

# Tidings

Dedicated to Colostomates their Families and their Carers



**Cover story...**  
**Bob's travels with a bag**

**Feature**  
**Big journeys begin**  
**with small steps**

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

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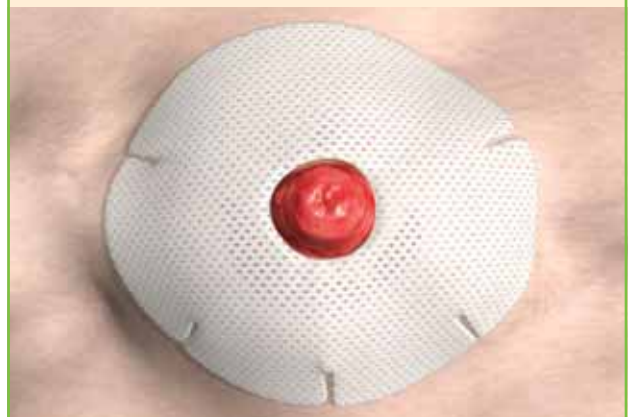


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welcome to **SPRING****In response to an interesting story in the Winter Issue of Tidings****Dear Editor,**

Your editorial page in the winter issue No.28 caught my attention! An Uncle of my late father travelled from Northern Ireland down to Cobb to board 'Titanic' on 11th April, 1912 – BUT he was late in getting there and missed his place on board! However, undeterred, he later on emigrated to Australia, sold Singer sewing machines for a living and then opened a garage business. His surname was 'DONAGHEY' and I believe that the garage business still exists today.

**With best wishes,  
A.U**

**Jane replies:**

Thank you for your letter it just goes to show that we are all connected one way or another!

**Congratulations to Lillie...what a star!**

Lillie aged 10 wanted to do something to help her Grandad (Dennis) who had a colostomy 14 months ago. With no prompting she decided to do a sponsored swim – she did 10 lengths and raised £205 from family and friends. The donation was gifted to the Colostomy Association.

**Well done! Lillie – a certificate will be on the way soon!**

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

Thank you to everyone who has written in, emailed me or telephoned! My head is spinning with all your ideas, queries, stories, letters and kind words. If I haven't responded – please accept this note as acknowledgement that I do read everything that comes into me and understand much more.

With the Olympics and Queen's Diamond Jubilee over – we turn to thinking what's next? As 2013 progresses and the unthinkable – spring – Yes! it is on its way – there is never a dull moment at CA, it is already proving to be quite a year!

If you are a regular reader of Tidings, (and I really hope you are) you will have read in the last issue of Tidings that CA is on the move! Well I'm glad to say, that the move has taken place. You can read more about it on Page 8, but not just yet!

This year the CA is having a Patient Open Day – Building on the success of previous events and celebrating our move we are holding it in Reading at the Royal Berkshire Conference Centre. CA is also launching its first Award. The Award, aptly named the 'purple iris', will recognise outstanding stoma care and exemplary service to patients, families and carers within a Stoma Care Department or Community setting. Read more inside about these two exciting ventures!

I want to tell you about another item in this issue but firstly – thank you to everyone who responded to the form 'Are you having problems with

your prescription?'. I have received over fifty responses. Many of you have taken the time to write and explain what is happening at your GP surgery, Healthcentre or Pharmacy - some very sorry tales indeed. This information helps CA gain a clear view of what is happening around the UK in these challenging times. There were many references to 'accessories' and to a lack of knowledge on the GPs part and to restriction of supplies. Now what I wanted to tell you is that, hopefully, this will change. An educational campaign is afoot to raise greater awareness of the needs of the ostomate – the term 'accessories' will be replaced by 'additional products' – read more on Page 52. There is much more to do and you can really help – it's time to stand up and be counted!

Tidings magazine extends a warm hand to YOU and to everyone involved in stoma care and to the ostomy community in its widest sense. Tidings is proud to provide a discussion platform that reflects and considers aspects surrounding the ostomate and stoma care.

**On behalf of the Editorial team enjoy this issue of Tidings. I would encourage EVERYONE to get involved with Tidings...YOU make it what it is...YOUR Magazine!**

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

**PS. For details of how to get in touch with the Editor of Tidings and the Colostomy Association – please turn to Page 6.**

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all your regulars

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**Don't forget your travel certificate this Spring...**

Contact CA office on 0118 939 1537 or [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

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

## About...the Colostomy Association

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

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

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

By telephone:  
**General Enquires:** 0118 939 1537

Stoma care queries only:  
**Freephone Helpline:** 0800 328 4257

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

Find us on FACEBOOK:



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

Visit us and register at: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

## Don't delay... Donate Online today!

There are NOW two ways to donate online...



Visit the CA website and simply click on the donate panel on the home page.



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

## Tidings is YOUR Magazine...

### Editorial Submissions:

Tidings is a quarterly publication. Your contributions to Tidings are always welcome. If you have a story, article or letter that you would like featured in the magazine we would like to hear from YOU!

If you have an idea for an article and would like to discuss this with the Editor or would like help writing your story please get in touch. We will always do our best to include your contributions in the next issue of Tidings or will hold them back for a future issue. When submitting your information don't forget to supply your name, address, phone number and e-mail address if you have one.

Please include any relevant photos or illustrations as these really help to bring YOUR magazine to life! You can send these as prints or digital images.

**Feedback...**We are always trying to improve your Magazine and welcome your feedback. Enjoy this issue of Tidings we look forward to bringing you the next edition...

### How to supply digital images:

When supplying digital images for inclusion in Tidings please try to observe some or all of the following criteria:-

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

### Advertising Enquiries:

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

### Publication:

Spring	April	2013
Summer	July	2013
Autumn	October	2013
Winter	January	2014

## EDITORIAL TEAM

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### Tidings Magazine:

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

### Disclaimer:

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

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**Dear Readers...**The Colostomy Association continues to reach out via its trustees, staff, volunteers, support services, Tidings magazine, website and increasingly through its 'closed' Facebook group – 1000 members strong...to make a difference to the 'real life' experiences of those 'living with a colostomy'. (Joining the group is easy...put Colostomy Association into your Facebook search bar, click on Group and click on 'Ask to join' where you will be met with a very warm welcome). The CA office continues its pivotal role – providing information, support and reassurance to colostomates, family members and carers. There are now 115 trained CA volunteers across the UK. All our volunteers have the skills to chat with new colostomates, attend open days, assist SCNs, listen and support callers on the helpline. In 2013 we plan to focus more on our existing volunteers rather than on further recruitment.

.....

## The CA has moved to its NEW home in central Reading... Enterprise House!

As of the 21st March 2013 the Colostomy Association moved to its new home in central Reading. CA now occupies the second floor of Enterprise House (pictured right) just a short walk away from our previous premises. It is another milestone in the charity's journey – aims and vision for its future – one that without your continuous help and financial support could have remained out of reach for some considerable time. The CA thanks everyone for their tireless efforts in making this a reality - one that we can all be proud of and say we all played a part in providing. A new home for this BIG hearted charity caring for colostomates, their families and carers.

Please see below our **NEW address** and be sure to make a note of it in your address books!

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

Please also note that our phone numbers and email and web address remain the same:-

**General Enquires:**  
0118 939 1537  
**E-mail:**  
cass@colostomyassociation.org.uk

**Freephone Helpline:**  
0800 328 4257

**Website:**  
www.colostomyassociation.org.uk



**Chairman of Trustees**  
**Monty Taylor says:** "Being able to bring everything together under one roof will allow the Colostomy Association to streamline its activities and make further use of valuable funds to support more people."

We are delighted to report that our new landlord has given us immense financial support as he has not only covered the cost of the internal refurbishment but also has also kindly donated a selection of office furniture, which is greatly appreciated!

A press release sent prior to the move to all local media in Reading and surrounding areas and to the stoma care manufacturers/suppliers

requesting help with providing new/second user office equipment, furniture or donations.

CA is delighted to announce that pledges of assistance from ConvaTec as regards office furniture have been received plus generous donations from Salts Healthcare and Dansac towards funding new office equipment – kindest thanks to all!

A list of items still required is available as a PDF file from Sue Hale - General Manager or Jane Wood - Tidings Editor/PR & Communications Manager. To obtain a copy of the list, please telephone: 0118 939 1537 or e-mail [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)

The new offices will greatly enhance our services by allowing us to provide:

- A quiet office space for trained volunteers/helpline's to take helpline calls.
- Desk space for more admin volunteers to help out in the office.
- Large storage area for CA literature and Tidings Magazine and despatch facilities.
- Meeting room for volunteer training workshops, trustee and staff meetings and other activities.
- Reception area and displays for visitors.
- Ostomy friendly toilet facilities.
- Improved working environment for staff.

**Please note:** A Royal Mail postal redirection is in place so all letters and donations sent to the previous address by post will still arrive safely at our new offices.



## Have we got your details right?



We had an excellent response to our **Reader Request Form** for updated information from readers and supporters inserted into the Winter issue of Tidings. Interestingly, 40% of those who returned their forms also included a donation, which was a welcome boost and a wonderful start to 2013!

A regular donation via standing order is preferred (where possible) as on going giving year on year offers the Colostomy Association security. It also

means that the CA is able to plan ahead and guarantees the provision of it's on going 24 hour services.

If you have not already returned the form, another is included with this issue so please help us ensure our database is up-to-date and return your form soon.

**Kind thanks to everyone! No matter what the size...every donation is put towards our good works and is much appreciated!**

## The CA is proud to launch its NEW Award recognising the professional practice and quality of stoma care provided by Stoma Care Departments in hospitals across the UK...

**Do you know of a specific Stoma Care Department (SCD) that you feel deserves our NEW Award?**

Perhaps your local SCNs, their service and department has really gone out of its way to support YOU on your patient pathway back to good health. Or perhaps the stoma care department offered your partner,

family members or carer extra support whilst you were poorly or maybe they have been instrumental in organising extra activities or open days for some years above and beyond their job remit.

The Colostomy Association would like to officially recognise those SCDs who are providing outstanding patient care and extra support. Further information and a nomination form can be found overleaf on page 10 – the closing deadline is 28th June 2013.

## New Support Groups...

We're always pleased and excited to hear from people wishing to set up a **NEW Support Group** as we get many requests from patients for support nearer to home. If you are thinking about setting up a group but haven't quite decided yet. CA can support you and help you set up a group...how? The CA will send out a publicity flyer to its supporters in specific geographical areas. The newest support group is starting up in Berwick Upon Tweed on 18 April 2013 and others are in the pipeline. For further details of groups in your area, please refer to our website: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk) or the support groups listing at the back of this issue of Tidings.

### Photo ID Card...

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

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

Alternatively, the form is downloadable from our website. Please allow 10-14 days for delivery.

### National Key Scheme (NKS) Radar Key and optional Photo ID card...

To obtain a **key or an ID card** please **complete the form and declaration**. Make your **cheque payable to the Colostomy Association**. Return all required items to: **Enterprise House, 95 London Street, Reading, Berkshire RG14QL**

(Any queries please contact the CA office on: 0118 939 1537)

### 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.

Signature of self or carer: \_\_\_\_\_

Date: / /2013

The misuse of any public or private conveniences constitutes an offence. Please note that there are penalties for making false declarations. Key holders' details are stored in accordance with the Data Protection Act and may be randomly checked by the Association



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



## Colostomy Association 'Purple Iris' Award...

for outstanding stoma care & exemplary service to patients, families and carers within a Stoma Care Department or Community setting

This NEW Award from the Colostomy Association recognises and celebrates the clinical and professional care and outstanding contribution beyond the nursing remit given by a team/department in a hospital or community setting directly involved with provision of high quality stoma care to patients. Nominations are invited from patients, family members, carers, stoma support groups, volunteers, sister charities, other healthcare professionals, associated healthcare organisations and industry.

### Award Nomination Form

I would like to nominate the \_\_\_\_\_ stoma care unit/department at the \_\_\_\_\_ hospital or community setting \_\_\_\_\_ as an extremely well deserving recipient.

This unit/department/community setting clearly demonstrates excellent clinical skills, expertise and compassionate care which exemplifies the kind of nursing that patients, their families, and carers recognise as an outstanding. The unit/department/community setting consistently meets all of the following criteria:

- **Demonstrates a caring and empathic attitude in all situations**
- **Focuses on meeting patient, partners, family members, carers needs**
- **Excellent educators of patients, partners, family members, carers**
- **Uses innovative ideas to deliver outstanding patient care and support – beyond the nursing remit**
- **Demonstrates professionalism in the work environment**
- **Collaborates with other agencies to meet patient, partners, family members, carers needs**

Please describe a situation involving the unit/department you are nominating that clearly demonstrates and meets the criteria of the Award (100-150 words):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Please continue on a separate sheet if necessary and attach to this form - many thanks

Thank you for taking the time to nominate an outstanding unit/department. Please tell us about yourself, so that we may include you in the celebration of this Award should your nominee be chosen.

Name: Mr/Mrs/Ms/Miss      Name: \_\_\_\_\_      Surname: \_\_\_\_\_

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

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

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

Telephone No: \_\_\_\_\_      Mobile No: \_\_\_\_\_      Email: \_\_\_\_\_

About You – (Please tick the appropriate box) below:-

Patient:  Partner:  Family Member:  Carer:  Stoma Support Groups:  Volunteer:

Sister Charity:  Other Healthcare Professional:  Allied Healthcare Organisation:  Industry:

Date of nomination:      /      /2013      Signed: \_\_\_\_\_

**Nominations must be received by the 28th June 2013. The Award will be presented at our Patient Open Day Event – 19/20th July 2013. Please return this Award Nomination Form to: Sue Hale – General Manager Colostomy Association Enterprise House, 95 London Street, Reading RG1 4QA.**

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





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# Pathways to a Colostomy...



**Peggy Thomas looks back on her life and her experience of diverticular disease. She recalls how she felt when she first had a stoma and tells us how she feels now, and why she has decided not to have a reversal...**

I was born in the USA in 1942, when bottle feeding, the clever new way to feed a baby, was the choice of the with-it, educated woman. From my first day I was fed on an unholy mixture of evaporated milk, water and sugar, glorified by the name of "formula". I grew up hearing stories of how I screamed for the whole of my first year. For the next nine years, I lived on a labour-saving diet of cornflakes, Coca-Cola, frozen and tinned everything. I gave up screaming and settled for whingeing. Periodically, my brother and I would be given enemas. Good children "went" every day, awkward children didn't! In 1952 we all went to live in Greece,

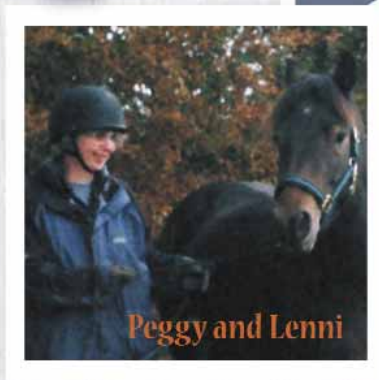
where I discovered brown bread, salad and other delights of Greek cuisine. The constipation disappeared for the next five years. I was rarely ill and by then felt abdominal pain only when I was worried or scared.

In 1957 we returned to the States and in my case, at least, to constipation. By age 16 I had haemorrhoid problems. Everybody did, I was told. It now strikes me as very odd that it never occurred to anybody that there might be a connection between diet and the state of the bowels.

At age 20 I left the States again, having married a British student.

Leaving home made it possible to pursue an interest in food and to learn how to make a soup without opening a tin and a cake without opening a packet. Delia Smith's Column in the Evening Standard was a great inspiration.

