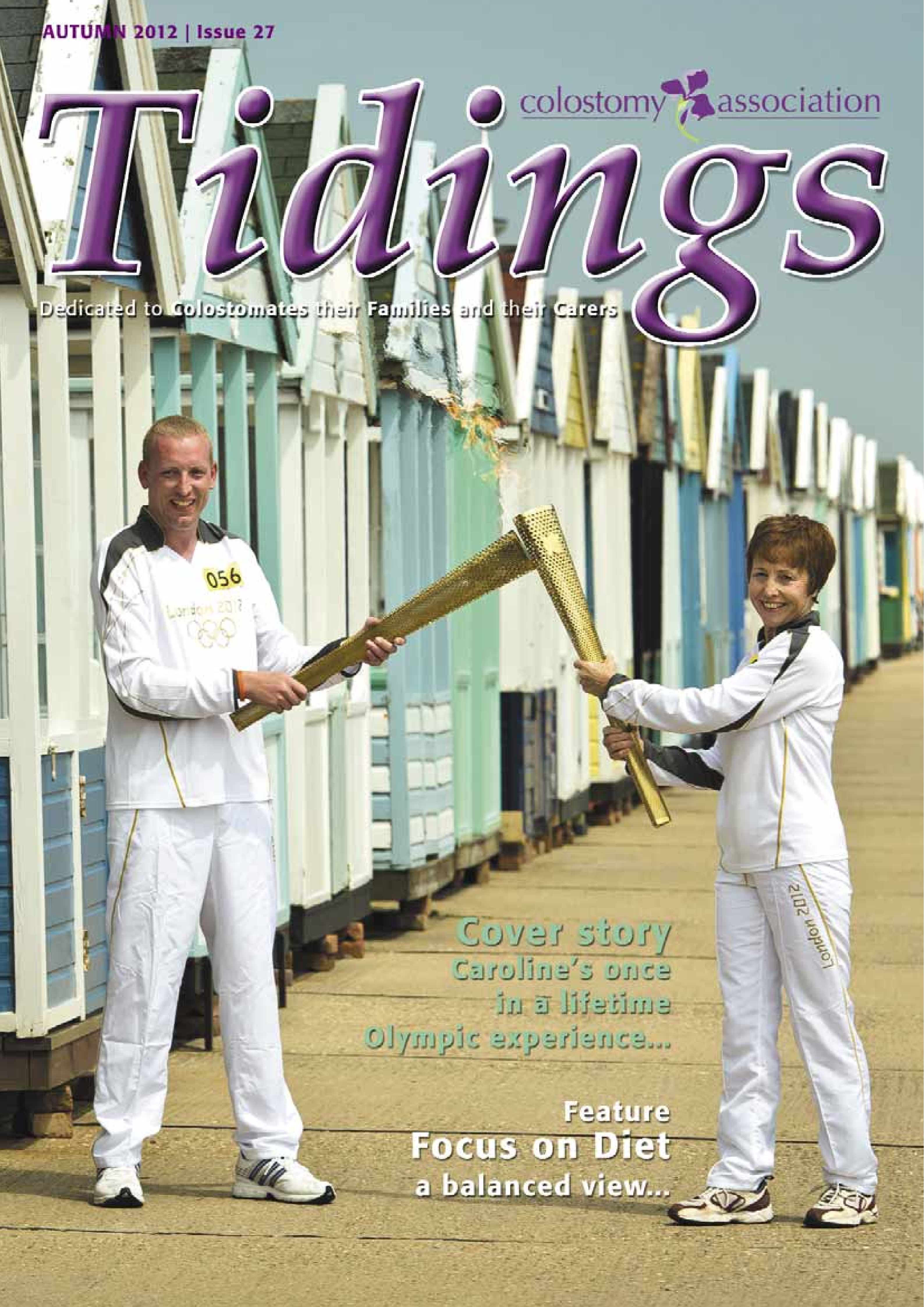
AUTUMN 2012 | Issue 27

# Tidings

colostomy association

Dedicated to Colostomates their Families and their Carers



## Cover story
Caroline's once in a lifetime Olympic experience...

## Feature
Focus on Diet
a balanced view...

**Brava™**

“I didn’t think
I could find
a tape that
would fit my
body shape.”

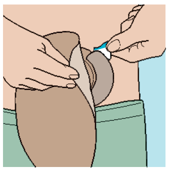
Steve, an ostomate since 2003

# Think again. Think Brava™

## Now there is an elastic tape that prevents baseplate edges from lifting

The new Brava Elastic Tape is elastic, which enables it to follow your natural body movements while keeping the baseplate in place for extra security. The new elastic tape is skin friendly and can also prevent the baseplate edges lifting, which can mean longer wear time.

Brava Elastic Tape is part of the new range of accessories from Coloplast, designed to reduce leakage and take care of your skin.



### How to use

Apply the Brava Elastic Tape to the baseplate and the skin where desired. Remove the remaining protective paper and smooth the tape onto the skin to ensure the baseplate is kept in position.

**See full instructions for guidance on how to use this product.**

## Sign up for free samples at brava.coloplast.co.uk or call our customer care team on 0800 220 622

Ref: ocacc0512

www.coloplast.co.uk

**Coloplast**

## To receive your free sample please complete the following:

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# welcome to AUTUMN

## Did you know...

**Manchester airport** is to ditch its controversial security ‘body scanners’ when a trial of their use comes to an end shortly.

The machines will be replaced by next generation ‘privacy-friendly’ scanners because the European Commission has not approved them for permanent use.

Five ‘ProVision’ scanners already in use at Heathrow airport will be installed. New software for the scanners turns the scan into a stick-man like cartoon with ‘suspect’ areas highlighted as yellow squares.

In the meantime, an additional 55 full-time security staff have been employed who will manually frisk passengers.

**Read more at:**
**http://www.dailymail.co.uk/travel/article-2204387/Manchester-airport-axes-controversial-naked-scanners-EU-fails-approve-them.html**

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

In the spring issue earlier this year I mentioned that 2012 was going to be a special year for our country and even though the years not quite out I think this has proved to be true.
With the Queen’s Diamond Jubilee celebrations in June and the incredible opening and closing ceremonies and athletic performances of the Olympics and the Paralympics in July and August how could 2012 be anything other than special! What strikes me most about each of these events is that although they focussed our attention on human performance and the achievements of the individual as well as the team – their lasting legacy will be their reach into the hearts and minds of thousands of people around the UK and the World.

The involvement of ‘the people’ was for me the ‘key’ ingredient making each event not only ‘memorable’ but ‘great’. There was a real sense of camaraderie across our nation – a joining of communities empowered to showcase to others ‘who and what was important to them’. The bringing together of people from all walks of life. Celebrating some people for ‘just being who they are’ as well as recognising others for their ‘courage, endurance and overwhelming urge to succeed’ (sometimes against great odds) this led to many of us re-evaluating our own lives.

The cover of the autumn issue of Tidings shows ‘Olympic Torchbearer’ – Caroline Emeny taking the Olympic flame forward on day 48 of the Torch Relay at Southwold in Suffolk. Caroline was one of 8,000 torchbearers who each had a truly inspirational story to share. You can read Caroline’s story on Page 32.

Reaching out to people is the main aim of the Colostomy Association. We exist to provide vital ongoing support to children and adults who, due to serious illness or trauma, have life saving surgery often resulting in a permanent stoma and colostomy. The impact on their lives and the lives of those around them cannot be underestimated. The CA provides support, reassurance and practical advice to colostomates, their families and their carers. Through our work we seek to find others who may need our support and services but as yet have not discovered us. We do not want any person to feel they are alone.

On Saturday 6th October the United Ostomy Association of America joined with ostomy associations around the globe to celebrate World Ostomy Day and Ostomy Awareness Day – the theme ‘Lets Be Heard’ – so, via this issue of ‘Tidings’, let’s ‘loudly’ voice our support and raise awareness for everyone ‘living with a stoma and colostomy’ in UK and around the World. If we do this – we may well engage with colostomates who have yet to find the Colostomy Association!

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

Jane

**Email:**
**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.**

# inside

## all your regulars

## cover story

**Caroline Emeny...London 2012 Olympic Torchbearer**

**Real Lives**
featured on page 32

# ...this issue

## & special features

### update...

### real lives...

### health...

### travel...

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

Contact CA office on
0118 939 1537

### support...

### interest...

# 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**
2 London Court,
East Street, Reading RG1 4QL

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:

Find us on Facebook

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

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

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

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

①

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

JustGiving

②

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

## 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 | 2012 |
| Summer | July | 2012 |
| Autumn | October | 2012 |
| Winter | January | 2013 |

## EDITORIAL TEAM

### How to contact the Editor

**By letter write to:**

**The Editor**
**Colostomy Association**
2 London Court
East Street Reading
Berkshire RG1 4QL

**By telephone:**
**0118 939 1537**

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

**or alternatively e-mail:**
**jane.wood@colostomyassociation.org.uk**

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New FreeStyle Vie® Convex is ideal for you if your stoma is recessed. Its advanced, flexible flange means you can feel secure with a leak-free fit. Combined with the comfort of a skin-friendly pouch, belt loops for added protection and a split back for easier monitoring, FreeStyle Vie® Convex is designed with your individuality in mind – helping you regain the freedom to do the things you love.

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# In touch – update from the CA office...

**Dear Readers...**The Colostomy Association continues to reach out via its staff, volunteers, support services, Tidings magazine, website and increasingly through its 'closed' Facebook group...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 almost 100 trained CA volunteers across the UK and in November this year we will be training our latest new recruits. One of our newest volunteers lives on the Island of Alderney and she will be supporting ostomates living in the Channel Islands. 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.

## Jo No. 2 joins the CA to increase admin support...

We are pleased to announce that our 2nd full time administrator joined the admin team at the end of July and this has allowed us to improve the quality of service we provide to our supporters.

## New support groups...

New support groups have recently started up in Crediton, Fareham, Norwich, Oswestry and Tameside. For further details please refer to our website or the support groups listing at the back of this issue of Tidings.

## Sam has a stoma...

Sam has a Stoma - This story colouring book is an ideal resource either for those caring for children with a stoma or to pictorially explain to a child that a parent has a stoma.

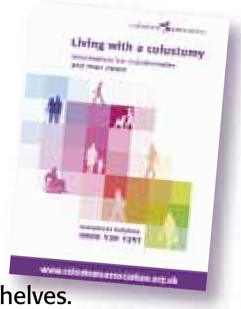
A copy can be downloaded from our website at www.colostomyassociation.org.uk on the 'Young Ostomates' webpage, ordered by phone 0118 939 1537 or via email: cass@colostomyassociation.org.uk

## Updating patient support literature...

Several leaflets are being revised and when ready will be downloadable from our website: Rectal discharge, Irrigation, Healthy eating and Reversal. So please keep checking the website.

If you have any ideas for future support materials please email the editor@colostomyassociation.org.uk

Available now on our website...newly revised 'Living with a Colostomy'...



We openly welcome donations towards printing and postage costs...as our patient literature flies off our shelves. If you can help – it would be much appreciated!

## 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:
**2 London Court, East 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.

Please **tick** the following as appropriate:

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

☐ I would also like to receive an optional photo ID card for an additional charge of £6.50 and enclose a passport ID photograph.

☐ I attach a copy of my prescription or recent delivery note as proof of eligibility and a cheque made payable to 'Colostomy Association' in the sum of £3.50* key only/£6.50* ID card only/£10.00* both the key and ID card (*Please delete)

Signature of self or carer: Date: / /2012

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


Handle with care
Appeel
No sting
Medical Adhesive Remover
Appeel
NO STING
Medical adhesive remover

# Pathways to a Colostomy...

**Following almost a decade of stress – marriage, divorce, redundancy, relocation, nursing her dad through cancer. Jo Gedik began to feel unwell on a regular basis...due mainly to Diverticular disease...at the age of 42 Jo underwent dual surgery – a Hartmann's Procedure and Salpingo Oophorectomy (surgical removal of one or both ovaries) this is her story...**


Jo Gedik

> **I guess my story started long before I even anticipated that medically things were not quite as they should be...**

Readers' PANEL contributor

My mind has gone over why at the age of 42 I have ended up with a colostomy as the result of dual surgery. By the time the surgeon told me I was to undergo a Hartmann's Procedure and Salpingo Oophorectomy (surgical removal of one or both ovaries) I was in the midst of losing any sense of reality and already slipping into a state of mind where I was unlikely to 'take in' anything that the medics had to say. I cannot remember signing the consent form and have a vague memory of my stoma nurse drawing two large circles onto my tummy with a black marker pen prior to being wheeled into theatre. I didn't really register what she was doing and nor at that stage, did I care. The pain was hellish.

I guess my story started long before I even anticipated that medically things were not quite as they should be. As a result of a number of years on the road at work, eating on the hop, pondering over hotel menus and experiencing the stresses and strains of project management, I hasten to add that I did not exactly treat my body with care. In hindsight, I believe that my lack of healthy eating and fibre in my diet, constant juggling of home and work life was to blame for the onset of diverticulitis. Put simply I did not exercise regularly, ate junk food and lived on a few hours of sleep daily.

If I recall, my very first symptoms came in 2003. I had spent a year living in Turkey and thought that the excruciating pains in my stomach were due to a change in diet. I put the episode down to a one off and pushed it to the back of my mind. Despite several re-occurrences, I convinced myself that I really was ok and made the excuse that I was always too busy to visit my local GP. For one second I did not think that I would be prone to any bowel related disease. I was young and invincible.

Following almost a decade of stress – marriage, divorce, broken relationship, redundancy, relocation, nursing my dad through cancer, I was starting to feel unwell on a more regular basis. I think people actually thought I was 'kidding' when I said I had stomach pains. After all, it's a good get out to taking a day off.

My lovely mum had been diagnosed with diverticulitis around 2005 and I started to notice that my symptoms were very similar to hers. Even now, she always says that I am like Dolly – a clone of her. Despite the joke, we had always assumed that there was no genetic link to this disease but in 2009 I was rushed into my local hospital – New Cross, Wolverhampton. I recall lying in the bed during a summer heat wave and just wishing that the pain would reside. I underwent a laparoscopy and was told that not only did I have a left ovarian cyst but that the outside of the bowel also looked slightly suspect. I wondered what that meant but was told that I had to return to see the consultant to discuss diverticular disease. Despite trying to manage the condition with Movicol and diet, I endured further episodes and in fact a further hospital stay. I remember watching the ‘X Factor’ whilst rolling with the wave of intermittent pain. In addition, fertility tests indicated that there might be some other issue.

The final part of my journey came in April of this year – 2012. I had resumed work after having to take a week off with pain and was taking a training course in Nottingham. I drove home feeling rather unwell and by the time I had reached my door, I was standing on my tiptoes, grasping at anything I could get my hands on. It was too late for an appointment and that night I submerged myself in 3 or 4 hot baths, loaded a hot water bottle onto my tummy and dosed myself with painkillers whilst my partner Metin slept unknowingly. My local surgery could not fit me in the next day and I was referred to a local clinic where the doctor took one look at me and said, “I’m calling an ambulance”. My temperature was up and indicated infection.


Jo pictured with Metin

Much of the next 10 days were a blur. During emergency surgery, they found that my bowel had a pinhole and was leaking; an abscess had formed which fused my bowel together with my left ovary and fallopian tube. Inside I was a complete mess. Critical Care followed my 8 hour operation and I lost 10 days of time. Mum tells me that an old friend came to visit but I have absolutely no recollection. I do recall seeing spiders on the ceiling and the inside of the washbowl being furry. Apparently I am allergic to all opium based painkillers. My mum told me that I commented she had ‘a face like a lion’ and I told my dad that ‘I hated his freckles’. Hallucinations were much a part of my hospital stay. My mum told me that she and Metin had been sitting by my bedside lost for words at my suffering, when I bolted up and said ‘look at you pair, you’re like two statues sitting there; one black and one white’. I felt mortified at my lack of political correctness whilst ‘out of it’. Metin is Turkish and I would never dream of ever commenting on such a thing as skin colour. It just indicated how sick I was.

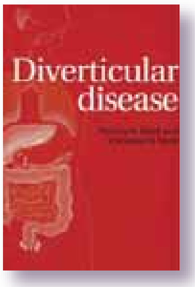
The worse part of Critical Care is when physiotherapy encourages you to stand and try to walk. That day, I was shaking and felt as though I was going to faint but I made myself get up and walk. I wanted to get home - 14 days after surgery I was - and attached to me was a colostomy pouch alongside a very big vertical scar. I counted up to 60 staples but couldn’t quite bend to count them all. I still cannot believe that I am a colostomate but the operation saved my life. When my pouch makes an impolite noise in public and I gingerly explain to people, they always comment that ‘surely I am far too young for that’. I have been off work for 12 weeks now. Psychologically I am getting used to the idea and I call my Stoma ‘Badger’ after my surgeon. In fact I should call it ‘Mrs Mirza’ as I believe she was the surgeon who actually repaired me with Mr Badger looking over. I am thankful to both. Physically I have had some tough times but I am getting there. Due to the dual surgery, the wound has been challenging. The people around me have been amazing and differ in their reactions. My stoma nurse is an incredible woman called Clair Higgs. If only she knew what a wonderful persona she has for supporting patients – she is so kind and gentle. My brother cannot cope with seeing ‘IT’, my mum, dad and Aunty Sue have been complete and utter rocks, my friends Janique, Bally, Robbo, John and work colleagues Sue and Steve have been truly supportive.

The person who has taken the brunt of my tears and pain has been my boyfriend Metin – he has been so kind to me that I could get quite emotional when I describe his support. Despite coming across as a toughie, he stands in front of me and shouts ‘left a bit’, ‘down a bit’ when I am fitting my pouch. I am thankful to all of these individuals, as their words have pulled me through. And of course myself – I am proud of my own courage. Sometimes you feel as though life is caving in but you have to keep the spirits high. So what if I have to wear bigger knickers and so what if I have to wear a swimsuit instead of a bikini – if that is the only issue then I’m lucky I’d say! Look around in this world and see the pain and suffering of some who have no power to make themselves better.

