

Tidings

Helping **ostomates** since 1967

Happy
New Year



Cover story

- A Day in the Life of a Volunteer

Inside

- From a Carer's Perspective
- A Stoma Friendly Society
- A Better Quality of Life

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COVER PICTURE

Jackie Dudley in her various roles at the
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dear READERS

As we begin a New Year, the Colostomy Association president, Colorectal Surgeon Ian Daniel FRCS, looks forward to 2016 and the launch of several new initiatives. Our chairman, Monty Taylor looks back at what has already been achieved since the Colostomy Association was formed by a small group of dedicated volunteers ten years ago.

We must never forget, however, that the roots of the charity go much further back to when the Colostomy Welfare Group (CWG) first began, and so in 2017 we will be celebrating 50 years of supporting ostomates. Back in 1967 CWG was composed entirely of volunteers who all had a colostomy and were committed to visiting patients in hospital to present themselves as living proof that it was possible to live a normal life. Although times have changed and today ostomates are probably more likely to meet one of our volunteers at an Open Day arranged by one of the many stoma appliance manufacturers, or on a social media site than on a hospital ward, our volunteers still remain at the heart of our organisation.

In this issue of *Tidings* we are taking the association's much appreciated volunteers as our theme. Many of you will recognise the face on the cover. Jackie Dudley became a volunteer in 2002 and is a long standing member of the editorial team. She began as an admin volunteer in our head office in Reading and has come in to help once a week ever since. We asked Jackie to tell us more.

Three other people who feature in our real life stories are also volunteers, Moira in North Staffordshire, Carole in the Southampton area and Mike in Wolverhampton.

These stories illustrate the two extremes of stoma formation; the life-saving emergency procedure as in the case of Mike who had

peritonitis following a burst diverticula, and Chris who had cancer and entitles his story *Life after All*. On the other hand, Carole and Peggy opted to have a stoma after suffering for years with IBS and incontinence and write about *A Better quality of life*.

Our volunteers, who all have a stoma, can use their experience to answer practical questions as Sue Hale, **Colostomy Association** General Manager explains in her article *How the Colostomy Association changes lives*. The telephone helpline is one way of providing support and in this issue we feature the type of questions that our volunteers will answer in the evening and at the weekend. Some of the callers may ask about irrigation or would like to talk to someone who uses this method of colostomy management. On the irrigation page Sarah Squire addresses a new irrigator's concerns.

When I meet new ostomates at Open Days, they will sometimes confide in me their reluctance to go out in case they need to attend to their stoma before they get back. With them in mind, in this issue we include hints and tips for changing your pouch while away from home. In the next issue we will move further afield to consider travelling and holidays. We are hoping that those of you who have had a stoma for some time will write in to tell new ostomates about your holidays – both in this country and abroad; how you felt before you left home the first time after your stoma surgery and how you coped when you got there. By sharing your experience you could encourage new ostomates to plan their holidays for 2016.

Look forward to hearing from you.

Happy New Year to All

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

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TIDINGS | WINTER 2016 | 3

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How to become a member of the Colostomy Association

Simply contact us by post:

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inside this issue

all your regulars & special features

Updates

- 8 **Colostomy Day**
- 9 **New Year Messages**
CA President,
Ian Daniels FRCS and
CA Chairman, Monty Taylor
- 19 **Fundraising**
A thank you for your generous
donations and fundraisers
- 30 **New products**
Keep up to date with the
latest products and services
- 39 **CA News**
Sue Hale reports from
Head Office

From Healthcare Professionals

- 50 **Dear Nurse**
Julie Rust answers your letters
and e-mails

Living with a Stoma

- 13 **A Guide for New Ostomates**
Changing your pouch away
from home
- 23 **Irrigation**
Sarah Squire answers a new
irrigator's questions
- 35 **From a Carer's Perspective**
Mack shares his experience
- 48 **The Colostomy Association Helpline**
Typical questions