Pretty soon there were babies to enhance our lives. The years rolled by and I became a good cook. I made my own bread – wholemeal of course – grew lots on the allotment and made everything from scratch. I bought sugar-free peanut butter and brown rice. Breakfast was home-made granola and eggs from our own hens. You get the picture!



Evening Standard

By the time I was in my sixties there were five grown-up daughters and six grandchildren. We had by then lived in five different countries in eleven different houses. Following a series of strokes, my husband died in 2000.

During all this, my insides were in pretty good shape, except for the worry pain and another funny sensation which appeared in my early twenties: Fifteen minutes before going to the loo I would feel discomfort in my lower left abdomen. There was an improvement in my thirties but this feeling never completely went away. I imagined that the right angle that joins the descending to the sigmoid colon was in my case an acute angle. A creative use of the information available, you might say.

Just to make life more interesting, I came out eventually as a gay woman. I was lucky to meet my partner, Catherine, pretty quickly. We moved

from London to Wiltshire, acquired a small-holding and I bought a young foal called Lenni. I was active and well: the only fly in the ointment was the pain brought on by worry, which had lately become worse. At 61, I had become a nervous rider. Every morning when I was due to ride, there would be pain which always disappeared the moment I stepped outside. On days when I wasn't due to ride, there was no pain. Since early childhood, all the pain I'd had was either negligible or clearly psychosomatic. It never occurred to me to mention it to a doctor.

By December 2007 I was running out of steam. I sold Lenni and stopped cycling. Everything seemed like a lot of effort, but I presumed this was normal for the mid-sixties. During the following summer the morning bellyache returned. The difference was that now it could be on a day when nothing was happening. A hot-water

bottle would stop the pain. By October the hot-water bottle didn't work until mid-morning. By then Catherine insisted I go to the doctor. 'What's the point?' I asked. 'He'll only say it's IBS.' I went anyway and was relieved and delighted when he told me it was indeed IBS. So I was right – it was nothing serious. The next day I took the new pink pills 20 minutes before each meal, ate well and felt really good. There was no pain. Such is the power of the placebo. It lasted 24 hours.

During the next month there were more visits. Diverticular disease was mentioned. I had never heard of it and was outraged to be told it was caused by a low-fibre diet. I was losing weight, going to the loo six to eight times a day, sleeping a lot and feeling lousy. I asked to see a specialist and shortly before Christmas was being seen by a surgeon who made a note of a palpable sigmoid →



lump, expressed concern about my weight and arranged for a colonoscopy.

After the colonoscopy the next step was a scan. A few days later the GP rang to say the picture from the scan looked more like cancer than diverticular disease. My first thought had been that I mustn't tell the children, but of course the "children" now aged 32 to 43 did need to know. The first three took it calmly, the fourth was a bit shaken and the youngest said coolly, 'That's what I've thought all along.'

We're now in the second half of January. I was in bed most of time: sleeping, crying, resting my hand on the lump – the size of a sausage – and watching my bones become more and more prominent. I felt like a snowman on a warm day. How could somebody so healthy be so sick? At least the diarrhoea had stopped, but only because I wasn't eating anything.

Catherine looked up diverticular disease on the computer and it said you almost always wind up with a stoma. She turned it off as soon as we saw that, but I didn't care. "Almost always" meant everybody else but not me. A few days later I started feeling rather cold. Soon I was shaking violently. I was glad the shaking continued long enough for the ambulance men to see it. In hospital I met many doctors and zillions of eager students, a nurse drew a circle on my belly 'in case you need a stoma'. The op lasted from 11pm to 2am. Infected material had wrapped itself around a ureter and attached itself to the bladder. That explained the pinching feeling I'd felt the previous week.

When the nurse woke me up I asked if I had a stoma and when she said yes all I could think was 'Now what?' The surgeon appeared, still wearing her green shower cap, and told me the op had gone well and she was pretty sure it wasn't cancer. I stared at her and said

nothing. She must have been thinking I didn't realise how lucky I was, but the news of a stoma had been more than enough.

Back in the ward, I had a look at my devastated belly. The wound was held together by some 30 metal staples and dressed with no more than a strip of sellotape. I was amazed by the stoma because it was so small. I had been expecting a large hole, big enough to drop a plum into. What I saw was like the end of a pink balloon tied with string. As I lay there feeling the curious mixture of elation and dread that can follow a trauma, suddenly the crack of a starting pistol echoed around the ward and I realised it was wind from my stoma that was responsible.

When Catherine appeared later that day, I pulled off the sheet, keen to show off the trophies. 'What's that?' A big beige thing covered the stoma. That's the bag she told me. So I had slept through the stoma nurse's first visit. My education began with her second visit. She picked up a new bag and proceeded to trim it to fit, ignoring my anguished howl: 'I don't want the bloody thing!' When I told her about the starting pistol, she said the noise would diminish and so it has. Now it's usually like a wistful sigh, not audible from the other side of the room.

By the third day there was no more elation. My weight, usually on the thin side of normal, had fallen by two stone. I was peeing and pooing into bags, my arms and hands were full of needles, my legs were skeletal and I couldn't walk. My 67 years felt like 97. I'd been reduced to infancy and propelled into old age at a single stroke. I spent most of the day in tears. The next day a wonderful auxiliary helped me take a shower and, after that, things steadily improved. By day 10 the catheter and staples had been removed and I had been persuaded by the physio to walk without a stick. The day after that I was home.

I can't imagine anybody finds getting used to a stoma easy, but by six months I felt pretty confident: I'd had a successful stay in a hotel in Weymouth, I could walk five miles and had gained a stone. It's just as well I was starting to feel fit, because in June, Catherine had a new aortic valve fitted. At least we'd had the sense to space our crises so we could nurse each other.

One of the first things the stoma nurse said to me was: 'You don't have to have a reversal!' I thought she was mad at the time and duly booked myself in for October. After five cancellations I was promised on a stack of bibles that the sixth date, end of January, would definitely go ahead. By then, the two youngest daughters were due to give birth in the spring. I thought I wouldn't be well enough to help if I had the ops so late, so I decided to ask for January of the following year.

As I was in for the long haul, I finally joined the CA. Tidings and the leaflets about reversals were helpful. One comment in particular stuck in my mind. A woman who had a reversal said she was delighted with it and only experienced urgency once a fortnight. One person's idea of acceptable is another's nightmare. Having experienced urgency before, when I was more or less normal, I decided Hector, as he is known, was here to stay. I felt more comfortable and secure with him than I ever had before. Why jeopardize that with another op and an uncertain outcome? The babies were born and I was glad to be able to help. Now four years on it still feels strange to worry without being in pain. Oh well, it just goes to show you can get used to anything. ♥

**Peggy Thomas**

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Mini  Standard  Maxi

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

**Donations**  
When sending your donation/s please mark your letter/cheque with Tidings Issue 29....  
Thank you!



Mike Lucas pictured with his wife Daphne

Regular readers of Tidings may recall an article by Mike in the autumn issue 2010, in which he relates how his colostomy was formed in 2007 following emergency surgery for diverticulitis. Then he discovered the local support group and CA and says what a difference that made. He received so much help from other ostomates and from reading Tidings magazine that he decided to make CA and his local support group two of his nominated charities during his year of office. He also invited CA trustees, Duncan Wells and Rosemary Brierley, to speak at his Rotary club, which helped the club members to understand more about these charities.

the friendly spirit he had felt among businesspeople in the small town where he had grown up. The name 'Rotary' was derived from the early practice of rotating meetings among member's offices.

**Mission:** The main objective of Rotary is service -- in the community, in the workplace, and throughout the world. Rotarians build goodwill and peace, provide humanitarian service, and encourage high ethical standards in all vocations. The Rotary motto is 'Service Above Self.'

**Membership:** Rotarians are professional men and women who work as volunteers to improve the quality of life in their home and world community. Club membership represents a cross-section of local business and professional leaders. The world's Rotary clubs meet weekly and are non-political, non-religious and open to all cultures, races, and creeds.

The money was collected by Rotary members shaking tins for many hours outside local shops, and going around the village with Santa's sleigh just before Christmas.



**About Rotary...**

**Rotary Facts:** The world's first service club was the Rotary Club of Chicago, Illinois, USA. The club was formed 23 February 1905 by lawyer Paul P. Harris and three friends -- a merchant, a coal dealer, and a mining engineer. Harris wished to recapture

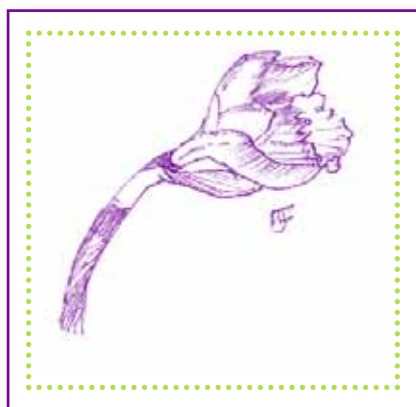
**Rotary Club of Wollaton Park... District 1220**

Mike Lucas, President of Wollaton Park Rotary Club, presented £1,000 to the Colostomy Association and a further £1,000 to his local support group at the January meeting of the Queens Medical Centre Nottingham – Colostomy, Ileostomy and Urostomy Support Group on whose committee Mike sits.

**Bletchingly Golf Club...nominates CA charity for 2012**

Last year I nominated the Colostomy Association as my charity for the year. I have had a colostomy for the past twenty years and have been helped and supported by your Association throughout this period. I am delighted to be able to donate the monies raised £305.10 to such a worthy cause.

A.P



**Dear CA, Spring Daff...**

Please accept my donation of £15 for joining CA and for Tidings magazine.

W.F

**From Ed:** The sketch opposite came with the donation - lovely!

**In Memory...**

Mr P T Fitzgerald	£ 60.00
Mrs F Hickton	£ 176.12
Mr D Pettifer	£ 150.00

**Thank you**



## 500 Club... December 2012 Draw Winners!

Mr Hall	£1000.00
Mrs S Hatton	£ 281.00
Mrs B Brown	£ 140.50
Mr M Pimm	£ 56.20
Mr F Parr	£ 56.20
Mrs C Summer	£ 28.10
Mrs G Simmons	£ 28.10
Mr G Williams	£ 28.10
Mr A McMinn	£ 14.05
Mrs J Holness	£ 14.05
Anonymous	£ 14.05

**Note: The following winners Mrs S Hatton and Anonymous donated their draw prize back to CA – many thanks!**

## Volunteer...Martin goes Up...Up and Sky-Dives for CA!



**Martin writes...**My sky-dive went really well – what an awesome experience! It just goes to show that having a colostomy doesn't stop you doing anything – if you really want to do it! I have had a great deal of encouragement and best wishes from so many people which makes it all really worthwhile, and as an added bonus when all funds are collected the sky-dive should raise around £700. Thank you to everyone for your support! I'll be thinking up something else to help raise the CA profile and raise funds at the same time! If you want to help Martin raise even more funds visit <http://www.justgiving.com/martinrobbins-skydive>

**Dear CA...**

I am delighted to donate a single donation of £50.00. I am very grateful for the Tidings Magazine, which I have been receiving for about 8 years now, I read it cover to cover! I have had my colostomy for 10 years and really appreciate all the information that this magazine provides - many thanks.

**J.W**

**Dear Tidings,**

I am pleased to be able to send CA a donation of £50.00. My daughter organised for me to receive Tidings back in 2009. Just before my surgery I chatted to Sue Hatton – Executive Trustee. Sue recommended 'irrigation' – which gave me hope! I have been irrigating for three years now and I really appreciate those few minutes on the phone with Sue!

**C.P**

**Dear CA,  
A fantastic 80th  
Birthday Party...**

Please accept my donation of £150 in lieu of gifts to celebrate the occasion of my 80th birthday. I had bowel cancer nearly four years ago. I have been so grateful for the help and support I have received from my stoma care nurse and fellow colostomates since.

**M.L**

**Dear CA,**

Please accept a donation of £40.00 in lieu of Christmas Carols, which has been raised at my over 55's Club.

**M.M**

**Dear Tidings,**

Please accept this small donation £50.00 for the CA. I am now almost 82 years old and have had a colostomy for ten years. I was very ill but made a remarkable recovery, hence why I am sending a further donation. I enjoy reading 'Tidings'.

**L.S**

**Dear CA**

**Coffee and a chat...**

My friends and I meet every Wednesday for a coffee and a chat. I am a colostomate as is another of my friends. Please accept our donation of £15 in lieu of Christmas cards.

**P.M.T**

Thank you  
everyone  
for your kind  
donations

## CA values YOUR commitment and donations...

As a non-profit organisation and self supporting charity the CA greatly appreciates all the donations it receives! Recently, we have received several donations that when added together amounted to nearly £800.00 which would have been great!

**But here's the sad reality...**

Unfortunately the CA cannot collect the £800.00 as there were several problems...the Donation Form/s received were filled in incorrectly, unsigned on the standing order authority and/or the gift aid authority. Cheques received were also unsigned and no contact details were attached - so none of the donors could be traced.

CA politely asks everyone who is kindly proposing to send in a donation to please review their Donation Form or cheque payment carefully prior to sending in the post to CA to ensure all the information is correct, signed appropriately and marked with their contact details.

**Many thanks for your  
kind assistance**



**Stamp Albums donated!**

Several stamp albums containing some very beautiful stamps were donated to the CA – the funds raised at auction came to £480.00.

**Kind thanks go to T.M for  
thinking of the CA!**

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

# Update on stoma care products and services

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

## Na`Scent Ostomy Odour Eliminator listed on drug tariff...December 2012

**Na`Scent Ostomy Odour Eliminator** – the new standard in odour eliminator. For use in colostomy, ileostomy and urostomy pouches. Available now in the UK from Bullen Healthcare.



"It's amazing how much confidence this gives you when you are out and about and having to use

public toilet facilities, it takes the paranoia away completely as I can empty my bag and leave the bathroom odour free for others to use," Annette Keenan, Ostomate and Senior Sales Manager, Vanilla Blush.

It is not simply a deodorant it actually eliminates the odour by creating an oxygen rich environment that's kills odour causing microbes in the pouch. Na Scent can give you the freedom and peace of mind you need to confidently go about your day to day life without those worries or stresses slowing you down or feeling a burden on your daily choices.

For further information or samples call our Customer Service Team on Freephone 0800 888 501 or alternatively visit us at [www.bullens.com](http://www.bullens.com)

Size	'PIP' Code	Product Code
2oz (59mls)	376-4735	02-NOOEW5
8oz (236mls)	376-4727	9901-NOOEW5
12oz (354mls)	376-4719	0112-NOOEW5

## New Additions to the Medi Skin & Wound Care Product Range

Medicareplus is pleased to announce two new variant additions to their popular Skin and Wound Care product range.

### Medi Derma-S Sterile Medical Barrier Film Applicators

These new film impregnated foam applicator wands are in addition to the existing wipe and aerosol formats and come in 1ml and 3ml sizes. Quick, easy-to-use and fast drying, the non-sting healthcare grade formulation protects tender skin from exudates and adhesives. Medi Product Code: 61076 (1ml) and 61090 (3ml).



### Medi Gelsorb Discharge Solidifying Powder Sachets

These water soluble sachets will absorb liquid waste to form a solid gel, reducing leakages, noise and odour whilst wearing your appliance. These new 100 sachet tubs are in addition to the existing 30 box format. Only one sachet is normally required, reducing the need to empty the pouch so frequently. Samples of this product contained as insert within this publication. Medi Product Code: 61052.



## OstoMART launches a new help and advice feature on its [www.ostomart.co.uk](http://www.ostomart.co.uk) website!



The new **Ask our Nurse** section of the **OstoMART** website gives you instant access to a series of helpful information sheets entitled "What if...?". These sheets give advice on a wide variety of topics such as ballooning, colostomy diarrhoea, parastomal hernias, rectal discharge, pancaking and many more.