Of course some days I get angry and frustrated but most of the time, I think ‘just how clever these surgeons are’. They actually saved my life. My only sadness is that I was about to start a family and now that may not be possible due to the removal of the ovary and fallopian tube. I guess this is life and one life it is – one to be lived to the full, one to be enjoyed and to be thankful for.

I may only be 42 years old and 12 weeks down the line but I am still smiling. My friend John Dooner told me once…‘Jo you are in a storm, but one day you will come out the other side, the seas will be calm and the sun will be shining’.

Such words of wisdom just keep me going. And if you are reading this and struggling to come to terms with being a colostomate and need someone to lend a hand – then mine is here.



**Editors Comment**

If you are interested in learning more about **Diverticular Disease** the above book is available.

Paperback
ISBN 1 86156 446 5

Pat Black (Author)
Christine Hyde (Author)

# **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 27**....
Thank you!

### Dear Tidings...

I have suffered from M.E. and Crohn's disease from the age of 11. Up until recently I have not been able to do any physical activity or sport so as a result I am extremely unfit. I was also housebound with restricting and horrid symptoms due to scarring from Crohn's. Last year before my stoma operation I decided I needed a goal to focus on – climbing Snowdon!

I knew after I had my stoma surgery I wanted to get fit and definitely climb Snowdon along with my family and my dog Maizy - who have supported me through some very tough times.

The Colostomy Association has been really supportive over the months with Neville (my stoma!). It has been a steep learning curve managing Neville's habits and tantrums – when I had any questions or just wanted a chat with people in a similar situation – the Colostomy Association was there for me!

I am now nearly 20 and have a transformed life. I have learnt Colostomy Irrigation, which has given me so much more freedom. I have a job waitressing, which is something that would have been impossible before Neville and I am also going to University to train to become a Paediatric Nurse.

I completed my climb up Snowdon on May 22nd! I have little muscle strength, as I have been unable to participate in any form of activity since age 11 so Snowdon was a big challenge! I have to say it was the best experience – really hard but the views were outstandingly beautiful.

When I reached the top it was such an achievement and I thought, 'if I can do this, I can do anything!' I don't regret having Neville at all. I wanted my life back and I knew what I had to do in order to achieve just that – it was daunting but the pro's outweighed the con's by a million miles!

It was a great moment on top of Snowdon – but what was even greater was knowing I was raising money for such a deserving charity. I am still fundraising and to date have raised £800.00 if you would like to add to this amount please visit: www.justgiving.com/MollyandNeville

**Thank you everyone for your kind donations**

**Thank you for your help,**
**M.B**

### Legacies...

| | |
|---|---|
| K Simister | £ 5,861.52 |
| G Wright | £ 5,003.04 |

**Thank you**

### In Memory...

| | |
|---|---|
| Mrs M A Lee | £ 91.80 |

**Thank you**

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

| | |
|---|---|
| Mrs P Swindells | £ 237.00 |
| Mr R Huckstep | £ 118.50 |
| Mr P Martin | £ 47.40 |
| Mr P Grogan | £ 47.40 |
| Mr P J Davies | £ 47.40 |
| Mr H Carson | £ 23.70 |
| Mr J K Mold | £ 23.70 |
| Mr D R Fenwick | £ 23.70 |
| Mr & Mrs D Price | £ 11.85 |
| Mr C Kendrick | £ 11.85 |
| Mrs D Garratty | £ 11.85 |

### Dear CA,

Your charity was recommended to receive a donation by one of our local Branches in the Yorkshire area. Please accept a donation for £1500 in respect of St. Clare's Hospice the proceeds raised from an event held in April.

**Yours sincerely,**
**J.T**
**Usdaw**

### Dear CA,
### 80th Birthday Celebrations...

I had my 80th birthday celebrations at the end of June this year, and asked for donations instead of birthday presents. As a result I have great pleasure in donating £85.00 towards your good works.

**Yours sincerely,**
**Mrs S.R.K**

### Dear Tidings,
### Annual Coffee Morning

I am pleased to be able to send you a donation of £250.00 which has been so kindly donated to me for this event.

**Mrs R.G**

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

colostomy association

## Donation Form

# The **Colostomy Association** is an **independent charity financed solely by donations.** Your **help and support** is **now 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 - we need to be here for them!**

### Here's how **your donation helps us** make a **difference**...to **fellow colostomates**

**We provide:**

- **An Outreach Programme** CA's own Open Day event for ostomates.
- **Advisory literature,** written by colostomates and health care professionals.
- **A quarterly magazine 'Tidings**' especially written for colostomates, their families and their carers.
- **A telephone helpline 0800 328 4257** manned 24/7 365 days a year!
- **Around a hundred contact volunteers cover the UK** fully trained and experienced, (who are ostomates) these dedicated individuals bring a human touch.
- **Patient visiting** a volunteer at the request of a stoma care nurse can visit a patient/s before their colostomy surgery, and afterwards in hospital. Home visits can also be arranged.
- **Attendance at organised stoma care nurses 'open days'**, that you can visit and where you can learn more about your stoma, in a friendly atmosphere and discuss any problems.
- **Attendance at manufacturers' and suppliers', 'open days' and exhibitions.** This allows us to 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.

### Here's how **YOU can continue to support us... simply by making a donation** you will **ensure our survival...here's how**

- **Regular Donation:** Regular donations can be made via standing order (see Donation Form overleaf). Regular donations help us to plan ahead and carry out our agenda. Every donation is vital to the charity's survival.
- **Single Donation:** Single donations from individuals, 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.
- **Donate via Telephone or online via our Website:** These donations are easy to make...and are secure. Telephone donations are via RBS WorldPay simply call the Colostomy Association office during working hours to donate. To donate online visit: www.colostomyassociation.org.uk
- **Legacy donation - A gift in your will:** If you are about to make a will, or are considering making a change to your current will, please consider leaving a legacy to the Colostomy Association. Your legacy could secure the Association's future and provide continued support to all those 'living with a colostomy' present and in the future.

## The **Colostomy Association** continues... with **YOUR help,** to **give support** and **reassurance** to **both experienced colostomates** and **those who are new to 'living with a colostomy'.**

**Your donation** to the **Colostomy Association...**will mean we can **reach out** to other **colostomates** their **families** and their **carers** with **support, reassurance and encouragement.** With your **help** we really **can** and **do make a difference - thank you**

**Please turn this page to donate today Thank you...**

To donate...Please fill in the form on the next page and return to the address overleaf - thank you

# Donation & Standing Order Form

## Thank you for your support

colostomy association

Please use this form to make either a **Regular donation** by **Banker's Standing Order** or **Single donation.** Simply **complete this form** and return by **post** to the **Colostomy Association 2 London Court, East Street, Reading, Berks RG1 4QL.** Telephone: **0118 939 1537** if you have any queries.

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

**My Details:** Title: Name: Surname:
Address:
Postcode:
Telephone number: Email:

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

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

## 1 Regular donation:

I would like to make a **regular contribution** to the **Colostomy Association** every **month/quarter/year** in support of the charity. I have ticked the appropriate box below and filled in the amount. I have also completed the **Banker's Standing Order Form** ☐ (Please tick.)

☐ Yes, I would like to make a regular donation of £ ☐ **Monthly** ☐ **Quarterly** ☐ **Yearly**
(Please tick.)
**(Important: Please tick your preference above.)**

### 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:
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**
the sum of £ amount in words:
**Date of first payment:** and thereafter on the same day every month/quarter/year)*
(*Delete as appropriate) until further notice. (Please cancel any previous standing order in favour of this beneficiary )
Name: (IN CAPITALS)
**Signature:** **Date:** / / 2012

## 2 Single donation:

(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 -** My donation is £

I enclose a **cheque/postal order form** made **payable** to the **C.A. Ltd - Thank you!** **Yes, I require a receipt** (Please tick.) ☐

giftaid it

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

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

**Thank you for your gift**

**Signature:** **Date:** / / 2012

Registered Office: 2 London Court, East Street, Reading RG1 4QL Registered Charity No: 1113471

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


SOS
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BARRIER CREAM
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LBF
BARRIER CREAM

# 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.**

## Introducing Deo-Mint - a brand new deodorant from Pelican Healthcare Ltd.

With a refreshing spearmint fragrance, Deo-Mint perfectly complements Pelican's existing range of accessory products, including the Pelican Protect Plus Non Sting Barrier Film and the Pelican Release Adhesive Remover.

Deo-Mint contains 'special molecular bullets' which target key types of odour, completely eliminating the odour, rather than just masking it.

Deo-Mint is available on prescription in a 50ml pump action spray, which means that not only is it environmentally friendly, you also get 100% active liquid in every bottle, so no waste at all.

**Why not try Deo-Mint today? To request your free sample please complete the coupon on the Pelican advert in this edition or, call Pelican Healthcare on 0800 052 7471.**

## Make Ballooning problems a thing of the past with the Osto-EZ-Vent!

OstoMART are pleased to announce that we are the UK distributors for the award- winning NUMBER 1 US preferred air release method called Osto-EZ-Vent .

Osto-EZ-Vent is a leading venting device suitable for use on all one or two piece drainable and closed pouches. Osto-EZ-Vent simply attaches to your pouch and enables you to quickly release air that has built up in the pouch causing it to balloon. It also prevents pouches from bursting and flanges from pulling loose. All it takes is a quick, discreet "pop open, snap close" of the vent cover and the pressure is relieved!

Because the Osto-EZ-Vent is not a filter, it works efficiently for the wear life of the pouch and is not made ineffective by water. Osto-EZ-Vent fits on any type of pouch and is simple and easy to use, providing pouch users of all ages with comfort, freedom and confidence.

**To order your free sample of the Osto-EZ-Vent just call freephone 0800 220 300 or visit www.ostomart.co.uk or email enquiries@ostomart.co.uk**

**Osto-EZ-Vent - the simple solution to your ballooning problems!**

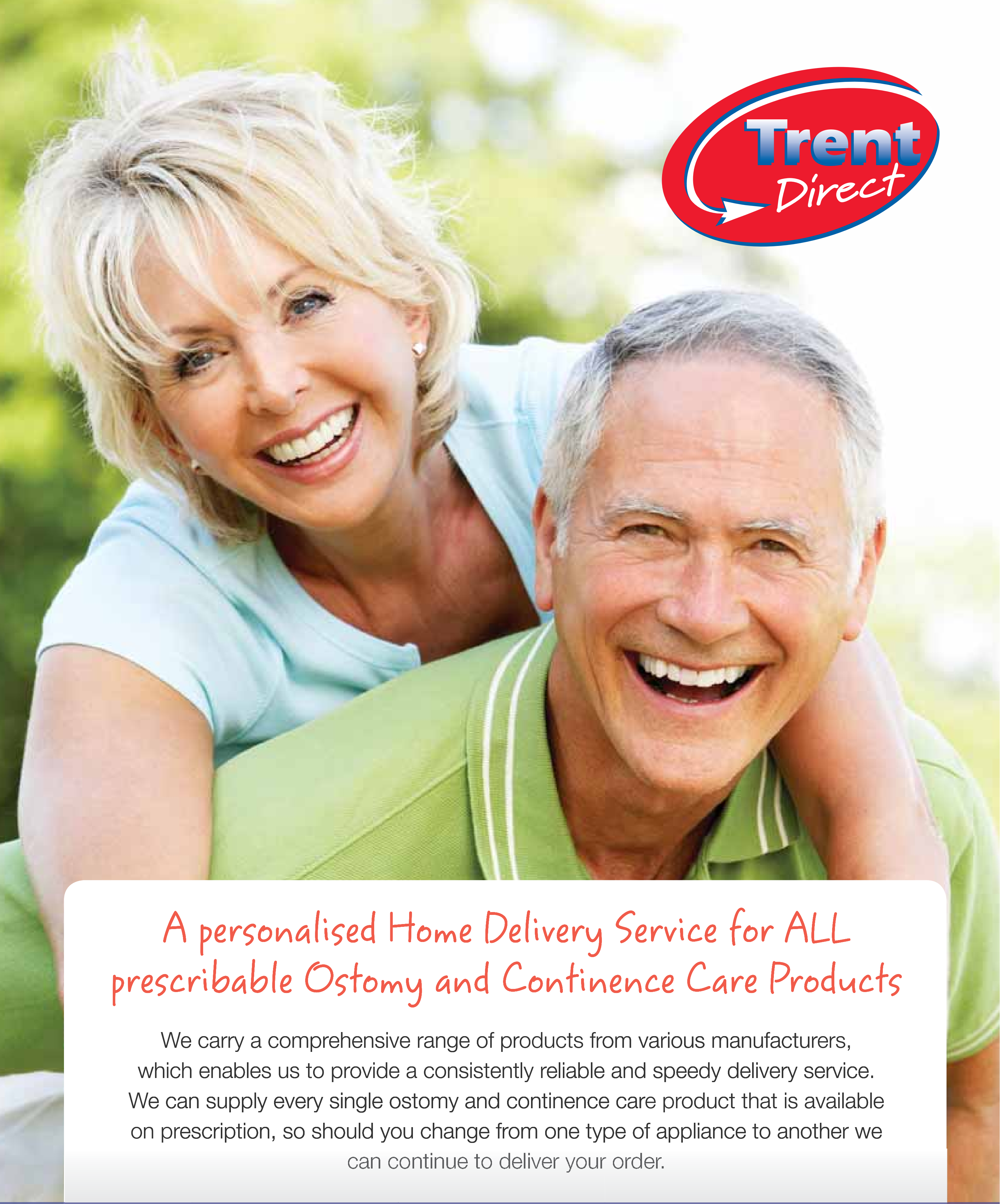
independence
PRODUCTS LIMITED

Independence Products are pleased to announce that all of their stoma accessory products are available through the UK on prescription but can now also be purchased privately through Stomawise, a UK information support charity for people who have a ileostomy, colostomy or urostomy.

The Stomawise website address is www.stomawise.co.uk and the our products can be found in the Stomawise Store.

stomawise

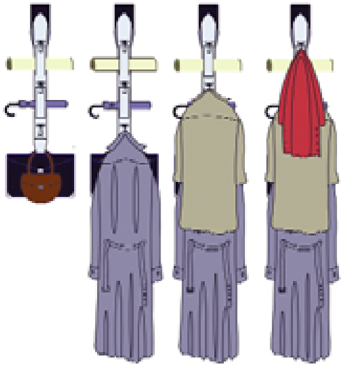
**Any enquiries please call us on 0115 9757254 or via email on enquiries@ independenceproducts.co.uk**



## Invented and developed by an Ostomate...for Ostomates!

### Tidy Pal is an award wining answer to the lack of hooks in toilets and changing rooms and weighs less than an apple.

Tidy Pal fits any type of door (for stall doors and partitions there is a special hook included) and needs no tools or fixing. Easy to use and fully portable it will support heavy winter clothes, an umbrella, newspaper and bag (Shopping, Lap Top, handbag) plus an Ostomy supply bag. After use, it folds into its own case.



### Make your life easier today! Use Tidy Pal...a unique portable storage device for use when travelling, shopping or on holiday!

**For more information, please visit the web site http://www.tidy-pal.com or e-mail sales@tidy-pal.com or phone 0795 431 8944**

## Comfizz are supporting juniors...

As well as the current range of underwear and waistbands for juniors we have now produced the girls and boys support vests. This complete range of discrete and stylish support wear allows children to be as children should be...carefree, to play without concern for their stoma...Seamless and breathable for comfort – longer length than standard vests for greater coverage to prevent riding up – keeps everything covered up and securely out of the way – gives discretion when changing for PE at school... comes in fun colours, so attractive for children. **Available in August to purchase at www.comfizz.com or on prescription...For more information call 01757 229 531**

ConvaTec

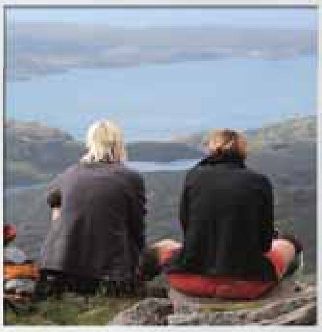

Excitement


Liberation

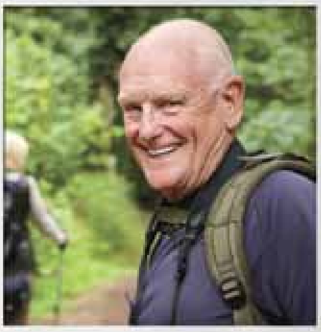

Normal

# WHAT'S YOUR WORD?


Control


Freedom


Exhilaration


Empowered


Comfortable


Secure


Confidence

## Don't just take our word for it. Vitala™ Continence Control Device (CCD) is already changing lives for the better

The single-use, disposable device provides faecal continence using non-invasive, pouchless technology. Vitala™ CCD is helping to make everyday life for people living with an end colostomy more manageable. To see if Vitala™ can support you call us on 0800 467866, email vitala.webcare@convatec.com or visit www.vitala.com

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Not all images represent actual product users. © iStockphoto

Vitala™ ConvaTec

AP-012572-GB July 2012

VIT7

# "Vitala™ puts you in control."

**Originally from Merseyside, Chris Connor, 53 years old, had always been fit, active and a Liverpool FC fan. When not busy working or raising his family, he liked walking and swimming and every year looked forward to beach holidays.**

But over the past nine years, Chris has been fighting cancer and recovering from three major operations. He was first diagnosed with cancer of the urethra, had the tumour removed and his urethra resectioned. The cancer then spread to his bladder and three years later his left kidney was removed when a tumour was found.

For five good years, Chris was free of the cancer and back at work and enjoying life.

