissue that behaves like the lining of the womb (endometrium) is found elsewhere in the body.

Obtaining Stoma Supplies

Prescriptions

Stoma bags and most additional stoma products are available on prescription. People who live in Scotland, Wales and Northern Ireland do not have to pay prescription charges. In England if you are over 16 (18 for those in full time education) and under 60 you have to pay for prescriptions unless you have a medical exemption (MedEx) certificate.

If you have a permanent stoma or are undergoing treatment for cancer your doctor or stoma care nurse will give you form FP92A to apply for a MedeX certificate. Once you have this certificate all prescription items (medicines as well as stoma products) will be free of charge. The certificate will be valid from one month before the date that the NHS Business Authority receives the application form. If you have to pay for a prescription before your certificate arrives ask for a receipt and you will be able to claim a refund.

You may not be given an application form for a MedeX certificate if your stoma is regarded as temporary; maybe it is a loop stoma intended to be in place for just a few months to allow the bowel downstream to heal. If this is the case and you live in England you will have to pay prescription charges unless you are exempt because of your age, you are on benefits due to low income or you are being treated for cancer. If you are not entitled to a MedEx certificate, you can purchase a prescription prepayment certificate. This will work out cheaper if you are prescribed more than three items in three months or 12 items in a year.

For further information visit the Prescription Pricing Authority (PPA) website: www.nhsbsa.nhs.uk/HelpWithHealthCosts.aspx or phone the PPA Helpdesk on 0300 330 1341

Don't forget: A MedEx certificate only lasts for five years, so make sure it is still in date. Fines are being imposed on those claiming exemption without a valid certificate. Reminder notices are sent out to the holder's last known address three or four weeks before it expires, so remember to inform the Prescription Pricing Authority (PPA) if you move house.

Ordering Supplies

If you have had a stoma for many years you will remember the day when the only way to order stoma supplies was to request a prescription from your GP, by phone or calling in at the surgery. In most GP practices the prescription was available for collection within 48 hours, so that it could be:

- Taken to a pharmacy and the supplies collected when they were in stock.
- Posted in a freepost envelope to a specialist stoma product delivery company, known as a Dispensing Appliance Contractor (DAC). Names of some of the larger companies which you may recognise are Amcare, Bullen, Charter, Fittleworth, Respond, Salts Medilink and SecuriCare. Supplies were then delivered to your door within a few days.

We regularly receive letters from long–standing ostomates to say that they still order their prescription themselves by telephone or by calling in at the surgery. Then they collect it and take it to a pharmacy or post it to a delivery company. They assure us that this still works very well and they receive their supplies within a week. For some the system is now even easier as they order their prescription online and the GP sends the prescription to the nominated dispenser (DAC or the pharmacy) via the Electronic Prescription Service (EPS)

To make it easier, particularly for people who find it difficult to get to their GP surgery, most delivery companies now provide a service where they will order the prescription from your GP. You can contact them yourself when you are down to the last box of supplies. Alternatively, the company can call you, often monthly, to check whether you need more supplies. GPs, however, are not obliged to deal with a delivery company; if this is the case with your surgery it may be worth making an appointment to discuss problems you have collecting and posting the prescription. Alternatively, you could try using your local pharmacy to dispense your products.

Delivery companies ordering the prescription has, however, added another step in the procedure. If the GP does not respond within 48 hours it can take longer for supplies to arrive. To combat this some companies used to send out supplies before the prescription was received. This sometimes made it difficult for suppliers to obtain prescriptions for products already dispatched, and in some cases led to over–ordering and stockpiling of stoma products.

The Department of Health consultation in May 2010 recommended that, except where there is a need for urgent supplies, delivery companies and pharmacies must have the prescription in hand before any stoma products can be dispensed. When this was implemented the **Colostomy Association** received many letters and e–mails complaining about the time that it was taking from when the order was first placed until the supplies were received. It was therefore recommended that a prescription request is made to a delivery company three weeks before supplies are needed to ensure there is no chance of running out before the order arrives.

In 2010 it also became compulsory for pharmacies (if they dispense stoma products in the normal course of their business) as well as delivery companies to provide Essential Services. This includes providing:

- A reasonable supply of appropriate supplementary items (disposable wipes and disposal bags).
- Home delivery in unmarked packaging– with reasonable promptness and at a time agreed with the patient.
- Referral or signposting to another delivery company if they are unable to provide any items on the prescription.
- An emergency supply of appliances, provided that the prescriber undertakes to furnish a prescription within 72 hours.
- Advice about appliances, on repeat dispensing and minimising waste.

Pharmacies and delivery companies can choose to sign up to the Advanced Service and offer all the Essential Services above plus appliance customisation i.e. cutting of flanges and/or an Appliance Use Review (AUR).

How you order your supplies is up to you. Your prescription can be dispensed by the delivery company or pharmacy that you choose. You can order the prescription yourself or ask them to do it for you. Modern technology is speeding up the whole process of ordering and dispensing. Patients can now order prescriptions online and delivery companies can make a prescription request electronically. The GP can then send a digital prescription to the dispenser.

The length of time people have to wait for their supplies still depends on how quickly a GP responds to a request for a prescription. The **Colostomy Association** therefore still recommend that ample time is allowed when making prescription requests.

The following article on the Electronic Prescription Service (EPS) was written and approved by the Patient, Industry and Professionals forum (PIPs).

Electronic Prescription Service for England only

In 2005 the way prescriptions were issued in England began to change. It has been a little over 11 years since the first Electronic Prescriptions were issued by GPs but you may have noticed little change.

Release 1 in 2005 printed a bar code on the bottom of the paper prescription, which allowed the dispenser to read the details straight into their electronic prescribing system (EPS).

Release 2 moved this forward with the GP being able to send a completely digital prescription straight to the dispenser, removing the need for a paper prescription at all. This system has been in use for a number of years now, and a majority of GPs have the ability to prescribe in this way, whilst dispensers (pharmacies and DACs) are now able to receive EPS prescriptions (they are actually referred to as Tokens in the system).

You may now be becoming more aware of EPS as there has been a major push by the NHS in England over the last year or so to encourage GPs to start to issue their prescriptions electronically and for patients to ask for this rather than the paper, FP10, version. Uptake has been good and 84% of GPs, 99.3% of Pharmacies and 92.8% of DACs can now send and receive electronic prescriptions. In fact, 46% of all prescriptions issued in August 2016 were sent electronically.

Using EPS to replace paper prescriptions has a number of advantages for both you as a patient and for prescribers and dispensers:

- Transmission of the prescription is very quick. In theory it will be at the dispenser before you can walk round the corner. This may not be that useful if you currently still take a paper prescription to the chemist, but if it is posted by the GP or if it is collected by the dispenser, then it will almost certainly reduce the delay.
- It's quicker:
  - for the GP as electronic prescriptions can be signed electronically.
  - for the dispenser as they do not need to type in the items on the prescription into their system.
- It's more efficient and less wasteful; there are not millions of green prescriptions being printed and then bundled up and sent to the NHS for payment.
- It's more accurate – as there are less people typing and inputting information, fewer mistakes are made.

So, how does EPS work?

You can still chose who dispenses your prescription, this is called "nomination". In the majority of instances both medicines and appliances will be required:

- Medicines must go to a pharmacy (or a dispensing GP if you live in a rural area) so you can "nominate" any pharmacy you wish, it may be in the Practice down the road, near work or one in a supermarket. The choice of who dispenses is up to you.
- Appliances prescriptions – stoma bags, catheters, sheaths, wound care and similar items, can be dispensed by a pharmacy, dispensing GP, or a Dispensing Appliance Contractor (DAC). You can choose which of these you use and you can nominate (choose) a different dispenser to issue your appliances to the one that dispenses your medicines.

Remember, with both paper and electronic prescriptions, the prescription belongs to you, the patient, and you can take it to, or nominate any dispenser, anywhere in the country. A prescriber or any other health care professional cannot tell you where you must take or send it.

How do you make a nomination?

You can nominate your dispenser at your GP surgery, at any pharmacy or ask your DAC to do it. They may often want you to sign a consent form as a record of your request so that they have proof of your choice. They will then update the EPS system and whenever your GP needs to prescribe items for you the prescription is sent automatically to the dispenser(s) you have chosen. It is very simple.

You can change your nomination at any time and this will change where any prescriptions are sent.

EPS works really well with repeat prescriptions. If you have the same appliances month after month, rather than contacting the GP every time, they can upload 6 or 12 prescriptions into the system. As each one is used, the next one is made available automatically. The dispenser MUST contact you each time they pull a prescription off the system to make sure you need the items and your condition hasn't changed – a sensible measure to prevent waste and over usage – but this really is no different to best practice with paper prescriptions.

How much is EPS being used?

EPS is now the norm, 84% of all GP practices can now issue electronic prescriptions and 99% of pharmacies and 93% of DACs can dispense them. Over 300m electronic prescriptions have been written and almost 700m items dispensed. Nearly 5 in 10 prescriptions are now issued electronically, so you can see this really is the way forward.

If you haven't used an electronic prescription yet, then speak to your GP or your dispenser.

Remember, you can have a different dispenser for your appliances to your medicines and the prescription is yours, so you can send it wherever you want!

What about Scotland and Wales

Scotland and Wales have their own NHS and they decided that they would introduce electronic prescriptions differently. They still issue paper prescriptions that are bar coded, much as EPS Release 1 in England.

At present appliances cannot have any form of electronic prescription and DACs or Approved Stoma Suppliers (in Scotland) are not permitted to use EPS. ■

Centralised Management of Prescribing of Stoma Products

Nottinghamshire Appliance Management Service – NAMS

At the beginning of August 2016 Nottinghamshire Clinical Commissioning Groups (CCGs) – with the exception of Bassetlaw CCG – introduced a new system for the management of prescriptions. Prescriptions were no longer to be requested from GPs. Over a three month period, details of everyone at the practice who had a stoma were passed over to the Nottinghamshire Appliance Management Service (NAMS). This included name and contact details, date of birth, type of stoma, prescribed appliances and date of the last prescription. Patients were contacted by letter and informed of the date after which they would be required to order their prescription from NAMS. They were also sent a booklet that explained the system.

In the early days when people ordering stoma supplies were unsure how the system worked, callers had to wait some time before their request was handled. Now that all 2,900 people in the Nottingham area who currently require stoma supplies have been registered, this problem has been considerably reduced. The highest volume of calls is received on Mondays and Fridays, so midweek is the best time to ring. There is a facility to leave a message and receive a call back. Supplies can also be ordered online; proof of identity is required to obtain a username and password.

A prescription co–ordinator prepares the prescription and it is checked and signed by a specialist stoma care nurse. It is then sent to any one of the many suppliers which could be a dispensing appliance contractor (DAC) or a pharmacy. Most people opt for the same company or pharmacy that they have used in the past.

So what prompted Nottinghamshire CCGs to adopt this new system? It has long been recognised that people with stomas can 'fall through the net'; they may not have seen a specialist stoma care nurse for years. GPs are not familiar with stoma care issues, and there are people struggling with stoma related problems and outdated products.

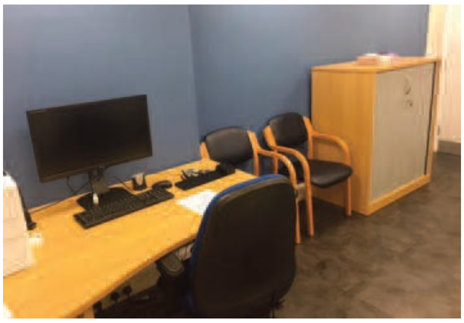
The five prescription co–ordinators who take the calls at NAMS ask two questions to establish whether the caller is having any problems and whether the products they are using are suited to their needs. If necessary, they can arrange for a specialist stoma nurse to call them back. If the issue is leakage or sore skin they can offer an appointment with the nurse and book it there and then. No doctor's referral is required.

The appointment can take place at the NAMS centre where there is a dedicated consulting room, or in the patient's home. At present the centre employs two specialist stoma care nurses and when the scheme is fully operational there will be three. This means that each day six or seven appointments are available at the centre or a nurse can visit two or three people at home. These nurses work closely with stoma care nurses at the local hospital and those employed by the stoma care companies.

Although the initial three–year contract has been awarded to Fittleworth Medical Ltd, an independent team administers the scheme. Specialist nurses are free to suggest any products and it is the ostomate who choses which company dispenses them. It is expected that the scheme will lead to a decrease in the prescribing of inappropriate products and hence some financial saving. Any changes to prescriptions will, however, be made by specialist stoma nurses in consultation with their patients rather than by GPs who may be unfamiliar with the needs of people with stomas.

A similar scheme of centralising stoma prescribing, covering a much smaller area and based on a slightly different model was trialled in Rotherham from 2010 To 2011. It has now been permanently adopted and is managed by the local continence service.

The core objectives of centralised prescribing are to provide a better service to patients and to improve outcomes. With an improved relationship with patients, it is hoped that these services will deliver better value for the NHS. It remains to be seen whether other CCGs will adopt the centralised management of the prescribing of stoma care products. There are several pilots running around the country, early days but change for the right reasons should be encouraged.



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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.**

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- See our main advert on page 54.