To view the "What if...?" fact sheets, simply click onto the **Ask our Nurse** section of the website and choose your stoma type then you can access the information sheets. You also have the option to print the information sheets as a PDF.

To view the "What if...?" information sheets online visit [www.ostomart.co.uk](http://www.ostomart.co.uk)

For more information about products and services available from OstoMART call freephone 0800 220 300 or email [enquiries@ostomart.co.uk](mailto:enquiries@ostomart.co.uk)

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From time to time, we may send you details of new products and special offers using the information you have given us. If you do not wish to benefit from this service, please tick here

## Announcement...changes to surplus stoma product donations to Hospices of Hope and S.C.A.R...

**Barbara Merron – Hospices of Hope Administrator writes...**Due to the wonderful increase of surplus stoma product donations over recent months, we have had to review the issue of capacity for both our charity shops' warehouse and our volunteers. The announcement below details where to send future surplus stoma supplies. Thank you for your support.

**If you wish to donate or learn more about Hospices of Hope contact:**

**Barbara Merron  
Hospices of Hope  
Head Office**  
11 High Street, Otford Kent  
TN14 5PG United Kingdom  
Tel: +44 (0)1959 525110  
E-mail: [office@hospicesofhope.co.uk](mailto:office@hospicesofhope.co.uk)  
Website: [www.hospicesofhope.co.uk](http://www.hospicesofhope.co.uk)

**Maggie Littlejohn – S.C.A.R. Organiser and contact writes...**  
I would like to thank EVERYONE who sent their surplus supplies to S.C.A.R. The response to our appeal has been better than we could ever have imagined! The announcement below details where to send future surplus stoma supplies – thank you.

**If you wish to learn more about S.C.A.R. contact:**

**S.C.A.R. (Stoma Care and Recovery) Support Group**  
1B Redburn Gate, Irvine,  
North Ayrshire KA12 8TH Scotland  
Rhona: Tel: 01294 557478  
Maggie: Tel: 01294 271060  
Mob: 07817736147  
E-mail: [maggie13@sky.com](mailto:maggie13@sky.com)

**Announcement:** Both of the above charities are now in **partnership** with a charity called **Ostomy Lifestyle - (Ostomy Aid)** who have offered the use of their facilities for receiving, sorting and boxing surplus stoma materials and who redistribute unused ostomy supplies around the world. If you have **surplus stoma product donations intended for either Hospices of Hope or S.C.A.R** please send them direct to:

**Ostomy Lifestyle (Ostomy Aid)**  
4 The Courtyard, Eastern Road,  
Bracknell, Berkshire RG12 2XB  
Telephone: 0118 324 0069  
Website: [www.ostomylifestyle.org](http://www.ostomylifestyle.org)



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(1800 721 721 ROI) or email us on  
[stoma.webcare@convatec.com](mailto:stoma.webcare@convatec.com)**



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# Irrigation and you...

Sue Hatton Executive Trustee writes...one of the CA volunteers – Judith Franks writes about her irrigation experiences and travels using an irrigation pump...

My Irrigation Pump was already well-travelled – USA, Peru, Israel, Spain, Italy, Crete, Cyprus, Austria, Germany, Poland, Holland and France (every 6 weeks or so) – but never in its 16 years had it been to the Far East! So when I got the opportunity to go with a friend, travelling for work, I decided at 69 it was 'now or never' for my Pump and me!

After a fair amount of preparation beforehand, my Pump behaved impeccably. Wary of the voltage difference between Japan, the USA and rest of the world – I did lots of trials with ready-charged and re-chargeable batteries at home in Norfolk. (Braun's booklet maintains the Irrimatic Pump should be kept charged permanently at the mains when not in use). I disproved that in the States, when I couldn't charge it at all, despite my adaptor, it survived all week! This trip was due to last 10 days and my Pump had never gone so long without being charged, so I tried some ready-charged batteries. They lasted 6 weeks! So, in November last year, armed with two sets (just in case), I left with just cabin luggage (including the Pump) for Japan and South Korea.

The trip was a wonderful experience – London-Paris-Tokyo-Osaka-Seoul-home – though the flights were long, especially in the back row of an enormous A380, when my seat wouldn't recline! Jet lag was not an issue, as my travel companion wouldn't let me go to bed till the appropriate local time and the weather was perfect for sightseeing – bright and sunny, though chilly. In Tokyo, left to my own devices while my friend was working, I managed to negotiate the Metro alone. I did a whole-day coach tour and spent two days in the charming company of my Free Guide, Sen – all organised in advance on-line from home. I saw shrines, temples, beautiful parks (still with their autumn colours), a traditional marriage and children in national costume, but was disappointed to see only the very grubby rear-end of a sleeping Panda in the zoo!

After four days, we took the Bullet Train to Osaka – I didn't see Mount Fuji, as it was in cloud. We only spent two days in Osaka, during which I did two more pre-arranged guided coach tours – to

Kyoto and Nara (Japan's answer to Machu Picchu). The Golden Temple in Kyoto is spectacular – just when I wanted to film the very imposing 'biggest Buddha' in Japan my camera failed! (I did manage to take 600+ photos before and after that!)

Seoul, the capital of South Korea, was a very pleasant surprise, as I didn't really know what to expect. I hadn't arranged any excursions from home, but had found out there was the equivalent of 'London Open-Topped Buses', which could be used all day for about £8. So I managed yet another Underground System and did two bus trips – I went up the North Seoul Tower, saw all five Royal Palaces/Shrines, the tiny Anglican Cathedral and the lovely 'Secret Garden' – I had to join a Chinese guided tour for this, but was lucky enough to meet a Singaporean family who spoke both English and Chinese and translated the essentials for me. (In case you'd forgotten my trusty Pump in this travelogue, it did what it was meant to in Seoul too, and anyway, I could have charged it in South Korea, as their voltage system is the same as ours!)

**Having read the account of my trip Sue Hatton suggested a series of Q&A's to clarify my references to the Pump for readers not familiar with it so here goes...**

**Tell readers about the Pump you use?**  
The Irrimatic Electric Irrigation Pump is produced by B.Braun and is designed solely to flush stomas. It is an alternative to the manual gravity systems. The Pump provides the following benefits – flushing is steady, its easy to use, gives independence from hanging and suspension devices and offers an indication of the water temperature. It looks like a square jug, and is roughly 6 inches square. It is powered from the mains or by batteries, and pumps the water through a tube, then cone into the stoma. At present, it isn't on Prescription and costs about £300.

**Why did you begin to use the Pump?**  
I began irrigating with a manual gravity system as soon as my surgeon gave me the 'go-ahead' a couple of months after my op, 17 years ago. I was still working; irrigation gave me the security I needed to get back to the blackboard with

confidence. I found the manual gravity system a little 'temperamental'! I was already spending quite a bit of time in bathrooms other than my own and it wasn't always easy to find somewhere to hang up the water-bag, so when Braun asked me to help 'pilot' the Pump, I jumped at the opportunity and have never looked back!

**When you travel, how do you transport the Pump?**

It depends on the how I'm travelling. When travel restrictions aren't an issue, it travels in an ordinary 'hold-all' deep and wide enough to hold it, together with my other stoma equipment. When travelling by air, it always travels in my hand luggage, plus stoma bags, as I couldn't bear to be separated from it. This means I often have very little space for other things, but I've had to get my priorities right and have learnt to cope.

**Have you had problems at Customs?**

Problems – no, but queries, certainly. My luggage often gets opened – though not always – even though I explain it's 'for medical purposes'. I've never had to go into more detail, but I know the essential vocabulary in a fair number of languages and always carry a covering letter from my Doctor, explaining why I need the Pump. It would be worth demonstrating its use, if only to see the faces of the Customs Officials!

**When you're abroad, do you use tap water or bottled water?**

Once again, it depends on the country. I used tap water in Japan and routinely do the same in Europe and North America. I used pre-boiled bottled water in South America and South Korea.

**What about food – can you eat everything when you're abroad?**

No! But then, I can't eat everything at home either and couldn't, even before I had less intestine than other people! I always take a 'solidifying' pill before my main meal and I am always careful when I'm out. I have to admit I ate little, other than breakfast and 'health bars' in South Korea, but the raw fish in Japan was delicious, as was everything else!

Judith Franks

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

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# Colostomy Association Bi-Annual Patient Open Day Event - July 2013

The event will be spread over two days – Friday and Saturday (to include a Gala Dinner Fundraiser for CA – Friday evening – ticket only). The extended Patient Open Day event will provide an additional opportunity for more ostomates, their families and carers to attend the event and visit exhibitors stands.

## CA Patient Open Day Event

**Date: Friday/Saturday  
19th-20th July 2013 (TBC)**

**Time: 10.00 onwards**

**Venue: Royal Berkshire  
Conference Centre  
Reading**

The Colostomy Association is very proud of its achievements to date and intends that this event brings together all those involved with stoma care - fellow ostomates, healthcare professionals, national and local support groups, manufacturers and suppliers. The event will also provide a platform for some excellent speakers - presentations on the day will reflect a positive outlook on 'living with a colostomy'.

## Proposed Event Agenda (Fri/Sat)

- Registration
- Welcome  
Talk about the CA raising awareness
- Introduction of mini workshops  
Patient story/Hernias/  
Stoma Care Overview
- Exhibitors stands will be available throughout the event and refreshments will be available on the Friday.
- Gala Dinner/Fundraiser Entertainment Friday only (Gala Dinner/Fundraiser. Ticket price: £TBC – tables of eight)

Ultimately, we hope everyone will take away great benefits from attending this event; improved knowledge of their stoma and its care, a greater awareness of stoma care products and additional products, plus an increased confidence and a sense of belonging to a charity which is there to encourage, support and reassure.

Manufactures and suppliers of stoma care products will be fully represented at this event and exhibits will be available throughout the event sited in the Windsor Lounge next door to the Princess Suite - presentation area.

The Royal Berkshire Conference Centre (RBCC) is located at the heart of Reading Football Club – perfectly located on junction 11 of the M4 motorway (<http://www.rbcc.org.uk/location.php>). There is disabled access, easy parking in front of the centre and a park and ride operates to and from the Railway station - Reading town centre to the venue.

The venue can hold 400 visitors and the evening dinner on Friday allows 200 attendees. So, why not treat yourself to a weekend away – meet new and old friends – support CA and discover more at the same time!

## The CA encourages YOU to attend! Register your interest TODAY!

Please complete this form to secure your place/s at the above event and/or Gala dinner and return by post to:-

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**Note: Updates will be posted on the CA website prior to the event please keep checking for further information visit: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)**



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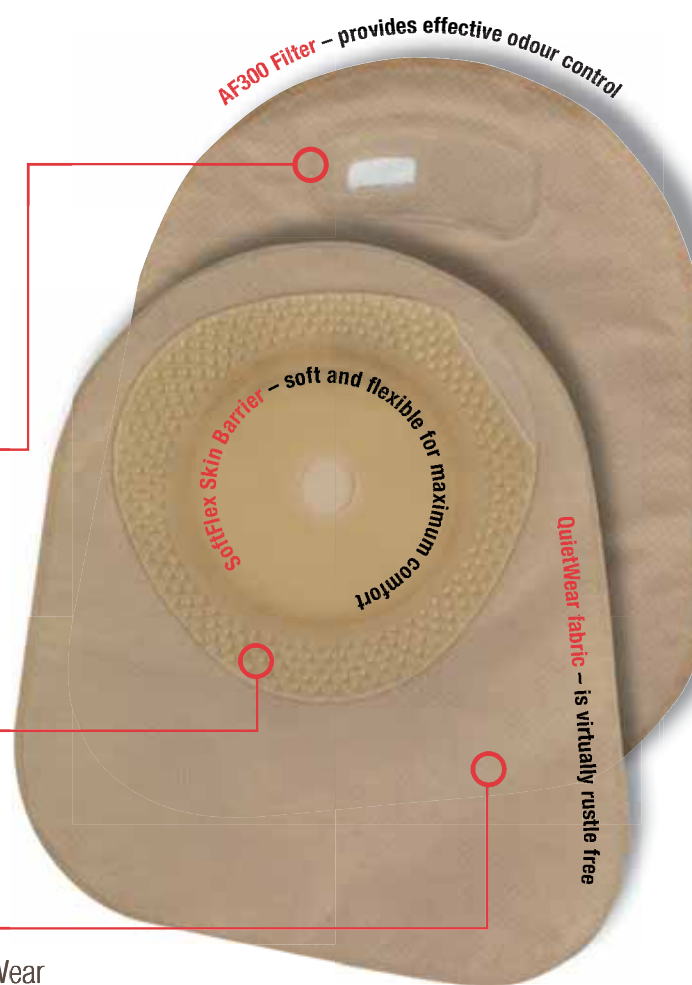
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\* In a survey of 190 ostomists who have evaluated a Hollister pouch with QuietWear material



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# My travels with a bag...

**Bob Adamson describes his holidays abroad since surgery for cancer eighteen months ago. He shares some of the entertaining incidents that have occurred, as well as the lessons he has learnt, during his travels with a stoma.**

When I was diagnosed with bowel cancer in June 2010 I thought that would be the end to my travels and I assumed I would live out my days sitting watching sunsets over the sea from the conservatory of our Cornish home: no more cruises or continental holidays. How wrong could I be? In the time between my radio and chemotherapy treatments and my radical surgery, my wife's nephew got engaged and announced the wedding would be in June 2011 in Cyprus. My wife promised them that, come what may, she would be there. She did her research into accommodation and flights and discovered travelling on her own would cost £1100 but as a couple £900 so she went ahead and saved £200 by booking for both of us. When the time came we spoke to our stoma care nurses who, as always, were 100% positive. They provided the travel certificate in eight

languages. Doctors signed me fit to travel and off we went on the early morning flight from Exeter wearing a fresh bag, and with all "my supplies" in the hand luggage. The only problem at the airport was that they required all sprays etc. in a clear plastic bag which we had to purchase from a machine for 1E or £1. I kept light on the food as that usually helps avoid problems and arrived in Paphos without any trouble. We had a wonderful week travelling in the Troodos Mountains and to lots of the sites of interest as well as surviving from 5-11pm on the wedding day without embarrassment or even attending to the bag. At that point I did leave my wife to party till the early hours while I retired to bed to rest.

It was on the journey home that I learnt my first lesson about travelling with a stoma. Our transfers from the hotel arrived late so we had less time at the airport than expected. I set off the sensors as I went through security. Before they tried to frisk me I showed them the Greek page of my travel certificate. When they took no notice I said it was medical. That was a mistake as they wanted to call a doctor and refused to let me get on

the flight. Once they understood I was not ill, but just needed a doctor to confirm my condition, we had an incident free journey home.

For our 35th wedding anniversary in October we booked a week in the Azores. In order not to cause problems by overeating we chose bed and breakfast as this had worked well in Cyprus. It was still less than a year since surgery and as I had a VRAM flap, which used some of my stomach muscles to reconstruct the area where my rectum had been removed, I was advised against carrying. So we had packed all the supplies into my wife's hand luggage, which was within size and weighed less than 10kg, our combined allowance. The check in staff at Gatwick airport refused to allow this so that my wife ended up carrying two 5kg bags through security!



The Azores lived up to our expectations; our only regret was that the ferry between islands had stopped for winter so we want to go again to visit some of the other islands. Yet again, however, I set off the security alarms at Ponta Delgada airport, even though I had duly emptied my pockets, and my coat and shoes had all gone through the scanner. Security staff tried to frisk me and then, sure they had a suspicious character, took me off for a strip search. My long suffering wife, left with the contents of my pockets, was assured by some other passengers who happened to be GPs that I would be permitted to travel, which of course I was. Combining the previous experience when leaving Cyprus I decided in future not to wait until the departure lounge to put on a fresh bag, but to change before going through security and the alarms have been much less sensitive and there is less concern on frisking.