In January 2010, screening identified bowel cancer. It had spread to his lymph nodes, so he had an intensive course of radiotherapy to shrink a tumour in his rectum before the operation to remove his bowel. In March that year the tumour was removed, leaving Chris with a stoma. He spent a few weeks in hospital recovering and getting used to the stoma.

He had barely returned home when he developed an infection and an abscess in his abdomen forcing him to be readmitted. Chris had reached a really low point. He became very ill and found himself back in hospital on antibiotics having the abscess drained.

He was finally able to leave hospital in May 2010, but needed to recover more fully before he was able to start chemotherapy.

## Missing his active lifestyle

Coming out of hospital with a stoma, Chris was very down. He felt too young to be facing the rest of his life constrained by a colostomy bag. He says: "I was depressed by the thought that the days of taking my shirt off on the beach and getting in the sea were over."

But his stoma nurse brought him some news which helped him think more positively about his life as a new ostomate. She knew it would mean the world to him to get out and about again and to feel confident enough to go on holiday. She wanted to help him build up his physical and emotional strength before the next course of chemotherapy.

Knowing Chris's full medical history and his desire to be more active, she thought he would be a suitable candidate for an innovative new device from ConvaTec, the Vitala™ Continence Control Device (CCD).

"You get used to it, forget you've got it and get on with your everyday life."

Chris admits to being very depressed knowing that his stoma would probably be permanent, so when he saw Vitala™ CCD it appealed to him. "I was intrigued by the low profile of Vitala™," he says, "I thought it was really exciting!"

"I tried Vitala™ and quickly got used to it, so the first thing I did was book a week's holiday for my wife and I to Portugal," he says.

Chris continues: "I wore Vitala™ on the plane out and planned the days of our holiday so that I could use it for 8 to 10 hours a day. That's a long time not having to worry about where the toilets are. Vitala™ really puts you in control."

Once on the beach, Chris could not resist the lure of the sea: "I was on the beach, wearing my swimming trunks and Vitala™ and I thought: that's it! I went running straight into the sea!"

As he came out of the sea his wife took a photo of him walking back to the sunbeds. His stoma nurse has been very supportive, so sent her the photo straight away saying: "Thanks. Without Vitala™ I wouldn't be able to do this!" "She was really chuffed!" he says.

**"A stoma doesn't have to change your life completely."**
Chris's wife and family have been very supportive throughout and are proud of how he has coped with his stoma.

He explains: "The stoma doesn't just affect you, it affects your partner as well. A stoma is an embarrassing thing to have and you worry that it isn't nice for the other person. It does take time but if you can get over that hurdle, you can lead a fairly normal life."

"A stoma doesn't have to change your life completely. I work with people who have no idea I have a bag or Vitala™ on. You get used to it, forget you've got it and get on with your everyday life."

**"Vitala™ has helped me lead a normal life."**
After 14 months off, Chris is now back at work. His job as a technical operator for a national water company takes him out in the field, which can be tiring. He is coping but admits that it was tough to start with. His friends have also helped motivate him to get on with life.

He explains: "During 2006 a group of workmates and I decided to do the Three Peaks challenge. Five of us did it in just under 23 hours and raised £3,200 for a childrens' charity," he says. "The Three Peaks was my biggest achievement. I felt so good afterwards, it was such a hard thing to do."

Since his recent bowel operation his friends have got him back into hill walking. He says: "A month ago we climbed Helvellyn in the Lake District."

"It's quite tough for me as since the chemotherapy I suffer from peripheral neuropathy, and don't have the strength in my legs that I used to. But when we were walking along a high ridge, it was really, really exhilarating! That made all the hard work worth it!"

Chris is setting himself further physical challenges: "We're doing another climb in October in North Wales, and planning a coast-to-coast on Hadrian's Wall next year," he says. "It's hard work, but when it's for charity, it's worth it in the end."

But in the short-term, he's looking forward to going abroad again. "We're off to Greece in 3 weeks and I'm looking forward to using Vitala™ on the beach again," he says, "Vitala™ has changed my life, it's given me the confidence to take my shirt off and sunbathe."

Please be advised that the testimonials above reflect only the experience of the user who has provided the testimonial. Results referred to in the testimonial may not be typical and individual results may vary.

**For further information on Vitala™ Continence Control Device, please call 0800 467866, email vitala.webcare@convatec.com or visit www.vitala.com**

AP-011591-GB
VIT011
August 2011

breakaway
putting smiles on young faces

# A family journey...Max's story

The problems began when I was approx 21 weeks pregnant, I went for my detailed scan at Hereford County hospital and they said all of the organs looked fine but I had too much amniotic fluid around the baby.

The radiographer didn't seem to be concerned and suggested I come back in a week or so for another scan as the fluid often settles down, I went back a week later on my own as my husband had recently started a new job after being made redundant so had only been in the job for four weeks, this scan was completely different. The radiographer immediately measured the fluid levels and then called in the Consultant to look at the scan, they said my baby had a funny shaped head with something visible on his brain. They didn't think his brain was developing properly and suggested an amniocentesis straight away; I waited for 3 hours in a waiting room full of happy expectant parents fearing the worst.

Two days later I was then referred to the specialist foetal medicine team at Birmingham Women's Hospital, we went up for the first check up where we met both a Consultant and Professor. After an hour long scan and lots of questions they suggested we have an MRI on my babies brain at the Children's Hospital and start the amino drain treatment as I was diagnosed as having gross Polyhydraminious (too much amniotic fluid in the womb), every drain carries a risk of miscarriage. Because of having the amniocentesis I had to wait a week for the first drain (at about 23 weeks) I now looked like I was carrying a full term baby, the first drain drained off 5 litres and I had to stay in over night. I continued to have the drains every week, because there was a risk I could go into labour at anytime over the next 7 weeks I had another five drains and in total they drained 26 litres of fluid, the drains were performed manually and could take up to 2 hours depending on how the baby was positioned, the results of the brain scan also came back inconclusive of my baby having full brain function so I also had to have another MRI at 30 weeks. Even at 30 weeks they were still unsure if Max would be OK and suggested perhaps we should think about a termination.

I went for my last drain at 32 weeks 1 day and it was the most painful ever, I asked them to deliver him but they were reluctant to, as they really wanted him to be born after 34 weeks by a planned section. I went home and my waters broke naturally but I wasn't in labour, Max was born by emergency C-section at Worcester hospital (no room in Birmingham and too many complications for Hereford to deliver).

He was 5lb 11oz born at 32 weeks 3 days (Thur 16/04/09) he came out screaming and weeing for England, he was put straight into the NICU unit, they thought he had something called diabetus insipidus which means he couldn't concentrate his urine properly and would need to take Vasopressin supplement for life, we were relieved this was all that was wrong with him and started to relax. On the Saturday morning I went to see him and he looked really unwell, the Doctor came to tell me he hadn't passed his meconium and they were finding him a bed for emergency bowel surgery, the transport team came within a few hours and took him to Alder Hey in Liverpool, he was a really poorly boy who had police outrider, they drove 120 miles in 1 hour 10 mins, Neil my husband got there in two hours but I eventually got there in my own ambulance nine hours later, we literally went with the clothes we had on and had to buy everything else there.

The Alder Hey consultants met Max and did lots of tests but no surgery, he was in Intensive care for another week having rectal wash-outs and on TPN (special line so that he could be fed directly into his blood stream) as he was nil by mouth, he was 4lb 4 by now and wasting away, they transferred him to the PICU ward with the other babies, they felt it wasn't anything to serious but just his gestation and he just needed to grow, he seemed to start pooing after 10 days.

We stayed another week and begged to come home, I had an infection and I was on my own as Neil had gone back to Hereford to be with our daughter Georgia who was nearly 4, she was struggling with me being away as she saw me go into the ambulance and not come home for 2 weeks. After being back at Hereford Hospital 10 days on the Friday Max was a really odd colour, he had been sick nine times and had a huge belly, I had a feeling he was on his way to Birmingham.

The call from the hospital came at 7am on the Saturday to say the high level transport team were on there way to pick him up. We left before them in the car but his ambulance passed us at Worcester as he was in trouble, because his belly was so huge he was struggling to breath and they had to keep resuscitating him. We got to Birmingham 40 mins later and he was in with the consultant for another hour washing his bowels out, they did the same on the Sunday, then performed a rectal biopsy for Hirschsprungs Disease on the Monday and gave him his first stoma on the Tuesday at just three weeks, five days old and weighing 5lbs. The difference was amazing, they were worried his whole colon was infected but luckily he is only short segment Hirschsprungs Disease, he was also diagnosed with a lactose intolerance and gastric reflux.

He finally came home at five weeks and two days old.

Now we fast forward 10 months – no major problems to stoma reversal surgery. Max was in theatre for six and a half hours and was roasted a bit but generally his Consultant surgeon was happy, he was eating within a few days and started pooing after 3 or 4 days (20 times a day). We went home after a week hoping we had reached the end of our journey!!

After six weeks Max was off colour and had a sickness bug, I had a strange feeling it was Enterocolitis, I rang the children's ward in Hereford who weren't very interested but said come in if he starts pooing for England, I rang them at 11.45pm and we went in within the hour. This resulted in 8 days in hospital here and in Birmingham.

Max never pooed again from this point, over the next fourteen months he had three doses of botox injections, huge doses of laxatives daily, a partial cut to the sphincter muscle and rectal washouts for 10 months but nothing worked, he constantly had a big sore belly and cried in pain. This was when I became really close to our stoma nurse as we constantly spoke and she was always there for us as a family at all hours.

Just before Max's 2nd Birthday we decided it was kinder to go back to having a stoma. He had his surgery on the 5th May 2011 and the first few weeks were really tough and much worse than first time around. Max used to kick me and hit me whenever I changed his bag, it leaked constantly and was a nightmare.

Going back to a new stoma was the best thing we could have done for Max and finally we have been able to function as a family, he also has had some mobility problems needing physiotherapy to help with his walking. Max is now a bright, funny and cheeky 3 year old who attends mainstream nursery three days a week 8am till 5pm.

He is aware his bottom doesn't work properly and has a stoma but he's not bothered and it doesn't hold him back in any way.

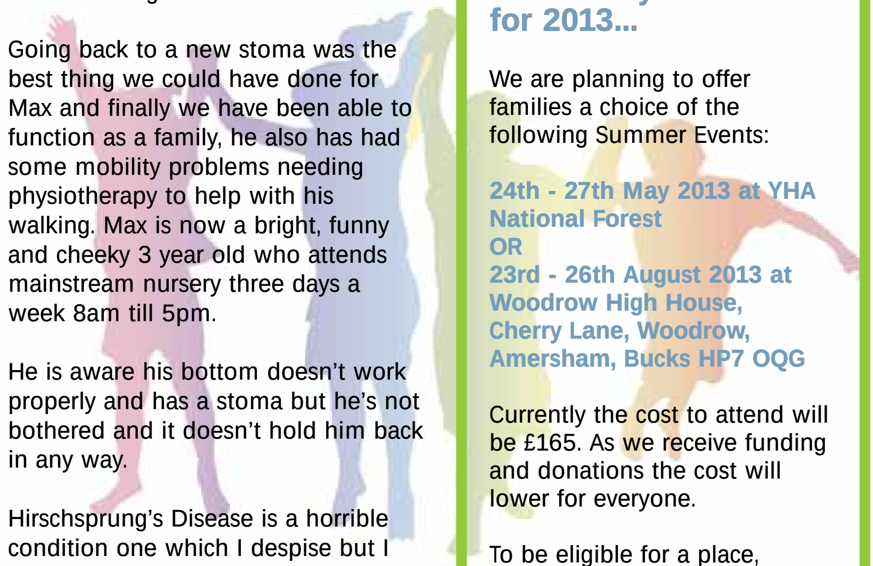
Hirschsprung's Disease is a horrible condition one which I despise but I can't change things, I've cried my tears and now I've learnt to live with Max's condition and we think about his future not the past, we have very little help for Max's condition in Hereford so our main support is our Paediatric stoma nurse from Birmingham .

She was always the person who picked up the pieces; and had spoken to me in depth about Breakaway and her involvement. I was keen to meet other families dealing with similar problems to us. After attending Breakaway I wanted to help raise funds so the idea of a 'Ball' came to mind! The overwhelming thing about the 'Ball' was having, friends, family, work colleagues and medical professionals all in one place supporting Me, Max & Breakaway! To date I have raised £7450 for Breakaway and still have more funds coming in from work and other donations.

The last three years have been tough, I work full time as a Business Manager for NatWest, and I must say they have been amazing employers.

Watch this space for our next fund raising venture!!

**Bev, Neil, Georgia & Max xxx**



## Breakaway NEW events for 2013...

We are planning to offer families a choice of the following Summer Events:

**24th - 27th May 2013 at YHA National Forest**
**OR**
**23rd - 26th August 2013 at Woodrow High House, Cherry Lane, Woodrow, Amersham, Bucks HP7 OQG**

Currently the cost to attend will be £165. As we receive funding and donations the cost will lower for everyone.

To be eligible for a place, children with a bowel or bladder diversion/dysfunction must be aged 4 to 18 years when the event takes place. Families may attend only one of these summer events. Places are allocated according to specific criteria including medical circumstances and whether the family has attended an event before. Payments must reach us 3 weeks before the event.

For more information please visit our website:
**www.breakaway-visits.co.uk**
**OR**
**Telephone:**
07903220040
**Email:**
info@breakaway-visits.co.uk

## More information about Breakaway...

**Write to us or send a donation to:**

Breakaway
PO BOX 7982
Swadlincote
DE11 1FB

**Telephone:**
07903220040
**Email:**
info@breakaway-visits.co.uk
**Web:**
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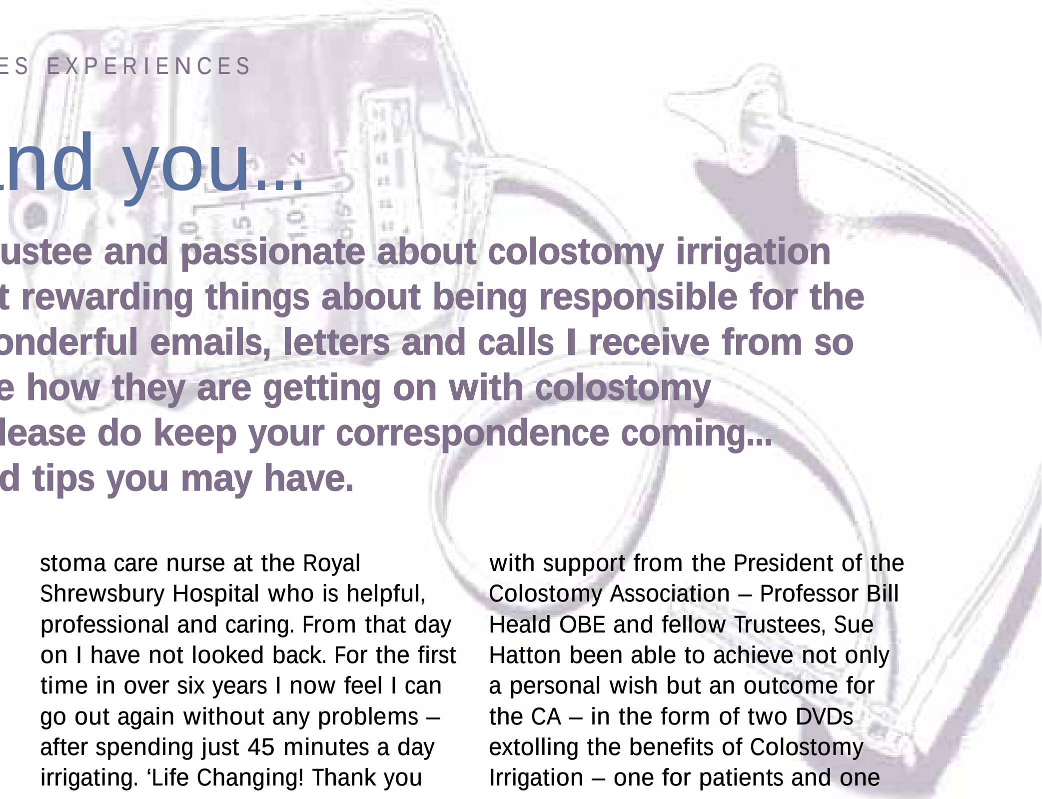

# Irrigation and you...

**Sue Hatton Executive Trustee and passionate about colostomy irrigation writes…one of the most rewarding things about being responsible for the irrigation page is the wonderful emails, letters and calls I receive from so many people...telling me how they are getting on with colostomy irrigation – or not! So please do keep your correspondence coming... along with any hints and tips you may have.**

**Editor writes...**It is a pleasure and privilege to write the following on behalf of Sue Hatton who as some of you may know is recovering in hospital having had major surgery…I'm sure like me you wish her well and a very speedy recovery.

Sue Hatton started her focus – highlighting the benefits of Colostomy Irrigation – in the spring issue of Tidings 2009 since then nearly every issue of Tidings has carried a feature called 'Irrigation and You'. The response to these features over the years has been amazing – many readers have only discovered Colostomy Irrigation through Sue's endeavours and in the pages of Tidings Magazine. Those who have been excited to learn more have done just that gone back to their stoma care nurse to find out more and some have since written in to say that they are now 'irrigators' and that their lives have been changed almost overnight.

**Here are a few of those whose lives have been changed...**

**Olive:** I would like to thank Sue Hatton and Tidings for the articles on Colostomy Irrigation. I am 79 years old and had my stoma two years ago. Having been told I cannot have a reversal and reading your articles on Colostomy Irrigation I thought why not me...I have nothing to lose. I could always go back to the 'bag.' So I approached my stoma care nurse team at Torbay Hospital and with their support and encouragement I have now been irrigating for three weeks. I have 24 hours free of worry, its wonderful. I am so grateful.