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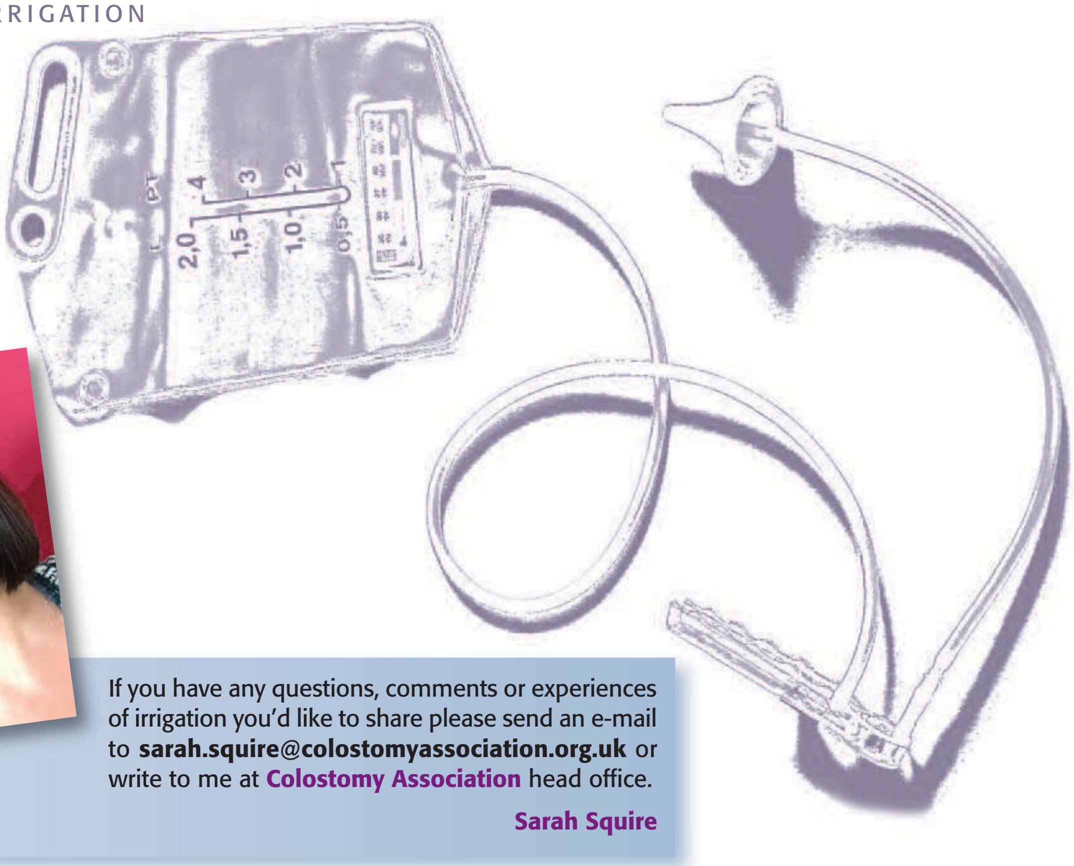

If you have any questions, comments or experiences of irrigation you'd like to share please send an e-mail to **sarah.squire@colostomyassociation.org.uk** or write to me at **Colostomy Association** head office.

Sarah Squire

Irrigation and You

I am always delighted to receive emails and letters from our readers. This time we hear from Bunny Kennedy who took up irrigation in preparation for a trip to Australia, and Jim Arkell who describes what happened when he had an issue with irrigation.

Bunny writes:

Deciding to travel to Australia to meet our newest great grandson was met with some trepidation. The first was that both my husband and myself were just into our 80s – going to the gym and using the rowing machine on a regular basis was sure to pay off. The second was that I had a stoma!

How would this stoma affect travelling such a long way? How would I be able to join in with family activities? How many bags would I need? How and where would I be able to change my bag? What food could I eat? The questions were endless. With all this in mind I decided to give colostomy irrigation a try, the idea being that I wouldn't need to change my bag as often, if at all!

I had a few lessons from my stoma care nurses and decided to use the irrigation pump. With the unwavering support of my husband, reassurances from my stoma team, luke warm water on tap, endless supplies of wipes, and a couple of spare hours, I was all set. By the time we left for Australia, I had mastered the technique. This meant that I didn't need to change my bag as often or have the worry that the stoma would start working at inconvenient times. To some extent I had some control over it now. I planned to do the irrigation every second or third day depending on our schedule.

I had wanted to give kayaking a go. I know! At 81! Really! I had a couple of lessons, thank you Gruff, prior to leaving the UK so was fairly confident in the water. I just didn't need the hassle of my stoma deciding to work whilst out in a kayak. A day before kayaking I spent a couple of hours doing my irrigation and was able to kayak with peace of mind knowing that my stoma was under control. Just look at the photo.

Jim writes:

I was given a permanent colostomy in 2008 following an operation to remove a lower rectal tumour in a procedure called an abdominoperineal resection (APeR). Eighteen months later I learned to irrigate and have continued to do so ever since. That decision changed my life so much for the good.

Irrigation is completely routine, or so I thought. I usually carry it out every other morning and have a stop–watch to keep an eye on progress. In general, it takes about 10 minutes to fill the bowel with about three pints of warm water, then a further 15 minutes for evacuation. The irrigation sleeve can safely be removed at the 40 minute mark and a small patch is then applied to protect the stoma.

On a recent occasion, having filled the bowel with the appropriate quantity of irrigation water, I was surprised to discover that evacuation was not happening. Although a small quantity of water drained from the stoma, peristalsis had ceased. Half an hour later I was becoming a little concerned. I tried massaging the tummy and jumping up and down, to no avail. An hour later, with no sign of progress, I removed the sleeve and applied a drainable bag to the stoma just in case it should become active without warning. Eventually the trapped water was absorbed by the digestive system and disposed of through frequent urination visits to the loo. Meanwhile, the drainable bag remained empty.

Worried about what to do next, I consulted my stoma nurse and sought advice from the local pharmacy. In the previous 24 hours I had prepared a meal including overcooked couscous, which severely bunged me up. We concluded that I was so constipated that irrigation had become ineffective and that I should take a laxative (Fybogel) and attempt irrigation 48 hours later. I am glad to say the subsequent attempt was successful and I have had no further difficulties since.

In summary, after seven years of trouble–free irrigation I had my first failure because of constipation. If this happens to you, don't worry: keep calm, take a mild laxative and try irrigating again a day or so later or if still concerned, speak to your trusty stoma nurse

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. For more information see the **Colostomy Association** website or purchase the *Irrigation and you* DVD using the form below.

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

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

To obtain your single copy of *Colostomy Irrigation and You* at the special price of £4.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **CA Ltd,** to:
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Total Payable ☐

3. Select your Payment method

☐ Direct Debit

Please fill in the form and return to **Unity**
Name and full postal address of your Bank or Building Society

To: The Manager: Bank/Building Society
Address:
Postcode:

Banks and Building Societies may not accept Direct Debit instructions for some types of accounts.

DD15

Instruction to your Bank or Building Society to pay by Direct Debit

Name(s) of Account Holder(s)
Branch Sort Code:
Bank/Building Society account number

Service User Number 4 2 1 1 0 2

Reference:

Instruction to your Bank or Building Society
Please pay **Unity** from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this instruction may remain with **Unity** and, if so, details will be passed electronically to my Bank/Building Society.

Signature:
Date:

☐ Payment by Cheque ☐ I enclose a Cheque made payable to Unity (minimum payment £13)

4. Your consent to Play (I confirm I am 16 or over and resident of GB)

Surname:
Date:

☐ Occasionally, **Colostomy Association** may send you samples and information that may be of interest to you. We do not pass on your details but may use them to keep you informed of what else is available. If you would prefer not to receive these, please tick the box.

For office use only:

Detach the form, put it into an envelope and return to **Unity** to the address shown on the right.

They will notify you of your **Unity** lottery number.

Post this form to:
Freepost RLZR-GSYJ-KSZA
The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

The promoter of this Unity lottery is Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA | Registration number: LOT000141

The Unity Lottery, Freepost RLZR - GSYJ - KSZA, Barrow-in-Furness | T: 0370 050 9240 | E: info@unitylottery.co.uk
Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 – www.gamblingcommission.gov.uk

Fundraising Focus

Annual Raffle

Our special thanks go to everyone who purchased a ticket for our 2016 raffle. Sales exceeded an amazing £18,000 and your support was very much appreciated. The draw was made on Friday 30th December 2016 and the winners are:

1st prize	**£2,500**	**Mr W**
2nd prize	**£500**	**Rose Galpin** from Chelmsford
3rd prizes	**£250**	**Sue Smith** from Somerset, **Ray Hopkins** from Coventry, **Elizabeth Vale** from Essex and **Edwin Shaw** from Blackburn

Congratulations to all the winners and a big thank you goes to everyone who purchased tickets.

0000000000

First name ....

Surname ....

Address ....

....

....

....

Postcode ....

Tel no ....

eMail ....

Please return payment, ticket stubs and unsold tickets no later than **Friday 15 December 2017** to:
Colostomy Association, Enterprise House,
95 London Street, Reading, RG1 4QA.
Draw to take place on: **29 December 2016**
at **Colostomy Association, Enterprise House, 2nd Floor,**
95 London Street, Reading, RG1 4QA
Late entries will be treated as donations.

CAM016 03v00r00 2017 Raffle Tickets

0000000000

Annual Prize Draw
Your chance to win

£1
Ticket
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1st prize £2,500

2nd prize £500 | **£250 x 4 prizes** | **£100 x 5 prizes**

Draw date: **Friday 29 December 2017** around 12:00noon
at **Colostomy Association, Enterprise House, 2nd Floor, 95 London Street, Reading, RG1 4QA**
No tickets may be sold by or to anyone under 16 years. No tickets may be sold on the street.
Promoter: Mr Monty Taylor, Colostomy Association, Enterprise House, 95 London Street, Reading, RG1 4QA
Winners will be notified by telephone, email or post and announced in the Spring 2018 edition of *Tidings*
Lottery Licence no: LOT000141
Colostomy Association is a charity registered in England and Wales No: 1113471

2017 Raffle – get your tickets now!

For the 2017 Colostomy Association annual raffle there's an even greater chance to win! There's still a fantastic first prize of £2,500, second prize of £500, and four chances of winning £250, but there are now five chances to win £100 as well.

Tickets are only £1 and all money raised from the raffle will go towards supporting vital **Colostomy Association** services such as our 24–hour helpline, free literature and *Tidings* magazine.

Inside this edition of *Tidings*, are two books of raffle tickets and more can be ordered from our office. Simply fill in your details on the tear–off slip and post that section back to us along with your payment. It couldn't be easier. All ticket sales need to be in by **Friday 15 December 2017** and the winners will be notified by email, phone or post and announced in the Spring 2018 edition of *Tidings*. What better way to start the New Year than spending your winnings in the sales or on a last–minute holiday!

Good luck everyone!

Are you an Active Ostomate?

The **Colostomy Association** is looking for ostomates and non–ostomates alike who are interested in representing the Charity in various sporting events in the near future. It could be as individuals or as a team. Whatever activity you enjoy be it running, cycling, bowls, walking, swimming, tennis or football, we'd love to hear from you!

For further information or to register your interest please contact our development officer Giovanni Cinque at Giovanni.cinque@colostomyassociation.org.uk

St John's Charity of the Year

Many thanks to St John's Evangelist Church in Fareham, Hampshire, who have nominated us as one of their charities of the year for 2017. Each year church members and friends knit chickens which hold a cream egg – these beautifully knitted chickens are then sold to raise funds for their chosen charities. There's a great community involvement as local shops and businesses also sell the chickens on behalf of the church. What a lovely way to donate an Easter egg to somebody too!

Fabulous Fundraisers!

Yet again our supporters, their friends and family members have been busy raising funds for the **Colostomy Association.** As always we're hugely grateful and humbled by the efforts of so many people who help to financially support our vital free services.

In this edition we would like to thank the following individuals and groups:

Wendy Green (pictured here) donated **£150** from a collection for her 80th birthday.

Romiley Methodist church donated **£200** from their Sunday coffee mornings.

The Shropshire B.O.T.S (Bums on Tums) raised **£250** from their 2016 open day.

Barr Teas in South Ayrshire raised **£750** from village teas and the annual ladies' lunch.

Stephen Axford and his Royal Mail colleagues raised **£657.**

Roy Tuckey donated **£200.**

Radcliffe Knit & Knatter group donated **£50** thanks to Mrs Janet Boddis, who phoned the office shortly after her husband had stoma surgery. Mrs Boddis spoke to a volunteer who was so helpful that she told the group how great the **Colostomy Association** was and they decided to make the donation from their small charity fund.

Colostomy Association trustee **Caroline Emeny** held her annual village cake sale in November 2016 and raised a brilliant **£900.**

Elsie Davidson donated **£100** to **Stoma Aid.**

Kingswinford & Stourbridge Lions Club donated **£200** for Stoma Aid.

Do you know your Oasis from your Elvis?

Caroline Emeny, fundraiser, volunteer and Trustee, will be holding her 6th Annual FUN Music Quiz at her local village hall in Laxfield, Suffolk (IP13) on Friday evening **19 May 2017**.

This event is always packed and is an evening of great fun, but great concentration as well, as teams delve into their memory banks to find the answers. Caroline insists the format is 50% easy that everyone will know, 30% a little bit harder that around half of the teams will know and 20% usually consisting two clinchers to separate the wheat from the chaff!

Written question rounds are interspersed with listening rounds where music is played and these are hugely popular. The atmosphere is always electric and great fun is had by all. Questions are taken from the 1950s right through to modern day, going through the different musical eras along the way.

Entry costs just £20 for a team of four and people take their own drinks making it a very cheap night out, while raising money for the **Colostomy Association**.

If you would like to know more, and Caroline would love to get some local ostomates and friends on board, please call her on **01986 798 422**.

Unity Lottery

It's now been over a year since the Unity Lottery replaced our 500 Club and we're glad to say that not only is its popularity growing with supporters on a weekly basis, they are also winning regularly as well!

unity

Members have the chance of winning a main prize of £25,000 each week (plus a £2,500 donation to the **Colostomy Association**), as well as smaller prizes of £5, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1 ticket sold. People can join by completing the form on page 25 or online by visiting **www.unitylottery.co.uk** but please remember to link to our Charity.

Grants and Trusts

The **Colostomy Association** is grateful to the following trusts and foundations who have recently agreed to support our work through contributions to our core costs and various projects:

The CB & HH Taylor 1984 Trust

The Pennycress Trust

The Stella Symons Charitable Trust

The Wilmington Trust

The Prudential Small Donations Fund

Textgiving

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

Whatever mobile network you're on, simply text our unique code **CASS01** and an amount of £4, £5 or £10 to **70070**.

Donating via text is free. There is no cost to you for sending the text message and your free allowance or bundle will not be affected – the only charge will be the donation itself.