Real Lives

- 7 **Life After All Chris Lewis**

- 11 **Souvenirs...and tummy upsets**
Moira Hammond
- 14 **A Better Quality of Life**
Peggy Farley & Carole Summer
- 17 **Pathway to a Colostomy**
CA volunteer, Mike

Focus On

- 31 **A Stoma Friendly Society**
The CA Campaign
- 32 **A Day in the Life of a Volunteer**
Jackie Dudley
- 37 **How the CA changes lives**
- 41 **Getting involved with the Colostomy Association**

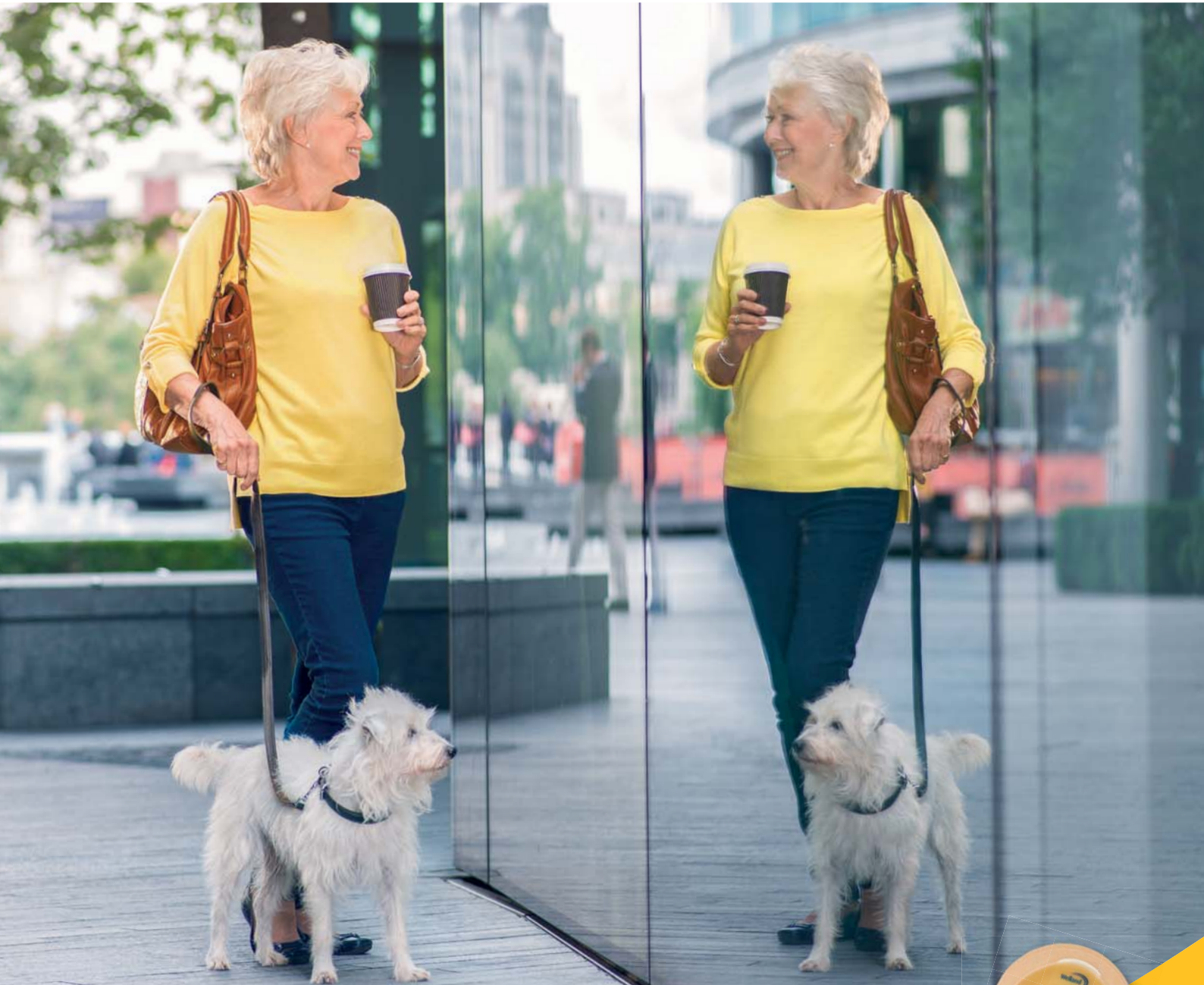
Support

- 27 **Stoma Aid**
How the Service will Work
- 43 **JOSH**
Helpline for carers of young ostomates
- 45 **The Facebook Group**
A mini Meet-up in Scotland
- 47 **The Breakaway Foundation**
- 52 **Readers' Writes**
Your letters and e-mails
- 59 **A Local Group**
Oldham Stoma Support Group
- 60 **List of local support groups**



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Life after all



On holiday in Canada, June 2015

just an
interminable
round of
bag emptying,
bag changing
and leakages...

..How wrong
could I be?

It was September 2014 and I had been feeling ropey for a little while. "Chest infection" said a GP. "Stress because of the death of a very close friend" was another suggestion. "Adverse reaction to antibiotics" was a third alternative as I became sicker and was unable to keep food down.

Eventually on Wednesday 24th September I had a scan and two hours later I was admitted to hospital. Less than a day after that, I had an emergency operation to remove a substantial blockage in my large intestine. The plan was to join the two ends of what remained and all seemed to be going well, as by the Friday I was taking slow walks around the ward. By Saturday the repair had torn, I had severe peritonitis and after a second emergency operation my wife was told that I probably would not survive the night and that she should get our two sons to join her.

After five days in intensive care and five weeks in hospital I defied the odds and went home. I had lost over four and a half stone, was very weak and had an ileostomy which I had never heard of (colostomy yes) and hadn't expected. I felt that life as we knew it had come to an end. No more travel (we had taken early retirement to do just that), no more rich food and drink, no more rough and tumble with the granddaughters, no more visits to my beloved Twickenham for rugby internationals – in other words no more of