By this time my wife was wondering why we had booked to fly to the Canaries for a cruise for her birthday in November, but we had learnt from experience. We had trouble free flights from Exeter to the Canaries and a wonderful cruise, just tipping the cabin girl extra in case she'd been affected by additional odours in the bathroom. Even the extent of overeating on the ship caused no problem so we booked a late deal cruise for December to the Caribbean.

Jamaica here we come. Nine hours in the air and no need to empty the bag, even with all inclusive food and drink. Soaking up the sunshine and swimming in the warm coral waters do a lot to improve the sense of well being. As a keen swimmer - forty lengths i.e. a kilometre per day - one of my big concerns before the colostomy was finding swimwear suitable as I had always been into Speedos and not these modern swim shorts. I bought one high-waisted pair of shorts which I now use as beach shorts as the only time I tried them in the water they caught on the bag and started to pull it away. Now I use the black lycra high-waisted unisex pants which resemble swim shorts and hug a clean bag close to



the body causing no embarrassment to anyone.

The highlight of security on the cruise was in Cuba where every other person set off the alarms because of bits of metal in their body. I said I had a new hip and when they held the scanner near my hip it beeped loudly so they laughed and said "Spare parts" and let me enter their fascinating country.

Four holidays in 2011 when I'd been told I would be dead without treatment. What could follow in 2012? First we found a good deal on an all inclusive week in Crete which went without a hitch. Then in the summer a two week Baltic cruise. Starting from Southampton, with valet parking and cases taken direct to our cabin, what could be easier? Millpond waters, 30°C in St Petersburg and spectacular sunsets make it well worth plucking up the courage to travel.

In December we flew to Hawaii. Our concerns about travelling to the USA proved unfounded as security at Los Angeles, San Francisco and Honolulu was easy. The only problem that I encountered was the new screening machine that required arms above the head, which, because of an injury, I was unable to manage. No problem: the older-style security gate was opened for me.

I was surprised to discover that, although American disabled toilets have acres of space for wheelchairs, they do not have a wash basin. This is one of my essential needs as I usually use dry wipes rather than the wet version. In future for travelling I will always carry wet wipes and hand sanitizer.

Incidentally the best disabled toilet, complete with wash facilities, was at the army museum in Waikiki.

**What next? This Spring we have booked the trip of a lifetime to Antarctica.**



### Bob's Tips for Ostomates travelling abroad

- Take supplies in your hand luggage - twice as much as you might use at home.
- On the journey always carry your CA Travel Certificate.
- Change your bag before you go through security rather than waiting until you're in the departure lounge.
- Before you go through the scanner tell them about any metal "spare parts".
- When travelling always carry wet wipes and hand sanitizer.



**If you are travelling in EEA countries, before you go check that your European Health Insurance Card is still in date, as they are only valid for five years.**

# CA FACEBOOK 'closed' group... approaches 1000 members!

I can hardly believe that since making the CA Facebook group "closed" in January of last year at a membership of 248 we are now rapidly approaching our 1000th member. I'm not sure any of us had expected it to grow so rapidly but it's fantastic!

As a closed group our members can post safe in the knowledge that their other Facebook friends who perhaps know nothing of their stoma will never see what they write on the group. It has allowed people to open up fully and discuss subjects they would have never shared on an open group. Many of us have brilliant support from our friends and family but our group provides a safe haven where members can get to know people who really understand, people who have walked a mile in their shoes.

Our members are a mixture of ostomates plus carers, parents and those who have been reversed. Between us we have a wealth of experience and everyone is quick to respond to a request for support. Often a problem seems too small to bother the stoma nurse with. Of course the stoma nurse would be happy to help, but on the FB group you can pretty much guarantee to find someone who has had the same issue. We have a "tips" file where strategies to overcome some of the common problems are logged, and a "food" file where people have noted certain foods which may cause problems to them. We don't offer medical advice but these resources allow members to see how other ostomates tackle the issues they may face.

Often new members will post an introduction, outlining their story –

many have said this in itself is very therapeutic, to write down their experience may often help them accept what has happened. Other new members prefer to stay in the background and watch. This too is absolutely fine. People may join with a specific problem and when they get advice you can almost feel their relief.

Recently a few members have shown an interest in irrigation. With the support of the group they have learnt the process with their stoma nurse and we all follow their progress, helping with little tips we've found, help us.

Different products are discussed, plus the additional products which we ostomates use and know intimately, have helped someone overcome their difficulties.

Supportwear and clothing are hot topics. Many people have body confidence issues after stoma surgery and our members offer advice on what has worked for them. Swimming is also a subject we've covered, and people have been quick to recommend swimwear or products that have given them the extra confidence they need to take the plunge. No query is too big or too small! If a member has an issue it's surprising how often someone else will say they too had been worrying about that.

A person new to Facebook may find it hard to imagine how friendships can form – but strong friendships do form – in a group like ours. Along with all the supportive discussions, there is a lot of lighthearted chat. It feels like a big family, everyone looking out for one another. Again, members can give as much or as little as they wish, but many of us

have formed long lasting friendships within the group. Personally I'm hoping for the first CA Facebook group wedding – imagine that, I could get a new hat!

Last year we had two "group meet ups" kindly sponsored by Salts Healthcare and fellow admin Duncan and I are discussing the next, so watch this space! To join the CA Facebook group just type "Colostomy Association" into the search box on Facebook. Choose the "group" and you will be taken to our main page. Just click on the "join group" tab and one of us admins will add you as soon as we spot you waiting. We do have guidelines on the group which we ask you to read before posting – common sense things really, to make the group a nice atmosphere for all members.

I'm really looking forward to adding the 1000th member to the group – perhaps it could be you! They will of course get a huge cheer, but actually all of our new members get a fantastic welcome. I am very proud of the group we've become and hope we continue to grow and support many more new members!

**Sarah Squire**  
Trustee and  
CA Facebook Admin

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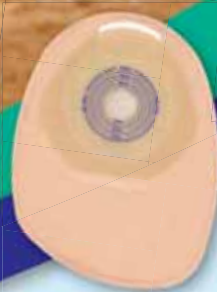
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## Through the front door...with a stoma for the first time!

**Rosemary writes...** Like most new ostomates, in the early days I felt apprehensive about venturing away from home. Would people I met be able to tell that I had a stoma? What if my stoma worked while I was out? Would I be able to cope with changing my bag in an unfamiliar toilet? I can still remember the first time I stepped over the doorstep wearing a colostomy bag; I didn't want to go out, but I had to. The skin around my stoma was getting sore. 'Come and see me tomorrow,' said my stoma care nurse. It's Saturday but I'll be at the support group.

It was too far to walk so I had to get the bus. The journey wasn't long but to me it seemed never ending; I kept feeling my left side to check everything was OK. When I got there I couldn't tell that anyone at the support group had a stoma, which reassured me that no one would be able to tell that I had one either. Several people came up to talk to me, and I shared my fears about coping while away from home. They said that at the beginning they had felt that way too and the best way was to take it easy – just one small step at a time.

The journey back on the bus was easier and seemed so much shorter. Back at home I thought well if other people can do it so can I.

I started with short walks to visit friends. With a few short visits and shopping trips behind me, I moved on to a half day and then a full day out. My confidence grew and by now I had changed my bag in a public toilet. It wasn't half as difficult as I had imagined it would be. Then came the issue of holidays. First in this country a few days staying with the family, then a week's self-catering, then hotels and finally trips abroad.

I'm not saying that my stoma has never caused problems when I am out, but, with a spare bag, wipes and RADAR key always with me, I have coped. The very few occasions when my stoma has misbehaved are far outnumbered by the times when it has been fine. I have visited places and met people I never believed would be possible when I first had my stoma almost twenty-three years ago.

**Jackie writes...** I received my colostomy through an emergency operation for cancer. I was quite ill for some time and when I finally arrived home with my stoma and colostomy supplies – I had two big worries on my mind plus a few others.

Would I smell? And, would my pouch drop off as soon as I stepped over the threshold into the world outside?

It took me a while to build up enough confidence to go through the front door and I remember very well my first outing, trying to walk past the house next door. I walked "up" the road as I didn't have enough strength to walk "down" the road and then walk back up the slope to my house.

As the days passed I gained more confidence. Every day I walked a few steps more – until the day came when I walked past the house next door and reached the corner! As my strength returned so did my desire to prove I could walk further, knowing that my pouch was secure on my body and I was sure I didn't smell. Two fears conquered. But that was just the beginning.



A car journey – be prepared I thought, this was my first long car journey and I really wanted it to go well. So, I went to it – I organised myself and my stoma supplies making up a travel kit with everything to hand! I also took a full change of clothing with me just in case.

Next came my first meal out in a restaurant. I studied the menu carefully and only ordered food that I thought would have little or no impact on the output from my stoma. I was fine!

Then came my first stay away since returning home. I booked the hotel but made sure when I spoke to reservations that I had a room with an en-suite bathroom. I felt secure and determined to enjoy myself.

Gradually, I built up my wall of confidence – brick by brick, layer upon layer – and over the years with advice, support and learned experience – I am happy to report my wall is solid – letting me live my life to the full!

**Sarah writes...**My stoma felt like having a new baby. It woke me up at night, was noisy, demanding and had completely turned my world upside down. I hardly left the house at the beginning – I was too scared. What if it made a noise, or needed changing. What if it leaked? No, I was safe indoors and that's where I stayed. But I knew this couldn't go on forever as I needed to get back to work and be able to do things with the kids but although physically I was healing well, the psychological barriers were huge.

After about four weeks I had a phone call from a good University friend who said we were going to stay with them for the weekend in Leeds, a three hour drive away. Not on your nelly I thought. But she insisted – we could go there for one night and I could stay in the house the whole time if I wished. It was an opportunity for my kids to have one nice weekend in what was turning out to be a miserable summer for us all so I agreed.

I was on edge the whole way there, worrying something would go wrong. In fact we had a lovely time and I actually started to relax. After this trip I realised I needed to push myself to make small trips out to the shops, or for a coffee and gradually build up my confidence. Someone told me early on I would be fine but I didn't believe them. In small steps though, my confidence grew and I am fine, I really

am. It seems like a mountain to climb and the steps frustratingly small but I got there. Now there's no stopping me, I work, we go on holiday and have days out with the kids. Life with my stoma is good.

**Georgina writes...**It's a well known fact that the only thing about 'fear' is fear itself, and nowhere is that truism more applicable than to the very first time a new colostomate ventures outside the security of his/her own home for the first time. Armed with all the encouragement and best wishes of hospital staff from surgeons to stoma nurses; here you are at home, having to rely on yourself plus if you're lucky, the support of close family and friends. Inevitably however, comes the day when you and you alone have to venture into the outside world all by yourself! You may well feel afraid of every real and imagined fear and that is absolutely normal.

How will you cope? Given that it is highly probable you are feeling physically weaker than previously, the combination of these physical and psychological factors may well weigh heavily on the new colostomate. Are you the same person you were before your op? You're having to wear this 'bag', will anyone notice? What if it leaks? What if it smells? How will you cope and above all whatever can you do if something untoward happens?

These are huge and very real worries to very many new colostomates, and no amount of well meant comments e.g. "don't worry, you'll be fine" will dispel those fears. After all if you were convinced of that you wouldn't be worried in the first place! So then - what can one do?

Speaking from personal experience I would strongly recommend two important steps that have for me proved highly beneficial. Firstly – be gentle with yourself; recognise the magnitude of what you have undergone and remember the old adage 'slowly, slowly catchee monkey'. You don't have to 'prove' yourself to anyone. There are no medals to be won, so take everything at your own pace - in other words it's a case of 'small steps' and that's absolutely fine.

So – here you are at the front door – can you do it? You've made sure your clean bag is securely attached; you are wearing comfortable clothes including 'sensible shoes' (high heels are best avoided at first); big breath then, walk tall and out you go! Stop for a rest if you need to, remember the rule 'small steps' and before you realise it you

will have completed that first journey, no matter how short, you've done it – be proud!!!

Surprise, surprise no-one knows you have a bag, because nothing is visible; you've done it and nothing has gone wrong. What an achievement! Now you can do it again, and again!

Secondly, please, please remember your new addition has saved your life - but don't let it 'rule' your life. As your physical strength returns to normal – and it will, grab your new life with both hands. That very first venture out of your own front door is the first day of a new and rewarding life - live it!

**Duncan writes...**When you fall out of the tree at night just after you've gone to sleep and you wake with a panic stricken jolt, well that's what it's like when you are out and about and you wonder for a fraction of a second if you have a spare bag with you. The relief in finding you do, and that you have a plastic bag for the waste is immeasurable.

Your next worry is 'where can I change?' 'Do I have my RADAR key with me?' We've all changed in the most public and open of places and no one has actually noticed but we always think they have. Much as we think everyone is looking at our rather odd shape. But answer me honestly, how many times have you noticed the shape of someone's tummy? Someone that you have met for coffee, for example - not someone naked, obviously. The answer is, never. I have no idea what the contours of my friends' tummies look like because I have never looked. And they are not looking at me either.

People don't notice nearly as much as we think. We colostomates tend to be oversensitive. I am, certainly. I've all sorts of waistcoats to disguise my shape. I have chosen a particularly fashionable brand from a nearby Huntin' an' Shootin' shop. Hugely expensive I have to add. And there I am kitted up in everything to commit genocide on the grouse population bar the gun of course and people look at me faintly oddly. Why is he wearing a jacket with padding at the shoulder for the gun and cartridge holders around the waistband? And the answer is that I have no idea but it is a barrier between me and the rest of the world and it gives me confidence!



## I have never climbed Mount Everest...

It was the most wonderful time of my life! I had just celebrated my 21st birthday. I was married to my wonderful husband Alan and had two beautiful children, two year old Ian and 4 month old Lynne. We had what we considered to be our perfect family living in the charming house we had worked so hard to create together.

We had just returned from a wonderful family holiday in Jersey when I started to feel unwell, tired and listless. I put it down to the long journey home from holiday. The feeling of being unwell continued other symptoms appeared gripping stomach pains and the need to rush to the toilet. I visited my GP and was given medication for my upset stomach – this was to be the first of many visits – as my condition worsened over the next four years. Hospital outpatient visits and time as an inpatient became the norm as doctors and consultants tried to identify and treat what was now becoming a debilitating illness. I was unable to eat anything without being sick and could never be too far away from a toilet.

Our family life suffered I became more and more debilitated, unable to do 'normal' things like cooking or cleaning and was continually running to and from the toilet. I couldn't take the children on outings and had to rely more and more on my husband and family for help, my children were growing up fast and I felt I was missing out! I was spending more time in hospital undergoing tests and taking large doses of medication, my condition 'whatever it was' was not improving. Just days after my 25th birthday while I was in hospital having yet more tests I

was diagnosed as having crohn's disease, at last my condition had a name! Then they told me I needed to undergo surgery as soon as possible and that I was to have an operation the following week to remove the affected bowel to give me a colostomy! It was a shock. 'What?' I exclaimed, "I am only twenty five and married with two young children how can I live with a bag attached to my stomach for the rest of my life". My fantastic husband reassured me the operation would be the best thing for me as 'being well' was the most important thing for me, and our family. He said he would always love me even with a colostomy.