What's more 100% of your text donation (including Gift Aid) will be sent to the **Colostomy Association**.

The amount you donate will be added to your mobile phone bill or deducted from your pay as you go credit. **JustTextGiving** will even send you a link in a text message confirming your donation.

Leave a Legacy

Leaving a legacy in your Will is a truly special way to make a lasting difference. It will help ostomates of tomorrow, as well as their family members and carers, receive life–changing support from the **Colostomy Association**.

What your gift means

Legacies large and small have an extraordinary impact for the thousands of people that we help and support. A legacy would:

- Ensure there is always a voice at the other end of our 24 hour helpline.
- Train volunteers to provide support at open days and in hospitals.
- Help fund our campaign for a stoma friendly society.
- Make sure that ostomates of tomorrow receive the same support from us that you yourself have received.

Every hour of every day we provide invaluable help and support. Please help us to help others in their time of need.

How to leave a legacy

A solicitor can help you to write a Will or, if you already have a Will, a codicil. Your legacy would be used wherever it is most needed – or you can choose to support a specific area or project if preferred.

Your solicitor will need the following information on our Charity:

Name:
Colostomy Association
Registered address:
Enterprise House, 95 London Street,
Reading, RG1 4QA
Charity Commission registration number:
1113471

After you have provided for your loved ones we hope you will consider a gift to our Charity. **Thank you.**

bowel & cancer research | saving lives changing lives

Bowel & Cancer Research is a national charity. We believe that **no one should die of bowel cancer or have to live with chronic bowel disease.**

To achieve this we fund the **best science** across the UK and invest in the **next generation of research experts** through a specialist PhD programme.

Our funding supports all aspects of research with a **clear patient benefit**, from better diagnostics, to improved treatments, right through to surgical innovation and after–care.

Join us at the Big Bowel Event – 8 June 2017

We're extending a warm invitation to the **Colostomy Association** and its members to join us in Birmingham on 8 June 2017 for a day dedicated to getting involved in bowel research. We're aware how people living with chronic disease can feel very isolated and we want to give people a small taste of the extensive amount of work that is being done to make life better and provide solutions for the issues that people face.

Held at a central Birmingham venue, with refreshments available throughout the day and lunch provided, the Big Bowel Event is free to attend. In the morning, presentations will be made on a variety of topics and in the afternoon, you'll be invited to participate in round table sessions.

For anyone who has an interest in bowel disease and research, this is an event not to be missed.

What's on at the Big Bowel Event?

You will have the chance to connect with some of the UK's leading researchers, covering topics from bowel cancer to IBD and IBS.

Session one – Lifestyle and your bowel disease

Self-help lifestyle factors after bowel cancer – what's the evidence – are they worth the effort? *Professor Robert Thomas, Consultant Oncologist Bedford and Addenbrooke's Hospitals*

IBD Relief: Developing an education and support app for Inflammatory Bowel Disease (IBD) patients. *Mr Seb Tucknott, Digital Innovator*

Session two – Clinical trials, what's new?

CapaCiTY – the world's largest programme of research into the treatment of chronic constipation in adults, performed in the UK NHS. *Professor Christine Norton, Florence Nightingale Foundation Professor of Clinical Nursing Research*

IBS School – a pilot study comparing an educational group with an online approach to support people to self–manage. *Dr Anton Emmanuel, Senior Lecturer in Neurogastroenterology at University College London*

SUBSoNIC – a study to find out if the most popular surgical treatment for faecal incontinence called sacral neuromodulation works and why. *Professor Charles Knowles, Professor of Surgical Research Queen Mary University*

Session three – Devices, data and developing services

Directing treatment – the expanding role of MRI. *Dr Alex Menys, Chief Executive Motilent*

Ostom-I Alert – smart stoma bag technology. *Mr Harrison Posner, UK Business Development Liaison Ostom-I Alert*

Bile Acid Malabsorption – developing a more effective and cheaper test for this common cause of diarrhoea. *Professor Matt Brookes, Consultant Gastroenterologist, Royal Wolverhampton NHS Trust*

Improving services for people with anal cancer. *Mr Mo Thaha, Senior Lecturer and Consultant in Colorectal Surgery Queen Mary University of London*

"ContactME-IBS"– Does the use of Consent for Contact increase patient opportunities to participate in clinical research, and improve recruitment to time and target in IBS clinical trials? *Linda Tinkler, Academic Research Nurse, Co. Durham & Darlington NHS Trust.*

Where is the Big Bowel Event?

The event is happening at **Maple House** in the centre of Birmingham. The venue is very accessible via rail, bus and driving. Full details will be forwarded upon completion of registration. Travel bursaries are available, please contact **deborah@bowelcancerresearch.org** for further details on these or with any other queries.

For more information and to register for the event:

https://www.eventbrite.co.uk/e/the-big-bowel-event-tickets-30849305102?aff=eac2

Telephone: **020 7882 8749**

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For gentle yet effective protection to the delicate skin around your stoma.

Use a Cavilon no sting barrier wipe every time you change your appliance to protect skin from leakage and harmful adhesives.

For a free sample:

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www.3M.co.uk/stoma

Complete and return the coupon below to Cavilon Skin Care Products, 3M United Kingdom PLC, Morley Street, Loughborough LE11 1EP

Long lasting
The protective film can last up to 72 hours[1] but re-application is required after each stoma pouch/adhesive dressing change.

Comfortable
Cavilon no sting barrier film is comfortable to use even on sore, damaged skin and does not decrease appliance or dressing adhesion.

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Non-sticky formulation that dries quickly for ease of use.

Ordering information

3M code	Description	Units per box	PIP code	NHS code
3344E	3M™ Cavilon™ No Sting Barrier Film	30	317-5692	ELY190

Reference

1 Issberner K, Schuren J. (2004) A comparative study of the skin protectant performance of five barrier films. 3M Germany Laboratory, Neuss, Germany, 2004.

The 3M Sample Request offer is open to adults (18 years and over) in the UK and Northern Ireland until December 31st 2017. Product samples are subject to availability and 3M reserves the right to cancel this product sample offer at any time. Information about you that you disclose to 3M United Kingdom PLC (3M) will be kept confidential. Since 3M is part of the global 3M Company, the information that you will provide us with will be stored on 3M's servers outside of Europe and other 3M companies or business partners may process this information on 3M's behalf, but always under strict conditions of confidentiality. 3M will keep this information to enable it to properly and effectively administer and monitor the customer relationship it has with you. 3M offers a wide range of products and services and would like to tell you about them and any other offers it believes may interest you. This would be by letter, telephone or e-mail. If you wish 3M to do this, please tick the following box ☐.

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Try Cavilon no sting barrier film for yourself

For a free sample please visit **www.3M.co.uk/stoma**, call us on **01509 613 192** or complete and return this coupon to 'Cavilon skin care products' at 3M United Kingdom PLC, 3M House, Morley Street, Loughborough, Leicestershire LE11 1EP.

Full name

Address

Postcode

PICTURE THIS

A reminder to all you lens men and women

Last Call for entries to our 2018 Calendar Competition

The theme for our photo competition is ‘travel’ but please feel free to interpret this broadly. Pictures of stunning landscapes are welcome, but maybe you can come up with an unusual angle? The idea is to show that having a stoma doesn’t prevent you enjoying life to the full. All photographs will be judged anonymously and the best 12 will be shortlisted for inclusion in our 2018 Calendar. It promises to be another stunning calendar and your photos are very much appreciated.

So please don’t delay, as the **closing date** for entries is **30th April 2017** and this is fast approaching! Just remember to set your camera to the highest quality and in landscape (so that your photograph/s will be suitable when blown up to A4 size) and then e-mail them to **arvind.anand@colostomyassociation.org.uk**

Our 2018 Calendar will be available to purchase from July onwards so keep a look out for the order form in the next edition of *Tidings* to continue to make this initiative an ongoing annual success.

JJ & H on Tour

In the hotel room in Sydney

Many people write about their anxiety and nervousness about travelling with a stoma so I decided to write about an adventure I undertook last year. I will try to be brief about the medical circumstances which led me to undertake my trip.

Cancer in 2007, metastatic in 2010 followed by chemotherapy. I returned to my job which, although busy and stressful, I loved. I was a primary school head teacher. Unfortunately, on holiday in 2013 I developed an abscess in my bowel and on return to the UK went straight to hospital with sepsis. They tried to reduce the abscess with intravenous antibiotics but unfortunately the night before the planned surgery to remove it, it burst causing irreparable damage to the internal and external sphincter muscles in my rectum and anus.

Then followed a difficult ten months when I was faecally incontinent. Various tests were done and I tried my best to work; as you can imagine, this was fraught with difficulty! After two episodes of near fatal sepsis the decision was made that I would have a colostomy. This I had at the end of July 2014 on the same day a group of my friends went on a holiday that I had organised!

Everyone, including my surgeon and the stoma nurses, told me 'my life would change for the better'. It did not. From the onset my stoma (I named him Heisenberg after a character in the TV series Breaking Bad, he's now been shortened to 'H') retracted and he constantly leaked; during the day, in bed at night, and I had many an embarrassing public leak. The stoma nurses tried absolutely everything to sort this but we got nowhere. I returned to my job but with the leaky H; this was not easy…I'd sometimes have to dash out of taking an assembly or in the middle of a Governing Body meeting, and I also couldn't do any teaching.

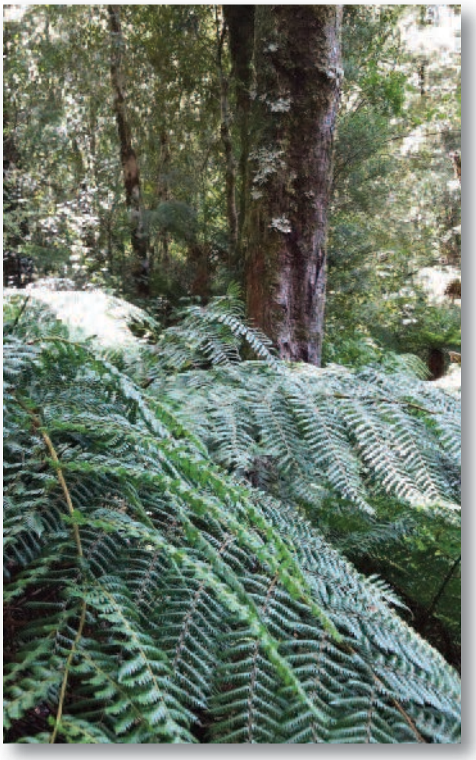
I sought a second opinion with a different colorectal surgeon who was recommended to me and in April 2015 he did a revision. The first time my new stoma worked he leaked and I could see he was still flush with my skin. I felt utterly broken at this point as I still had the same problems with leaking. In June 2015 my surgeon moved the stoma to my ascending colon on the right hand side of my body. Unfortunately, it was also retracted and the same problems were still occurring.

When I saw the surgeon in August 2015 he gave me the devastating news that there was nothing more to be done and I would have to 'live with this as a lifelong condition'. He also recommended I apply for ill health retirement and said he would support my application. Meanwhile the Governing Body at school had lost patience with the amount of sickness absence and

I knew it was only a matter of time before I lost my beloved job so I took the retirement.

I felt utterly and completely devastated at the loss of my job and the change in my health. The biggest thing I felt I'd lost was the ability to leave the house without anxiety because of what 'H' might do. At this point I know I was in danger of becoming agoraphobic and never leaving the house. With the help of a great therapist, the stoma nurse, excellent friends and the **Colostomy Association** Facebook group I decided to change my attitude and 'live' with whatever H could throw at me! I mean I'd survived a public leak in a restaurant more than once, in the shopping centre, in an airport and so on. I found it humiliating and embarrassing but realised that anyone who saw me wasn't likely to ever see me again. On a cold winter day I changed my leaky bag on the hard shoulder of the A1 with traffic slowly trundling past because of an accident. By now I guess I just thought 'the worst has already happened and I'd survived it so what now?'

At the turn of the year I decided to treat myself to a trip to two places I'd always wanted to visit, Australia and New Zealand. Once I'd made the decision to go, the trip kind of took on a life of its own! If I was flying via Singapore I may as well stop off to look at it, right? If I was picking up a cruise ship in Sydney, Australia, I might as well have some time to explore the city, right?! If my ship docked in Perth, same thing, and as I flew back via Dubai, another place I'd never been to, then I arranged a stopover there too! My trip was going to take a month in all. Needless to say I was incredibly excited!



The tree trunk in New Zealand's National Fjord park that provided cover for a bag change

What was lovely was posting on the **Colostomy Association** Facebook Group and very soon people began to share my excitement asking for photos/posts etc. I didn't want to flood the page so with the help of others set up a Group within the main Group called JJ & H on Tour. (JJ being the initials of my nickname, and H just being H!) I was amazed at how many people requested to join and at its peak I think there were over 88 members!

I had great fun posting pictures and posts about my adventures and received so much response. When you travel solo you don't have anyone to share those 'oh wow', moments with. Well with JJ & H on tour I felt lots of people were sharing my wow moments!

I had an absolutely fantastic time, from getting into the cockpit and sitting with three dishy pilots when the plane was delayed in Singapore to swimming at Bondi beach. I adored Sydney and was beyond excited when I boarded the cruise ship there exhausted after three days of trying to fit everything in! I toured New Zealand and the bottom coast of Australia. The highlight was a two–day trip from Dunedin in New Zealand through the National Fjord Park to rejoin the ship in beautiful Milford Sound. Just breathtakingly gorgeous!

H was his usual self but by now I felt I could just deal with him and move on. I had to change my bag behind a tree in the National Park with some bottled water. Still to this day I don't know what the guide told everyone on the coach to explain why I got off! I had an amusing moment, and a rare moment of gratitude for having a stoma; when the vacuum toilet system on the ship was out of order for nearly 21 hours – apparently, the state of both public and cabin toilets wasn't pleasant – it didn't affect me!