all the things I really enjoyed; instead, just an interminable round of bag emptying, bag changing and leakages.

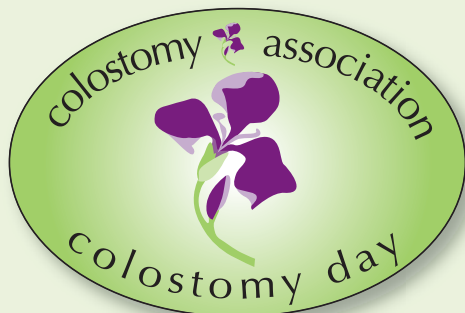
How wrong could I be? The stoma nurses were great in helping to sort out leaking bags. My wife, Jo, was just fantastic in making me feel loved, wanted and normal. Her patience and understanding were invaluable. Family and friends were wonderfully supportive and I gradually grew stronger.

Three months later we went away for a few days to the Cotswolds and I survived, even though my wound had not fully healed and was being dressed every other day. Christmas was spent with one of my sons and then in February a corner was turned. My wound healed and life started improving. With a nervous son and brother to watch over me I went to Twickenham to see England vs Italy, thoroughly enjoyed it and drank a few beers! Two more visits to Twickenham followed and a visit to Wembley to see Bristol City play. We went to Center Parcs and I cycled round the park with Sophie my granddaughter and even went down the flume with her (my son couldn't bear to look!). We started travelling again; Lanzarote for 10 days in May and then Canada and Alaska in June, a belated 60th birthday treat for my darling wife. And my appetite has returned!

I think I have been lucky. Care in the hospital was very good, I didn't need chemotherapy and my first six month scan came back all clear. Life has returned to near normal and whilst there are occasional accidents with the bag, they are few and far between and we cope with them without the dramas of the early days. Bag emptying and bag changing are simply parts of the usual routine. With a little thought and preparation there is very little I can't do. We have joined the local support group, Stevenage Ostomistics, and it is supportive to meet other people in the same situation at our monthly meetings or at the pub for our petanque sessions.