The operation went ahead on the 26th March twenty days after my 25th birthday I was very worried! As I was wheeled into the operating theatre my husband blew me a kiss! The next few days were a blur as my body began to recover. I could hear lots of noises coming from my abdomen, my husband and I laughed at the sounds it made – gurgling – just like a baby! We both felt that as my colostomy was now a big part of our lives, we ought to give it a name so we decided to call it Fred! I spent the first few days after my operation recuperating in hospital and getting to know Fred. I soon began to realise what a difference Fred had begun to make to my life! I could now sleep the whole night through without having to rush to and from the toilet. I was feeling better each day so I decided to make

a list of things I would now be able to do again...leave the house to take my children to school...go shopping...cook for my family. Simple things that you normally take for granted but that I hadn't been able to do for such a long time! Then I started to list the things that I really wanted to do that my illness had prevented me from doing. Learn to drive...go out to work...go on family holidays abroad...because of Fred all of these things were now going to be possible providing I took one day at a time.

When I returned home from hospital I was feeling much stronger, I remembered my 'to do list' and slowly started to complete it through sheer determination! I pushed myself to stand and peel the vegetables stand and do the ironing...walk the children to school...and so on. I worked through my list and, Oh! What joy it gave me, the sense of achievement was wonderful, a BIG thank you to Fred as the need to visit the toilet was now minimal!

Why do I feel the need to write this story well in March 2013 I will be 65 and have realised that on the 26th of March 2013, Fred will have been with me for 40 years! I have achieved many things that before my illness I would have taken for granted or perhaps not pursued! No! I have never climbed Mount Everest or run a marathon! But I have run a home, cared for my husband and children, gone out to work and travelled the world! In the 40 years I have spent with Fred, I have laughed and cried, loved and hated some of Fred's antics but have always been grateful that Fred is with me. So happy 40th Fred and thank you for all we have achieved together!

**Sue Derbyshire**





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## Focus on Bowel Cancer Awareness Month...

# Len's story A good call...The day my life changed!



My life changed on the 18th February 2011. The story begins when my wife received a Bowel Cancer Screening test. I had previously had one in 2009 but this time I didn't receive a test kit. This procedure stops when you reach the age of 70, so I decided to telephone the Cancer screening centre to ask if I could have a test kit. This proved to be the best phone call I have ever made. I received the test kit, carried out the procedure, and then on the 18th February I received the news that the test had shown abnormal results. The letter stated that 9 out of 10 people would be found not to have bowel cancer so I was not too worried, as I did not have any other symptoms. It turned out that I was the unlucky one!

On the 1st March I had my first consultation followed by a colonoscopy on the 16th March. Afterwards I was told that the test showed a possible colorectal cancer. This turned out to be a very aggressive tumour. Then followed the usual CT

and MRI scans, consultations, and radio and chemotherapy. I still couldn't believe it was happening to me and every time I had to go to the hospital for a consultation, I would ask them if they had got the correct diagnosis. Each time they had to show me the pictures of the scan with my name on it to assure me I was the person involved.

The date for the operation was early September. I had already been told that I was to have an Abdominoperineal resection (APR) and would end up with a stoma and that there was no chance that I could have a reversal. I arrived at the hospital at 7.30am. Apart from going to hospital for blood tests, x-rays and minor surgery to remove cysts I had never been in hospital for any length of time. I was shaking like a leaf. I said cheerio to my wife and daughter, the nurse took my hand and said 'don't worry we'll look after him' and led me away.

After checking my details and getting me prepared I was taken to the anesthetic room. Suddenly a calm voice said, 'I think they are ready for you now'. I looked at the clock it was 8.00am. The next thing I remember I was being woken up and it was 4.30pm. Where had the day gone?! I was in hospital for eight days. When I got home the deep wound in my backside meant I couldn't sit down, very easily, walking was slow progress and I couldn't drive the car for nearly three months. The district nurses came in every day to dress the wound and it was to be the end of June before the wound had finally healed and the district nurses signed me off.

I have had my ups and downs with the stoma, like the first time my wife and I went away for a short break to a hotel in Norfolk six months after my operation. On the first day I ordered



garlic mushrooms as a starter, twenty minutes later I was rushing back to my room. That night, in bed, my bag came away. Luckily my wife had taken a big towel to put on the bed to cover me. I was a bit upset about what had happened on my first trip away, but after chatting with my stoma care nurse, I was reassured that this kind of thing doesn't happen very often, and that it was probably due to the fact that I was apprehensive and nervous about going away from the comfort and security of my home for the first time. She was right of course! Getting used to having a stoma is a long, learning curve but then isn't anything when it's new to us.

Well here I am sixteen months after the operation and thanking my lucky stars that I made that phone call and did the test. It's not all doom and gloom, and I am gaining more confidence as the time goes by. I've just had my six monthly check with my surgeon and was told all was OK!

Many of my friends said they had received the Bowel Cancer Screening test but had just thrown it away. I know it's not pleasant but as my story shows it can be a lifesaver!

The next article highlights  
Bowel cancer screening  
and your stoma...

# Focus on Bowel Cancer Awareness Month...

## Bowel Cancer Screening and your Stoma

Bowel Cancer is the third most common cancer in the UK and the second highest cause of cancer deaths. Whilst survival from the disease has improved over the last decade, over 36,000 people are diagnosed each year and approximately 16,000 will die from the disease. Treatments for bowel cancer often include surgery with the possibility of chemotherapy and/or radiotherapy – treatments which in themselves are often debilitating and lengthy. However, when diagnosed early it is in fact very treatable this is why it is so important to raise awareness and encourage more people to go to their GP.

**April is Bowel Cancer Awareness month – this is the time to improve bowel cancer symptom recognition amongst all of us and to promote services such as the National Bowel Cancer Screening Programme which increases the possibility of early detection of the disease. If bowel cancer is detected early less treatment may be required and the outcome is generally better.**

### The Bowel Cancer Screening Programme

Every two years the programme automatically invites all between the ages of 60 and 74, registered with a GP, to complete a Faecal Occult Blood Test (FOBT) at home. If you are older and wish to participate you can request a test kit from the programme. It is a simple test kit requiring two small specimens of stool from three separate bowel movements to be placed in the windows on the card (dated appropriately) and then sent back to 'The Hub' – the testing centre. If the test is unclear you may need to repeat the test up to three times.

The FOBT detects traces of hidden blood in the motion, but it cannot determine the actual cause. Therefore following an abnormal result you will be referred to your local screening centre. You will be sent a clinic appointment with a specialist nurse, called a screening practitioner, to

discuss the findings and, if fit enough, offered further investigation, usually a colonoscopy (a telescope examination of the bowel) to potentially determine the cause of the abnormal result.

As the FOBT detects traces of hidden blood in the motion, there are many harmless reasons why this test can show an abnormal result.

### Ostomates' questions about Bowel Cancer Screening

**As I already have a stoma do I need to do the test?**

Remember having a colostomy does not safeguard you from developing a bowel cancer in your remaining bowel and it certainly does not exclude you from participating in the screening programme. You may not be sure how much of your bowel is left following your surgery, but your stoma nurse or GP may be able to explain this. If you are participating in the programme the specialist screening practitioner can, with your permission, check your medical records to confirm this.

If your stoma surgery was due to bowel cancer, you are likely to be having regular check-ups with your consultant. If your surgery was many years ago any follow-up investigations may have now stopped and in this case it would be advisable to do the test. However, even if follow-up is continuing you can still participate in the programme, but remember that no investigation should be performed or duplicated unnecessarily as all procedures carry potential risks so it may be useful to discuss this with

your consultant or stoma nurse.

**If I have no colon or rectum will this test pick up signs of cancer in other parts of the digestive system?**

The programme is to detect polyps and cancers in the bowel and the subsequent investigations following an abnormal result on the FOBT are designed to look at your rectum and colon (large bowel). Therefore if you no longer have a colon or rectum this screening programme is not suitable for you as the initial FOBT is not a diagnostic test and the investigations offered are only to visualise the colon and rectum.

**How do I collect samples for the FOBT?**

The most important part of the process is collecting your stool samples. Remember you need two samples from three bowel movements within two weeks. Ideally you need a fresh sample, not stool already collected in your appliance. Whilst your stoma may not always be predictable, if you know when it is likely to be active and are prepared to set aside some time in the bathroom to obtain your sample each time, this is the ideal. Collect the bowel motion on a tissue and then take samples from 2 different parts.

If you need to take your samples from your appliance, apply a new pouch and once your stoma has worked take two samples from the fresh stool, endeavouring to take them from different parts of the specimen. (It may be easier to cut open the pouch allowing the contents to be spread →

out enabling easier access to the stool.) If you use a flushable pouch you can still follow this procedure and then simply flush away after obtaining your samples.

If you irrigate your colostomy try taking your initial specimen when the first formed stool is expelled down the sleeve and then take the second specimen later on in the procedure. If your output is loose it may be helpful to have two receptacles (e.g. two clean margarine tubs) ready to collect samples.

**Are there any precautions I should take to avoid contaminating the sample?**

The most important factor is to exclude any obvious blood. If you see blood it is likely to cause an abnormal FOBt result. So when you clean your stoma prior to collecting a sample, make sure you do this as gently as possible to prevent bleeding from the mucosa (the surface of the stoma).

If you have any granulomas that bleed on a regular basis, either from the

edge of your appliance rubbing on the stoma or when you are cleaning it, consult your stoma nurse. She will be able to advise if this can be treated or whether any ointment or solutions can be used to reduce the problem.

**I have a Hartmann's end colostomy/I have a loop colostomy. Do I need some other test to screen for cancer in the redundant section of my bowel?**

In most cases this type of stoma should be temporary and therefore the redundant part of your bowel will be checked by the surgical team managing your care.

Participating in the screening programme requires faecal specimens taken from your stoma which is from the functioning part of your colon and therefore it cannot detect abnormalities in the redundant section of your bowel. If, however, you do participate in the programme and end up having a colonoscopy the redundant part of your bowel will also be checked.

This Screening programme is about keeping you healthy and to reduce your risk of dying from bowel cancer. The method of specimen collection may be lengthy and it may be awkward but you are the expert when dealing with your stoma – it hasn't stopped you from leading a full and active life – so go on do the test!

**Shelley Biddles**  
Lead Nurse, Nottinghamshire Bowel Cancer Screening programme  
**Diana Wilson**  
Clinical Nurse Specialist, Stoma Care, Charter Healthcare

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## Now that Spring's on its way... you may be thinking of getting back into the garden... doing some DIY or playing your favourite sport!

Whilst exercise is good for us, many people who have a stoma are at risk of developing a parastomal hernia – so it is particularly important to take extra care when doing any form of lifting or exercise.

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# Dear Nurse

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

*Q: I have an ileostomy, which I have had a number of years. My wife pointed out to me a meeting locally of the Prostate Cancer Support Group during which after a talk about the subject a blood test would be made to determine my Prostate Specific Antigen (P.S.A.) level. Being of an age that such a test was recommended I agreed to their offer. After two weeks to analyse the sample the result was fine.*

*I took the opportunity to talk at the meeting with the Consultant Urological Surgeon - and explained I had an ileostomy and all that entails. I enquired if I needed further treatment how would it be done. I never really got an answer. Julie would you care to comment? I'm sure I'm not the first to ask this question – many thanks.*

**A:** You do not state the reason for your surgery involving an ileostomy or when specifically it was performed so it is difficult to answer your query in detail. You will probably have had regular follow ups from the Consultant Surgeon post operatively, probably for several months or years dependant on the reason for the surgery. Routine follow up with the surgeon for ileostomists does cease after a set period, again dependant on the reason for surgery but you will always be able to contact your General Practitioner who will be able to refer you to the specialist if it is deemed necessary or even to your local Stoma Care Nurse if it is a stomal specific problem. You may also still be reviewed by a Consultant Gastroenterologist if the condition is



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

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

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

crohn's disease. I hope this helps but if you feel you need a review it may be worth contacting your GP or your Stoma Care Nurse to see if this is necessary.

*Q: I suffered with crohn's colitis 16 years ago, which resulted in the removal of my large colon and a temporary ileostomy. After 6 months of resting the bowel my surgeon re-connected my small bowel to my rectum. I had 8 years free of symptoms apart from loose motions and the odd flare up of crohn's.*

*However these flare ups became more frequent and I developed an extremely painful anal fistula, which affected my sphincter muscle, and unfortunately I underwent a third operation 4 years ago of the removal of my rectum and a permanent ileostomy. I am now 39 years old and my partner and I are currently undergoing IVF treatment as we have no children and been trying for 3 years on and off. Do most crohn's sufferers or ostomists have to undergo IVF to conceive? Please could you give me some feedback?*

**A:** I have checked with one of my specialist gastroenterology colleagues and she informs me that patients with crohn's, which is well managed, are as fertile as the general population. However for patients who have active crohn's, especially perianal, can have an effect. Therefore for someone who has well controlled crohn's you are as fertile as the general population. For patients who have had pelvic, and to some extent abdominal, surgery fertility could be reduced. I hope this helps.

*Q: Recently I have had a few products discontinued on my prescription:-*

- 1). Underwear with internal pockets
- 2). Ostomist deodorant spray
- 3). Odour mint drops

*I was not given any prior warning that this was going to happen and no information on how or where to find alternatives. Odour drops are essential to my daily confidence! Can you please advise as to why this has happened? Are there any alternatives?*

**A:** There are many companies who provide such products and it may be worth contacting your local Stoma Care Nurse to see if she can help. I have spoken to OstoMart who make the deodorant spray and the mint



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drops and they assure me that these are still available. They have added new fragrances and I wonder if this is where the confusion has arisen. The underwear with the internal pockets are made by CUI and again I have contacted the company and they are still available. I hope this helps.

**Q:** *My stoma was bleeding inside but now on the outside – it looks very red and feels sore. My GP says he doesn't know why or what could be the cause and has suggested surgery. Can you tell me if this is normal and whether you think I might need surgery?*

**A:** You need assessing to identify the source and cause of the bleeding. If the bleeding is surface bleeding from the stoma only and occurs on washing then it is very common and if it is caused by irritation Orabase Paste applied to the stomal surface can help. However if the bleeding is identified as being from inside the stoma then you will need to be seen by a specialist to identify the cause and to discuss treatment options. The treatment plan is dependant on the actual cause so it is difficult to say if surgery, as suggested by your GP would be helpful.

**Q:** *I am 70 years old and had my colostomy due to cancer last year. I am managing my stoma quite well. Recently I received a faulty batch of bags. I am all sorted now. To help others who may find themselves in a similar situation could you explain the best way of dealing with this type of problem? It was quite a worry at the time.*

**A:** If you have problems with pouches which you feel may be due to a faulty product, such as the pouch splitting, then I would advise you contact the relevant company, the contact numbers are often on the packaging or you can get them from your pharmacist. Explain the problem to them and they will arrange for the products, with the relevant batch number (again on the packaging) to be returned to them. They should replace the products with a new batch of a different number for you to continue using. The company will then investigate the problem and should inform you of the findings. If a problem is identified with a particular

batch the company can then request withdrawal/replacement of that batch. I hope this helps to explain the process and I am glad your particular problem is now sorted out to your satisfaction.

**Q:** *I have had my stoma for about two years I had two operations and have a colostomy. I'm afraid I'm not coping with my stoma I just don't want to look at it or change my bag. The bags I am using don't seem to adhere very well and I am suffering from leakage and I am very worried about going out in fact I haven't been out for several months. I feel very low and I'm not sleeping well either. Can you give me some advice?*

**A:** It is often difficult to accept the formation of a stoma especially if you are having practical problems such as leakage. It is difficult to assess the reason for your adherence problems without physically reviewing your stoma as it can be due to many different reasons. I would suggest a review by your local Stoma Care Nurse who will examine the stoma and assess the cause of the problem. She/he can then advise regarding a solution, which may include the use of other accessory products or even a change in product. There are certain products which may help you to manage the stomal output better so that your confidence improves, as you will not need to wear a pouch all of the time. These are not suitable for all colostomates but again your Stoma Nurse will be able to advise. They include irrigation and the Conseal Plug. The nurse will also be able to assess your psychological concerns and with either be able to help you develop your own coping strategy or will be able to refer you to another agency who is better equipped to help you. Have you been able to speak to a local/national volunteer who again may be able to help? The Colostomy Association volunteers are specially trained and equipped to assist you and will be able to sit and talk through any concerns you have and again signpost you in the right direction to get help. I hope this helps, there is plenty of support available and I hope you feel able to access it.