Perhaps the best thing about my trip came at the end. I asked that if people had enjoyed following me on Facebook would they donate a small sum to the **Colostomy Association**. I was overwhelmed when both my **Colostomy Association** friends and my 'home friends' donated because they had enjoyed following my trip, and so astounded that donations hit over **£700** for the **Colostomy Association**! Again, thank you to all who donated.

Finally, something I had not considered when I wrote JJ & H on tour was the impact it would have on others with a stoma. I got so many messages saying I had inspired others or given them the courage to explore further away from home. My favourite was a message from a man who said: 'In the six years my wife has had her stoma she has refused to go on holiday abroad. By the third week of following your tour she said to me: "If that lass, with her leaky stoma, can travel all that way on her own, I can go abroad." We have booked a week's holiday to Spain and it's all thanks to you!'

Priceless. Don't let the stoma stop you!

Janey Jane

Thank you to Janey Jane for sharing her story and proving that it is still possible to travel to faraway places even with a troublesome stoma, and to her followers on Facebook for donating **£700** to the **Colostomy Association**.

A daily swim

Florida Trip

The alarm went off early on the 29 July. My wife and I were Florida bound to fulfil a promise we had made to ourselves and our daughter and her husband that we would take our granddaughters to enjoy the theme parks once they were old enough. Oh and to meet Micky! So how did I get on as a colostomate?

Jennie and I were going a week early so we could have a few days to ourselves and had chosen to drive down to Key West then back via the Everglades before reaching Orlando via Tampa.

Arrival at Heathrow was achieved without alarm and check in completed without fuss. I had checked in the night before online but had been unable to print boarding passes so we had to go through the process again. Seating was not an issue as we were traveling Premium Economy and seat allocation was part of the deal. If you can afford the extra over standard economy I would certainly recommend this upgrade, bigger seats and a number of worthwhile extras including two checked cases on Virgin if needed. My supplies were split between two sets of hand luggage and two checked cases.

Security beckoned. Since my operation I have flown a number of times and have adopted the approach of not to tell. The colostomy is for them to find! My wife has had hip replacements, which includes metal parts, and adopted the other approach. She told the security officers and was told the certificates she had were not needed as when the scanner alarms went off she would undergo a full pat down search.

Before the personal check, we had to get our hand luggage ready for the scanner. All liquids must come out of the carry–on bag and go into a small clear bag for scanning. For me that meant the medical adhesive remover and odour neutralizer plus the personal liquids and gels had to go into the clear bag and into the tray for scanning. I have never been asked what the adhesive remover and odour neutralizer are for and today was no different. If you are thinking of traveling you should note that there are limits to the liquids that you can carry. You are allowed up to 100ml of any liquid and if you don't take it out as required you will have it confiscated and you may even be stopped from flying. But it is no big deal, just a need to be aware and be ready.

I also had to take off my bum bag to put that through the scanner as well. The bag was to carry my papers, wallet, small change and my mobile phone, except something was missing from it as I was to find out.

Now the walk through the dreaded arch. Jennie had gone through and was undergoing the pat down search as expected. I would be fine. Yes, you have guessed it all the alarms went off and as they did so my hand went to my pocket and found – my mobile phone! Full search for me as well but 'they' did not find my colostomy!

I had not changed before security as my bag was nearly empty but I would need to do so before boarding. We were booked into the No 1 Travellers' Lounge, so I changed my bag in the accessible WC there, a couple of hours later.

The flight passed without incident but again Premium Economy had benefits. As the nearest loos were shared with first class there were a smaller number of people using them than those at the rear, so easier to get into when required.

Entry in to the USA was without incident, but if going to the States make sure you have your ESTA (Electronic System for Travel Authorization) well before your departure date. You won't fly without it. Also be aware that many airports now have automated customs control. Easy to use if you follow the on screen instructions.

Preparation they say is everything. We were to stay at a local hotel and I had worked out the route and driven it using google earth a few times so I knew where to go and what lane to be in. Just as well as we could not get the Sat Nav to work. My homework paid off!

Sat Nav fixed next morning, all it required was to see the sky (which it could not inside the car rental multi story), we set off on our journey. A new hotel each night for

the next eight days. When I needed to change during the day the US accessible loos were a bit hit and miss. They are located inside both ladies' and gents' loos as a large cubicle, and you may not find a wash basin. Rubbish bins were in the main area so disposal bag discreetly placed there.

Public restrooms are few and far between but most main shops have them. If using the freeway go off and you will almost certainly find something immediately. If using Sat Nav that will get you back onto the freeway afterwards.

I wear flushable bags but have given up flushing at home as I have encountered sewer problems. As they suit me in other respects I have kept using them. I did not flush at the hotels but I did empty the contents through the stoma hole as a courtesy to the hotel staff. Not that pleasant but easily done. Disposal bags then left with other rubbish. I also followed this practice at the villa we stayed in at Orlando as by the loo in the bathroom was a warning about not flushing anything other than small amounts of toilet paper due to the inadequacies of Florida's drains. I took it as read that poo could go down as well!

And so to Disney and the other theme parks. Security! Bag checks and scanners at all of them. Sadly, a sign of the times. Again my approach 'say nothing'. The security personal quite clearly saw my supply of pouches but said nothing. Scanners were not always compulsory but when I went through: no issues. The mobile was always in the bum bag!

Changing in the theme parks could be a challenge. Accessible WCs are inside the main rest rooms so get used by normals, but there are family rooms outside which double as disabled. They get very busy, not least as the parks attract lots of visitors with disabilities, which is a good thing but…I always set off with a clean bag and most days I found I got away without changing. Going on the rides was fine but I did not go on the fast upside down roller coasters.

Then the highlight of the tour: SeaWorld's Discovery Cove and a close-up encounter with dolphins. I had wondered should I tell? There are strict rules about the use of only their approved sun cream to avoid water contamination, but again I kept quiet. I did change just before our allotted time slot. Being in the water here and elsewhere, including the pool at the villa, caused me not the slightest issue.

Time to go home and two flights, Orlando Miami which went quite smoothly and no issues for me and then the security check at Miami and for the first time I encountered the new style body scanner. I said nothing as did the security staff but I did have my fingers wiped over with a swab which went under a light which went green and I was on my way. I have since found out the finger test is for explosives and standard procedure if they find what they believe to be a colostomy bag. The logic is that if it is something else, the explosives will be on your fingers.

So came to an end a fabulous holiday. I encountered no problems with my colostomy. If you are thinking of going on a trip abroad and have worries, my advice is go for it, just take a common sense approach and follow the advice in the **Colostomy Association**'s travel booklet.

Philip Young

Your Travel Checklist

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

The ostomate needs to remember to:

☐ pack sufficient supplies for your stay;

☐ take all supplies and travel stoma kit as hand luggage;

☐ ask the airline in advance if you need extra hand baggage for your supplies;

☐ 'check in' online 24 hours before departure to secure your preferred seat;

☐ avoid food and drink that are likely to cause upset or excessive wind the day before you travel;

☐ pack all your normal medications and any that may help an upset stomach;

☐ carry your Travel Certificate with you especially when passing through immigration or security areas;

☐ pack some form of electrolyte replacement solution in case you become dehydrated;

☐ drink bottled water, avoid ice in drinks and use boiled or bottled water to clean around your stoma in countries where water could be contaminated; and

☐ store your supplies in a cool place, out of direct sunlight.

CA Booklets, Leaflets and Factsheets are available

Simply contact:

General Enquiries:
0118 939 1537

Monday to Thursday
9am – 5pm and
Friday 9am – 3pm

or

E-mail:
cass@colostomyassociation.org.uk

or download from our

Website:
www. colostomyassociation.org.uk

The breakaway Foundation

Our tenth birthday year came to an unexpected end with the power of the wider Breakaway family really highlighted. Everyone pulled together to support one of the Breakaway mums who was going through the worst time that any parent could ever go through.

We always knew that **Breakaway** had created some truly unbreakable bonds between families. What we didn't realise was just how much everyone really does feel connected, even to people that they have never met, either in real life or online. It was that power, that feeling of total togetherness that was almost overwhelming at times. Something that started on a wet weekend in Wales ten years ago, had almost become this living, breathing creature.

Looking back, it's because of the personal connections, not just those that have met in real life, but the bonds and friendships that have been forged in our closed Facebook Group. When we set up the Group three years ago, it was because we knew that the helpline had run its course, parents needed the immediacy of connecting online. If they have a problem they want to be able to speak to someone who understands and can help there and then. Not only that but it's a great way for families to get to know each other and then connect outside of Facebook. It's no surprise therefore that it was to the Facebook Group that people turned when we experienced what has to be the worst news ever in the ten years of **Breakaway**.

One of the **Breakaway** kids had been in hospital for four months after straight–forward surgery hadn't gone so well. Things were looking up and they were hoping to be discharged. It was planned for the following week when suddenly everything went wrong. We had a text from Mum to say that her daughter had suddenly become very sick; her heart rate was very high, with a very high temperature and low blood pressure. We instantly panicked. It sounded like sepsis.

The next update was that they were looking to move her to Intensive Care. The next morning a text came to say that she'd been taken to theatre as her lungs had collapsed. All we could do was sit and wait. Then came the text that no one wanted to read; her heart was malfunctioning and she was being moved to Cardiac ITU and placed in an induced coma on full life support. For ten days her life hung in the balance. #teambreakway pulled together. We posted regular updates on the Facebook Group. Our families wanted to do something to help so a fundraising page was set up for donations as that was all that most people could do, being so far away. Almost **£2,000** was donated.

Families that were also inpatients or visiting for clinic appointments went in to support mum. Our trustees and professional volunteers travelled hundreds of miles to London to visit them. Scott, our design guru, produced a gigantic A3 poster full of all the Get Well messages. Ten days later, on the day that Julie visited, she was taken off life support and woken up – we think it was the threat of Julie that did it! She made slow but steady progress and was able to go home early in the New Year.

It was the most awful time in her mum's life, not knowing if her daughter would survive or not. She kept saying that the overwhelming show of love and support from **Breakaway** got her through those very dark days.

Mum writes:

"If it weren't for all the little lit hands that I received during my daughter's stay in the Cardiac Intensive Care Unit of Great Ormond Street Hospital, I wouldn't be writing this testimony. By little lit hands I mean all the luminous messages I kept receiving on my phone during the darkest hours of my life. In retrospect, I have no idea what I was going through. All I know is that every single message was like a human chain of hands pulling me through it all. I was clinging onto my phone like my life was literally depending on it. It was, because my daughter's life was.

*I have never felt such an overwhelming wave of love and support. I was not on Facebook and yet messages were pouring in day and night, I was unable to process the enormity of what was happening and yet the closest **Breakaway** friends like the instant anonymous ones were there for me, silently understanding what I was going through and sending a card, bringing a soup or putting together tokens of friendship, of that friendship that meant that we would win this battle together and that we wouldn't give up so easily.*

*The trip to America I promised her before she was put into her induced coma was a desperate and helpless plea from a mother trying to make sure her daughter would fight through it all. I had no idea how I would send her there, but I had to promise her that… and **Breakaway** made it happen. When my Sleeping Beauty eventually woke up, she was so surprised by the work that had been put together for her behind the scenes. The giant poster with all the messages from **Breakaway** friends brought joyful tears to her newly awoken face. Like fairy godmothers, they all silently, appropriately, delicately and warmly kept me going. It is all a blur in my mind, but all I can remember is the silver lining **Breakaway** was relentlessly sewing onto my dark cloud. The cloud has gone, but the silver can still be seen in both my daughter's and my smile."*

It's a time that we will never forget, traumatic for everyone, but it showed that **Breakaway** really is more than the sum of its parts. It's a family, probably a very odd family, but a family none the less, and we will always pull together when one of our families need that support. ■

More information about Breakaway Foundation.

Donate online via:

http://uk.virginmoneygiving.com/charityweb/charity/finalCharityHomepage.action?charityId=1008990

Write to us or send a donation to:

Breakaway Foundation
PO BOX 7982
Swadlincote
DE11 1FB

Telephone:
01283 240253
Email:
info@breakawayfoundation.org.uk
Web:
www.breakawayfoundation.org.uk

Junior Ostomy Support Helpline (JOSH)

Our Junior Ostomy Support Helpline for carers of children with bowel and bladder dysfunctions.

We want to hear from you!

In the next issue of *Tidings* we would like to make the **JOSH** page more exciting for our younger readers.

Send us your photos, drawings, poems and more for us to feature…perhaps you've travelled abroad with your cuddly **JOSH** snow leopard and have a picture with a famous landmark or have something else exciting to share.

Contact us at **cass@colostomyassociation.org.uk** and let us know what your child would like to see on this page. We look forward to hearing from you.

JOSH On The Road

On 8 June 2017 the JOSH team will be attending a Kidz to Adultz South event at the Rivermead complex in Reading.

Kidz to Adultz is one of the largest, free UK exhibitions dedicated to children and young adults up to 25 years with disabilities and additional needs, their families, carers and the professionals who support them.

There will be over 120 exhibitors including JOSH, offering advice and information on areas such as:

- Funding
- Mobility
- Seating
- Beds
- Communication
- Access
- Accessible vehicles
- Education
- Legal matters
- Style
- Sensory
- Sports activities
- Holidays
- Leisure and much more!

If you are interested in attending this major event, tickets are free and registrations can be made by calling **0161 607 8200** or by visiting **www.kidzexhibitions.co.uk**

Josh resources

Do you know of, or are you a stoma care nurse that cares for children and babies with bowel and bladder dysfunctions? Our range of resources explains stomas to children and includes colouring books, cuddly toys and comics. Our Josh snow leopard can be given to children pre or post surgery. Not only can Josh provide comfort but with details of our helpline on his tag, he reminds parents and carers that support is only a phone call away. If you are interested in finding out more about our free resources please email **cass@colostomyassociation.org.uk** or call **0118 939 1537**.

In December 2016 we were delighted to attend the Birmingham Children's Hospital Christmas party for children affected by bladder and bowel dysfunctions. Our JOSH ambassador, Aled, took along Josh the Snow leopard and each child was able to take one home.