**Paul:** I hadn't heard about Colostomy Irrigation until I read the 'Irrigation and You' pages in Tidings. I decided to make an appointment to see my stoma care nurse at the Royal Shrewsbury Hospital who is helpful, professional and caring. From that day on I have not looked back. For the first time in over six years I now feel I can go out again without any problems – after spending just 45 minutes a day irrigating. 'Life Changing! Thank you CA and Tidings for your help!'

**Dave:** I knew nothing about Colostomy Irrigation but thanks to Sue Hatton and Tidings I do now! I decided after reading some of the readers experiences, irrigation could be for me. So, I talked to my stoma nurse (who is fantastic) she was in favour. So after much deliberation, at the age of 63, and one year after surgery, I took the plunge. At the beginning, I had three teaching sessions with my stoma care nurses at home. This was invaluable. Now I irrigate every morning, which takes me, about 45 minutes in all, and lasts between 24 to 36 hours. What a difference. Freedom at last!

**Carol:** I am an experienced irrigator and despite initial misgivings I now feel...'my self-confidence and body image has improved dramatically I feel emotionally stronger. I firmly believe that irrigation contributed to my being able to pick up the pieces of my life and achieve my ambition of starting and running my own small business.' I am glad to see Sue Hatton and Tidings promoting irrigation.

I think you must agree that the above accounts are awe-inspiring so much so that Sue Hatton has gone further with her campaign – influencing not only patients but stoma care nurses as well to rediscover and perhaps challenge their current practice to make 'Colostomy Irrigation' more visible to patients. With the help of sponsors Coloplast and Dansac and with support from the President of the Colostomy Association – Professor Bill Heald OBE and fellow Trustees, Sue Hatton been able to achieve not only a personal wish but an outcome for the CA – in the form of two DVDs extolling the benefits of Colostomy Irrigation – one for patients and one for Healthcare professionals. A short excerpt from the DVDs will be launched at this year's WCET (World Council of Enterostomal Therapists) UK Conference in Edinburgh this October.

**Further information about how to obtain copies of the DVDs will be available from the CA office in early November.**

**Facts...Colostomy Irrigation and individual suitability...**

The potential irrigator needs to have reasonable hand/eye coordination, the ability to learn and perform a sequence of steps and the motivation to give time to learn the procedure and give discipline to a daily or near daily routine.

Irrigation would not be suitable for those with active cardiac or renal disease or ongoing bowel disease. The individual will need to have a colostomy that is visible and without complication, such as prolapse or large parastomal hernia.

It is important to discuss individual suitability with your stoma care nurse so that the procedure can be started safely and with opportunity for success.

It may take several weeks for someone to achieve a predictable bowel pattern with irrigation, but once mastered it can afford the individual new freedoms and an enhanced quality of life.

# Don’t get mad on holiday

## Even when you are away, if you have an emergency, we are still here for you!

**FREE Offer:** To kick start your travels, be one of the first 100 people to return the reply slip below and we will send you a Travel Advice Pack absolutely FREE! Tick here ☐

We have a range of information sheets available, please tick the relevant boxes and we will post them to you.

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# Have you got our number?... 1-2-1 support via 0800 328 4257 24/7...365 days a year!

**The Colostomy Association freephone helpline is much more than just a number on a list...to many it's a lifeline**

Calls are answered every day of the year...including Christmas and New Year! The help and support available to people about to have a colostomy or living with a colostomy, and to families, to friends and to healthcare professionals is invaluable.

The freephone helpline is manned during CA office hours by staff (Monday–Thursday 9am–5pm, Friday 9am–3pm). After office hours calls transfer to one of several trained CA volunteers known as telephone 'Helpliners'. Calls are taken through the evening, overnight and early morning until the line is transferred back to CA office staff the next day at 9am.

Volunteers on the freephone helpline are fully trained, having completed both a volunteer induction course and bespoke telephone helpline course. Each 'helpliner' is chosen for his or her suitability and interpersonal skills – all have stomas and all are well adjusted and experienced in supporting others 'living with a colostomy'.

There is no doubt that Helpliners are dedicated, compassionate people willing to go the extra mile for someone in need!

The freephone helpline provides quick and easy access to support and information. Every caller is able to speak to someone who has a colostomy and is empathetic to any problems a caller may be experiencing. Discussion is of a supportive nature based on 'real life' practical experience. The advice given is strictly non-medical. The caller is always referred back to their stoma care nurse, GP or Consultant.

## What does a CA Helpliner do?

**Listen & reassure**

**Empathise & support**

**Understand & help**

**Discuss & refer**

**Encourage & motivate**

## Directory of volunteers

The Colostomy Association has a directory of volunteers willing to talk about their experiences of specific conditions and situations i.e. travel, sport, exercise, irrigation and stoma reversal as well as coping with leakage, parastomal hernias, rectal discharge, rectal pain etc. If a stoma care nurse has a patient with a particular query, volunteers can be matched to that patient by age, sex, location or by problem.

**To find out more about services provided by CA for patients and healthcare professionals ask for our One to One leaflet available from head office today!**

Medi

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Tidings Magazine - Autumn 2012.

# Find WHO on FACEBOOK?... the **Colostomy Association 'closed' group** of course!

**L-R: Duncan Wells - Trustee, Sarah Squire and Helen McTurk, (CA volunteers and CA FACEBOOK Admin Monkeys) pictured with Adrian Priest - Salts Healthcare.**

The idea for a Facebook Group meet came from a member one Friday night in January after a fun afternoon of chat. "After all this afternoons hilarity, wouldn't it be great if we could "all" meet up? I know we are spread all over the UK but what about the Midlands? A Travelodge? Someone must know of somewhere to have a good night out? An overnight for the far away people? What do you all think?" An exciting conversation developed over the next few hours. Where could we go? What could we do? Where would we stay? "I have a 6 berth tent lol xx" came an offer. "I don't do tents. I want en suite and somewhere to plug in hair straighteners!" was my reply. The original idea of the Midlands was agreed, and the subject of a focus for the meet, other than chatting and enjoying a glass of wine was brought up. Duncan suggested the idea of a factory tour and of course Salts Healthcare are based in Birmingham, AND they have a hotel right next door! So the idea was turning into a very real possibility. Adrian Priest from Salts very kindly agreed to do a factory tour, provide lunch and cover the cost of our evening meal. A group deal at the hotel was agreed and the date of April 14th was set as the first CA Facebook meet!

For those who don't use social network sites it is possibly hard to understand the way you can form strong friendships with people you have never met in person. On the CA Facebook group many people have found a haven where they can come to chat, moan, support, be supported and over time strong friendships develop. The idea of meeting these new friends is both exciting, and for many of us, a little frightening too. I for one had to use my "emergency kit" twice on the way thanks to my nervous tum.

Twelve FB members' plus three partners met at noon at Salts for a buffet lunch and the hugging began. Helen McTurk, Duncan Wells and me (the Admin monkeys) were joined by Sue Hatton, Alfred Levy, Denize O'Leary, James Cartwright, Trudi Pearse, Teresa Renwick, Faye Jones and friend Will, Shirley Tanner and husband Chris plus the lady who came up with the idea that cold January evening, Karen Macqueen and husband Haydn. Nerves were soon forgotten as everyone matched faces to profile pictures. I think most present will agree it was like meeting up with friends you have known for years.

We all had a good laugh and chat over lunch then split into two groups. I went on the first factory tour where Production Manager, Marcus and foreman Bill talked us through how the factory works. It was really very interesting and we learnt lots about how the products are produced and tested, including a demo making a drainable bag by hand. It was clear Marcus normally spends his day managing rather than making, but luckily, in true Blue Peter style, he had one he'd made earlier and all was well. I think we were all impressed at the time and effort put into producing the products we ostomates rely on to make our lives comfortable. The automated line was set up to make one closed bag every eight seconds which even on a bad day with an upset tum we would struggle to keep up with! We were all surprised to see a white PVC pouch still being produced but Marcus explained some of their older customers still prefer these to the newer lines and Salts will continue to produce them for this small number of people as long as possible. He also took the trouble to explain how they train their staff and develop the careers of their workers. It really did have the feel of a family company, looking out for its staff and customers. We had a quick trip to the samples room where we were able to take a couple of items of interest before heading back for a cup of coffee. I think it's a good job one or two of us didn't have a handbag search on the way out of that sample room!!

Back upstairs we swapped with the other group who donned their "flattering" white coats and hats for the second tour. Adrian gave us a short presentation about the history of Salts and he was also happy to answer our endless questions about deliveries, products and the ins and outs of the stoma care business.
I had been very much looking forward to the tour but the whole trip to Salts was far better than I could've imagined. Who knew stoma bag production could be so interesting! Mid afternoon we all headed over the road and met up with Julie Bastin and Bev Stacey from Breakaway who would be joining us for dinner. After a few drinks Teresa had to leave us unfortunately but the remaining group enjoyed an evening of more chatting and many laughs. More hugs were exchanged as people left after a brilliant day. A few of us stayed over at the hotel and it's rumoured that Duncan, Julie and Bev may have been spotted still up at 3am but they won't admit to anything!

So the first CA Facebook meet was a huge success. We are very grateful to Adrian Priest and Salts for their hospitality and support. We monkeys have already been discussing ideas for the next meet up, which we hope, will be even more popular. Many thanks to all those who attended. It was a pleasure to spend the day in your company. I know many of you will be my friends for life.

**Sarah Squire**
**CA Volunteer**

* * *

# FACEBOOK Group update...

Since the two articles appeared in the Spring issue of Tidings Magazine we have put on over 225 new members. We now number 530. And the relief expressed by new and existing members at the opportunity to talk to others who understand is wonderful to behold. The group is a tremendous source of support for everyone. Often people arrive in a state of distress and within a very few posts the members row in and help them out. Every new member who joins is welcomed immediately and made to feel part of the family, because that's what we are, one large family helping each other out and looking out for each other. There's one member who seems to have a mind for dates and so if anyone posts that they are due for an operation or a scan, up will pop a post the day before wishing them luck. It's a wonderful touch.

We have manufacturers and suppliers amongst our members, which is extremely important so they can see what it's like living with a stoma and how their products make a difference to our lives and while we don't allow them to advertise or place links on the group, we do ask for their help and advice every now and then. Recently one member was having problems getting flanges to adhere, because their skin was reacting to the adhesive and so they wondered if there were any hypoallergenic flanges available. This member said they were happy for manufacturers to contact them directly by private message. And so they did and one company has supplied samples, which the member is trying out.

Of course we can also get messages out to the members fast using Facebook. We have used the group to find volunteers for the CA, to find candidates for research projects. We have asked for personal stories for Tidings Magazine, we have publicised Open Days and of course as Sarah has written we organised and held a very successful group meeting. We have arranged our next meeting for Saturday 10th November and again Salts Healthcare have very kindly agreed to sponsor us. This time we will be having a tour of Cadbury World in the morning, a presentation by Salts Healthcare in the afternoon and a meal at the Premier Inn in the evening. And this time we have over double the number if people coming. This time we will be 45 strong!

**Duncan Wells**
**Trustee**

**Join the CA 'closed' FACEBOOK 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!

# **The little bag...**that saved a life... a friend, a father, a grandfather and my husband!

**Love them…hate them…for many people reading this a colostomy bag has become part of their lives..**

My husband's colostomy was a life saver after having one operation to remove the dreaded big 'c' failed (and I am not giving it a capital letter because I don't think it deserves it) was followed by an emergency operation to save his life.

The first operation seemed go well and when I sat watching over him in a very lonely recovery room, he opened his eyes and looked at me with a little smile on his face and said 'have I got a bag'?! No, I said and he drifted back into his deep sleep.

Three days later he was home but not well, and two days after that he was rushed into hospital for an emergency operation to save his life. He was so poorly that I thought I was going to lose him; it was the worst feeling in the world to me. I met Dennis on the first day of secondary school at 11 years old so you see I have known him for most of my life. Although we have only been married for 8 years we are more than husband and wife or best friends, we are soul mates.

I could not imagine being without him. It was at this point that I prayed like I have never prayed before, I would have sold my soul to the devil just to ensure that Dennis would recover, with or without a bag did not enter my mind. All I wanted was my husband back home with me and the family.

I remember when Dennis came home he was very secretive about his bag and was reluctant to let me into the bathroom when he was changing his bag. He used to say that it was too smelly for me but I told him I was sure I have smelt worse but still he refused. However I had a plan and I was not going to give up, so I gave him a few days to adjust to our new body well after all it was as much mine as it was his. I waited for the stoma care nurse to say how he was doing. She thought that there was no need to visit us any more, that told me that he was becoming confident in dealing with the little bag.

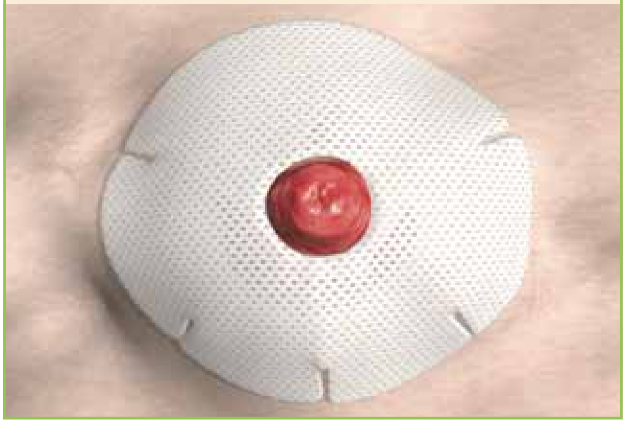
Then one evening I waited for him to go to the bathroom and sat on the top of the stairs and talked to him through the door. It did not take him long to realise that he was not getting away with not letting me be part of his new life and I was not going to let a little bag come between us.

So he let me in and I looked and asked questions and then I had a go at fitting the bag and that was that. We have had a good laugh and a good cry at times and we have made mistakes but I have never laughed so much as I did a few days later when he was in our bedroom and our little Spaniel, Sam had followed him in.

The family have always said that Dennis looks and behaves like a little boy, just like Sam but when I got to the bedroom and saw them I wish I'd had a camera handy, Dennis was standing with his boxer shorts on and a bag on his side and Sam was sat beside him with a colostomy bag stuck on his left side too!!!

So this is why I am so glad of the little bag on my other half's left side, the little bag that saved a life, a friend, a father, a grandfather, my husband and his wonderful sense of humour.

**Mrs Doris Pilmoor**



# **London 2012 Olympic Torchbearer...Caroline** chats about her journey and once in a lifetime Olympic experience

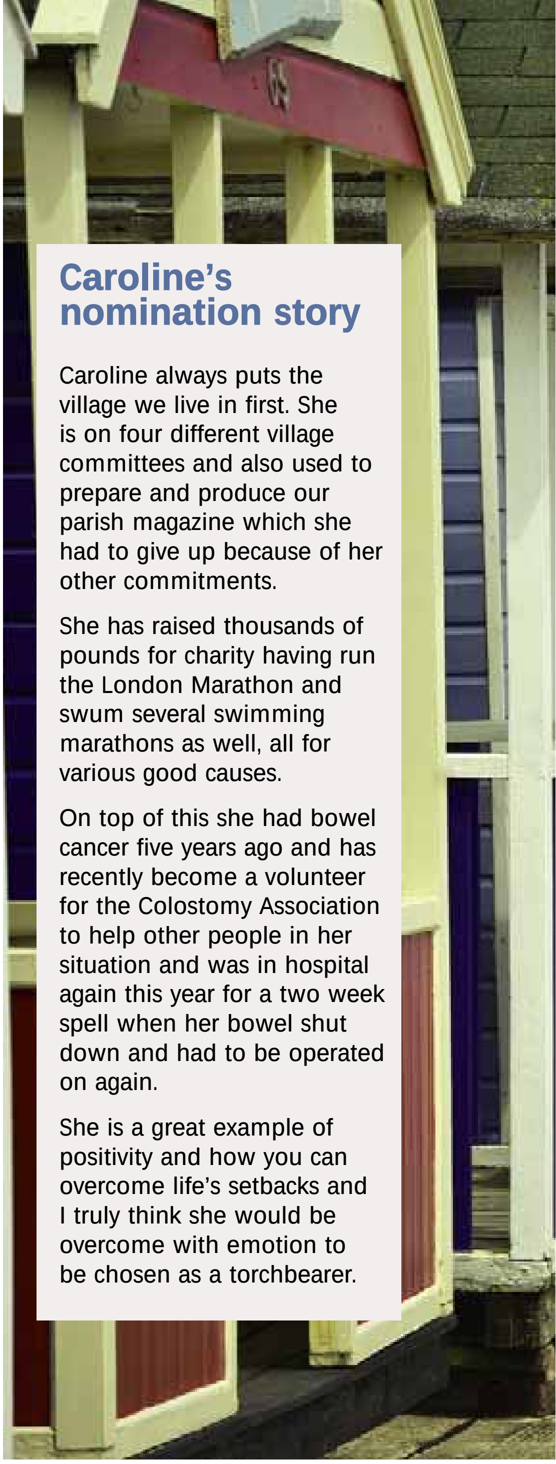
When the editor asked me to write for Tidings magazine, my immediate thought was when... I don't have time! I certainly have the inclination but time is a luxury to me and very precious! So here goes...

I became interested in the Colostomy Association (CA) about four years after my journey with cancer, which ended with a colostomy in April 2006. I desperately wanted to give something back to help others – women in particular.

You see I have had body issues for most of my life so a stoma, in my mind, was about the worst thing that could have happened to me. I didn't know about the CA back then and I'm sure if I had done the Association would have put me in touch with other girls like me with similar issues (we women always refer to ourselves as 'girls' as we hit our 50's!). Girls who had overcome body image issues and in doing so had found out that fashion and style doesn't have to end when you have a stoma and colostomy. Unfortunately I didn't meet any such 'girls' sadly I did meet a couple of people but they didn't inspire me with confidence when it came to discussing what I could or couldn't wear – I know now that you don't really have to change what you wear you just need time to adjust to living with a colostomy and stoma!