The bag is just a bit of a nuisance. I sometimes call my stoma: "that bloody thing". My wife more accurately calls it: "our life saver". She is right and life is just great again. ■

Chris Lewis



Colostomy Day 2015

On Saturday 3rd October 2015, dozens of supporters, individuals and businesses across the country helped fight the stoma stigma by going purple for our annual Colostomy Day.

It is estimated that over 120,000 people in the UK of all ages currently live with a stoma, and for many it can be an isolating and challenging condition. Colostomy Day was created to compliment World Ostomy Day to put a spotlight on the issues that many people living with an ostomy face each day.

Launched in 2014, Colostomy Day rapidly grew last year with more individuals and businesses from across the country taking part. Independent businesses in Reading went purple by baking purple cakes, dressing in purple and selling purple soup. Olympic rowers trained on the River Thames wearing **Colostomy Association** T-shirts, runners wore purple tutus, the team at SecuriCare had a purple dress down day, nurses at Royal Berkshire Hospital held a cake sale, a bowls tournament was held in Derby and a postman in Crawley did his rounds in a lady's purple outfit and wig.

Speaking about our 2015 Colostomy Day, Marketing Communications Officer for the **Colostomy Association**, Niall Norbury said:

*"It was fantastic to see so many people across the country help fight the stigma of having a stoma for our **Colostomy Day**.*

*"An ostomy is an invisible condition so it is vital that organisations such as the **Colostomy Day** continue to highlight the challenges that many people with a stoma face. In 2015, we encouraged people to go purple and in 2016 expect another attention-grabbing way of highlighting why we must continue to raise awareness."*

Building on the success of last year's Awareness Day, preparations are already under way for this year so please try to keep Saturday 1 October 2016 free if you'd like to get involved.

SHED

What they did: Baked a purple cake and a special purple soup.



Quote: "We've never been asked to make a purple soup before or a purple cake for that matter, what a great way to raise awareness of a sensitive issue."

EMMA BOYCE

What they did: Ran 5k in purple sunglasses and tutus.



Quote: "It was an enjoyable day and I'm really looking to having my daughter Beth take part next year."

TIM SMITH

What they did: Held a charity bowls tournament in Nottingham.



Quote: "The game was played with great spirit and everyone was happy to spend a

Saturday afternoon doing their bit to help raise awareness and funds for the Association. A great fun afternoon was had by all and a good amount of money was also raised. This tournament is set to continue I am sure, so we look forward to the next one – same time same place as it were."

NIBSY'S

What they did: Baked special purple gluten-free cakes.



Quote: "Simply - It was a pleasure to take part in the awareness day."

STEVEN AXFORD

What he did: His round as a postman in a purple outfit and purple wig.



Quote: "It was really fun and I thoroughly enjoyed making everyone laugh and smile. If anything, I expected everyone to look and laugh. Instead, customers on my round told me stories about their friends and relatives who also had a colostomy." ■



Message from our President

Commemorating 10 years as an independent charity, 2015 was a period of reflection, contemplation and celebration for all of us that are involved with the **Colostomy Association**. However, it was also a year of transformation as our charity prepares itself for the challenges and opportunities for the next decade.

2016 will see the launch of several new initiatives as well as improvements and advancements in our existing services. In line with our new five year strategic plan, we plan to launch:

- Stoma Aid, a service that aims to distribute unwanted supplies to developing countries, is closer than ever to reaching its fundraising goal. The **Colostomy Association** frequently receives enquiries from supporters on how they can ethically dispose of their unneeded supplies following the loss of a loved one, reversal or change in stoma size. In 2016, we hope to provide the solution.
- New initiatives such as our Caring for Colostomates and Active Ostomates pilot projects, which will improve the quality of life for many people living with a stoma.
- Campaigns that will enable us to become a louder and stronger voice for the ostomy community.
- A new website; a much-needed update.

There are even more plans in the pipeline that we can't wait to share with you in the coming year.