Fundraising for JOSH

JOSH is part of the **Colostomy Association** and we are funded purely by donations. Your help and support allows us to carry on providing a range of free services such as JOSH. If you are interested in holding a coffee morning, cake sale or similar to raise funds for JOSH, please get in touch for information on fundraising. Any funds raised for JOSH should be sent to the **Colostomy Association** and clearly be marked 'JOSH'. ■

Diverticulitis and eighteen months with a stoma

For many years, I suffered with IBS and then I developed diverticular disease. This was controlled by watching my diet and taking Fybogel which really helped. Over time it gradually got worse and eventually I was taking antibiotics almost every month to combat the infection. I did not realise how unwell I looked and how much weight I had gradually lost. Eventually the oral antibiotics did not help and this resulted in me being admitted to hospital to have antibiotics intravenously.

The infection did not clear up and eventually I had to have an emergency operation as my bowel was blocked. I was very unwell and in a great deal of pain, on so much morphine that I was not fully aware of what was happening. Before my operation, the stoma nurse came to mark me up as the surgeon had informed me that I may need a temporary stoma.

I was 62 years old and accepted having a stoma very easily as I was relieved to be out of pain. After a further week in hospital I returned home but was very tired and unable to walk far, so needed a wheelchair to get into town for the first few weeks. The stoma after care was marvellous. Salts in Bournemouth supplied all my bags and other items and were so helpful whenever I rang. Delivery to the house was brilliant. The stoma care nurses at Winchester Hospital were extremely helpful and especially supportive in the early days. I had been so ill that I had lost a stone in weight but as my appetite improved I have put the weight back on. Then my stoma bag became very uncomfortable; I had not realised my stoma had changed shape so the hole in the flange needed to be bigger. I found stoma bag covers very useful and I always used scented nappy bags for disposal of used bags especially in public toilets. Elasticated trousers were the most comfortable and Damart produce a good range. Having a stoma did not stop me doing anything. I was soon back swimming; I had a ruched and patterned swimming costume. Then I went back to the gym and to my Pilates class. I always remember to wear a support belt when doing these activities.

Six months after my surgery I had an appointment with my surgeon and told him I did not want a reversal as I was no longer in pain. He arranged to see me again six months later to make sure I was certain. My stoma nurses told me that over the next year I would change my mind several times, about having a reversal. Then I began to have skin problems and some days, mostly in the evenings, I had awful irritation. I eventually decided to have a reversal.

As I had lived with a stoma for eighteen months, I was quite anxious about the operation. In November 2016 I went into hospital and the operation was a success. I stayed in for five days and had very little pain and was only on Ibuprofen and Paracetemol. Obviously, I was concerned about how my bowels would adjust and just hoped everything would work normally. I found I needed to go very frequently in the first two weeks. This resulted in an extremely sore and itchy back passage. I looked on the internet and discovered this was quite common. The pharmacist recommended Preparation H cream and toilet wipes which are available over the counter. These were brilliant and within a few days all was fine.

It took about three weeks to retrain my bowels and they are completely back to normal now but I still avoid mushrooms, sweet corn and too many onions. I gave myself time to recover and took things very easily. Once home I was very tired and sleeping well at night and I often had a mid–afternoon nap.

It is now two months since my reversal operation and I can't believe how well I feel. I am very fit and not overweight so I think this has really helped my recovery. I am already swimming and doing Pilates and light gym work. I now feel ready to improve my stomach muscles.

I feel very fortunate to have been able to have a successful reversal. I knew nothing about stomas before my operation but it was not as bad as I imagined it to be. It is just a case of getting used to your body working in a different way. I think we are so fortunate in this country to have such marvellous surgeons and amazing medical equipment available through the NHS. It is so different for thousands of people across the world. I cannot imagine having a stoma and no proper equipment. These people's lives must be awful as they have to improvise with the little they have.

Ann Coleman

When she had a date for her reversal, Ann was careful not to order too many stoma bags, but still have enough in case her operation was postponed at the last minute. She was left with about forty bags which she posted to Stoma Aid (see pp 42–43).

In the winter edition of *Tidings* we celebrated the first anniversary of our Stoma Aid project. As you may recall, we reported having sent a huge quantity of stoma bags to developing countries across the globe. Such large numbers are obviously impressive, but it's the human stories behind the project that really drive home the value of our work.

One Beneficiary's Story…

The case of Anil Jowaheer, who lives in London, and his relative Sada, in Mauritius, illustrates the value of Stoma Aid well. In the spring of 2016, Sada began to suffer from altered bowel habits. A colonoscopy and biopsy revealed a malignant tumour. Thus, with little warning or time to prepare, Sada underwent an anterior resection of the recto–sigmoid colon. A traverse colostomy was also formed. As with many countries in the developing world, Mauritius possesses the surgical expertise to carry out such procedures, but lacks the sort of post–operative support we regard as normal in the UK. It was on this issue that Anil contacted Stoma Aid.

Quite simply, the cost of stoma supplies was such that they were beyond Sada's reach. The situation was aggravated further by the position of his stoma. Formed just above the vertical abdominal

incision line it meant that frequent bag changes were required. Luckily we were able to help, putting together a package of supplies including colostomy bags, adhesive removers and skin wipes. This package should contain sufficient items to see Sada through until his anticipated reversal operation, which is scheduled for this Spring.

Anil recently got back in touch to tell us what an incredible difference the intervention of Stoma Aid made to Sada and his family. As Anil said, the surgery was traumatic but life afterwards has been made just a tiny bit easier and more bearable thanks to everyone that has kindly donated to the project.

Thousands of people have already benefited from Stoma Aid and further life stories will follow in forthcoming editions of *Tidings*.

Behind the scenes

Our voluntary team in Bolton do all they can to ensure the donated items reach the right recipients. Various checks are carried out and wherever possible UK based reputable charities are used to distribute the supplies abroad, direct to those on the ground.

Collections by Local Support Groups

The following support groups are happy to act as collection points for donations of supplies for Stoma Aid:

Coventry Stoma Support group
Able to collect in the Coventry area
Contact Martin Robbins on 07947 385 643 or martinrobbins14@hotmail.com

Milton Keynes Stoma Association
Able to collect in Milton Keynes
Contact Thia Cooper on 01908 679 295 or mksa.sec@gmail.com

Shropshire B.O.T.S (Bums on tums)
Able to collect within Shropshire
Contact Irene Constable on 01691 238 357 or ireneconstable@phonecoop.coop

Solent Ostomates Support Group
Able to collect in the Southampton area
Contact Carole Summer on 07527 707 069 or solentostomates@hotmail.co.uk

Stevenage Ostomistics
Able to collect in Stevenage area
Contact Judy Colston: 01438 354 018 – neilcolston@btinternet.com
or Alfred: 01767 616 958

Wessex Stoma Support Group
Able to collect in South Wiltshire, West Hampshire and North Dorset
Contact Kenneth Edwards on 01722 335 351 or kenneth.edwards@tesco.net

We are immensely grateful to these support groups for their generosity. If your own support group is also willing to act as a collection point and will also transport donated items up to the warehouse in Bolton, please let us know.

How you can make a difference

You can help make a difference to thousands of people across the world who cannot afford stoma supplies by either donating supplies or making a financial donation. Please send supplies you genuinely cannot use to Stoma Aid at the following address:

Dean Philps
Stoma Aid
c/o Stone Logistics/PRS Limited
Lorne Mill
Lorne Street
Bolton
BL4 7LZ

The cost of sending unneeded supplies to Stoma Aid can be reduced by using Hermes which has over 4,500 collection points across the UK. Prices start from as little as **£2.70** per parcel and more details can be found about the locations of their Parcel Shops on their website below (or by telephoning the **Colostomy Association** office with your postcode):
https://www.myhermes.co.uk/parcelshop–finder.html

Stoma Aid will accept the following:
All types of stoma appliances for adults and children including:

- Closed bags
- Drainable bags
- One piece bags
- Two piece bags (must include matching baseplate/flange)

Additional Products (which must all be at least 6 months in date):

- Absorbent gels
- Adhesive remover wipes, sprays and swabs
- Aerosols (spray and pump)
- Cleaning wipes, barrier wipes and dry wipes
- Dressings and bandages
- Frames and flange extenders
- Night/drain bags
- Pastes/creams
- Powder
- Seals, rings and washers
- Support belts, briefs and stockings

Stoma Aid cannot accept syringes, deodorants, prescription medications or drugs of any kind.
Stoma bags do not need to be in date but all additional products must be at least six months within their expiry date. Additionally, all two–piece donations must have both the stoma bag and matching baseplate/flange.

DO NOT be tempted to over–order or over–stock your supplies with the idea of sending the surplus to Stoma Aid. We cannot accept donations on this basis. Please only send items that you have ordered in good faith but find that you can no longer use. As we all know, helping the NHS save funds is vital and this in turn could also help prevent GPs questioning the quantity of stoma bags required.

Haven't got any supplies to donate but would still like to make a difference? Why not make a financial donation to Stoma Aid? (Please make all cheques payable to Stoma Aid and send them to the **Colostomy Association**, Enterprise House,
95 London Street, Reading RG1 4QA.

Help Stoma Aid with a Bag for Life

Order our NEW Stoma Aid 'bag for life' and help give ostomates worldwide a 'bag for life'.

Our new Stoma Aid 'Bags for Life' come in two styles, a cotton Tote Bag at only £2.49 + £2.50 P&P (measuring 38cm x 43cm) and a larger more robust Jute Bag for £4.99 + £2.50 P&P (47cm x 32cm)

An ideal present, both bags make a statement when you are out shopping! The caricature was designed by a professional cartoonist whose work has appeared in a number of famous comics.

All profits from sales will go to Stoma Aid. So help us to continue our support of thousands of ostomates in need worldwide by buying one (or more) of our Bags for Life.

Enter our Caption Competition

5 lucky readers will win a set of both bags by entering our caption competition.

For a chance of winning, tell us what the conversation between the man and the world might be in no more than 50 words.

Please send your entry to Giovanni.cinque@colostomyassociation.org.uk or post your answer into Giovanni Cinque at the address below. The competition closes on **30 April 2017** and winners will be announced in the next issue of *Tidings*.

Order Form

To order your **Bag for Life** simply fill in your details below and return it with a cheque made payable to the **CA Ltd** and send to:

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

Alternatively, you can order your **Bag for Life** from our online shop at **www.colostomyassociation.org.uk/shop**

Insert quantity of bags required in each box:

☐ Cotton Bag £2.49 each plus £2.50 P&P ☐ Jute Bag £4.99 each plus £2.50 P&P

Title:

Name:

Address:

Postcode

Tel:

Email:

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

Colostomy Association Facebook Group

The CA Facebook Group are out and about again!

In November 2016 we were invited to visit the new Welland factory in Crawley. Having been to other meets with The CliniMed group I must admit I was excited. A factory tour, on the face of it, doesn't sound very exciting. Or so I thought. I have been to a number of stoma appliance factories now and they are absolutely fascinating. We ostomates rely 24/7 on these products to live our lives comfortably and seeing what goes into their manufacture is really very interesting.

We arrived to a lovely buffet lunch and met the many staff who had kindly given up their Saturday to host our group. Chris Primitt, MD of Welland and Marc Blamire, Marketing & Regulatory Affairs Director Designate for CliniMed/SecuriCare welcomed us to the very impressive new premises and gave a brief overview of the company. Then it was time to don the flattering (not) paper coats and mob caps ready for the factory tour. We were split into two groups and shown around the factory, stopping at each section from the beginning of the process where flanges resemble a big lump of play–doh, to the slick automated production of a bag, and then the finished product, watching every single appliance being checked for quality. The thing I am most impressed with every time we visit manufacturers is the care taken to ensure these products are as good as they possibly can be for the end user. All the staff I met, from management to shop floor factory workers really seem to 'get' how a good product allows us to live a happy and confident life.

Following our tour, we returned to the meeting room for tea and coffee. Some might say I had a chocolate or two but don't believe them (LOVELY spread Welland, you know me so well!). We then had an interesting talk from Moira Evans, Product Development Clinical Lead, about a survey carried out by users of the Welland Flushable bag, followed by the opportunity to ask questions about this and other products.

To finish off the afternoon we were invited to take part in an ideation session with the Research and Development team. Say no more, a group of outspoken ostomates being asked to voice their opinion on things we would like improved on stoma appliances – we LOVE to give our opinions on what works and what could be better. We split into three groups to come up with our ideas which we then ranked in importance. The groups then fed back and it was interesting to see what came up. Generally, the groups agreed; problems like pancaking, sore skin are issues important to us, along with various other ideas for improving products. We are the ones living life with a stoma and it feels good to have appliance manufacturers listen and take on board what we think. After all, WE are the experts really!

We left Welland for the very short walk back to the hotel and as we left we were all given a lovely bag with all sorts of goodies inside – another thing that gets me over excited. I really am easily pleased! We met back at the hotel for drinks and dinner, costs very kindly covered by our hosts. As has become tradition now, Facebook Group admins and CliniMed provided prizes for a raffle, including a unique version of the group Mascot, Tomas Bear. Some members kindly donated back their deposits paid to hold their place on the meet and along with the raffle proceeds we raised a brilliant **£300** for **Colostomy Association**.

A lovely evening continued and as always, I am delighted to meet members for the first time as well as catch up with old friends. I am hugely proud of how the Group come together online to offer support to fellow ostomates, and I know I have said it before, but to meet members in person is the icing on the cake. I've not once been disappointed when meeting a member of the Group. And oh how we laugh and laugh at these meets – they really are very special. Many thanks go to all Group members who came along to the event and I would like to say a very special thank you to Frances Chalmers, Research, Education and Market Development Manager at CliniMed. She went the extra mile to organise the meet up to suit our needs and along with her team made it a very enjoyable, informative and successful day. As well as those I've already mentioned I would also like to thank the following for giving up their time to welcome us:

- CliniMed / SecuriCare
- Loretta Bramley–Brant
- Catherine Haywood
- Moira Evans
- Katherine Lada
- Jennifer Pagan

The ideation session was run by:

- Mark Newton (head of the department)
- Kim Frampton
- Chris Bray
- Jack Hopper
- Theo Poole

Also from Welland:

- Chris Primett (MD)
- Alison Brighton (PA to the MD and organiser at Welland)
- Marketing attendees
- Sam Jackson (Sales and Marketing Director)
- Claire Marsden
- Lydia Downey

If you would like to join the closed CA Facebook Group, search "**Colostomy Association**" in your Facebook search box. Choose the Group and when you get the Group page, click on the join tab. One of the admins will add you as soon as they can. We look forward to seeing you there.