After six months of wearing my colostomy bag I was introduced to Colostomy Irrigation – for me it was my lifesaver – it turned my life around, so much so, that people in my village forget that I have a colostomy. Now nothing is visible to the eye – no funny bulges, no baggy clothing (not that this was the case before but I felt it was). I feel I am just like I was pre-surgery, which is how I like it! With my confidence regained I decided to live life to the full, which is my motto! I changed to part time work, only 3 days a week and in my leisure time squeeze in Golf, Swimming, Pilates, Badminton and Zumba!

Recently I felt ready to contact the CA about volunteering and did! I was added to the training list but sadly due to lack of funds, training was delayed for some considerable time. This was addressed last December and I attended a 2 day volunteer induction and helpline training course which took place in Reading. I am now delighted to say I am a fully fledged Colostomy Association volunteer! I man the Helpline, raise much needed funds and cover Open Day events when I can – I am passionate about supporting the CA.



## Caroline's nomination story

Caroline always puts the village we live in first. She is on four different village committees and also used to prepare and produce our parish magazine which she had to give up because of her other commitments.

She has raised thousands of pounds for charity having run the London Marathon and swum several swimming marathons as well, all for various good causes.

On top of this she had bowel cancer five years ago and has recently become a volunteer for the Colostomy Association to help other people in her situation and was in hospital again this year for a two week spell when her bowel shut down and had to be operated on again.

She is a great example of positivity and how you can overcome life's setbacks and I truly think she would be overcome with emotion to be chosen as a torchbearer.

Little did I know other things were afoot that December which would put me in the public eye for everyone to see…

There are certain iconic days in your life – the day you get married, the day you have your children and then there's the day you become a London 2012 Olympic Torchbearer…really? Yes! Well, there was for me! I have to say it's up there as one of the all time best days of my life! But how did it all begin? Well, my husband Colin had something to do with it…he, wait for it...nominated me! It was in December (around the same time as I was training to be a CA volunteer or a little later) when I knew I'd made it through to the final selection by Samsung, my torch sponsors.

The day I received my confirmation email I immediately texted my daughter who was on holiday in Australia and with it being evening over there, just happened to be in a pub. She apparently shouted out her delight and surprise that her mum was going to be an Olympic Torchbearer – the pub broke out in cheers and clapping so it was a wonderful moment for her as well!

The next part of the process was

Torchbearer 056 Richard Game passes the Olympic Flame to Torchbearer 057 Caroline Emeny in front of the beach huts at Southwold during Day 48 of the London 2012 Olympic Torch Relay.

LOCOG© London 2012

security checks – certified proof of ID had to be sent off to LOCOG I kept my fingers crossed that I didn't have any hidden gremlins in my cupboard that would prevent me from carrying the torch. Fast forward to early March and the names of all the 8000 torchbearers were released to the press – torchbearers were then free to tell all and sundry their good news!

It seemed to be an absolute age between March and July when I was going to do my run – the flame landed in the UK in May – and seemed very remote. Suffolk is a great place to ground you; everyone goes quietly about their business, not really taking much notice of what's going on elsewhere in the country. The Olympic Torch Relay seemed very distant and almost irrelevant. It was only when the relay approached East Anglia that people began to get excited and talk about it and then of course the local media got involved which upped the ante!

About a week before my due date (it sounds like I was going to have a baby!) my official pack arrived with all the necessary details and of course, the tracksuit that I had to wear! The pack brought everything home to me it wasn't distant anymore my time to shine was very nearly here. I felt an immense shudder go through me as the excitement started to kick in. I immediately tried on the suit, even though I was at work, as I was so excited and texted all my family to say it had arrived! It was then that I found out I was to have one of the most memorable spots in Suffolk for my leg of the relay – the beach huts at Southwold! How on earth did I get that gig? I just don't know, but I do know how very special it was and what a photo opportunity it was going to be. Book the hair appointment now, I thought to myself!

In the preceding week I went into our local primary school for a Q&A session as part of their morning assembly – all about the torch relay – the kids loved it and I found it very rewarding, we arranged another date for a few days after my relay so I could bring in the actual torch for them to see!

As the day approached, so did the bad weather. The county was awash with rain and the forecast was worrying, as was my hair, as it doesn't cope too well with drizzle! Well, I shouldn't have worried, the day of the relay arrived, the sun shone, and the streets were crowded with cheering onlookers. The atmosphere was simply fabulous. It really was a very, very special day!

The torchbearers had been instructed to arrive two hours before the torch was due into Southwold for a briefing, security and so on. I was worried about how we were going to fill the time. I needn't have been as there were people to greet us, the LOCOG relay team were very helpful and before we knew it, it was time to depart on the bus!

We were given instructions as to what would happen and what we could and couldn't do and then we were whisked away to await the arrival of the torch from Wrentham. During this time our own small group of six torchbearers told each other our individual nomination stories which turned out to be a great bonding experience, the LOCOG team told us their special memories of the relay so far, and mentioned some of the celebrities, especially Will-I-Am who tweeted the entire distance of his run!

And then came our own 'moment to shine'. Each one of us was dropped off at our 'kiss' point in advance of the torch's arrival. I was standing at the beach huts with a huge bank of cameras in front of me all waiting to take 'that shot' in front of the beach huts at Southwold. The shot was published in all the major tabloids and broadsheets – it was such an iconic image. How that happened to me, I'll never know, but I do know how lucky I was and I'll remember it forever! The amount of times I welled up that day are too numerous to mention, the tears did break out a few times, sometimes uncontrollably.

Suddenly I became aware of myself and the situation and was overwhelmed by the huge honour granted to me and became very emotional…what a privilege I thought to be carrying the Olympic flame en route to London! The reality finally hit home – everyone cheering you on, waving to you, it makes you feel very special, like 'royalty' I suppose – but it was me – Caroline – a London Olympic 2012 Torchbearer – WOW! The smiles on faces in the crowd couldn't be wiped away, the odd tear here and there, reminded me of my wedding day – you know – when you have that grin on your face that you just can't get rid of and don't want to!

We went to the celebrations in Ipswich to round off the day (sitting at home drinking tea didn't seem fitting), so we piled in a car and headed south and managed to get into the event, even though it was a ticketed affair. I think the tracksuit helped us get through the gates, we had a wonderful evening soaking up the atmosphere, entertainment and finally watching the cauldron being lit really topped the day off!

The following week I took the torch into two local primary schools – the children took the opportunity to have their class photos taken with the torch and me! I also made an appearance with the torch at our local Heveningham Hall Country Fair as a means of fundraising for the CA!  I'm pleased to say it raised £200 – what a result – thank you to everyone who gave that day.

The whole experience has been very humbling and I continue to get invitations to various events around the county, which is very exciting!

I will be keeping my torch – in answer to everyone's questions – it will be made into a light and put on a wall in our sitting room, we think it will look quite special between the two windows. Samsung who were my sponsors bought my torch for me – I will treasure it forever, and yes, it is the actual torch that I carried!

Being a torchbearer for the London 2012 Olympics is an experience I will never forget – I'll treasure my memories of the day forever and look forward to telling my grandchildren all about my very special day!

## The London 2012 Olympic Torch Relay...

Lit in Greece, the Olympic Flame arrived in the UK on 18 May 2012 before setting out the next day on a 70-day Olympic Torch Relay, bringing the excitement of the Games to everyone.

The Olympic Flame stands for peace, unity and friendship. It was carried by 8,000 truly inspirational Torchbearers.

The Olympic Flame travelled to within an hour of 95 percent of people in the UK, the Isle of Man, Guernsey and Jersey during the 70-day Torch Relay. It enabled local communities to shine a light on the best their area has to offer.

The towns and cities hosting evening celebrations, the island visits, and all of the communities on route were displayed on the Olympic Torch Relay map.

Together with Presenting Partners Coca Cola, Lloyds TSB and Samsung, London 2012 found 8,000 truly inspirational people from across the UK to carry the Olympic Flame – a truly once-in-a-lifetime experience.

## The Torch...

The Torch was designed by east Londoners Edward Barber and Jay Osgerby, who won the opportunity through a competitive tender run by the London 2012 Organising Committee and the Design Council.

The Torch is made up of an inner and an outer aluminium alloy skin, held in place by a cast top piece and base, perforated by 8,000 circles. The circles represent the inspirational stories of the 8,000 Torchbearers who carried the Olympic Flame on its journey around the UK.

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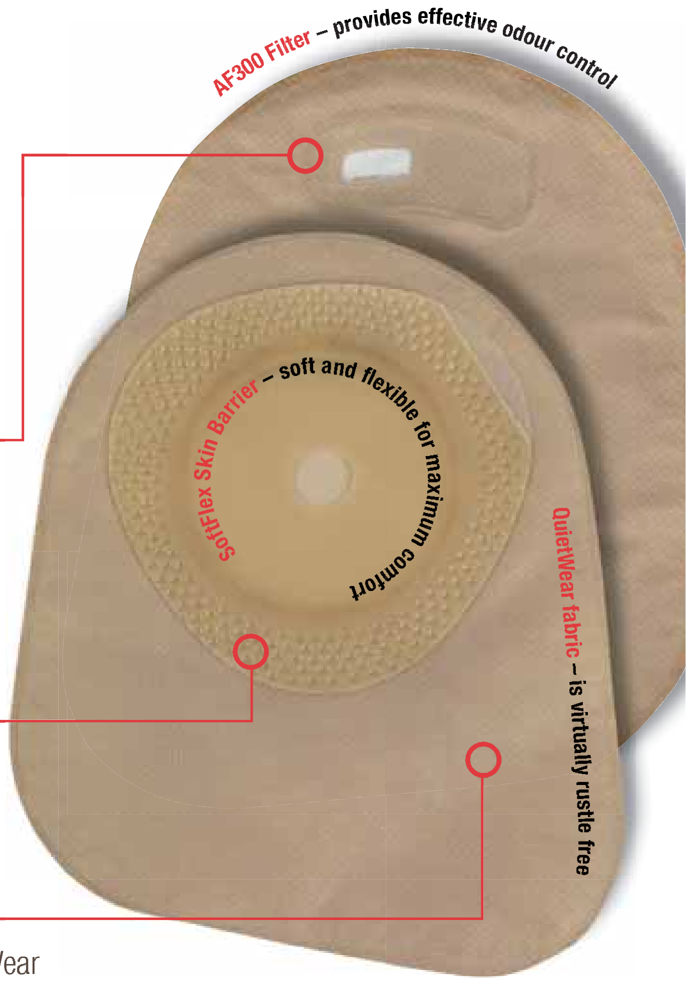

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* In a survey of 190 ostomists who have evaluated a Hollister pouch with QuietWear material

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## *SAMARITANS and Stoma Care Nurse Specialist Initiative*

# Caring for the 'carer'...

**Samaritans offers confidential support to anyone passing through a crisis, in despair, or thinking of taking their life. This voluntary organisation gives people the time and space to explore their feelings and think through their options for facing the future. Samaritans is not a religious or political organisation.**

**Derek Baker writes...**Towards the end of 2011 it was brought to the attention of the Harrow Branch, by a Colorectal and Community Stoma Care Nurse Specialist at St Mark's Hospital that she and many other senior nursing staff, from several other disciplines in Northwick Park Hospital, had for some time been concerned that people involved in the care of patients so called 'carers' (who could be a parent, a child, a friend) are often under enormous stress.

Nursing staff felt that they wanted to help but did not have the time, or the appropriate listening skills, to emotionally support the 'carer'. Although some departments did have access to internal counsellors they were unable to provide 365–24/7 support – unlike the Samaritans.

In considering this problem we, the Samaritans in Harrow suggested that in the first place the Healthcare professional (Nurse Specialist, GP, Community Nurse, home visitor) could suggest to the 'carer' that they call the Samaritans – where they would be offered confidential support. If the 'carer' accepted the concept he/she would be given a credit sized card, which included all the necessary contact details.

However if the 'carer' intimates that for whatever reason they would be unable to call – the Healthcare professional could suggest (if it was acceptable to the 'carer') that they pass on the 'carers' name (or a nom de plume) and telephone number to the Harrow Branch of the Samaritans. The Healthcare professional will have a similar card detailing the procedure.

The information would then be passed to a specific Samaritan Branch volunteer (the 'carer' volunteer or CV) via a dedicated email address in order to allow the Branch to set up a Follow-up procedure. The CV would complete a 'Carer' Information Telephone Follow-up Form, as well as make the relevant entry (excluding the telephone number) in the duty room diary in order to facilitate a call to the 'carer' by volunteers on duty. On completion of the call the duty volunteer would complete the form. If a 'carer' requested a further follow-up to the initial call a new standard Follow-up Form would be created.

Activating Samaritans Emotional Support
If You See A 'Carer' In Distress.

- If appropriate give them a Samaritan contact card.
- Let them know they can call Harrow Branch immediately on **020 8427 7777** or Samaritans national number 08457 909090.
- With their consent, arrange for Harrow Branch Samaritans to call them.(See over for details)

SAMARITANS

A Registered Charity.

1.) Check that the 'carer' is comfortable for you to give Samaritans their name, or an alias if they prefer, their telephone contact number and a convenient time for Samaritans to call them.

2.) If the 'carer' agrees, tell them that a Samaritan will phone them, quoting your name as a reference.

3.) **VERY IMPORTANT:-** When a 'carer' has agreed to this procedure ensure that you notify Samaritans as quickly as possible via e-mail to:-
xxxxxxxxx@xxxxxxx

Samaritans - offering emotional support 24/7 every day of the year.

Nursing staff/Carer Contact Card

At the end of each month the 'carer' volunteer would analyse the forms and provide the Healthcare professionals concerned, with the following information via email:

- Number of email contacts received
- Number of follow-up calls made
- Number of contacts made

In line with normal Samaritans principles no further detail would be provided. The forms would be shredded as per standard Caller Care procedures.

It may well be that in the fullness of time this 'Carer' procedure will simply be integrated into the Branch Caller Care system.

Should the volume of follow-up calls reach too high a level for Harrow to handle both the Putney and the Watford Directors have indicated that they would pick up some of the load. In the event that this procedure becomes very much more popular it would be referred to our General Office for roll out across all Samaritans branches.

Should an occasion arise in the normal course of duties that a volunteer takes a call and the caller provides the fact that they are a 'carer' this information would be recorded in the log; but only for statistical reasons.

Since originally discussing this initiative with St Mark's we have been approached by a number of other organisations wishing to participate. Samaritans Harrow has made presentations to almost all of them, and in some cases a number of follow-up presentations.

On the 2nd April 2012 the system went live: All the relevant information cards have been printed and are being distributed, some 5000 to date, and the dedicated email address is being monitored several number of times a day.

A selection of the many organisations now participating in this initiative follows:-

- Alzheimer's Society
- Crossroads
- Harrow Borough Council Carers (they have some 6,000 registered, unpaid carers on their books)
- Harrow Borough Council Mental Health Carers
- Harrow Carers
- Harrow Stroke Association
- Harrow Community Services
- Marie Curie Nurses
- Macmillan Nurses (Lynda Jackson Macmillan Centre, Northwick Park Macmillan Centre)
- Northwick Park Hospital - Several departments (Stroke Unit, Occupational Therapy Department)
- North West London Mental Health Trust
- St Mark's Hospital


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In Pouch Deodorant
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Directions
Warning: Not to be taken internally
Storage: Store in a cool dry place.
2

# Accessible toilets...?

Duncan Well's article a while ago regarding the not so perfect conditions in an accessible toilet for a bag change was oh! So true. No shelves or flat surfaces, automatic taps turning on at the wrong moment etc. However, for would be travellers to Dubai – a word of advice – be brave, if you have to use a public toilet there!

We stopped over in Dubai a while ago en route to New Zealand, and on the first day after our late night arrival, met up with friends who are familiar with the city for a day touring the sights. I asked Jackie what the loos were like and she said, if you are in a tourist destination there would be no problem as they are excellent, otherwise just walk into any decent hotel and use theirs. It is quite acceptable to do this and they are always beautiful. And so we set off for our day out. After viewing the fort area by the creek we took the Abbra (water taxi) and went to the Gold Souk – the Souk consists of over 300 retailers that trade almost exclusively in jewellery. My husband and I are celebrating our Golden Wedding anniversary this year and my little wedding ring no longer fitted my finger – so it was an appropriate time to treat myself to another one. The Gold Souk is an amazing place; several streets of tightly packed little shops, crammed with the most extra-ordinary gold articles. We browsed for quite a long while and I had almost chosen one when of course that very unwelcome whiff drifted up. There is a four hour jet lag from England and that meant that my usual early morning action had been delayed.

So, where is the nearest hotel I asked our friends, they looked worried? There were none that they knew about very near at all. There was however a public toilet down by the wharf – quality unknown. There was no time to loose so I headed back to that. It was clean – but oh dear! They were the traditional type!

You know the sort, a hole in the floor and two places to put your feet to keep you off the wet floor, because Muslim tradition provides a hosepipe for cleansing, (no paper), no shelves or hooks to be seen. I was aghast, but there was nothing else for it. I gave my handbag to Jackie to hold and armed only with my small bag of supplies, went into the very tiny cubicle.

So, with tissues, wipes, disposal bag, new pouch etc., in various places – tucked behind and over the side of my glasses, down my bra, under my watchstrap and under my armpits, and still having to put my small cosmetic bag holder somewhere – I forget where exactly, I commenced my change. I had only just got there in time otherwise I might have had to use the hosepipe!

It really was quite a challenge, but eventually I completed it and emerged triumphant!

Travelling is all about new experiences but I did not anticipate that one! It is surprising what can be done when it has to be – and yes, I did celebrate by buying a new wedding ring. What a souvenir!