**Q:** *I had my colostomy in 2010 and now have a parastomal hernia. I wear*

*a support belt but haven't received any clear guidance. I am concerned that wearing it may restrict my stoma and prevent it from working. My stoma is active in the morning and evening. Your help would much appreciated.*

**A:** Many people wear support garments without any problems. They should not restrict the stomal output or cause any problems with pouch adherence. Some support garments are bought as set sizes and tend to give lightweight support. These can be worn easily without causing any problems. Often if the support is to give stronger support then they are made by a specialist company and you should have been reviewed and measured for the support and provided with information and contact numbers for the manufacturer. All these supports can be worn from the moment you get up in a morning through to when you retire at night but should not be worn in bed. Obviously these supports are made from elasticated material and the support provided reduces over time. Also you may find that the support does not work as well if you gain or loose weight. For this reason you may occasionally require remeasuring to ensure that the support works correctly.

**Q:** *My daughter recently had a loop colostomy and is recovering. She has a young family and the operation and associated round of appointments and time out of work has impacted on the family finances. I would really appreciate your help, can you tell me if there is any financial help available to support patients after their operation. Are there any services, agencies available within the hospital that could be of help?*

**A:** You do not state the reason for your daughters operation. There are many different benefits available but I am not a specialist in the area of benefits. What I would suggest is that at many hospital trusts there is a group who can advise as to what benefits are available or you may find that the Citizens Advice Bureau can help.

**Q:** *I had my stoma recently about three months ago. I am careful with what I eat and follow the five a day*

*routine. I am constantly getting wind, which is making me fed up can you advise as to which types of fruit and vegetables might be causing me problems. Also I would quite like to explore other alternative methods of bowel management please could you advise me on what else is available.*

**A:** You do not say what sort of stoma you have. Excessive wind is common after bowel surgery and does tend to improve over time. However it may be that a change in diet or the timing of your main meal may help or some people do find peppermint (tea, mints or cordial), fennel (vegetable, mints or tea) or charcoal (tablets or biscuits) may help. With regard to the bowel management options it depends on the type of stoma you have. If you have an ileostomy then the only option is to use a pouch. This can be a 1 or a 2 piece product. If you have a colostomy, depending on whether it is a loop or an end stoma, then there are a couple of other options to use. These are stomal irrigation, which you use to wash out the bowel so that you do not have to wear a pouch. It is performed daily or alternate days and you can wear a mini pouch or a cap over the stoma. Alternatively there is the Conseal plug, which is used to 'plug' the stoma so that it does not work whilst the plug is in place. The plug is worn for 12 hours and for the rest of the 24 hour period you wear your usual pouch. For more information and to assess your suitability you will need to contact your Stoma Care Nurse.

*Q: I keep getting the urge to go to the toilet. I had my operation about fourteen months ago, I have had no rectal discharge and my surgeon is happy with me but I just can't stop wanting to go. Why is this happening please can you help is it normal?*

**A:** Some people do describe the symptoms you are describing. It can be due to a mucous plug in the rectum and the insertion of a glycerine suppository into the rectum can help to move this. Your GP can prescribe this and arrange for a District Nurse to visit to assist you in inserting it. If this does not solve the problem for you it may be that you need to see a specialist pain management team to help to manage the discomfort.

*Q: I had my colostomy six weeks ago I am in quite a bit of pain and getting discharge from my anus every other day. I am taking Co-codomol and have been to my GP. The discharge is thick brown and pinky. Can you tell me if this will continue or will it go away soon.*

**A:** I presume you are still under the care of the hospital for the post operative care. I would suggest that you contact them to discuss this, as I do not have access to your surgical records. Some discharge is common after surgery but should settle in time. However if there is a join (anastomosis) in the bowel then the hospital will need to keep a close eye on this to ensure there are no problems. If you do have a join in the lower part of the bowel, which the stoma is protecting then, it may be you have an infection here and will need assessment and treatment.

*Q: My husband is 60 and had his colostomy recently due to a perforated bowel. He is quite angry and doesn't want to change his bag himself so I am caring for him and his stoma. I am very concerned about him. Is there anything I can do to help him come to terms with his situation? Should I encourage him go back to the hospital and request help from his stoma care nurse?*

**A:** It sounds like your husband is really suffering with accepting his stoma formation. I would suggest he re-visits the hospital Stoma Care Team where he had his care. They may be able to help him and assess whether he needs referral for more support. It can be difficult to accept a stoma formation and people cope in many different ways but some people do require extra support, especially in the short term. It may be useful to speak to a volunteer visitor who has undergone similar surgery and the Colostomy Association can help with this. Alternatively he may require referral for some counselling/psychological support and this is where your Stoma Care Nurse can help with putting him in contact with the relevant people. I hope this helps and both you and your husband get the support you need.

## What kind of stoma do you have?

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

### Five facts about an ileostomy

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

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

### Five facts about a colostomy

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

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

---

## Editors Comment

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

If so write in and tell us:

Colostomy Association  
Enterprise House  
95 London Street  
Reading RG1 4QL

or e-mail your query to:  
[editor@colostomyassociation.org.uk](mailto:editor@colostomyassociation.org.uk)

## 85 years young...

I suppose my story really began in earnest some ten years ago, during which I suffered from chronic diverticulitis and colitis; in fact life had become so grim because of pain and alternating bouts of severe constipation and diarrhoea, I gradually lost interest in almost everything and suffered really bad depression. Everyday living became increasingly dominated by an urgent need to stay within close reach of a toilet, often needing to use a whole toilet roll accompanied by pain worse than that of childbirth. Result – I was afraid to go out because of the fear of ‘accidents’ and felt like a prisoner in my own home. Despite numerous visits to my doctor, nothing was being resolved and I really felt like ‘giving up’.

Things came to a head in June 2011 when my daughter phoned for an ambulance during a particularly bad attack and I was admitted to hospital. After carrying out various tests, doctors diagnosed colitis and diverticulitis and recommended I have a colostomy. I have to say at that time I had no idea what a colostomy was,

and was nervous about the whole thing. How would I feel about wearing a ‘bag’, how would it affect my everyday life. I had always been a ‘fighter’ but this seemed to be different. I was 83 years old and this was major surgery! However I needn’t have worried. Due to the skill of the surgeon the operation was 100% successful and my recovery was very quick, which I put down to the excellent care I received both before and after the operation. Within a space of approximately four weeks I was feeling ‘back to normal’ and raring to go.

To aid recovery, my daughter suggested we go to Tunisia for a two week holiday so that I could recuperate in the sunshine. During one of our afternoon walks along the beach I noticed people paragliding. Instantly I wanted to ‘have a go’. I remember thinking “if they can do it, so can I”, and so with my daughters full support – “Up I went”. It was an absolutely wonderful experience, despite the boat stopping accidentally which resulted in my being ducked under the water. I remember being

hailed as quite the ‘celebrity’ with everyone clapping this old lady, as I waded slowly up shore.

When I look back I cannot believe that having been a slave to pain and the toilet for so many years, I was now pain free, fit and able at 84 years old to enjoy life to the full.

So what I’ve got a colostomy! I consider myself lucky, it’s the best decision I’ve ever made. It’s given me freedom and a whole new life. I would say to anyone with a similar decision to make, don’t be afraid, go for it and LIVE.

**Harriet Norkett**





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# Readers' writes

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

## Letter reprinted from the Winter issue of Tidings submitted by V.M.W

### Dear Editor

I have had trouble obtaining my colostomy bags from my doctors. My stoma care nurse requested a prescription for 4 boxes of colostomy bags per month. My husband picked up my prescription from our doctor. It was for 2 boxes per month. He was told it was because they were "high value items". My stoma care nurse then tried to contact the doctors but he was met by the same result as my husband had been – they could not get past the receptionist.

The nurse then sent a further request, I assume saying that this was causing me a great deal of stress. I was then given another prescription for 4 boxes of bags. This did cause me so much stress that for a week – until it was sorted - I could not eat, causing me to use less bags. When I mentioned this to the nurse, his immediate response was that we might be able to cut back on the quantity of bags requested.

As I am now back to eating and going through bags at a higher rate, I am now very afraid that I may be faced with this dilemma all over again. Also, the nurse told me that the only supplies I could be supplied with by the NHS were the colostomy bags and 2 aerosol of remover. He told me to use kitchen roll to clean myself and nappy bags for disposal of used colostomy bags. He said I did not need stoma powder or any other products. People at the Hull support group say I should have more. I do not know!

Yours in anticipation  
V.M.W

## Letters from Tidings readers in response to the letter from V.M.W

### Dear Editor

I was astonished to read about the problems encountered by Mrs V.M.W. in trying to obtain her necessary ostomy supplies from her G.P. No doctor or nurse, and certainly no receptionist have any right to dictate how many pouches an ostomate needs. It is true they are "high value items" (though not as costly as many other prescription appliances and drugs) but how can anyone but the patient know what his/her personal needs in this respect are? Is her doctor implying that she should have only a certain number of bowel motions per day?

Every issue of "Tidings" contains numerous advertisements for ostomy products designed and developed expressly to help us manage our individual stomas and their activities more effectively. Adhesive removers, skin barrier tissues to combat sore skin around the stoma, lubricants, ostomy paste, deodorisers, powders' to turn the pouch's contents into a gel and thus render the leaking pouch - one of the ostomates worst fears – a much less likely occurrence, and many other items whose very existence acknowledges the personal and individual nature of an ostomates medical needs.

I do hope Mrs V.M.W doctor does not regard these products as merely cosmetic or optional extras. They are not; and for a specialist stoma nurse to share that view is disgraceful. Yes, the pouch itself is obviously the key item (though even this, it seems, would be "ratified" by the G.P. what on earth does the doctor think Mrs V.M.W. is doing with the bags?) However it must be emphasised that the other items on my list are also vital to helping the ostomate cope

with the sometimes awkward or embarrassing demands of life with a stoma.

It must also be made clear that, when Mrs V.M.W's stoma nurse tells her that the NHS can supply her only with "the bags and two aerosols of removers" he is completely wrong. Her doctor is free to prescribe any of the products I have mentioned if it has a prescription order code.

I am not naive. These are difficult times and economies have to be made, and discretion exercised, but not like this. Incidentally, why does Mrs V.M.W. refer to her nurses' recommendation to use kitchen roll when changing her bag? Wetted and softened first, it is perfectly acceptable for cleaning round the stoma. I've used it for this purpose for 30 years. And as for disposal bags: the supplier who cuts my bag holes also sends a free supply of these – scented, even! I write as an ostomate who had his first colostomy in 1982; whose cancer returned in 2003 and necessitated another stoma (this time, just for a change, on my right hand side – not much colon left) whose earlier stoma was consequently closed; and who will always be grateful to those engaged in the research that produces the variety of medical aids available to us today. Far more than when I greeted my first stoma 30 years ago!

Personally I am also very fortunate in my doctor. When I ask him if he will add a new item to my list of repeat prescriptions he knows I will have tried samples first and proved them to be effective. He has never queried such a request. When I see him later about some quite unrelated matter, he will ask how the new stoma item is doing – am I satisfied? Is it proving successful? He is the professional G.P. but believes I am the best judge of what I need to manage my stoma.

...continues on page 50 →

# Readers' writes

Every stoma is different. Mrs V.M.W. must, I believe, enlist the help of her Hull Support Group in making the case for adequate supplies. None of us would ask for an item if we did not need it. I suggest she would also benefit from having a doctor and nurse who could show rather more sensitivity and understanding. They cost nothing.

Yours sincerely,  
D.S

## Dear Editor

I have had my colostomy for a relatively short period really sixteen months and am appalled at the G.P.s that will not provide the necessary equipment on prescription for people like myself who need these products. I luckily do not have a problem with my G.P. and he has admitted he has very few patients with a colostomy and knows very little about it.

I wish to reply to V.M.W letter regarding her supplies. The lady can order her own prescription from her chosen supplier if she so wishes and build up a relationship with them regarding her needs, delivery etc., this still needs to be approved by her G.P. but I have found it quicker this way and receive lots of free samples to try from my supplier which I did not get from the nurses. I found the nurses quite obstructive over the products I could have too, and asked if I could choose my own supplier, which you can, and I did.

I know I am only new to this but the nurse has no right to suggest using kitchen towel to clean such a sensitive area it is too harsh and I am sure barrier cream or spray is required to look after the peristomal skin as well as the adhesive remover. (I use sachets of these products for travel, which I keep in my small travel kit). The lady may find she would receive complimentary dry wipes (which are so soft) wet wipes, sentees bags for disposal of the pouch and sealaway bags to double

bag the pouch for the bin. I receive all of these from a company called Charles S Bullen Stomacare Ltd, 85 Kempston Street, Liverpool L3 8HE, Tel 0151 207 6995 they have been in business since 1858 and are fantastic. I do not know what areas they deliver to or cover.

My output is like water all the time and I have to order 3 or 4 boxes of pouches a month. Good Luck to everyone and keep fighting these wrongs.

Best regards,  
J.R

## Jane replies:

More information about 'obtaining supplies' can be found on the Colostomy Association website visit: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk) Click on the tab 'Information' and drop down to 'obtaining supplies'. If you need this information in a paper format contact the CA office on 0118 939 1537 or e-mail: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk) You may also like to read page 52 - Stoma Prescribing Guidelines.

## Dear Editor

I would like to pass on my experience as it may help your readers. I had an operation in March 2010 for colon cancer, which resulted in a permanent colostomy. Just as I was getting used to this I developed a very large hernia four months later, which I was told, is inoperable necessitating me in wearing a surgical corset all the time I am vertical. As I have to put this on lying down, I am unable to remove the corset whilst out so a drainable bag is the only answer for me. I did, however, try closed bags before the hernia developed but I found that disabled toilets did not cater for colostomates. There were no hooks to hang clothes and no shelves to put equipment and most of the time the mirror was in the wrong place above the basin. The point I am

making is that it is so much easier to drain a bag in any toilet facility. I am sure your readers would find a drainable bag more convenient if they were travelling or out on a day trip. I certainly did when the plane I was travelling in was diverted and this delayed us for several hours waiting for coaches.

Kind regards,  
P.T

## Dear Editor

I have just read Tidings magazine from cover to cover for the first time and I thought all the letters came over with such a friendly feel which spurred me on to write to you to share my thoughts and experience.

I have had a colostomy for the past two and a half years owing to a prolapsed bowel coupled with IBS. Mr. B. George, a brilliant surgeon at the Radcliffe Hospital Oxford performed the operation – you can imagine what a change this made to my quality of life.

Because I was happy with my new situation I considered becoming a counsellor, but when I read some of the problems colostomates can have I realised that I knew very little - so I have put this idea on the back burner for now, until I learn more.

What surprised me most was that there were no readers who mentioned 'flushable bags'. My stoma care nurse introduced me to Welland Flushable Bags on day one and I can only say that I thought they were the best things since 'sliced bread'! Now I know they are not suitable for everyone but I am sure a lot of people would benefit from them. This may sound like the type of copy found in an advertisement for Welland Flushable Bags by CliniMed – but I just can't contain my enthusiasm for this amazing product!

I understand that a lot of people do not trust them because they are

biodegradable and therefore think they will disintegrate – this is just not true!