Last year we celebrated 10 years of the **Colostomy Association**, but the original roots of the charity stretch back to 1967 with the formation of the Colostomy Welfare Group (CWG). The purpose of the CWG was to provide a free service *'to relieve suffering by providing, throughout Great Britain and Northern Ireland, a welfare service for patients who have had or are about to undergo colostomy surgery'*. A special event is being planned in 2017 to celebrate our 50th anniversary to acknowledge that we have been helping ostomates since 1967 and details will be announced later in 2016.

As our charity continues to grow and develop, our vision and purpose remain unchanged. The **Colostomy Association** is committed to creating a society where having a stoma is no barrier to living a full and active life. Looking ahead beyond 2016, we are in a better position to achieve this goal than ever before and I look forward to being part of this journey.

Ian Daniels FRCS
President
Colostomy Association



Message from our Chairman

It is hard to imagine that the **Colostomy Association** might not have existed. After funding for the British Colostomy Association was withdrawn by Macmillan just over 10 years ago, it was only due to the incredible passion of a small group of volunteers that the **Colostomy Association** was formed.

From those small beginnings, the **Colostomy Association** has grown into the UK's largest stoma charity that supports over 21,000 people across the country. In 2015 we celebrated our 10th anniversary. Our hugely successful weekend event captured the values and purpose of the **Colostomy Association**: *a commitment to providing support and the courage to champion the rights of everyone living with a stoma in the UK.*

The past year has seen us develop new products, services and initiatives. Our Pouch Craft competition has helped children learn about stomas in a friendly and accessible manner, while fundraising for Stoma Aid continues, our new helpline for parents (JOSH) officially launched at the beginning of the year and our second Colostomy Day proved even more popular.

Our charity has adapted to changing times by improving our digital presence; the launch of our monthly e-newsletter, an active presence on social media, improved online links and a surge in membership of our closed Facebook group. It has also been a period of significant growth with the highest level of supporters in our history, so we have been supporting more people than ever before.

Our team of staff has expanded which has enabled us to improve our marketing, fundraising and range of products. As a result of these appointments we have seen growth in publicity, a rise in the number of fundraisers and the launch of our online shop.

We have also become members of the 'Delphi Games' run by the Association of Coloproctology of Great Britain and Ireland. The Games will help influence research on various bowel diseases.

The scope of the **Colostomy Association** cannot be understated. Despite only having a team of six full-time members of staff we are able to act as a vital lifeline for thousands of people living with a stoma.

Thankfully, 10 years ago, a team of passionate and committed volunteers decided that they couldn't afford to lose a support charity for people living with a colostomy. Looking back at what we've achieved in the past decade and in the past year, I believe we can make those key people feel immensely proud.

Monty Taylor
Chairman of the Trustees
Colostomy Association

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SOUVENIRS?

(and tummy upsets)



We've all done it – gone on holiday and come back with souvenirs. Some are ones we like to keep, others we regret. However, following my recent trip to Kefalonia I brought back something I definitely did not want – Campylobacter!

Tummy upsets on holiday happen now and then and we just have to cope with them, with the aid of drainable bags with, hopefully, not too many missed sunny days.

My husband, Chris, and I had enjoyed a wonderful two week holiday in beautiful Kefalonia. We had enjoyed all our meals, tried the local dishes and seafood with no ill effects at all. As soon as we exited the airport on our return – on a bitterly cold evening at the end of May – I felt very cold and shook with shivering for a couple of hours. After a quick unpack I got to bed and felt queasy during the night. The next morning the diarrhoea started.

Initially I thought it was a chill on my tummy but I did not feel well at all with tummy cramps as well. This went on for four days and on the fifth I felt better, but still there was no respite from the diarrhoea, I had not had any sickness so felt it could not really be food poisoning.