**Moira Hammond**

an eakin company

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Pelican Protect Plus – Non Sting Barrier Film ☐

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TIDINGS09/12

## Sophie Medlin BSc RD Colorectal and Nutrition Support Specialist Dietitian at Torbay Hospital, South Devon Healthcare NHS Foundation Trust writes for Tidings on aspects of diet and your stoma...

Courtesy of South Devon Healthcare Foundation Trust

**Sophie focusses on diet and outlines how people with a stoma can adjust and return to their usual eating and drinking patterns post operatively...**

> For both colostomies and ileostomies, the introduction of solid food helps the gut to begin to work as normal and allows the stool to thicken and become less watery. It is important to eat as well as possible, as soon as your surgeon allows. This will help to establish a normal stoma output as soon as possible post surgery.

Many people with a new stoma find getting established back on their normal diet a struggle, particularly in the early stages. This is probably due to the unpredictability of new stomas and the period of adjustment needed to get used to the function of the stoma. It is very important to be aware that, in the majority of cases, people with stomas can return to their usual eating and drinking habits very quickly post operatively.

In most cases, a new ileostomy will start working within 24 hours and the output during the first week can be expected to be watery and around 1200mls per day. Over the next couple of weeks, ileostomy output usually decreases to around 600-1000ml per day and the stool becomes porridge like in consistency.

New colostomies usually work within 2-5 days and the output is likely to be watery at first, settling to between 200-600mls daily of semi solid stool.

With both colostomies and ileostomies, the introduction of solid food helps the gut to begin to work as normal and allows the stool to thicken and become less watery. It is important to eat as well as possible, as soon as your surgeon allows. This will help to establish a normal stoma output as soon as possible post operatively.

In many hospitals, the reintroduction of food after your operation will be established as follows:

**Stage one:** Clear fluids – black tea/coffee, jelly, clear soup, water, cordial.

**Stage two:** Free fluids – any liquids including nutritional supplements and ice cream.

**Stage three:** Light diet – this is very subjective but would usually include soft moist foods which are easy to digest and avoiding fried, spicy and high fibre foods.

**Stage four:** Normal diet – no restrictions.

The time period between progressing through these stages will depend on the hospital and your individual recovery.

In hospitals where an enhanced recovery programme is run, patients are encouraged to eat a light or soft diet as soon as possible after their operation. In most cases, with new stomas, this is most appropriate as there are no ‘joins’ in the bowel (anastomosis) and the problem in the bowel downstream of the stoma is no longer affecting digestion.

Patients with new ileostomies will lose salt from their stomas as the secretions in the small bowel are very salty. Salt is normally absorbed by the colon which is no longer in

## The eatwell plate

**Use the eatwell plate to help you get the balance right. It shows how much of what you eat should come from each group.**

continuation with your bowel. Adding salt to your diet when you have an ileostomy will compensate for the lost salt and should not affect your blood pressure. As time progresses, your small bowel can adapt to absorb more salt and water and you can decrease the added salt in your diet. If you are concerned, speak to your doctor, specialist nurse or dietitian.

After your discharge from hospital, you should feel confident to progress to your usual diet. Many patients will be given dietary advice to avoid certain foods as they can cause watery stools or wind for example. This is very personal, however, and I would strongly recommend you avoid restricting your diet unless you find you have a specific problem for which you should seek individualised advice from your dietitian or specialist nurse. Trying to eat little and often is usually the best way to build your confidence with food and your new stoma.

It is often quoted that patients with ileostomies should be cautious with high fibre foods such as skins, peel and pips due to risk of the ileostomy 'blocking'. However, unless you have been told you have strictures or adhesions in your bowel, this is not necessary. If you are unsure, please ask a member of your healthcare team.

### Healthy Eating with your Stoma...

Getting the balance right with your diet is as important for you as it is for the rest of the population. Following your surgery and if you have been ill, it is even more important that you eat well to allow for a full recovery.

The above diagram depicts the different food groups and the proportions in which you should try to include them in your diet. This 'plate' shows the overall proportions of your diet as opposed to each individual meal.

Carbohydrate foods such as bread, pasta, rice and potatoes should make up a third of the diet. These are good for improving the consistency of a loose stool and give energy.

Fruit and vegetables should make up another third of your diet (see below for tips on how to increase your fruit and vegetable intake). >

Protein foods such as meat, eggs and pulses are essential for healing and maintaining strength and immune function. These should make up a smaller proportion of your diet and you should aim for 2-3 portions per day.

Milk and dairy products are good sources of protein and calcium as well as other essential vitamins and minerals. You should include 2 portions of these per day. A portion of milk is a third of a pint.

Fats and sugary foods do make up a part of everyone's diet and some fat is essential for cell function. Unless you are underweight, these foods should make up the smallest proportion of your diet. They include spread/butter on bread or toast and oil used in cooking. Aim to keep to 3 portions of fats per day.

Many patients with stomas find getting their recommended 5-a-day difficult, due to the high fibre content of fruit and vegetables. If you have this problem, below are some tips for increasing your fruit and vegetable intake whilst avoiding undesirable side effects:

- Try peeling your fruit and vegetables to reduce the fibre content.
- Try fruit smoothies such as blended strawberry and banana with a little milk or yogurt.
- Cook your vegetables well and try steaming which helps vegetables to retain their water soluble vitamins better than boiling.
- Choose soft fruit which is well ripened, nectarines, peaches, melons and mangoes, for example, are well tolerated by most people.
- Try vegetable juice for a nutritious vitamin boost.
- If you have an ileostomy, add salt to your vegetables (including vegetable juice!) to help you absorb the liquid components more readily.

If you feel that you cannot eat as many fruit and vegetables as you need, it is worth speaking to a health care professional about starting a good quality vitamin and mineral supplement.

The last part of your small bowel (terminal ileum), absorbs vitamin B12, if you have had your terminal ileum removed, you may require three monthly vitamin B12 injections. If you think this applies to you, speak you your doctor, nurse or dietitian for further information. Vitamin B12 deficiency can make you feel tired and low in mood so it is worth pursuing this if you are concerned.

If your stoma output remains high post operatively, alongside advice and medication from your health professional, you could try:

- An isotonic sports drink.
- Arrowroot powder added to drinks and sprinkled on meals, which can thicken output.
- Adding salt to your food (ileostomies only).
- Avoiding drinking 30 minutes before and after meals.

**Note: If you have any dietary hints and tips you would like to share, any questions you would like answered or topics covered do get in touch. Please bear in mind that all the information in this article is general and if you have been advised differently by your nurse, doctor or dietitian, their individualised advice should always be followed.**

## Helpful Ostomy Support Groups & Organisations...

- IA The Ileostomy and Internal Pouch Support Group
  Freephone: 0800 0184 724
  www.iasupport.org
- UA Urostomy Association
  Tel: 01889 563191
  www.urostomyassociation.org.uk
- IOA International Ostomy Association
  www.ostomyinternational.org
- Stomadata & Stomafr
  www.stomadata.com
  www.stoma.fr
- Macmillan Cancer Support
  Tel: 0808 808 00 00
  Mon - Fri: 9am - 8pm
  www.macmillan.org.uk
- Crohn's and Colitis UK
  Tel: 0845 130 2233
  www.nacc.org.uk
- The Gut Trust
  (Irritable bowel syndrome)
  Tel: 0114 272 3253
  www.theguttrust.org
- Bladder and Bowel Foundation (B&BF)
  Formerly Incontact and Continence Foundation
  General enquiries: 01536 533255
  Web:
  www.bladderandbowelfoundation.org
- Bowel Cancer UK
  Tel: 020 7381 9711
  Email: admin@bowelcanceruk.org.uk
  Web: www.bowelcanceruk.org.uk
- Beating Bowel Cancer UK
  Tel: 08450 719300 (Lo Call rate)
  Web: www.beatingbowelcancer.org
- Gay & Lesbian Ostomates (GLO)
  (The United Ostomy Association in 1982 established the Gay and Lesbian Concerns Committee, now called Gay and Lesbian Ostomates (GLO) Network.)
  Web: www.glo-uoaa.org
- Ostomy Lifestyle
  Tel: 0118 324 0069
  Email: admin@ostomylifestyle.org
  Web: www.ostomylifestyle.org

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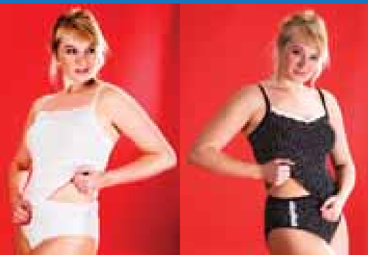


ami COLLECTION

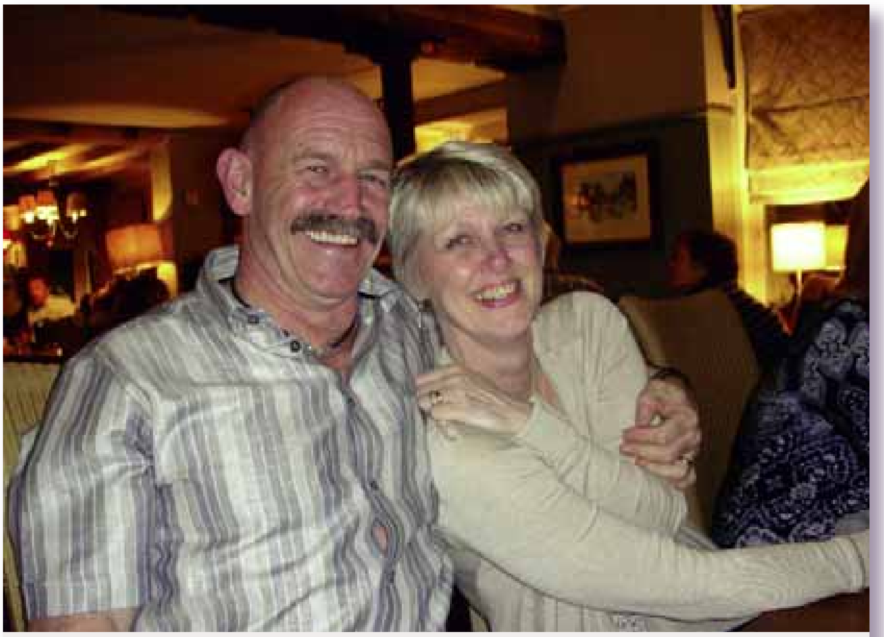
# Intimacy and a stoma...

It was 10 weeks after my operation that I finally made love with my husband and I cried, I cried so much he thought he had hurt me. I actually cried because I had achieved what I thought was my biggest challenge following my surgery.

Being Intimate had always been an integral part of my relationship with my husband, not the be all and end all but a part of the whole package and after my surgery looking at this monstrosity attached to my tummy and the scars that came with it I actually gave my husband the chance to leave me and find satisfaction elsewhere.

I have to say that I am a very lucky woman, my husband just looked at me and said remember our vows? This is the sickness part and we will get through this, adjustments may need to be made but at the end of the day you are alive and that's what counts. I think I realised then that the man really loves me. But my mind needed to make big adjustments that were not as easy as the ones my body was making.

Every couple has their way of 'doing it'. In the dark, with clothes on, lights blazing, stark naked, with toys, without toys, in kinky clothes (him as well!) or just plain old 'give us a cuddle'. Well just because you have a stoma it shouldn't change, everyone has to adjust to the change of body image but then as we grow old bits sag, stomachs thicken, boobs drop and that includes man boobs and we go grey and/or lose our hair so what is so different about a stoma?



**Sue pictured above with husband Tony**

Most people have a stoma because of a life threatening illness and the fact that they are still around and considering being intimate means that hopefully things are getting better and what better way to feel better than being close and loved by your other half. You don't have to go the 'whole way' the very first time or even every time, kiss, caress, in bed or on the sofa, drink some wine to loosen you up, stay under the covers and 'Play' or just cuddle and talk about your hopes and fears, your wishes and dreams, forget about your stoma and enjoy each other like before your surgery.

You are both still the same people but now you have a stoma.....treat it as a new arrival like a child maybe, and adjust your lives around it, if you don't want your 'bag' on show get a pretty wide suspender belt type band to cover it up when you are being intimate, or make a joke out of it by writing silly or loving messages to your partner on it, wear pretty or sexy underwear to draw your partners eye away from your bag, whoever said you had to be naked to make love.

People come in lots of shapes and sizes with personalities and confidence levels to match, you are still the same person as before your surgery and your new friend or foe will take some getting used too but don't shut your partner out, they loved you before and they still love you now, share and enjoy each other, making love is in itself a very healing process!

**Profile:** Sue is 53 and works for a busy garage. Sue and her husband Tony live in Milton Keynes and have just celebrated their 22nd Wedding Anniversary. Sue had her stoma six years ago following emergency surgery for a perforated bowel.

**Sue writes:** Looking back to when I received my stoma seems such a long time ago – without Tony's support – I'm not sure I would have had the energy to go on!

Today I think I live my life much the same as I always did but with more enthusiasm – I'm eager to try new things like, abseiling and a half marathon for example.

I work in a very busy garage and try my best to keep 14 guys in line which is easier than trying to sort out Tony, two stepdaughters and three grandchildren!

My time off is spent in the gym, going motorcycle racing, caravanning, walking, reading and spending time with friends.

Donna takes the plunge...

Flying across the river

Challenge Complete!

# Dear Nurse

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

**Q:** *My wife has recently had undergone surgery and received a colostomy. However she is suffering not only from the physical changes the surgery has brought but the psychological issues of accepting the change to her body. I know it's early days but I really feel the need to contact you. Is there any form of professional counselling available to her? And if so how do I find out about it? Here's hoping.*

**A:** It is often difficult for patients to psychologically adjust to living with a stoma. Your wife's stoma care nurse can help and can refer her to a counsellor if your wife agrees to this. It may also be helpful for your wife to speak to someone from the Colostomy Association as they have members who are specially trained as volunteers to provide support and advice to patients. These volunteers are extremely good and speak from experience, talking through any concerns your wife may have. There is a lot of support available and I would hope that with time and support your wife should be able to live a full and active life.

**Q:** *Some 10 years ago I had a colostomy and anal removal. In the last 4 years I have had terrible pain in that area. I have seen three surgeons had MRI's and CT scans plus a visit to a pain clinic. They do not know what is causing the pain and guess it is phantom pain. I cannot understand why they can't identify the cause of the pain with all the modern scan machines. I have been advised that more surgery at my age (74) would not be good for me and may cause more trouble. The pain is excruciating. My doctor is not very helpful and gave me Opoid painkillers but the side effects are terrible. Other than that nobody wants to know me, which I find distressing can you suggest what course of action I should take?*

**A:** It is very difficult sometimes to explain this type of pain. Phantom rectal pain is well documented and is extremely difficult to manage, both for the patient and for the Healthcare professional. Many people with this type of problem are continually under the care of the Pain Service, who can offer a range of treatment options to manage the symptoms. I would suggest a re - referral to the local Pain Clinic Consultant and recommend you are very frank and open with him as to your concerns and the restrictions this is placing on your lifestyle.

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

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

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

**Q:** *I had a colostomy about 10 years ago and I'm glad to say that the top end has worked very well. I enjoy playing squash and fell-walking so the operation itself has had little effect on my lifestyle. Following the operation, an abscess formed somewhere near the top of my rectal stump and eventually this started draining through a fistula that discharges quite close to my anus. I understand that an abscess happens in about 5% of colostomy procedures. I manage the discharge with non-sterile dressings changed 2 or 3 times a day and this again has little/no impact on my lifestyle. I am a little anxious however about the existence of the abscess, whether it's growing in size, whether it might "burst" and whether there might be some new treatment that has evolved over the last few years that might deal with it. Or should I just stop worrying about it!*

**A:** If this is causing you some concerns I would suggest a re-referral to your consultant surgeon who could reassure you or even arrange some scans to assess the abscess. The consultant could then discuss with you any treatment options available. It may be that there is no further treatment other than what you are currently doing but at least it would settle your mind to have discussed it in detail.

**Q:** *In May, this year I had a reversal operation however find myself increasingly depressed as I am having problems with incontinence. I seem to be passing just fluid, no real substance or bowel movement and its quite painful in my lower abdomen if I strain. My GP thinks it may be a blockage, albeit admittedly this is not her area of expertise. It's as though I have no control over my bowel movements and my anal sphincter cannot control output. Is this to be expected and also do many patients go back to a stoma after having had a reversal. I would so appreciate your opinion.*

**A:** Following reversal it is common for the bowels to be erratic but this usually settles after a few months and although pain is to be expected following surgery it should have settled by now. If your GP is concerned it could be a blockage I would suggest a review fairly urgently with your consultant, which your GP can arrange. It may be that you require investigating as to the cause of these symptoms and the consultant can arrange this once you have been reviewed. There are patients who, due to many reasons, need to have a stoma reformed following reversal and this would be one option but I think you need to discuss the cause and treatment options with your consultant.

**Q:** *I'd like to make a point about stoma care management. In your column 'What kind of stoma do you have?' You mention that if there is only a small length of colon remaining, then stoma output may be fairly liquid, and the colostomate may prefer to use a drainable bag. I was in that position, having had my first stoma in 1982 and my second (on the right side this time) in 2003. 'Liquidity' being then a problem, my surgeon suggested I use Loperamide or Imodium capsules. These are an effective cure for diarrhoea and he recommended their regular use. When you find the dosage that suits you, you don't need the drainable bags! They really do work. They can be prescribed by your GP and on included on a repeat prescription.*

**A:** You are correct that the use of Loperamide (Imodium) is a common treatment for loose stool and can be used very successfully by ostomates to manage their loose output to enable better control and the use of different products.