The flushable bag is made of two parts, an inner liner and an outer pouch both are biodegradable but they don't disintegrate through usage. When I want to change my flushable bag – I simply pull the two parts apart – flush the soiled inner liner down the loo (which dissolves) and retain the clean outer pouch for disposal later – with my other household plastic recycling. Even if your output is rather liquid these bags stay completely intact. I have used them for two and a half years and can honestly say that they have never let me down – they stick like glue even in the shower and I have never had sore skin.

I cannot imagine what one does with a non-flushable bag when out socialising in a private house where there is no bin (and who would want to put a bag in a friend's bin anyway!). The inner liners are designed to go down any type of loo including aeroplane loos which I use a lot as I travel frequently to visit my grandchildren in the East.

So, if there are any of you out there who haven't heard of flushables or are too nervous to try them and find disposal a rather unpleasant problem – why not give them a go! I am sure you won't be disappointed.

I hope this letter helps other readers.

Yours sincerely,  
J.H

### Dear Editor

Back in 2010 we (my wife and I) travelled to Australia to visit our son, we were there for 3 months. I heeded the advice I had read in Tidings and doubled up on everything I would need. Packing our cases turned into a nightmare, continually checking the weight and moving the supplies around the cases and hand luggage. I know that

some airlines allow extra weight allowance for anything medical but it isn't always the case.

In September and October 2012, we were off again. (6 weeks in all) This time to our daughter also in Australia, but I was determined not to have any hassle. I contacted my supplier who offered to post (not courier) most of what I would need before we went. It arrived within 5 days, long before we were due to leave. I thought there might be a problem with customs but there wasn't.

I was recently at a Hollister open day and someone there was worried about a forthcoming long haul holiday and how they would manage their supplies, I imparted this information which seemed to be appreciated, I thought it might be of interest to Tidings readers.

Best regards,  
G.C

### Dear Editor

I have enjoyed reading Tidings magazine for a number of years now, and I can't help wondering how many people must be suffering in silence, due to wind and other factors.

My colostomy was performed almost eleven years ago and for the past few years I have taken it upon myself to alleviate as much wind as possible, by having some me time in the bathroom before going to bed. This is the time I change my bag (yes, one drainable bag per day) shower or bathe before going to sleep. It's a feeling of wanting to be clean before getting into bed. To help myself with wind I sit with a book, whilst gently massaging my tummy this encourages wind to come away easily. I have the stoma covered with a dry wipe, should anything else try to escape. Then I sit there until everything feels comfortable enough to put on a clean bag.

I have been doing this about five years now, and it does work for me, everyone is different I know, but if it helps only a few others, then I shall be pleased to have mentioned my little routine to you all.

Thank you for being there for me, and everyone else, and good luck with future issues.

Yours sincerely,  
J.W

**Before acting on suggestions from other ostomates you are advised to check with a doctor or stoma care nurse that this course of action is suitable for you.**

**Thank you for your letters and e-mails. Please keep them coming. We will do our best to print them or we may hold them over for a future issue.**

**Editing may be required for reasons of clarity or space. In the interests of confidentiality we will publish only your initials and not your full name, unless you give us permission to do so.**

**If you want to be involved in the next issue of Tidings magazine simply drop us a line**

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

or write to:  
The Editor

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



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

## Introducing...Stoma Prescribing Guidelines

The move from Primary Care Trusts (PCTs), where managers made all the budgetary decisions and told the clinicians/GPs what to do, to Clinical Commissioning Groups (CCGs) – now upon us – where the clinicians/GPs make the decisions for themselves, is seen by some in the NHS as an opportunity to cut costs. The CA sees it as an opportunity to educate GPs and prescribers about our condition and our needs.

The GP still has it in mind that a colostomate requires only one or two changes a day. Added to which when the NHS could not afford to fund a nationwide complement of stoma care nurses, the Primary Care Trusts came up with the idea of 'sponsored nurse' posts paid for by stoma care product manufacturers and suppliers. There is inherent suspicion that this has led to the favoured brand being the only brand offered to the patient and encouragement from the supply arm of the manufacturer to order 'plenty' of product. Being aware that this sort of criticism could be levelled at the manufacturers whether true or not, the

British Healthcare Trades Association (BHTA) wrote a Code of Practice (OFT approved) specifically for this area to which all the manufacturers work. Nonetheless some GPs and others are suspicious of the 'sponsored' aspect within stoma care.

'Additional Products', the term we now use for what used to be called, somewhat emotively and inaccurately, 'Accessories', is also a particular area of concern for the GPs, who may regard these as frivolous. When you consider that Additional Products include flange extenders, stoma adhesive, inner rings and support belts, all of which are designed to reduce leaks, you realise that these Additional Products are not only fundamental to the confident and comfortable management of a stoma as are the bags themselves but also save money. Then also under Additional Products we have adhesive removers - essential for preventing damage to the peristomal skin around the stoma. Then there are odour treatment options - sprays or drops – used prior to emptying or changing the bag, again vital for ostomate

confidence and comfortable stoma management.

The Patients Industry and Professional Forum (PIPS) for stoma and continence products – the body that represents everyone involved in stoma care, has produced the Stoma Prescribing Guidelines (see below). The CA has been instrumental in ensuring that the widely varying needs of the colostomate are made clear. These Guidelines have been sent to every GP in the country, the Medicine Management Teams at the CCGs and the Pharmacy Advisors. We will also try to get these aired on every public forum or broadcast available.

**You Can Help:** We are going to have to help ourselves and so we can all do our part in educating the GPs. Contact your local CCG, write to the Medicine Management Team, send them a copy of the Stoma Prescribing Guidelines (available to download from the CA website). Send these to your GP as well.

### Stoma Prescribing Guidelines

Type	Recommended wear time	Qty per month
<b>Ileostomy</b>		
One-piece drainable pouch	Pouch changed every 1-3 days	10-30 pouches a month
Two-piece drainable pouch	Baseplate changed 2-3 times a week	8-12 baseplates a month
	Pouch changed every 1-3 days	10-30 pouches a month
<b>Colostomy</b>		
One-piece closed pouch	Pouch changed 1-3 times a day	30-90 pouches a month
Two-piece closed pouch	Baseplate changed 2-3 times a week	8-12 baseplates a month
	Pouch changed 1-3 times a day	30-90 pouches a month
Because colostomates have differing amounts of large bowel, their stomas behave differently and the number of changes they need to make each day, varies enormously. At one end of the scale certain colostomates may manage their stoma by using a drainable pouch while at the other end certain colostomates may be able to irrigate. In between there will be a wide variety of one and two piece appliances and additional products used and a wide variety of changes required each day.		
<b>Urostomy</b>		
One-piece closed pouch	Pouch changed every 1-3 days	20-30 pouches a month
Two-piece urostomy pouch	Baseplate changed 3 times a week	8-12 baseplates a month
	Pouch changed every 1-3 days	20-30 pouches a month
Open night drainage bag	Bag changed weekly	4 bags per month
<b>Convex Products:</b>	Convex products should only be used on the recommendation of the Stoma Care nurse.	
<b>Additional Products:</b>	Barrier cream, skin protector wipes/spray, powders, adhesive remover, washers and pastes, deodorants, retention strips and support garments may be essential for problem solving with stomal complications or to extend wear time and increase confidence.	

The quantities mentioned above are guidelines only. Some patients will require a higher or lower quantity than stated. If there are any prescribing concerns please refer to the patient's Stoma Care Nurse for details or an assessment.



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- UA Urostomy Association  
Tel: 01889 563191  
www.urostomyassociation.org.uk
- IOA International Ostomy Association  
www.ostomyinternational.org
- Stomadata & Stomafr  
www.stomadata.com  
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- Macmillan Cancer Support  
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Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO) (The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)  
Web: www.glo-uoa.org
- Ostomy Lifestyle  
Tel: 0118 324 0069  
Email: admin@ostomylifestyle.org  
Web: www.ostomylifestyle.org

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

For a comprehensive list of Patient Open Days events...visit the CA website. Details can be found on Page 6. Listings are updated throughout year.

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

Don't forget the CA Patient Open Day in July see Page 24

## SASH

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**The Colostomy Association is an independent charity financed solely by donations. Your help and support today is more important than ever in this changing world...**

Our findings show there are approximately 60,000 colostomates living in the UK and with over 6,400 permanent colostomy operations being performed each year - the CA needs to be here for everyone 'living with a colostomy'.

### Here's how YOUR donations help CA make a difference...

- **A telephone helpline 0800 328 4257** manned 24/7 365 days a year by fully trained volunteers experienced in living with a colostomy.
- **An Outreach Programme** CA's own Patient Open Day event for ostomates. Come and visit us it's a full day packed with information and friendly faces.
- **Patient Advisory literature**, written by colostomates and health care professionals.
- **A quarterly magazine 'Tidings'** especially written by colostomates for colostomates, their families and their carers.
- **Over one hundred contact volunteers cover the UK** fully trained and experienced, (who are ostomates) these dedicated individuals bring a human touch. A volunteer can discuss emotional or practical problems with you and be matched to a patient by age, sex, location or by problem
- **Patient visiting** a volunteer can at the request of a stoma care nurse visit a patient/s before their colostomy surgery, and afterwards in hospital. Home visits can also be arranged.
- **CA attendance at organised stoma care nurses 'open days' around the UK** – that you can visit and learn more about your stoma, in a friendly atmosphere and discuss any problems.
- **CA attendance at manufacturers' and suppliers', 'open days' and exhibitions.** These allow you to come and see us and we can update you on stoma care products, accessories and services via 'Tidings'. Display our literature and chat to ostomates.
- **A voice for your opinions at ongoing consultations with the National Health Service** keeping you informed of issues that may affect you.

**Donate and make a difference to CA..today!** Here's how...simply dial 0118 939 1537 to donate over the telephone • visit [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk) and donate online make a regular donation via standing order • make a single donation of £15 or more • donate online at justgiving • donate a gift in memory • leave CA a legacy in your will – THANK YOU!





Thank you for your support

Regular donation

Your ongoing support means we can plan our services with confidence knowing when donations will be coming in – and reach out to more colostomates their families and their carers with support, reassurance and practical advice. With your help we really can and do make a difference - thank you.

Please use this form to make a Regular donation by Banker's Standing Order. Simply complete this form and return by post to the Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.

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

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

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

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

**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  £5  £10  £25 or other amount (please state) £ \_\_\_\_\_  
 monthly  quarterly  annually starting on the  1st  15th  25th of month: \_\_\_\_\_ year: \_\_\_\_\_

thereafter until further notice. \*Please state your donation amount in words: \_\_\_\_\_  
 (Please cancel any previous standing order in favour of this beneficiary).

Please pay: **NatWest Bank Market Place Reading Branch 13 Market Place RG1 2EP**

Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**  
 Name: (IN CAPITALS) \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / 2013



Thank you for your gift

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

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

Signature: \_\_\_\_\_ Date: \_\_\_\_ / \_\_\_\_ / 2013

To donate via standing order...Please fill in the form and return to the Colostomy Association - thank you





Single donation

Thank you for your support

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

Please use this form to make a Single donation to the Colostomy Association. Simply complete this form and return by post to the Colostomy Association, Enterprise House, 95 London Street, Reading, Berks RG1 4QA. Telephone: 0118 939 1537 if you have any queries.

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

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

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

**(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  £10  £15  £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.

*giftaid it*

**Thank you for your gift**

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

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

Signature: \_\_\_\_\_ Date: / / 2013

To make a single donation...Please fill in the form and return to the Colostomy Association - thank you



# FAQs – Getting back to normal...

## Do I need different clothes?

Most colostomates are able to find suitable clothing in ordinary retail outlets and High Street stores. However, there are companies who manufacture specialist clothing for colostomates.

These include:

- high-waisted trousers for those whose stoma is at waist level.
- underwear which is high-waisted or with an internal security pocket.
- support garments to prevent or control a parastomal hernia.

## Will I be able to return to my job?

Once you have fully recovered, providing there are no other medical implications, there is no reason why you should not return to the job you did before you had your colostomy. Your doctor will advise you when you are fit enough.

If your work is strenuous and involves lifting heavy weights, or puts a strain on the abdominal muscles, there is a risk that you may develop a parastomal hernia. Consult your stoma care nurse who will probably suggest you wear a support garment and avoid heavy lifting whenever possible. However, if you have to lift something remember to place your feet apart (one foot in front of the other), keep your back straight, bend your knees and keep the object you are lifting close to your body.

After surgery it's normal to feel tired more quickly even if you are not doing strenuous work.

## Will my driving be affected?

You should wait until at least six weeks after your surgery before you start driving again. Then, once you feel confident, having a stoma will not affect your driving ability. However, it is wise to check with your motor insurer as policy conditions can vary. If you find the seat belt is uncomfortable across your stoma try fitting a "Klunk

Klip" device. These can be obtained from most car accessory stores, or on line. The klip is attached to the inertia-reel of the seat belt and reduces the pressure on your colostomy. Forward movement releases the klip allowing the restraint system to operate normally.

## Can I travel at home or abroad?

At first it is natural to feel a little apprehensive about how you will cope with your colostomy away from home. Start with a short trip in this country and as your confidence grows venture further afield.

If you are travelling abroad:

- check that your holiday insurance covers pre-existing conditions. A factsheet listing companies providing travel insurance for colostomates is available from CA Head Office.
- remember to pack your stoma supplies (twice as many as you think you will need) in your hand luggage.
- carry a travel certificate (available from CA Head Office) which explains in different languages that you have a stoma and need to carry medical supplies.

Every year many thousands of people with a colostomy travel by road, sea and air – even on long haul flights!

## Making the decision to talk about your colostomy

To tell or not to tell? Obviously you will need to involve your partner and you may feel more comfortable telling the rest of your family together. Only you can decide who else you should tell. Some people prefer only their close friends to know. Others are quite happy to tell anyone that they have a stoma. The decision is up to you.

Remember, having a colostomy has not changed who you are. You are still the same person you were before surgery. It may take some time to come to terms with your altered body image. If you would like to talk to someone who has a colostomy call our Helpline 0800 328 4257.

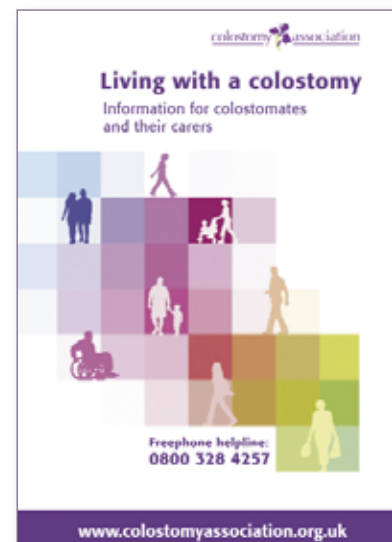
## Will it affect my sex life?

Most people with a stoma can enjoy a healthy sex life. It is often the case that the person with the colostomy is more aware of the stoma than their partner. Some colostomates feel more comfortable wearing attractive underwear, use a cummerbund to conceal/support the bag or use a pouch cover. Mini-pouches and stoma caps are also available.

If the rectum is removed during stoma surgery:

- some women may experience a different sensation, pain or dryness in the vagina during intercourse. This can be helped by using a lubricant.
- some men may experience difficulty in getting an erection. However, this can be successfully treated in 90% of cases.

Should you experience any such problems do not be embarrassed to discuss them with your surgeon, GP or stoma care nurse. The Colostomy Association has a number of male and female volunteers who are willing to talk in confidence about any concerns you may have.