Photo ID Card

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

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

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

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

Alternatively, the form can be downloaded from our website: **www.colostomyassociation.org.uk**

Please allow 10–14 days for delivery – thank you

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

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

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

National Key Scheme - Key and photo ID card purchase

Title:

Name:

Address:

Postcode:

Tel:

Email:

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

Please **tick** as appropriate:

☐ I would like to receive a **key** for a charge of **£3.50** (including postage and packing).

☐ I would also like to receive a **photo ID** card for a charge of **£6.50** (including postage and packing) and enclose a passport photograph.

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

Signature of self or carer:

Date: / /2017

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

Julie Rust answers your questions about skin care

Why does the skin around the stoma become sore?

Skin around the stoma, known as peristomal skin, can become sore for many reasons. Firstly, it may be due to stool getting onto the skin which can then 'burn' the skin making it sore. This is often due to the template used for cutting the hole in the bag's adhesive flange being too large and leaving skin exposed to the stomal output. Another reason is that the bag may be leaking and again this exposes the skin around the stoma to the stool. This is easily remedied in that a change in template size may by itself solve the problem and the skin will heal or it may require short term use of additional products such as barrier sprays, powder or seals. Another reason for sore peristomal skin may be an allergy to the adhesive of the bag and again this is easily solved by changing the bag type to another product.

How can I prevent my skin from becoming sore?

The easiest way to prevent skin from becoming sore is to ensure the template size fits correctly around the stoma; the adhesive of the bag should be cut so that it fits snuggly around the stoma with a gap of 1–2mm only. The stoma can change shape and size, especially in the early days after surgery and if you lose or gain weight, so the template should be measured regularly. Your stoma care nurse specialist can show you how to do this. You also need to change the bag at the correct intervals. Too frequent bag changes can lead to trauma to the top layer of skin causing soreness and too infrequent changes can increase the potential for leaks.

When is it important to consult a stoma care nurse?

The skin around the stoma should look like the skin on the opposite side of the abdomen. If you notice that it is red or sore you should check the template size to ensure it is fitting as above and if necessary cut it to the correct size. Hopefully then the skin will settle but if it does not improve then contact your stoma care nurse specialist. If the bags are leaking or you feel that you are using the incorrect product and they are causing the skin to become sore, then you need to see the stoma care nurse specialist to try to resolve the issue.

What can I do to help myself until I can see a stoma care nurse?

As before you need to ensure that the template is cut to the correct size and the pouches are changed regularly but not too often. If the pouches are leaking you need to change them immediately. As soon as you notice a problem you can telephone your stoma care nurse specialist and they will advise what to do until they can see you. This may involve you collecting a product from the hospital to trial or they may arrange for a company to deliver some samples to you at home.

How may a stoma care nurse treat sore skin?

There are many products that the stoma care nurse specialist can use to treat skin soreness, including barrier wipes or sprays, powders, seals and of course many different types of bags. The stoma care nurse specialist has a great deal of experience to advise you on which product to use but may need to see you several times to ensure that the product is working as it should and if not to be able to change it for a different product.

Use of Additional Products

Many stoma companies not only produce pouches but also a wide variety of additional products. These include such things as:

- Adhesive remover in the form of sprays or wipes. They help to ease the adhesive flange away from the skin without causing trauma.
- Seals in a variety of sizes and thicknesses. They help to smooth skin which has creases, to absorb fluid secreted from skin which is sore and wet, and are used to provide security.
- Paste which comes in a tube. It can be used to fill skin creases and 'moats' around the stoma which will help adhesion.
- Barrier film in the form of sprays, wipes or creams. They provide a protective barrier for those with sensitive or irritated skin.
- Flange Extenders, which are adhesive strips. They are used around the flange so that the adhesive surface is increased in size to give added security.

Often these products i.e. adhesive remover or barrier wipes, flange extenders or pouch deodorants are given out as samples. However, as not all of these are essential or suitable for all patients, it is advisable to contact your stoma care nurse to see if there is a clinical need for the use of the product.

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.

Q: *I have had a colostomy for nearly 20 years and an ileostomy (following a proctocolectomy) for the last three years.*

Because of back and knee problems I am finding it very difficult to empty my bag. The problem is that I can no longer stoop or bend my knees to reach the toilet. The result is that the waste is going all over the seat of the toilet and the surrounding floor. I have tried sitting on the toilet to empty my bag but I am sitting too far forward for the bag opening to reach the bowl.

Is there any advice you, or any readers, can give to help me with this problem?

A: You can angle the pouch towards the middle so that when you sit on the toilet seat (you would need to sit quite far back) you can empty the pouch more easily. A change in products may be useful; a pouch with a longer 'tail' is easier to empty. Alternatively, a two–piece system may be an option so that the pouch can be removed without traumatising the skin, it can then be emptied and reapplied to the baseplate. I would recommend arranging a review with your local stoma care nurse specialist so that they can advise you further.

When a similar question was posted in the **Colostomy Association** Facebook Group, the most popular response from Facebook members, including those who are wheelchair users, was to line a small bowl with toilet paper, empty the bag into that, then empty that bowl down the toilet.

Q: *I have an ileostomy and have now developed a painful prolapse. My stoma nurse showed me how to massage it down (with the bag off). However, no matter what I do, it does not remain down. It is the size of the whole pouch and moves constantly. I am very frightened. I belong to an ostomy group, and nobody there has even heard of a prolapse.*

A: A prolapse of the stoma occurs when the bowel protrudes through the stomal opening in the skin to a greater extent than was intended. As long as the stoma is a healthy colour with no sore areas on the stoma or surrounding skin and is acting well they are often not operated on. A prolapse can be reduced but will never remain reduced, as when you tense your abdominal muscles when standing, coughing or lifting your head and shoulders off the bed it will prolapse again. The only way to resolve this completely would be for a review by your surgeon who may be able to amputate the prolapsed bowel and refashion the stoma. A review by your local stoma care nurse specialist may help with regards to management.

Q: *My wife who is in her late eighties has had Parkinson's disease (PD) for more than 20 years and I (her carer) am in my early nineties!*

As a result of a rectal prolapse about two years ago, she had a colostomy. And, probably due to the PD, her colon has prolapsed to such an extent (typically six to seven inches) that fitting the pouch has become very difficult.

I found a remedy for this was to put a lubricant in the pouch thus allowing the prolapsed stoma to slide into it. This allows me to position the bag before attaching it to the skin.

I would appreciate any comments and also be most interested to hear of anyone who has experienced this problem.

A: You seem to manage this problem well and the tips you have given may well help other patients with a prolapse. The important thing is that the template is a good fit to prevent sore skin around the prolapsed stoma and also to ensure that there is no trauma to the stoma itself. Also make sure that the stoma is healthy and acting well. If you have any concerns or you want any reassurance you can arrange to see your local stoma care nurse who will be able to advise with regards to products etc.

Q: *I have had a colostomy for two years. During the past nine months, I have suffered an offensive green discharge from my rectum which was firstly treated with Mesalazine suppositories and then enemas. I could not retain the latter and so am now again using the suppositories to help control it.*

Can you please tell me how common this is? I would also like to hear from anyone else who may have this very unpleasant problem.

A: If the surgery entails leaving a rectal stump in place then there is the potential to pass mucus from the rectum and many patients have this problem. This may be clear or discoloured but may have an odour especially if the surgery was done for inflammation, Crohn's disease, ulcerative or defunctioned colitis or proctitis. Controlling the discharge can be difficult for some people and the use of suppositories or enemas can be beneficial to empty the rectal stump or to reduce the inflammation. I would suggest a review by your GP or consultant to see if there is anything else they can offer, whether this be medication, or possible surgery to remove the rectal stump, which would make the stoma permanent.

Q: *I had my stoma in 2011 when I was 54 and have had very few problems apart from a parastomal hernia which was successfully repaired last year. Recently I have experienced bleeding when I change my bag. It is from a small sore on the skin close to my stoma. I am reluctant to use any cream because this may affect how the bag sticks to my skin. Can you suggest anything that will help this sore to heal?*

A: There are many reasons why you would get a sore or ulcer on the peristomal skin and I would advise a review by your local stoma care nurse specialist so that they can assess the sore, identify the cause and provide advice with regards to the correct treatment. Hopefully this will be a simple use of additional products such as powders or seals or a change in appliance.

Reply to an answer on this page in the last issue of *Tidings*

Dear Julie

I was very interested in your response to my query published as the first letter on your Dear Nurse page in the Winter edition of Tidings. However, I was even more interested in the article about granulomas where you 'hit the nail on the head'.

I had never heard of granulomas before but I actually have three. You wrote that they can be painful when touched and I realise this is my problem. The weight of bedclothes when I am lying horizontal add pressure on the stoma area and thus cause discomfort and burning. I have spoken with a stoma nurse at the hospital and am being referred back to them for further investigations. Thank you so much for such a useful article.

If you have a general medical question or a query about stoma management:

E–mail:

editor@colostomyassociation.org.uk

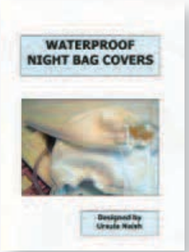
or

Write to:

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

Your questions will be passed on to Julie Rust. Although Julie is not able to reply directly to you, her answers will be published in the next issue of *Tidings*.

Julie's answers to questions about issues such as leakage, rectal discharge, or managing hernias or retracted stomas etc. may not only help you, but may also provide advice and reassurance to others experiencing a similar problem.



From One Ostomate to Another

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

Wind and ballooning

A colostomy does not mean that we are more likely to produce wind; it's just that it is not possible to control when it is expelled through the stoma. In the early days after stoma surgery it is normal to pass more wind and this may cause sudden noises. As the bowel settles into a routine this decreases and becomes much less noticeable.

Most people will be aware that eating some foods can result in more wind; the most commonly quoted example is beans. The food we eat passes down to the stomach where digestion begins. This continues in the small intestine and nutrients are absorbed into the body. The undigested remains, fibre and resistant starch, pass into the large intestine (colon). Here they are fermented by bacteria to produce gas which passes out of the body as wind.

Foods which contain resistant starch include wholegrain seeds, sweetcorn, muesli, green bananas, garlic and onion. Resistant starch can also be formed when foods are cooked and allowed to cool down before being reheated. Cutting down on these foods, ready–meals containing potato, pasta or rice and oven chips or other preheated potato products may help to reduce the amount of wind.

Some people find that that Brussels sprouts, broccoli, cauliflower and cabbage can cause wind. Remember, however, that everyone is different. A diary recording what you eat and when you experience wind can help to identify any foods which may affect you.

Other tips to help reduce the amount of wind:

- Eat regularly.
- Chew your food well.
- If you use artificial sweeteners or sugar–free foods check they don't contain sorbitol.
- Cut down on fizzy drinks.

Probiotic drinks have the potential to change the type of bacteria in the colon so they may help to reduce the amount of wind and may be worth a try. Peppermint oil capsules, may also help.

Although changes to the food that you eat may reduce the amount of wind it is unlikely to eliminate it altogether. Wind from a stoma passes into a bag and is deodorized as it is slowly released through the filter. As we all know, however, some filters are more efficient deodorizers than others. If you find you are having a problem with odour it may be worth trying a different bag.

Everyone with a stoma will have heard of ballooning, where wind becomes trapped inside the bag causing it to inflate. This problem was much more common in the past when stoma bags did not have filters. So that wind could be released without changing a closed bag or disturbing the seal, some people chose to use two–piece bags as the bag could be unclipped from the flange, a process which became known as "burping". Those using a drainable bag could release wind through the opening at the base of the bag.

Ballooning can still occur with modern appliances, if the filter becomes blocked. This is often due to the filter getting wet. If liquid or semi–solid stoma output comes into contact with the filter this can cause it to block. A solution may be to find a different make of bag where the contents of the bag are less likely to come into contact with the inside of the filter.

The sticky patches, that come in your box of stoma bags are designed to keep the outside of your filter dry. If you leave your bag on while you are in the bath or shower always stick one over the filter, and do the same when you go swimming. When you come out of the water dry your bag carefully and remove the sticker. Most people leave the sticker off at all other times to allow any wind to escape. It may be, however, that you have found that keeping a small amount of gas in the bag helps to prevent pancaking. In this case, any excess gas can be released when needed by peeling back the sticker.

Many of you may have heard warnings of stoma bags 'blowing up' on aeroplanes. As cabin pressure is maintained slightly lower than it is on the ground any gas or air trapped inside an airtight bag will expand. In the days before stoma bags had filters it may have been the case that stoma bags became inflated. But not today.

Modern filters mean that we can all fly to distant destinations without worrying that our bag will 'blow up' on the plane. Just avoid eating a whole tin of baked beans the day before you travel and make sure your filter is at its best – it's a good idea to put on a fresh bag before you board the plane. And if you usually cover your filter with the sticky patch leave it off for the flight. However, if you normally produce a lot of wind and are still worried that your filter won't cope there's always the option of using a drainable or a two–piece appliance. But please don't let these tales of outdated bags 'ballooning' prevent you for travelling by air. Seasoned travellers, who regularly take long–haul flights assure us that it definitely isn't a problem and I agree. On a 22 hour flight to Australia my bag behaved just as it does on the ground…no ballooning at all.