**Q:** *My husband has a colostomy and has had no problems until recently. He is experiencing leakage from his bag everyday and is getting very upset. He has no contact with any stoma care nurse or local hospital, as he's been fine up until now. What do you suggest, who should he contact after such a long time. I wait your answer with anticipation.*

**A:** This is a very distressing problem for many ostomates and needs to be resolved as soon as possible, not only to prevent or treat physical problems but also to prevent psychological problems for the patient. I would suggest an urgent review by your husband's GP who can then refer him to the local stoma care nurse. The stoma care nurse can then do a full assessment of the potential causes of the problem and prescribe a treatment plan to resolve the issues.

**Q:** *My mother has a colostomy and is having a lot of pain from mucus but is unable to pass it. Her GP referred her to her surgeon who has told her that there is nothing wrong. She is feeling vulnerable and is unable to leave the house or let my father leave the house. Her stoma care nurse has recommended that she stops the enemas as they were hyperstimulating her. Can you explain why the mucus is causing her pain and what I can do to help bearing in mind her surgeon has said nothing is wrong.*

**A:** I presume the mucus is from the rectum or defunctioned end of the stoma. I agree that enemas may be over stimulating the bowel and making the problem worse but a small glycerine suppository occasionally may help if there is a build up of mucus, increasing the feeling. You do not say if she is having a problem with leakage of the mucus which could be making her reluctant to leave the house. If this is occurring a small pad such as a panty liner may help to boost her confidence so that if she does get any leakage she will not soil her underwear. I hope this helps and that your mum gets her confidence back and is able to lead a more normal life. Speaking to a member of the Colostomy Association may also help psychologically as they are the true experts in living with a stoma and may be able to encourage your mum to venture out.

**Q:** *I am attempting to get used to my colostomy after having very extensive bowel surgery and complications. I am very careful to keep the skin around my stoma clean but sometimes my skin becomes sore. In fact I have intense soreness in an area, which is not even under the adhesive ring and is brought on by changing the pouch. I take paracetamol continually to reduce this but it hardly helps. The last hospital visit/examination was as it should be. I do not have hernia but still have intense soreness. I had the operation at the end of December and was in for quite a few days due to a septic condition. If I attempt to do anything manual the level of soreness increases badly and takes several days to subside. Is this normal? Is there anything I can do to cope with this as by the evening I resort to going to bed just to escape it? I find I have to change my pouch on average five times daily and everything adds to the soreness. Can you help please as this is miserable?*

**A:** This sounds very complicated and obviously is causing you severe problems. I would suggest making an appointment with your stoma care nurse who can examine the stoma and surrounding area to give a more detailed insight into the problem and it's possible causes. It is difficult to assess the level of soreness and excoriation of the skin without being able to look at it and identify the cause as there can be many. If the stoma care nurse is unable to identify the cause she may be able to get a review from the medical team who can arrange relevant investigations to help identify the problem and therefore recommend a treatment.

## 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
2 London Court, East Street
Reading RG1 4QL

or e-mail your query to:
editor@colostomyassociation.org.uk

# Stoma Care Open Days...Join in...

Open days give ostomates the opportunity to meet and share experiences with other ostomates. Many people attend with friends and family as they are very sociable events.

## Coming up very soon...

Title: Salts Healthcare/Health & Wellbeing Roadshow 2012
Venue: Black Country Living Museum, 'The Exhibition Suite' Tipton Road, Dudley, West Midlands DY1 4SQ
Date: October 5th 2012
Time: 10.30am – 12.30pm
Organiser: Salts Healthcare

Title: World Ostomy Open Day
Venue: The Terrace Suite, Botanical Gardens, Westbourne Road, Edgbaston, Birmingham, B15 3TR
Date: October 6th 2012
Time: 10.00am – 1.00pm
Organiser: IA Birmingham
Mary Coterill

Title: Annual Patient Day & Exhibition
Venue: Bradwell Lodge Community Centre, Bradwell Lane, Porthill, Newcastle, Staffordshire ST5 8PS
Date: October 13th 2012
Time: 1.00pm – 3.30pm
Organiser: OUTLOOK (North Staffs Ostomy Support Group) Moira Hammond 01782 627551 or Ernie Hulme 01782 324441

Title: Stoma Care Open Day Northern General Hospital - Sports Hall of the Spinal Injuries Unit
Venue: As above
Date: October 15th 2012
Time: 10.00am – 3.00pm
Organiser: Sheffield Teaching Hospitals NHS Foundation Trust

Title: Medway NHS Foundation Trust Open Day
Venue: Commissioners House, The Historic Dockyard, Chatham, Kent, ME4 4TZ
Date: October 16th 2012
Time: 10.00am – 2.00pm
Organiser: Stoma Care Dept

Title: Medway NHS Foundation Trust Open Day
Venue: Wanstead & Snaresbrook Cricket Club, Overton Drive, Wanstead, London. E11 2LW
Date: October 27th 2012
Time: 12.00 Noon – 3.00pm
Organiser: Whipps Cross University Hospital
Christina Gonzalez

Title: Ipswich Stoma Care Open Day
Venue: Community Centre Bell Lane Kesgrave Ipswich Suffolk IP5 1JF
Date: November 7th 2012
Time: Morning Session
10.00am – 1.00pm.
Closed for lunch
1.00pm – 1.30pm.
Afternoon Session
1.30 pm – 3.00 pm.
Organiser: Ipswich NHS Stoma Care Specialist Nurses and Community Nurses

**Open day events are posted on the Colostomy Association website throughout the year...**
visit: **www.colostomyassociation.org.uk**

SASH

- The Sash belts are available on prescription and suitable for both male and female.
- All belts are custom made from information given on our Order Form and a hole is cut into the belt flange to fit your preferred pouch.
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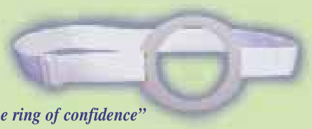
Security and Leakage Belt

- The Security and Leakage Belt is made of a soft 32mm (1.25") elastic belt attached to a retaining flange that fits between the bag and the adhesive section of the pouch.



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- This lightweight unobtrusive belt is designed to help eliminate leakage problems by holding the adhesive section of the pouch against the body during all activities.
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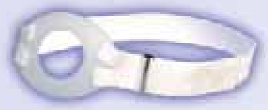
- The Stoma Support and Hernia Belt is made of a 50mm (2") non elasticized webbing attached to a restraining flange that fits between the bag and the adhesive section of the pouch.



- The SASH Stoma Support and Hernia belt is designed and manufactured by an Ostomist and gives support to the muscles surrounding the stoma.
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# A passion for teaching and enhancing stoma care...achieving more!

## Nancy Thomas – Stoma Specialist Nurse at Nevill Hall Hospital in Abergavenny, South Wales decided to write to Tidings Magazine to show there are nurses out there willing to go the extra mile to enhance and improve the patient journey...

By way of introduction I am Nancy Thomas a Stoma Specialist Nurse at Nevill Hall Hospital in Abergavenny, South Wales. I have been with the stoma care team a year now and prior to that in the same Trust for eight and a half years I was a senior staff nurse on the acute surgical ward predominantly colorectal and for seven of those years I was the stoma care link nurse.

Last year I attended the ECET (European Council Enterostomal Therapists) and heard about a course for healthcare professionals sponsored by Dansac Limited, who are dedicated to education in stoma care. The course entitled 'Knowledge, Skills and Practicalities for Healthcare Professionals in Stoma Care' - tasked students with completing the following 4 modules:-

- 1: Anatomy, Physiology, Operations
- 2: Observing, Recording, Reporting
- 3: Stoma Care Products
- 4: Concerns, Care, Discharge

On satisfactory completion of each module students would be given a recognised certificate.

I have a passion for teaching and enhancing stoma care and was eager to return to the two surgical wards to introduce this course.

When I realised students would not be able to have study leave due to financial constraints within the organisation, I was apprehensive that there would be any takers for the course. However, to my amazement not one, but four nursing auxiliaries came forward – Lillian Wright, Isabel Weston, Ruth Hartshorn and Christine Morgan, three from ward 3/4 and one from 3/3 registered.

Their experience within the ward ranged from 2-11 years and their enthusiasm for taking the course was refreshing to see. The contents of the course allowed students to gain specific knowledge in stoma care - an understanding of anatomy and physiology involved in digestion and to recognise the appearance of a normal stoma and peristomal skin through vigilance and to report and record any adverse changes to relevant members of staff. Students were also given a case study of a patient to complete to understand the surgery involved and the care and level of support needed in order for the patient to become independent in preparation for discharge. They also had to familiarise themselves with the appliances and accessories, which aid patients with complicated, or problematic stomas to return to their everyday activities. This was done with the support of myself, (their mentor) and the support of the other stoma/colorectal team Sister Gill Jones and Colorectal Cancer Nurse Mandy Watkins.

Each candidate worked extremely hard, first attending a registration day and completing their workbooks in their own time with commitment and dedication to further improve the quality of care and satisfaction of patients undergoing surgery and stoma formation on their wards.

As you can see from the photographs these nursing auxiliaries gained their certificates in March this year and I was really proud to have been part of that special day!

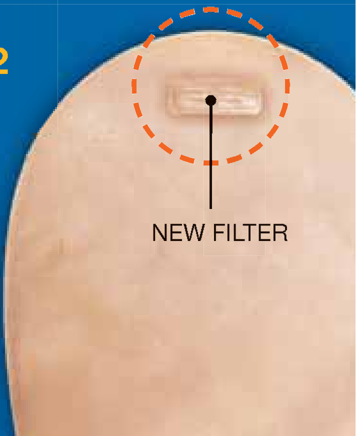
Since passing their course, positive feedback from ward sisters states staff appear more confident when caring for stoma patients and they feel the ward and patients have really benefited!

A letter received from a patient highlighted the anxiety and vulnerability he felt overnight... this is an excerpt:

When the lights went out, Nursing Auxiliary Lillian said, 'don't worry I will check the bag every two hours while you're asleep and she did and for the first time I slept well – she was true to her word and it really made such a difference to me'.

I can teach support but it requires the nurse to – perhaps put themselves in the patients shoes – to really understand their needs, to empathise and try and address any fears or anxieties the best way they can.

The enthusiasm that has surrounded this initiative has encouraged others to apply for the course – to take up the challenge and become a part of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this special group of patients. My wish is to have a continuous flow of healthcare professionals eager to apply for the course with the same 110% dedication and professionalism.

A few words from each nursing auxiliary, to say what they gained from the course.

**Isabel:** Recently I was given the opportunity to take the stoma care course run by Dansac. Well my achievement was a pass. I will say the folder presented to us at the Induction day was very thick and scary. But all was explained by tutors Nancy Thomas (mentor) and supported by Gill Jones (stoma sister).
The course was very interesting and helpful to me in my on the colorectal ward. The most enjoyable part was writing a case study of one of my patients who I'd nursed and to follow their progression through and after care. The course detailed the anatomy and physiology of the body, the operation/s required, how stomas function and the products that are available to the patients whilst in hospital and the community. Dietary needs, advice with sexuality needs and so on. The care, understanding and knowledge to help support people with most stoma care problems. The course took a lot of work, many hours but it was well worth it!

**Ruth:** I felt the course gave me the knowledge behind the skills I was already using – by obtaining the knowledge I gained more confidence whilst practising those skills and I'm glad I did the course even though it created more work, which at times was difficult to fit in! But I did it!

**Lillian:** I cannot believe I am trying for an ology at my age! After reading the case studies that had been created I thought, 'we must help these patients their life has been turned upside down!'

**Christine:** I enjoyed doing the course but it was hard work and I am glad I managed to get through it, as I have a wider knowledge of appliances and accessories available to patients.

## Dansac writes about Education and Training for Stoma Care Nurses...the following article outlines how continual development makes a difference to quality of care for stoma patients...

# Supporting the patient...how continuous training and constant evaluation of stoma care in practice improves nurse and patient confidence

Education and training are essential for healthcare professionals at all levels if they are to deliver a high quality of care to patients, in a confident and competent manner. Education and the development of new knowledge and skills should form part of a continual cycle of progression throughout the career pathway, necessary in order to keep up to date with changes in treatments within the health service. As Black (2000) suggests 'The practice of nursing requires specialist knowledge and skills, a concern for other human beings and the exercise of clinical judgement'.

When caring for the stoma patient it is important that the nurse has some knowledge of the anatomy and physiology of the bowel, the type of diseases/ trauma which may affect the bowel and the surgical/ drug therapies which are available to treat the bowel, In order that they can understand the reasons for the surgery and the effects this will have on the ostomate.

The level and depth of knowledge held by the nurse will vary according to grade, experience and knowledge acquired through education.
During their pathway, the patient will encounter many healthcare professionals with a variety of knowledge and skills from the healthcare assistant to the specialist nurse all of which have differing roles to play.

Black (2000) identifies five areas of the Specialist Nurse role: - clinical expert, researcher, consultant, teacher and change agent. These highly skilled and educated nurses are an invaluable resource to support the patient, carers and families also colleagues, both medical and nursing thus enabling them to ensure the individual makes a good recovery and adapts to the life change in a satisfactory way.
It is clear education is important to both ostomate and healthcare professional if they are to achieve their shared goals. Burch.(2008) suggests, 'it is a huge change in an ostomate's life to have stoma forming surgery, however with appropriate support and advice the ostomate can enjoy a good quality of life'. This is the aim of both healthcare professional and ostomate.

Advances in surgical technique, keyhole surgery and the introduction of enhanced recovery programs within hospitals has contributed to a reduction in the overall length of stay for many groups of patients, including those undergoing bowel surgery and stoma formation. This means that the time available to educate and support the patient/carer to competently manage their stoma has reduced, the management of the pouch change is only one aspect of the care, skin care, diet, exercise, body image, sexuality and psychological well being are also just as important. >

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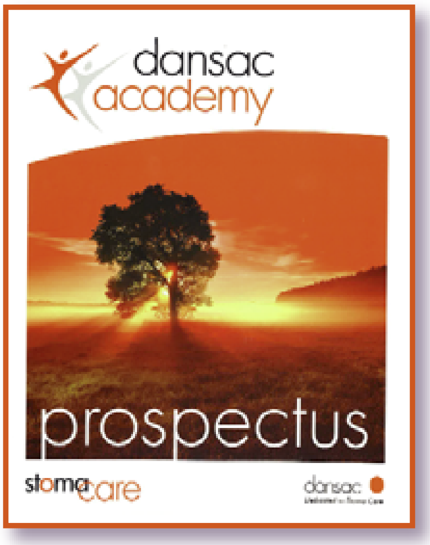
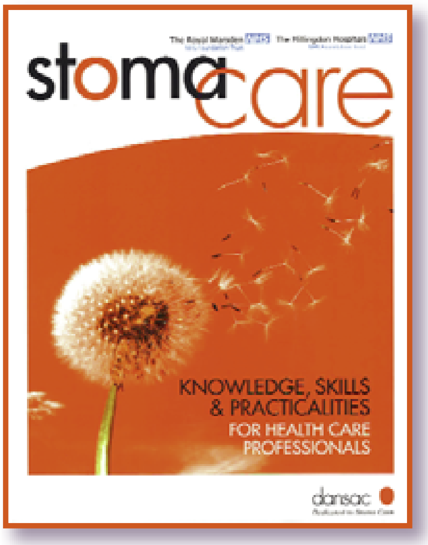




< The involvement of the multidisciplinary team in this education and support process is essential, to ensure that the ostomate is able to adapt swiftly. In order to assist with the support and education of the ostomate and healthcare professionals, Dansac like other manufacturers has developed a range of information, teaching tools and support materials, which can be used to train and inform both healthcare professionals and ostomates in various aspects of stoma management in the clinical and home environment.

Access to formal education for healthcare professionals resulting in a professional qualification in the specialised field of stoma care is limited; Over time venues which previously offered specialist education have ceased to do so, with the economic climate as it stands this is likely to continue, access to courses is now often via distance learning, a limited number of universities or industry supported.

Dansac an ostomy manufacturer for more than 40 years is ‘Dedicated to Stoma Care’. This dedication is reflected in our work, which goes beyond the development of innovative new products and support materials for both the healthcare professionals and ostomates but also in our commitment to education.
Dansac has along history of supporting healthcare professionals education, this has been formalised in more recent times with the formation of the Dansac Academy.

Dansac has not only sponsored a number of courses but has worked with and continues to work with a number of specialist nurses and doctors from centres such as Hillingdon, The Royal Marsden, St Marks, University College London, York, Birmingham Children’s Hospital and New Buckinghamshire and Birmingham Universities to develop a range of Courses and Master classes designed to suit the varying educational needs of the healthcare professionals at all levels, from the Health Care Assistant up to the Stoma Care Specialist.

The Academy Courses all provide a recognised qualification, at Diploma, Degree or Masters Level via a University or in the case of the Knowledge Skills and Practicalities Course a City and Guilds qualification, which meets the new Quality Credit Framework (QCF) Healthcare support diploma which replaced the previous National Vocational Qualification (NVQ). This course is available to both registered nurses and health care assistants, the specialist nurses act as mentors to guide and support the candidates to achieve a successful pass, assessing practical skills and guiding them through the completion of a work book which is submitted to the City and Guilds for verification prior to awarding diploma credits and a nationally recognised certificate.

The aim of this course is to develop and build upon the candidates existing knowledge and skills, to enable them to confidently support/educate the ostomate at a time when they feel most vulnerable, ensuring continuity of care throughout the ostomates stay in hospital and as they progress towards home and onwards in community care.

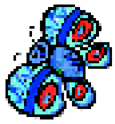
The Master classes are a series of short one/two days study focusing on more specialist aspects of education for example: - Urology, Dermatology and Sexuality, most have Royal College of Nursing (RCN) Educational Credits some have Credits which count towards a Masters Degree Qualification.

Ostomates have much to learn as they adapt to a major life change, the support, advice and skills of those seeking to help them to adapt is invaluable, this care is part of an ongoing process and not just a one off event.

For many having a stoma is permanent, ongoing contact with specialist nurses may continue throughout the ostomates lifetime when additional advice may be needed to address any issues arising due to for example change in body shape/ dexterity or activity, this relationship is important as it helps to maintain the ostomates confidence and can seek to boost morale when difficulties may be encountered.