The above article is taken from the CA booklet **Living with a colostomy – Information for colostomates and their carers.**

This booklet is available from the CA office or online at: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

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

## **Carole Summer writes....about Solent Ostomates Support Group – members provide ongoing support to one another and strong friendships have formed over the years.**



**Carole writes...**The Solent Ostomates Support Group (S.O.S.) which meets on the last Wednesday of each month, celebrated its 6th Anniversary in March this year. It seems like such a long time ago since I set the group up with just six people and support from a stoma care nurse and the CA.

Originally the group was named Southampton Ostomates Support Group (S.O.S.) but it now covers such a wide area that we have re-named it Solent instead of Southampton! Over the years more than 70 people have attended the group, sadly people have died as not everyone will fully recover from having a stoma for various reasons. Members provide ongoing support to one another and strong friendships have formed over the years. Within the group – we have a dear lady who is a telephone buddy to someone who cannot get to the group, her continuing contact with this lady is a life-line for her and much appreciated.

The group has its Christmas meal in January when everyone is less busy than in December, this is well attended and partners are always welcome, we try to subsidise the cost from our funds. In the summer we have a BBQ again well attended. The Church where we hold our meetings also supports the group and gave us £50 towards this event which was most welcome, so far the weather has always been kind to us!

As I have explained the group covers a very wide area and includes a part of the New Forest near Southampton. The stoma care nurse who covered this particular area noticed the benefits S.O.S. group brings to patients so she asked me to help her set up a group. The Solent Ostomates Support Group (New Forest Branch) has thrived from the outset with many members keen to help out with the various duties necessary. The group is growing and I am delighted to see these lovely people supporting each other with the help and support of their stoma care nurse.

One of the most important people on the S.O.S. is of course, the treasurer, without his continuing support the group would have faltered long ago. We charge £1 for tea/coffee and cake and also run a raffle at each meeting, all the funds are entered in a ledger. Visiting members in hospital and at home is an important part of the group's work, the treasurer calculates the petrol money and also money for flowers. He pays the church where the group is held from monies gifted by CliniMed, which is a great help to us. He gives out receipts for money spent and arranges an audit of the books, he also types up a treasurers report for the A.G.M. You can see from all of this that he is invaluable to the group and deserves nothing but praise for doing such an excellent and responsible job.

Recently I have been unwell and had to spend some time in hospital, when first admitted I was sent to an assessment ward, unfortunately for me I was admitted to hospital on a Friday and as we know weekends are not a good time to be in hospital as there does not seem to be the same staffing levels as during the week. On the Sunday evening I was finally moved to the stoma care ward having received no help for my condition on assessment and feeling very ill, to my amazement the ward sister, Sister Anne, was on duty and recognised me following the patient visits that I do on

her ward, she pulled out all the stops and I was immediately given the attention that I needed and was put on the road to recovery! During this time in hospital a total of 15 days I became very aware of what would happen to the group if I did not make a full recovery, I am now determined to make sure that there is someone who can take over the group should I be unable to in the future!

To anyone who does not have a Stoma Support Group near them and is thinking about setting one up I would encourage you to do so. I had never done anything like this before, but through my endeavours I can see clearly how the groups have helped so many people. It was quite a journey initially but step by step it all came together, your stoma nurse will help you and obviously the CA will be with you all the way! Should I be able to help in any way then please don't hesitate to contact me.

**Carole Summer**

### **Regional Stoma Support Focus...**

#### **Hampshire:**

COGS (Colostomy Only Support Group)

Contact: Sarah Anderson  
07907 820125

Solent Ostomates Support Group  
Contact: Carole Summer  
07527 707069

Solent Ostomates Support Group  
(New Forest Branch)

Contact: Carole Summer  
07527 707069

Wessex Urology Support Group  
Contact: David Morris 02392  
361048

#### **Isle of Wight:**

Optimistics

Contact: Stoma Nurse Natalie  
Sayer SCN 01983 534009

Semi Colon Group Isle of Wight  
Contact: Tony Crowson Chairman  
01983 559326

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

## Stoma support groups in your region...



Information about **stoma support groups** is regularly updated both in **Tidings** and **online visit: [www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)**. If you know of a **stoma support group** near you not mentioned in our listings please let us know...if you are interested in setting up a group the CA can help. Contact the **CA office: 0118 939 1537** or **E-mail: [cass@colostomyassociation.org.uk](mailto:cass@colostomyassociation.org.uk)**

### Scotland

#### Midlothian:

Maggie's Edinburgh  
Contact: 0131 537 3131

#### West Lothian:

GOSH  
Contact: Alex Topping  
01501 772154

#### Glasgow:

Glasgow Stoma Support Group  
Contact: Maureen O'Donnell  
01236 436479

#### Ayrshire:

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

#### Fife:

Fife Ostomy Support Group  
Contact: Ishbel Barr 01592 772200

### England - North

#### Cheshire:

Cestrian Support Group  
Contact: David Burgham 01244  
310461  
Stockport Support Group  
Contact: Angela Simpson  
0161 419 5059

TOMAS (The Ostomates of  
Macclesfield and Surrounding Areas)  
Contact: Kath Wood 01625 875442  
Warrington Ostomy Support Group  
Contact: Jane Shaw 01925 662103

#### Cleveland:

Oops Group  
Contact: Julie Morrisroe SCN/Carol  
Younger 01287 284113

#### County Durham:

Bishop Auckland Stoma  
Care Group  
Contact: Betty 01388 814535  
Jen 01325 311266 or  
Maureen 01388 818267

#### Cumbria:

Grange Cancer Support Group  
Contact: Marie 015395 33279

#### Derbyshire:

Stockport Support Group  
Contact: Angela Simpson  
0161 419 5059

#### Lancashire:

Oldham Stoma Support  
Contact: June Wilde 0161  
312 5538  
Tameside Ostomistics  
Contact: Paul Seavers 0777 1359046  
Trafford Bowel Care  
Contact: Jackie Carey (Secretary) 0161  
7489 659 Doreen 0161 9627 818  
John 0161 7484 655

#### Merseyside:

Crosby Support Group  
Contact: Stoma Care Nurse  
0151 529 2842  
Aintree Stoma Support  
Contact: Stoma Care Nurse  
0151 529 2842  
I.C.U.P.S  
Contact: Stoma Care Nurse  
0151 604 7399

#### Northumberland:

Northumberland Cancer Support  
Contact: Mary Miller 01434 622 392  
Jim & Dee - 01434 230 398

#### Tyneside:

NHS Molineaux Centre  
Contact: Stoma Care Nurse  
0191 2380011  
Royal Victoria Infirmary Support Group  
Contact: Gordon Weatherburn  
0191 234 1109

#### Yorkshire:

Airedale Stoma Support  
Contact: Jenny Shaw 01535 652516  
or Sue Hall 01535 210483  
Behind You (Calderdale & Huddersfield  
Bowel Cancer Support Group)  
Contact: Stoma Care Nurse  
01484 355062  
Barnsley-Bottoms Up  
Stoma Support Group  
Contact: Stoma Nurses 01226  
432528 or Celia Utley (Chairman)  
01226 284262

## SUPPORT GROUPS IN YOUR REGION

CROPS (Colo-rectal ostomy & internal pouch support)  
Contact: Gloria 0114 2879503  
Dewsbury & District Ostomy  
Contact: Janet/Eileen 0844 8118110  
Rotherham Ostomates Caring Support  
Contact: Karen 0788 0575758  
Scarborough Stoma Support  
Contact: Sister Jean Campbell 01723 342388  
Amanda Rowe 01723 342446  
The Hull and East Riding Colostomy Support Group  
Contact: Pete Smith 07989 565335 and Pete Rennard 01482 793966

### Isle of Man:

Stoma Support Group  
Contact: Carole Cringle 01624 650212

## England - Central

### Buckinghamshire:

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

### Nottinghamshire:

Nottingham Colostomy, Ileostomy & Urostomy Support Group  
Contact: Rosemary Brierley 0115 982 6691  
Nottingham Stoma Support  
Contact: Mrs B Heath 0115 966 3073  
North Notts Stoma Support Group (Sutton-in-Ashfield)  
Contact: Tore and Nicky Norman 01773 715460

### Shropshire:

Oswestry Stoma Support group  
Contact: Irene Constable 01691 238357

### Staffordshire:

Outlook  
Contact: Ernie Hulme 01782 324441  
Moirra Hammond 01782 627551

### Worcestershire:

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

### West Midlands:

Coventry Stoma Support  
Contact: Martin Robbins 02476402616  
Newhall Stoma Support Group  
Contact: Sarah French 07773 396236  
02476402616

## England - East

### Bedfordshire:

Saturday Social Club  
Contact: Karen Richards 01234 792278

### Cambridgeshire:

Ostomistics  
Contact: Alan Wright 01354 653290/07836 661102

### Essex:

Connect  
Contact: Lin Hart 01279 505273  
M.E.S.S (Mid Essex Stoma Support)  
Contact: Paul Foulger 01245 224374  
Jeanette Johnson 01376 511862  
N.E.S.S (North Essex Stoma Support)  
Contact: Mr Bill Hatch (Chairman) 01255 503688  
Brian Waller (Secretary) 01206 540449  
Optimistic Ostomates  
Contact: Angela Taylor/Carol Booth 01702 385509 or 01702 385510  
STEPS  
Contact: Jackie Coleman 01268 451937  
Redbridge Ostomists Club  
Contact: Stoma Nurses: Chris/Lisa 020 8970 8321

### Hertfordshire:

Connect  
Contact: Lin Hart 01279505273  
Colonise  
Contact: Anastasia 01727 760 981  
Hertford Stoma Support Group  
Contact: Ralda 01992 535311  
Stevenage Ostomistics  
Contact: Alfred Levy 01767 316958

### Lincolnshire:

Friends East Coast Support Group  
Contact: Betty 01205 724120/Sheila 01205 364493  
Grantham Support Group  
Contact: Bobbie/Amanda: 01476 464822

Email: grantham.colorectal@ulh.nhs  
March Group  
Contact: Maureen 01754 874 485  
Sutton Bridge and Long Sutton Ostomy Group  
Contact: 01406 351617

### Norfolk:

Kings Lynn Ostomy Friendship Support Group  
Contact: 01533 691370/768271 or 01533 775698  
Stars  
Contact: Anne Browne 01603 661751

### Suffolk:

East Suffolk Ostomy Group  
Contact: Marion Fisher 01473 311204  
James Pagett Ostomy Support Group  
Contact: Sandra Hutchings 01502 585955  
West Suffolk & District Stoma Group  
Contact: Jessica Pitt 01638 515525

## England - South East

### Berkshire:

EBOC (East Berkshire Ostomy Club - Bracknell)  
Contact: Jackie Dudley 01344 426652  
WBOC (West Berkshire Ostomy Club - Reading)  
Contact: Jackie Dudley 01344 426652

### Hampshire:

COGS (Colostomy Only Support Group)  
Contact: Sarah Anderson 07907 820125  
Solent Ostomates Support Group  
Contact: Carole Summer 07527 707069  
Solent Ostomates Support Group (New Forest Branch)  
Contact: Carole Summer 07527 707069  
Wessex Urology Support Group  
Contact: David Morris 02392 361048

### Isle of Wight:

Optimistics  
Contact: Stoma Nurse Natalie Sayer SCN 01983 534009  
Semi Colon Group Isle of Wight  
Contact: Tony Crowson Chairman 01983 559326

### Kent:

Ashford Stoma Support Group  
Contact: Ron Huckstep 07941 310681

Margaret Webb 01233 628807  
Atoms Support Group

Contact: Maria Culleton SCN  
01227 769679 or 07827997424

Dover & District Stoma Support

Contact: Maria Culleton SCN

01227 769679

Dover Stoma Friends Group Support

Contact: Julie Bell & Ros Marshall

07771345701/01233616646

Maidstone Stoma Support Group

Contact: Judy or Kirsty

01622 224305

Medway Ostomy Group Support  
(MOGS)

Contact: Val Solly or Helen or Tracey

07773 605534

### London:

Homerton Hospital Bowel & Stoma  
Support Group

Contact: Toni Johnson 0208 510 7599

Angela Davy 0208 510 5318

Shepherd Bush Stoma Support Group

Contact: Roslyn 0208 354 0121

or Jackie 0208 740 4790

South Woodford Support Group

Contact: Christina 0208 5356563

Surrey & South London Bowel Cancer  
Support Group

Contact: Sue Berry: 01737 553134 or

John Amos: 0208 668 0796

### Middlesex:

Inside Out

Contact: Bob (Chairman) 0208

4284242 Sarah Varma 0208 2354110

Semi-Colon Club

Contact: Pat Black/Katheryn Foskett

01895 279391

### Oxfordshire:

Oxfordshire Ostomy Fellowship

Contact: Pat Longworth

01235 524163

### Surrey:

Epsom & District Stoma Support  
Group

Contact: Sheena 01372 735925

### Sussex:

(SAS) Brighton & District Stoma Care  
support

Contact: Sylvia Bottomley

01273 554407

The Ostomy Friends Group

Contact: Jane Quigley 01323 417400

Ext 4552

West Sussex Princess Royal Stoma  
Support

Contact: Tina Walker 01444 441881

Ext 8318

## England - South West

### Avon:

B.O.S.S Bristol Ostomy Self Support

Contact: Christina 01179 075326

Joyce 01179 558236

Rob 01179 668021

### Cornwall:

Hayle's Angels Stoma Support Group

Contact: Sue Hatton

01326 340058

Ostomist and Carers Support Group

Contact: Christine Davey

01208 831471

Optimists

Contact: Sue Hatton 01326 340058

### Devon:

Mid Devon Ostomy Group

Contact: Janice Parkyn

01363 776417

Devon IA

Contact: Margaret Bond

01392 447374

Devon Stoma Support Group

Contact: Donna Ashbrook

01626 854862

### Dorset:

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

Contact: Colin Clare

01305 853 288

### Wiltshire:

Swindon IA

[www.swindon-ia.org.uk](http://www.swindon-ia.org.uk)

Wessex Stoma Support Group

Contact: Michael Slater 01722 741233

## Wales

Blaenau Gwent Self Help

Contact: Celia McKelvie

01873 852672

Bridgend Ostomy Patients  
Support Group

Contact: Anita Brankley (Secretary)

01656 645602 or

Pat Jones 01656 786103

Royal Glamorgan Stoma Care  
Support Group

Contact: Domenica Lear

01443 443053

Swansea Ostomy Self Help Group

Contact: Glynis Jenkins 01792 418245

## Northern Ireland

Antrim Area Stoma  
Support Group

Contact: Chris Wright

07720 717771

Belfast Royal Victoria

Contact: Sarah Haughey/  
Audrey Steele 02890 240503

Ext 3483

Causeway Patient

Support Group

Contact: Mary Kane 028 70 346264

Colostomy Association

Volunteers Northern Ireland

Contact: Chris Wright

07720 717771

Daisy Hill Hospital Newry

Contact: Bernie Trainor

028 3883500 Ext 2222

Mater Hospital Belfast

Contact: Karen Boyd

028 90741211 Ext 2329

North Down Stoma

Support Group

Contact: Adrian Ewing

07850 741511

Southern Trust

Contact: Mary Jo/Bernie

028 38612721

Ulster Hospital

Contact: Hazel/Martina

028 90 550498

## Eire

Bowel Cancer Support Group

(Irish Cancer Society)

Contact: Olwyn Ryan

+353 12310500

Mayo Stoma Support

(Castle Bar Hospital)

Contact: Marion Martyn

094 902 1733

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		Code: TGN50 Size: 50ml
<b>NEW</b>	<b>Smooth and fresh VANILLA BEAN</b>	Code: VBN25 Size: 25ml
		Code: VBN50 Size: 50ml
	<b>Clean and fresh MINT</b>	Code: SPN6 Size: 25ml
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