Rosemary Brierley

If you have an experience or anecdote you would like to share or hints and tips you'd like to pass on to other people living with a stoma:

e–mail:
editor@colostomyassociation.org.uk

or

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

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

Just read about how you wanted stories about other reasons for colostomy formation. Two years ago, I went for routine surgery for endometriosis. Unfortunately, three days later I was rushed back to theatre with a perforated bowel and needed a Hartmann's procedure. I spent three days in the High Dependency Unit and ten days in hospital.

Due to the extensive endometriosis. I have decided not to have a reversal. The surgeon cannot guarantee trouble free surgery and I cannot risk things going wrong again.

After reading your magazine I pushed to try irrigation and this has worked very well for me. I irrigate daily and wear a plug until my next irrigation is due.

Unfortunately, I had an episode of bowel obstruction two months after surgery and was advised to go on a low residue diet which has prevented any further obstructions. The only change I made was to become a meat eater, after 32 years of following a vegetarian diet.

I have a great life. I tried online dating, and then met my lovely partner through friends, so having a stoma has not affected my love life. I travel the world with my irrigation kit: Canada, Iceland, Thailand and Spain. What surprises and worries my friends the most is my love of white jeans; I have five pairs! But I have confidence in the irrigation. I listen to my body and always have emergency supplies with me.

Julie (age 55)

Dear Editor

My stoma was formed following an emergency operation to sort out a volvulus, or twisted bowel. In March 2016, my abdomen suddenly became very bloated and mildly painful. The next day the pain had intensified. My GP thought the problem was just constipation, and prescribed Movicol. When this did not achieve the desired result and my abdomen was getting more swollen and painful, she suspected that I had a bowel obstruction and rang for an ambulance. At the hospital, a CT scan confirmed that I had a volvulus and needed an emergency operation. They could not guarantee that I would survive.

The operation took five hours and I awoke to find that I had an ileostomy and a mucous fistula. I was told that a 20cm length of bowel had been removed because it had died due to loss of blood supply. I spent the next two days in the Critical Care Unit followed by another two days in the Enhanced Care Unit. Then I was transferred to a ward where the output from my ileostomy was monitored. To slow the output I was put on Loperamide capsules. Although the output remained fairly high I was allowed to go home after about another two weeks.

In hospital, I had leakage problems but, with the aid of my stoma nurse and experimentation, I found a secure system which I still use. It comprises a Hollister adaptor ring with a Hollister convex maxi drainable bag. Both are cut with a 38mm hole. To add more security I fit two Coloplast elastic tape half–moons on the outer edge of the pouch.

I went along reasonably well until mid–July when one day I noticed that there was no output in the pouch. Suspecting a blockage, I called an ambulance. A CT scan confirmed another volvulus. I was starved for five days to see if it would sort itself out but it didn't and so I went under the knife again. I went through the same routine as before and was released after nearly three weeks.

The whole experience has resulted in me being about three stone lighter than before the first operation. I have been taking Fortisips and eating well but I cannot put back any of the lost weight. I've seen a dietitian and been put on Vitasavoury soups so hopefully they will help. Also, I have been found to have anaemia so am on iron tablets.

Like many people, I suffer badly from ballooning. The Hollister filters are not very effective. I like the equivalent Coloplast filters better but have found their adhesive to be less secure so I've stayed with Hollister. I have baths with the bag in place and dry it with a towel and my wife's hair dryer.

I will probably have my ileostomy closed this year and my mucous fistula will become a colostomy. Having just one pouch to attend to will hopefully make life easier for me.

Regards
Barrie Vinten

Dear Editor

I decided to write to warn other colostomists about a problem that I recently suffered as a result of not being given adequate information by the hospital.

I was scheduled to have a colonoscopy at my local hospital. I was sent, in very good time, a letter telling me what to eat and when, what to drink and when, which of my tablets I should take and when and so

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Readers' writes

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forth. With the letter, I was supplied two sachets of a solution called Moviprep, and instruction on when to take it.

I was instructed to mix one packet with water at 17:00 hrs and drink it. The second sachet I was told to mix and drink at 19:00 hrs. I was told that this would clear out my bowel by 23:00 hrs. What it did not tell me was that these were generic instructions and assumed that I had a normal colon.

The time between taking my first sachet and about 3:30 am the following day was hell! The output from my bowel affected the stoma bag glue and it kept coming off making a mess of my clothes, the floor and the towels that my long–suffering wife kept giving me to try and stem the flow. This carried on, almost without respite, until the early hours of the next morning. By the time I arrived at the hospital I was cross, exhausted and extremely frustrated. Although the staff were apologetic and understanding I did not feel that they really understood the problem.

I would recommend that anyone who has a similar procedure booked takes the medicine much earlier, say 14:00 and 16:00 hrs and that they have a ready supply of drainable pouches or an irrigation belt with sleeves. Finally, do not go far from the toilet! It would also be sensible to talk to a stoma nurse to get advice on best practice.

Regards
Simon Jones

Editor's note: The ***Colostomy Association*** *booklet, Colonoscopy through the stoma, provides advice on how to cope with the bowel cleansing required the day before, as well as describing what happens during the colonoscopy procedure.*

Dear Editor

In March 2013 I was rushed to hospital and had an emergency operation and had a colostomy.

Adverts tell people to see their GP if they are concerned, but if the GP does not take it further what do you do? I went to my GP three times and each time was told to have a blood test. I asked him to send me to hospital for some tests and he said that he had no evidence for that. I told him I was going to the toilet more and one time there was some blood.

I had colon cancer and I was in hospital for eight weeks. When I came round in Intensive Care the surgeon said if they had not got me into hospital when they did I would not have been talking to him.

Yours sincerely
G Miller

Dear Editor

When I was four I was diagnosed with diabetes. I thought one life–long illness was enough. Then at 23 my life changed again. What I thought was a stomach bug turned out to be a lot worse. I had this bad stomach for a week and then passed blood. My GP thought I had piles. In total I saw three different doctors and had loads of tests. Nothing.

In April 2015 I had no energy. I couldn't even get off the sofa, and knew I had to go to hospital. My stools were like water so they put me on a steroid drip. I was in hospital for a week and they diagnosed ulcerative colitis. Finally, it hit me that I had another life–long illness.

I was discharged on oral steroids and told it would be hard because I had diabetes; the steroids would affect my blood sugar levels. I gradually reduced my steroids but in June the colitis flared up again. Same story: back onto a steroid drip and home on a high dose of oral steroids with instructions to work my way down, but the colitis flared up again. Doctors gave me the option to have Infliximab, a slow acting drip every four weeks. I had no other choice.

This worked to begin with and I went back to work. Then in September I had a really bad flare up and was in hospital for the fourth time. Because of my diabetes nothing was working. An operation and an ileostomy bag seemed the best option. Being a chef I couldn't have the operation in December, my surgeon was on holiday in January, so it would have to be February. The date was set for the 19th, my birthday!

Then I was told that I couldn't have the op as my blood sugars were too high due to the steroids. I felt so down that I just wanted to give up. My new date was 29 March 2016. My op lasted four hours and I was in hospital for two weeks; it was hard but I knew I could do it. I had such an amazing team at Peterborough Hospital which helped me through. I can't thank them enough.

Since then I have never looked back. Having this bag is the best thing that's happened to me. Yes, it's not nice but I couldn't live with how I was before. Back to working 60 hours a week cooking in a busy kitchen.

Hope my story helps. Just never give up.

Steven Melton

Dear Editor

Interesting reading your wonderful *Tidings* and the travels of Len Faulkner. From only personal experience I find that ladies have the most confidence to travel and swim and certainly not worry about having a stoma and a bag.

Personally, I am not against folk knowing, privately, that I could have to make a dash to the toilet or need a stop on a tour, but it is seldom required and certainly only the tour guide needs to know. O.K. there have been emergencies like my bag breaking loose on Lake Galilee and a 'surge' of movement in Morocco but you overcome such things and the less fuss the better.

Leakage in general is now nearly a thing of the past with the realization that a drainable bag makes life much more normal. With a hernia, the light convex bags have solved my problems and added to my confidence.

My colostomy is not going to stop me doing anything I want to do. I have been swimming in the Red Sea and twice in the Dead Sea. I am a performer and wear neat clothes and bright colours and it's great when my close friends completely forget that I am any different from them.

I travelled to Lithuania recently with just hand baggage and had no problems carrying medical necessities. You DO have to plan ahead but there is a whole world out there to explore. Go for it. Life doesn't stop with a colostomy so why should you.

PO

Dear Editor

In the Spring 2013 edition of *Tidings* you published my story about how my life had changed the day I discovered that I had bowel cancer. Then in the Winter edition 2017, you published my story about how I had coped over the last five years.

On 19 December I had my last hospital appointment at Lewisham Hospital. I was

Readers' writes

told that all my final tests were OK and that I would be discharged having completed my five years in remission. This was my best Christmas present ever.

You read and hear a lot about the failings of the NHS, but I cannot fault the staff at Lewisham Hospital who have looked after me over the last five years.

Regards
Len Faulkner

Dear Editor

I had a colostomy two years ago, at the age of 61. When I recovered from my surgery I started to look for high waisted trousers. I found the suppliers on the **Colostomy Association** list seemed to cater for the fuller figure i.e. above 34" waist, not skinny 32" like me!

I eventually found that Craghoppers Kiwi outdoor trousers were very suitable. I now have two summer pairs and two winter pairs (with a warm lining). However, formal trousers are still a problem.

Best wishes
John Niven

Dear Editor

During my first year of wearing a colostomy bag, some ten years ago, I experienced the leakages described by MP in issue 44 of *Tidings*. At times, I was in despair as there was no warning as to when the bag would lift and the tell–tale aroma arise.

After much trial and error, I decided to keep the filter cover on at all times and to introduce air by blowing into it when affixing the bag. I also make sure there is a good seal immediately surrounding the stoma. Since doing that, I have never looked back, had no daytime leaks and just a few at night when something I had eaten made me loose.

Kind regards
Joyce

Dear Editor

I have been hoping that somebody somewhere will have some unused and unwanted TWO piece Coloplast plugs (known as the Assura or Conseal plug).I have the one piece plug but the two piece worked much better for me. I have the actual plugs (ref 1235) but I don't have the Conseal baseplates (ref 1200) to go with them.

It would make my day if some *Tidings* reader found some at the back of their wardrobe! I will gladly pay for postage and make a donation to the **Colostomy Association** on their behalf.

Kind regards
Ros

Please Note: 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

Dear Editor

Thank you for *Tidings*, which I have been reading with great interest for many years, having had my colostomy in 1998.

In the Winter 2017 issue, your correspondent SP requested advice concerning the removal of hairs around the stoma site. My own stoma site is very hairy, and I too found it difficult to get flanges to adhere. So, I tried a number of hair removal methods. First, I tried a hair removal cream, and all I can say is DON'T – the pain when the cream got onto the stoma was excruciating. Next I tried careful shaving. I found that this method worked in the short term, but when the hairs re–grew they were very stubbly, again making flange adherence difficult. Finally, I tried individually plucking the hairs, a few at a time, and I have found this to be the best method for me. Hairs do eventually reappear, but I only need to go plucking a couple of times a year. After plucking, I apply an alcohol–based stoma skin lotion to avoid any soreness and to prevent skin problems. Hope this helps your correspondent.

Best regards
DC

Dear Editor

To follow on from SP's letter in the last issue, I also shave around my stoma. Hair refuses to grow on the top of my head but grows in profusion on the rest of my body!

I find that the BIC 1 disposable razor is ideal. I can get about three to four uses from one then throw it away. They can be bought from Amazon in packets of 5 or 20 at a good price.

Regards
DS

Moved by something you've read in this issue of *Tidings* magazine? Do you have an issue that needs addressing or an experience you'd like to share with our readers?

The **Colostomy Association** regularly receives correspondence from supporters across the UK who would like to share their thoughts, experiences and personal tips.

All letters and e–mails are considered by the editorial team who decide which will be published in *Tidings* magazine.

If you'd like to send a letter to be considered for inclusion on the Readers' Writes page please send an e–mail to:

editor@colostomyassociation.org.uk

or a letter to:

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

Please make sure you include your full name and address and telephone number so we can contact you. Additionally, please mention whether the **Colostomy Association** has permission to publish your letter and whether you would like us to use your full name or just your first name. In the interests of confidentiality, if you do not give us permission to use your name we will publish only your initials.

Local Support group Events

Solent Ostomates Support

10th Anniversary Celebration
Saturday 22 April 11am – 3pm

The event will be opened by the Mayor of Eastleigh

Manufacturers of stoma care products will be present and refreshments will be available,

Come and join us at:
Kings Community Church
Upper Northam Road
Hedge End
Southampton SO30 4BB

The Solent Ostomates Support Group (S.O.S.) was founded in 2007 by **Colostomy Association** volunteer, Carole Summer. It began with only six members. Today the group is run by a committee chaired by Jayne Lewis. On average thirty members attend meetings held at Kings Community Church at 2pm on the last Wednesday of the month (except August and December). A representative from a stoma supply company is present at most meetings and sometimes a stoma nurse. A barbeque is held in the summer and an annual dinner in January.

For more information:
Tel **07527 707 069**

Does your local support group have a special event in the autumn or winter of 2017?

Our summer issue will go out in early July so if you have:

- an interesting speaker attending your meeting;
- an outing you'd like local ostomates to know about;

or any other special event:

send an e–mail to

editor@colostomyassociation.org.uk

or a letter to:

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

SASH
Freephone
0800 389 3111

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. HB102

Ref. No. SR103 "The ring of confidence"

CUSTOM MADE BELTS ARE AVAILABLE ON PRESCRIPTION
No fittings required. Belts are processed and mailed within two working days

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.

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

Ref. No. SS104

Support Groups *are places where people can share personal stories, express emotions, and be heard in an atmosphere of acceptance, understanding and encouragement.*

Hexham Stoma Support Group

There has not been a stoma support group in Hexham for a long time but our excellent and very caring stoma nurse, Christine Watson, has always wanted to start one. When she helped me with my stoma four and a half years ago, we both decided that it was time we put our heads together to form a very necessary group in this area.