The provision of ongoing education is vital to ensure that the quality of care for ostomates is maintained and the healthcare professionals have the confidence knowledge and skills to meet any challenges they may encounter.

**References**
**Black.PK .(2000) (p197) and (p192) Holistic Stoma Care. BaillierelTindall.London.**
**Burch.J.(2008)(p11) Stoma Care Wiley-Blackwell.Chichester.West Sussex.UK.**

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# Readers' writes

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

### Dear Editor

I am responding to a query from Mrs. S.W. in 'Readers' Writes' in the spring issue of Tidings, about where to source 'tops' that would cover up a hernia bulge. 'Woolovers' catalogue/website shows many long line tunics and smocks in both wool and cotton/silk blends (very reasonably priced) which may be suitable. Also, BHS often have attractive loose smock-type tops, or would an upmarket maternity smock solve the problem?

R.M

**From Ed:**
The Autumn/Winter Catalogue 2012 is available on request from 'Woolovers'. Simply contact: 0845 073 1040 (UK LOCAL RATE) to order a copy or visit the website: www.woolovers.com

### Dear Editor

I have had a stoma following an operation (Hartmann's procedure) I had in July 2009 for a diverticular perforation. In November 2011 I was admitted to hospital as an emergency patient for treatment of a sudden urinary tract infection, which was eventually diagnosed as septicaemia of unspecified cause and effectively treated, with injections of Ertepenam. Some three days into this treatment I had the worrying and unwelcome experience when urinating of pressure in my back passage, followed by the involuntary passing of significant quantities of stool, liquid in consistency and chocolate brown in colour. This was repeated over a period of three days, in dwindling quantities, whenever I passed water. The team treating me were mystified by this occurrence and, despite consultations with relevant departments, were unable to come up with an explanation. Tests of my kidneys and bladder were normal and no abnormality was found in my rectum or pelvic cavity. I have experienced no recurrence of the problem since I was discharged, but I thought it wise to consult my GP and the stoma team at my hospital. They can offer no explanation either.

I am aware of the not uncommon experience of stoma patients of the phantom urge in the back passage to pass a motion and the phenomenon of anal discharge of mucus, which can sometimes accompany this; indeed I have had on occasion such experiences myself. I am aware, too, that it is not uncommon for ostomates to pass small quantities of stool, but I understand this normally happens within a few weeks of the operation. In my case the occurrence was some 2 years and 3 months after my operation and this seems unusual, to say the least. It occurs to me, therefore, to ask whether you or your colleagues are able to shed any light on this problem from your familiarity with the experience of members.

M.J.W (Mr)

### Dear Editor

I have had a colostomy for 10 months and have a problem with very loud wind. I am so embarrassed by this uncontrollable noise that I won't go anywhere quiet e.g. church or meetings. I am also constantly worrying that it will happen when I am with my young grandsons aged 10 and 12, knowing how obsessed young boys are with 'toilet humour'. I know wind is a natural thing but what can I do to deaden the noise? Also does it take the same amount of time from eating, to the wind exiting the stoma, as it does for faeces, as I've tried eliminating certain foods and reintroducing them but found it impossible to find the culprits. Peppermint and charcoal tablets have failed to make any difference.

I irrigated for two months, which helped but have had to give up due to a heart condition.

Has anyone found any solutions to this problem?

L.M.B. (Mrs)

### Dear Editor

My colostomy is two years old and I have learned much from 'Tidings'. I would like to comment on one letter and ask about another. Both appeared in the spring issue 25. First from Mrs S.W on parastomal hernias. I have had one on my urostomy for a long time and it's never caused me any problems. I don't have a hernia around my colostomy but I do have a prolapsed stoma, which is large and bulky. I have chosen not to have it re-sited yet. As Mrs S.W is asking about clothes to cover up a hernia I have a similar problem covering up my bulging stoma therefore I buy tops larger than I need to cover it up for my own comfort. I wear skirts and trousers and a top to go over the skirt or trousers. I do wear hernia support pants that I get on prescription because I have pain without them.

The question in the other letter from Mrs L.C about wind and filters I get a lot of wind and I always thought it stayed in the pouch until I go to the toilet and let it out. I don't know anything about filters. Does this

# **Readers'** writes

mean if I choose a pouch with a good filter the wind comes out of the filter? Can someone advise me?

M.F

**From Ed:**
All modern ostomy appliances have air filters that have charcoal in them. The charcoal acts as an odour eater, and neutralises the smell. Most people will be aware of the smell of their colostomy because it is their own body. However, someone standing next to you will not be able to smell the stoma. Immediately after your surgery your colostomy will make excess wind and noise. This will slowly reduce as your bowel recovers. Your stoma nurse can advise you of products that you can use to help reduce any smell and dietary advice to reduce wind.

## Dear Editor

Tidings makes a fascinating read I just can't put it down! The topic that caught my attention in the summer issue was regarding prescriptions. A year or so ago I could order my colostomy products direct with the supplier who then obtained the prescription. That system changed and I am now required to obtain the repeat prescription from my GP, which is more sensible providing the GP, understands what is involved. From the letters it would appear that some GP's need educating. When the system changed I could foresee many of the problems that might be encountered so I made an appointment with my GP to review all the items she had on her computer relative to my colostomy needs. I was astonished, and so was she, by the number of items. Some I had never ordered or used (catheters) whilst others were of a type or style that I didn't need (drainable bags). The fact that I now irrigate made my list very short but my GP insisted that it would be prudent to include the 2 part system I had used in the past just in case. Perhaps since I have passed Tidings on to her this may explain her understanding of living with a stoma.

Finally I thought Duncan Wells last paragraph suggesting the NHS encourage irrigation as a management technique very appropriate. I am about to set off on a 30 day 1000 mile bike ride down the Rhine, which is only possible because I irrigate. I am fortunate to be able to use this method of bowel management and understand it's not possible for everyone.

F.B.K (Mr)

## Dear Editor

Thank you so much for publishing the form for an I.D Card for use in accessible toilets etc. I have been trying to obtain one for sometime but couldn't find a source anywhere. As I look fit and well some mis-informed people don't like it when I emerge from an accessible toilet without a stick or wheelchair and I feel disinclined to explain my needs, as it can be very embarrassing. I will now be able to flash my card without saying a word. Great!

Many thanks,

B.H (Mrs)

P.S I love the Tidings Mag very helpful information.

## Dear Editor

I always look forward to receiving the excellent Tidings. This letter is to enquire whether you might be able some time to include an article on intra-operative radiotherapy.

Several years ago I had an operation for rectal cancer (which resulted in a permanent colostomy). In the course of that I was given intra-operative radiotherapy - described at the time as an experimental technique.

While it would be of interest to learn whether any other of your readers underwent the same technique, perhaps more generally helpful would be an article by a relevant specialist, to report on use of the technique - its benefits and drawbacks.

Yours sincerely,

K.W.B

**From Ed:**
If you have any experiences of the above or you are a Healthcare professional with relevant experience who can comment on the above please get in touch – go to page 6 for contact details - many thanks.

## Dear Editor

Greetings from Selby Yorkshire!
I have been a member of the CA for approximately two years.

I was very pleased to read the section in the summer issue of TIDINGS from a member who has had a stoma colonoscopy - my turn comes soon!

My local stoma care nurse has already dropped in five drainable

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## Crediton Support Group Advance notice

The Boniface Centre, Crediton is booked for meetings for Crediton Support Group the 3rd Saturday 2-4 every as follows:-

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- **April 20th 2013**
- **July 20th 2013**
- **October 19th 2013**

**Contact Janice Parkyn via CA at cass@colostomyassociation.org.uk**

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**contact: editor@colostomyassociation.org.uk**

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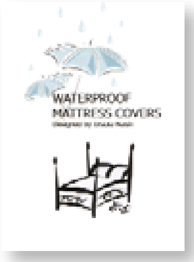
Designed by Ursula Naish

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

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



**For further information please contact:**
**Ursula Naish, 9 Oast Meadow, Willesborough, Ashford, Kent TN24 0AS**
**Tel: 01233 640 863 Email: ursulanaish620@btinternet.com**

# Readers' writes

bags, so I was partly prepared.

Yesterday I called your office, downloaded the article recommended and phoned my usual supplier - Fittleworth.

In the post today – next day!
I received three lots of samples of BIG BAGS!

I am delighted with all this help and want to thank you all!

At 81 my wife and I can do with all the help we can get!

Many, Many, Thanks to you all!

Regards.

R.E

## Dear Editor

I had a colostomy in April last year and apart from a few minor problems, I now cope quite well.

I joined the CA last year and find 'Tidings' most informative and a great comfort. I get furious that so few contribute to such a worthy cause.

I had occasion recently when I was unable to contact my stoma care nurse. So I phoned the CA helpline and was most impressed by the response, firstly from a very nice lady (Jo) who answered the phone, who said she would ask a volunteer to ring me right away. In less than 15 minutes a charming gentleman rang me and was able to help me out.

So this letter is to say thanks a million for a great organisation!

J.S

## Dear Editor

Like the ostomate in 'The fight for our dignity' article (Tidings summer issue 26) I too change my appliance, on average, four or five times a day. This has never been raised with me as a problem by the Doctors at my Health Centre.

However I do have a problem with the length of time involved between me requesting supplies and the supplies been delivered. I order my supplies by e-mail each month through my delivery company. They in turn request a prescription from my Health Centre. After obtaining the prescription from the Health Centre my delivery company send my supplies directly to my home. This whole process is never less than two weeks but sometimes it takes three weeks or more. If I contact my delivery company to ask why the delay I always get the same answer, which is to say that they are waiting for the Health Centre to send them the prescription.

When I request a repeat prescription from the Health Centre, for medication which I need, it is ready within three days. Apart from the above, I am happy with the service I receive from both my delivery company and my Health Centre. I just wish they could liaise with each other a bit better.

Yours sincerely,

J.R

**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**

or write to:
**The Editor**

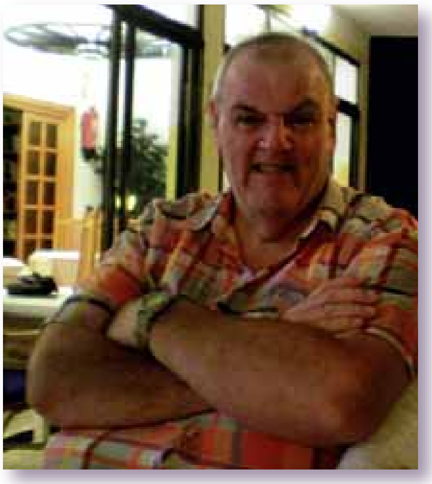
**Colostomy Association**
**2 London Court,**
**East Street,**
**Reading RG1 4QL**

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

Readers'
PANEL
contributor

**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.

# Paul Seavers – CA Volunteer writes on.... The ups and downs of starting up a support group...



On a chilly and cold evening last February in Oldham as the Oldham Support Group was in session, I sat and thought wouldn't it be great if there was a support group nearer to home. Where's home I hear you ask – Tameside, Greater Manchester. Then I thought how shall I go about it?

My starting point was naming the Group, so Ostomisticles was conceived basically from...'ostomates,' which we all are, 'optimistic' which we are and 'miracles' which we are – survivors of serious illness. So, Tameside Ostomisticles came into being.

Next up, finding a meeting place. We needed somewhere central to Tameside, near bus routes, the train station and easily accessible by car. So we went venue hunting. After a few visits and emails – Ashton Primary Care Centre on Old Street, Ashton-Under-Lyne was decided upon. Just by coincidence the manager of the centre was the Dad of a potential member and an ileostomate. The venue met all our criteria, ideally situated, easily accessible and on ground level.

Next came meeting day and time. The well established Oldham Support Group meets on a Tuesday evening at 7pm in the months of February, April, June, August, October and December. So I decided rightly or wrongly to set up our meeting day in the months not covered by the Oldham Support Group. So September, November, January, March, May and July were pencilled in. The day chosen was a Thursday as it was the 'weakest' TV night! Then the date (using Oldham's idea of second Tuesday). I chose second Thursday, making the first date Thursday 13th September 2012. The time 7pm, allowing people to get home from work etc.

Now to find members...Over lunch I met up with June Wilde who runs the Oldham Support Group to discuss how to find members and how to let people know about our group. June said that getting the word out was the hard part but shared some ideas. So off I went. First port of call was of course Sue Hale and Jo Mckenzie at the CA. They gave me all the assistance anyone could possibly hope for and more. Invites, posters letter templates. They also contacted all the CA members in the Tameside postal area too.

I contacted the Urostomy Association and they in turn contacted their local branch who contacted their members. I also contacted the IA - The Ileostomy & Internal Pouch Support Group HQ who asked me to contact their local Branch Secretary, which I did. Unfortunately, due to a forthcoming committee meeting (which was not scheduled to be held before my September meeting) they couldn't contact members until after their meeting. It was a bit of a blow and I felt a little down.

Undeterred and with renewed enthusiasm – invites along with copies of the CA support group posters were sent out mainly to local Doctors surgeries. Gill Wood our stoma care nurse at Tameside General Hospital was really helpful giving out invites and contacting patients. I also contacted local newspapers and our radio station, who obliged by not only giving us a mention, but also giving out all the details of the event on top!

I also contacted Adrian Priest at Salts Healthcare/Medilink. Adrian said he would come along and be our first 'Rep', but unfortunately Adrian became ill just a few weeks before our big night. Due to work constraints some of his colleagues couldn't make our launch night either. However with a little more phoning around and to my delight, Bianca from Coloplast volunteered to be our first 'Rep', attending on the night and staying right until the very end. Thanks Bianca!

I wanted the first night of our meeting to be special, something different, so I decided a 'finger buffet' would be really good – but how to pay for it? Well, as I am a very resourceful chap I had a few ideas up my sleeve. I sold football cards at work, arranged a bottle in a box and contacted the managers of a few local businesses for some 'Raffle' prizes!

The night of the first meeting came. I must say I was a little nervous, gnawing doubt followed by questions in my head. Will it work? Will people attend? Will it go well? It was Yes,Yes and Yes, to all three!

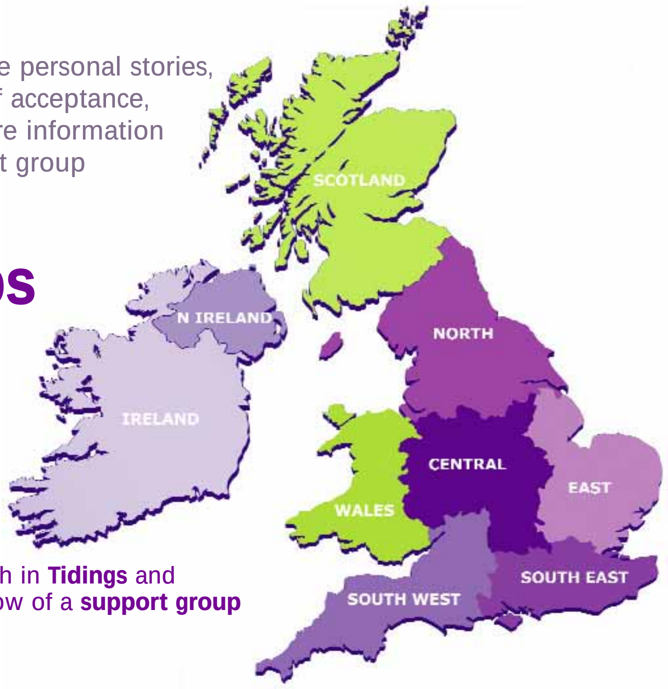
Over 25 people attended (during the day both myself and Gill had received calls from 13 people stating that they couldn't come along due to hospital appointments and illness). This turnout was really promising for our next meeting! Bianca gave her presentation on Coloplast products and Gill spoke to every one of the attendees on a one to one basis. I ran a 'Chocolate bar quiz' and awarded a box of Celebration Chocolates as a prize donated by a local business. The game of musical bingo (same as normal bingo but with songs instead of numbers) went well too! A prize of a bottle of wine was very kindly donated by a Cancer survivor. And the 'finger buffet' was a real success!

So, here's to our next meeting at 7pm on Thursday 8th November 2012.
I hope to see you there!

**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 **support groups** is regularly updated both in **Tidings** and **online visit: www.colostomyassociation.org.uk.** If you know of a **support group** not mentioned in our listings please get in touch...**e-mail: 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'Donnel 01236 436479 or Charlie Sutherland 01698 822075

**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 Ostomisticles
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 01661 842029

**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
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

**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: Carole O'Ryan 01691 671624

**Staffordshire:**
Outlook
Contact: Ernie Hulme 01782 324441
Joan 01782 710828

**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: Heather Connor 01733 768332 Mob: 07757167422

**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
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

**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:**
Credition Support Group
Contact: Janice Parkyn 01363 776417
Devon IA
Contact: Margaret Bond 01392 447374
Devon Stoma Support Group
Contact: Donna Ashbrook
01626 854862

**Dorset:**
Colostomy, Urostomy, Pouch & Ileostomy of Dorset-CUPID (West Dorset)
Contact: CA for details 0800 328 4257

**Wiltshire:**
Swindon IA
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: Jackie Walker 07843 988 432
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

RADAR
the disability network

NATIONAL KEY SCHEME
How to obtain a key to gain access to toilets for the disabled

Colostomates are entitled to a key which will open 8,000+ locked toilets around the UK. Some local councils will provide this key free, or for a small charge.

Keys can be obtained from the Colostomy Association at cost of £3.50+VAT
Contact head office: 0118 939 1537 for an application form.

Keys can also be purchased for £3.50+VAT
from RADAR:
Tel: 020 7250 3222
Web: www.radar-shop.org.uk

From RADAR
National Key Scheme Guide 2011
Price: £16.99 incl. delivery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