Christine suggested that I contact the **Colostomy Association** for help and advice on setting up and running a group. I then attended a short course and received wonderful teaching, training and advice from Helen Bracey and Evelyn Cowell. Many, many thanks to you all.

Our first meeting was held in November 2013 in the Education Department of Hexham Hospital, and since then all our meetings have been held there. On average between 12 and 14 people attend. We meet once a month and have a regular programme: one month we invite a representative from a manufacturing company, the next month we will have a speaker. A pharmacist, a physiotherapist, a dietitian, an audiologist and many other people have given us very interesting talks. The following month we will have what we call an open meeting with, hopefully, a stoma nurse present. This three–month cycle means that we all know in advance what we will be doing at each meeting.

Our open meetings are very important to us, because it gives us the opportunity to talk about any personal problems that we encounter. Someone invariably has a solution to help or a suggestion to make. The group allows us the opportunity to air our worries in complete understanding and complete privacy.

One of our members had her stoma 23 years ago. After the operation, she did not see a doctor or a stoma nurse until she came to one of our meetings. Another member has had good help and advice from both doctors and nurses. However, she still finds our open meetings invaluable.

A representative from ConvaTec very kindly organised a trip for us to visit the Amcare distribution centre in Sunderland to see how orders are received and dealt with, all very interesting. Our last meeting of the year is our Christmas dinner which is very much enjoyed by all.

Thank you again for all the help you gave us when we started to set up our group three years ago.

Judy Yeoman
Group organiser

For further information:
Tel: **01434 681 972**.

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cass@colostomyassociation.org.uk

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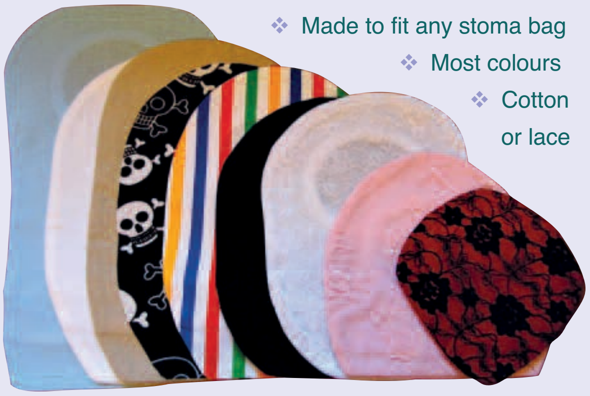
www.colostomyassociation.org.uk



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Thank you for your support

Regular donation

Every donation makes a difference – your support can help change lives across the UK. With your help, thousands of adults and children living with a stoma will be able to receive invaluable support through the Colostomy Association.

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 ongoing 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 cancel any previous standing order in favour of this beneficiary).
***Please leave one month's notice to ensure donation processes through banking system and**
state your donation amount in words:
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:** / / 2017

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 want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: **Date:** / / 2017

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

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

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

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

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Thank you for your support

Single donation

Every donation makes a difference – your support can help change lives across the UK. With your help, thousands of adults and children living with a stoma will be able to receive invaluable support through the Colostomy Association.

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 ☐
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)

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 Colostomy Association – with your help – we can change lives!

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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 want to Gift Aid my donation and any donations I make in the future or have made in the past four years. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Thank you for your gift

Signature: **Date:** / / 2017

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

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

National Support Organisations

Support organisations for people with stomas and other bowel and bladder diversions

IA The Ileostomy and Internal Pouch Support Group
www.iasupport.org
Telephone 0800 0184 724
e–mail info@iasupport.org

UA Urostomy Association
www.urostomyassociation.org.uk
Telephone 01889 563191
e–mail
secretary@urostomyassociation.org.uk

Mitrofanoff Support
www.mitrofanoffsupport.org.uk
Telephone 01202 674336
e–mail info@mitrofanoffsupport.org.uk

IOA International Ostomy Association
www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)
via the **Colostomy Association** Helpline
0800 328 4257
e–mail cass@colostomyassociation.org.uk

Breakaway Foundation
www.breakawayfoundation.org.uk
Telephone 01283 240253
e–mail info@breakawayfoundation.org.uk

Support Organisations for associated medical conditions

Beating Bowel Cancer UK
www.beatingbowelcancer.org
Telephone 020 8973 0000

Bowel Cancer UK
www.bowelcanceruk.org.uk
Telephone 020 7940 1760
e–mail admin@bowelcanceruk.org.uk

Macmillan Cancer Support
www.macmillan.org.uk
Telephone 0808 808 00 00
Monday–Friday, 9am–8pm

Crohn's and Colitis UK
www.crohnsandcolitis.org.uk
Telephone 0300 222 5700
e–mail info@crohnsandcolitis.org.uk

The IBS Network
www.theibsnetwork.org
Telephone 0114 272 3253
e–mail info@theibsnetwork.org

Colostomy Association volunteer, Mike, manning the stand at an Open Day in Shropshire

Stoma Care Open Days

Attending a stoma care Open Day is an opportunity to find out about all the ostomy products and services available. It is also a chance to meet other people who have a stoma and visit the Colostomy Association, IA and Urostomy Association stands.

Colostomy Association volunteers, who all have stomas themselves, attend stoma care Open Days all over the country whenever possible. Do come along, call at our stand and have a chat.

Open Days that we are aware of at the time of going to press are listed below. An up to date list, including events in your area, can be viewed on the **Colostomy Association** website.

Royal United Hospital Open Day
Bath Racecourse & Conference Centre
Lansdown, Bath BA1 9BU
25 April 2017 10am – 2.30pm
Stoma Therapy Secretary 01225 824 056

Countess of Chester Hospital Open Day
The Civic Hall, Ellesmere Port
Cheshire CH65 0AZ
26 April 2017 1pm – 5.00pm
Stoma Care Department 01244 366 170

Information about forthcoming Open Days in your area may be sent to you by the **Colostomy Association**. These invitations are sent by our volunteers, who stick an address label on the envelope. The company involved provides the stamps or pays the cost of postage and pays an administration cost which helps to boost **Colostomy Association** funds. Your personal details are never disclosed.

Stoma Care Appliance Exhibition and Coffee Afternoon
Rhondda Suite Conservatory
Rhondda Heritage Park, Trehafod CF37 2NP
28 April 2017 1.30 – 3.30pm
Royal Glamorgan Hospital Stoma Care Team
01443 443 053

West Suffolk Hospital Ostomy Open Day
The Read Room at Tattersalls
Newmarket, Suffolk CB8 9AY
11 May 2017
Stoma Care Team 01284 712 697

Bristol Ostomy Self Support Group Open Day
The Radison Blu Hotel
Broad Quay, Bristol BS1 4BY
3 June 2017 10am – 1pm
Christina Hammond 07773 869 503
chris@ostomy.org.uk

Hillingdon Hospital Open Day
Education Centre, Hillingdon Hospital
Uxbridge, Middlesex UB8 3NN
24 June 2017 9.30am – 11.30am
Andrea Thomas 01895 279 391

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

Channel Islands

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

Jersey
Jersey Ostomy Society
Fiona Le Ber: 0153 4445 076 or jerseyostomysociety@gmail.com

England

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
High Wycombe Stoma Support Group
Wendy Hetherington: 07717 335 884

Milton Keynes Stoma Association
Thia Cooper 01908 679 295 / mksa.sec@gmail.com

You Are Not Alone Stoma Support Group
Carla 0784 6354 918

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

Peterborough Stoma Support Group – Ostomistics
Alan Wright 0135 465 3290 / 0783 666 1102
http://www.ostomistics.org/

Cheshire
Countess of Chester Hospital Stoma Support Group
Stoma Nurses 0124 436 6170

East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071

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

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 or email: pgill82171@aol.com

Darlington Support Group
Sister Jacqui Atkinson: 01325 743005

Durham Stoma Support Group
Katie: 0191 3332184

Cornwall
Cornwall & Plymouth Bowel Cancer Support Group
The Chairperson: 01726 828 419 or The Secretary: 01872 241 145, cbcsginfo@gmail.com or website www.cornw

Cornwall Ostomy Support
Ken Jones: 01872 863 106 or www.cornwallostomysupport.org.uk

Lanhydrock Ostomist Support Group
Mandy Rowe: 01726 832 642
E: murphy.rowe781@btopenworld.com;
Henry Kendall: 01208 850 986
E: h.kendall380@btinternet.com or Anna Rennie: E:anna@thesilverocean.com

Cumbria
Grange Cancer Support Drop in
Marie: 0153 953 3279

Stoma Support Groups in North Cumbria
Stoma Care Nurses 01228 814 179

Derbyshire
Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

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

Mid Devon Ostomy Support Group
Janice: 07923 975 051 or 01363 776 417 or jdkelly234@gmail.com

Plymouth & District Bowel Cancer Support Group
Wendy Wilson or Keith Anderson: 07934 922 156 Facebook: Plymouth Bowel Cancer

Dorset

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

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

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

East Midlands

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

Essex

Connect
Lin Hart 0127 950 5273

Mid Essex Stoma Support Group
Paul Foulger: 0124 522 4374

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

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

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

STEPS
Jackie: 0126 845 1937 or email: stepsessex@gmail.com

Gloucestershire

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

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

Hampshire

Solent Ostomates Support Group (New Forest Branch)
Ron Lever 0238 089 3949 / rdlever@sky.com

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

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

Wessex Urology Support Group
Adrian Kuczynzki: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 0143 288 0656 or email: carolsteeleglo@gmail.com

Hertfordshire

Colonise
Anastasia 0172 776 0981

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

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 01983 559 326 or Cancer Clinical Nurse 01983 534 180

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 0782 799 7424

Dartford Ostomy Group Support (DOGS)
Tracey, John or Sue: 0794 897 4350 or dogs-uk@hotmail.com

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

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

Maidstone Stoma Support Group
Judy/Kirsty: 0162 222 4305

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

Sheppey Ostomy Group Support (SOGS)
Shelley 07714 734 194 / sogs-uk@hotmail.com

SWAN Stoma Support Group
Heather: 0771 144 5312

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

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

Phoenix Bowel Cancer Support Group
Sandra and Nicola 01253 291919, www.phoenixgroupbvh.com or eMail: phoenixbvh@aol.com

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/Rachel: 0147 646 4822

Sutton Bridge and Long Sutton Ostomy Group
0140 635 1617

London

Bowel Cancer Newham
Scyana: 0208 553 5366 scyana@tiscali.co.uk

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

Homerton Hospital Bowel & Stoma Support Group
Angela Davy: 0208 510 5318 or 0208 510 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: 0173 755 3134 or John Amos: 020 8668 0796

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

Norfolk

Kings Lynn Ostomy Friendship Support Group
For more info please call 01553 775 698 / 01553 674 962 / 01553 768 271

STARS (STоma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733448 sylvia.ruth.hughes@gmail.com

Northamptonshire

Northampton Ostomy Support Group
Ian: 0780 1316 403 (evenings) or Trish 0770 3188 386

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 0771 447 9320

Hexham Ostomy Group
Judith on 0796 792 7286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

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

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

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

Oxfordshire

Oxfordshire Ostomy Fellowship
Pat Longworth: 0123 552 4163

Shropshire

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

Staffordshire

Outlook
Moira Hammond 0778 840 2195

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663363

James Pagett Ostomy Support Group (Evening Meeting)
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

Normandy Colostomy Support Group
Marina Harkins: 01483 233 126 or 07852 554 049 or Jackie Sanders: jackie-sanders@hotmail.co.uk or 07815603742. Website: http://www.normandystomagroup.wordpress.com/

Stoma Support Group
Robin Young: 01428 723 255

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

Tyne & Wear

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

NHS Molineaux Centre
John Burchell 0191 265 1047

Royal Victoria Infirmary Support Group
John Burchell 0191 265 1047

Warwickshire

Warwickshire Stoma Support Group
nuneatonstoma@aol.com

West Midlands

Coventry Stoma Support
Martin: 0794 738 5643

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

Yorkshire

Acorn Ostomy Support Group
Michelle: 0758 069 3155 (After 6:00pm)

Airedale Stoma Support
Sue Hall: 0153 564 6373

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

Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses – Judith Smith and Mary Hugil

Leeds Bowel Cancer Support Group
Lynda Castle (Colorectal Nurse Specialist) 0113 206 5535

Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388

The Hull and East Riding Colostomy Support Group
Pete Smith: 0798 956 5335 or Pete Rennard: 0793 951 8642 / 0148 279 3966 or Rosanna Grimsby:
0148 280 1575. www.hercosg.org.uk

Northern Ireland

Co. Antrim

Colostomy Association Volunteers Northern Ireland
Chris Wright: 0772 071 7771

Mater Hospital
Karen Boyd - Stoma Nurse:
0289 074 1211 Ext 2329

Royal Victoria Hospital – Belfast
Sarah Haughey/Audrey Steele:
0289 024 0503 Ext 3483

Co. Armagh

Craigavon Area Hospital
Clare Young/Lynn Berry/Janice Garvie
0283 861 2721

Daisy Hill Hospital Support Group
Bernie Trainor: 0283 083 5000 Ext 2222

Co. Down

North Down Stoma Support Group
Adrian Ewing on 0785 074 1511

Ulster Hospital
Hazel/Martina: 0289 055 0498

Londonderry

Causeway Support Group
Mary Kane: 0287 034 6264

Republic of Ireland

Co. Mayo

Mayo Stoma Support
Marion Martyn: 094 902 1733

Dublin

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

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: Morag Sinclair
0141 779 1322 or Jackie McChesney
01505 324 052

Moray

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

Scottish Borders

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
bridgend.ostomy@gmail.com

Carmarthenshire

Support Group
Iris Williams: Iris.Williams@wales.nhs.uk

Conwy

North Wales Ostomy Support Group
Hazel: 07976 817 246 or Lesley:
07828 837 325

Flintshire

Bag For Life Stoma Support Group In.It.Together
Faye Jones 0785 275 0772

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 Suport Group
Colorectal Nurse Team on
0168 572 8205

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield 0143 776 0701

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


Ready to get on your bike?
Coming soon...
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colostomy association
Helping ostomates since 1967


Tube Belt