With any diarrhoea etc, the normal advice is to cut back fibre, keep food simple and easy to digest and reduce fat including dairy produce, so my diet was very carbohydrate based. To avoid dairy produce, I used fruit teas and black coffee but had to allow a couple of cups of tea with skimmed milk. I also bought some soya milk and used probiotic yogurts and drinks. I had bits of fat free cottage cheese occasionally; I longed

for some proper cheese but that caused a really drastic reaction. Normally I really enjoy my vegetables and fruit, so being denied those I decided to move away from my usual Slimming World routine and said, "I shall eat cake". There had to be some compensation to make up for this inconvenience!

Then I decided to visit the doctors – or rather our nurse practitioner in order to get a quick appointment. Her advice was predictable: "It should work its way out soon. Continue with your food regime. Keep up the fluids and come back in a few days if you're not better." So a few days later I was back again, this time to see a doctor. She said much the same thing, but added that if there was no improvement soon they would do a faecal analysis. So some two weeks after it had started I submitted a sample and a few days later got the result.

Campylobacter bacteria are present in many foods, most notably chicken, but are usually killed off during cooking. They can occur in unpasteurised milk or untreated water and, occasionally, shell fish and mushrooms as well. Cross contamination can also occur from knives, chopping boards etc, so it can make things like salads vulnerable to the bacteria.

When abroad we are always advised to use bottled water and not to have ice cubes in drinks. This can result in some very generous drinks if the barman is used to filling the glass with ice and then topping up with spirits and therefore does not know when to stop pouring from the bottle! We are also warned about salads but I am afraid I did not heed this advice so maybe

that was my downfall – but how can one go to Greece and not enjoy a Greek salad?

Campylobacter, which develops anything from two to five days after contracting the bacteria, is a notifiable condition. Your doctor is required by law to report this and the Environmental Health Office would then investigate any premises where you had eaten. Of course if that is overseas they would probably not contact you and I haven't heard from them at all.

I am glad to say the problem gradually improved but in all it lasted about five weeks off and on. Apart from the first few days I did not feel ill and it became evident that fats in dairy products would cause a brief episode of diarrhoea a few hours after eating. Chris did not experience any problems at all, despite us nearly always having a taste or even sharing each other's meals.

I love travelling and enjoy foreign food and don't intend to restrict either because I am worried about what one might pick up – it is just the luck of the draw when one is eating out, either abroad or in England, for that matter.

All I can say is that if one has a tummy upset and it goes on for longer than five days then visit the doctor.

I have since enjoyed another overseas break with no ill effects. So enjoy your food on holiday; you know what sort is best for you. Personally, I don't worry too much about the 'what ifs' but will reinforce the no ice-cubes rule in future!

Cheers!

Moira Hammond

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A Guide for New Ostomates

Changing your pouch away from home

You will no doubt change or empty your pouch before you leave home, so it will only be occasionally that it is necessary to change a pouch while out and about. It is important, however, to be prepared and make sure you have everything you need to change your pouch with you, just in case.

What to take with you

- A spare pouch, the hole in the flange already cut to the right size.
(It's unlikely you'll need to change more than once but if you include a drainable bag as well you'll be prepared for all eventualities.)
- Any additional products you normally use ie adhesive remover, skin barrier etc.
- Wet wipes or a sachet of ostomy cleansing gel.
- Disposal bags.
- Deodorant spray.

All this can be carried quite discretely in a pocket, or in a handbag inside a zip compartment or a small make-up bag. And

it needn't take up too much space as adhesive remover and skin barrier are available as individually wrapped wipes and some manufacturers produce refillable mini, sample-size deodorant sprays.

If you find you rarely need to use your emergency kit, it is a good idea to check it over every few months and replace any of the contents with fresh supplies.

Where to change

Because you have a stoma you are entitled to use Accessible Toilets. This makes the process easier as there is more space, and a wash basin and running water at hand. There is also always a bin where you can dispose of the used pouch. If you are unsure where to find an accessible toilet, head for the nearest large supermarket or McDonalds. Here these toilets are rarely locked. However, at other places you may find you need a RADAR key to gain access. These keys are available free from some local authorities or you can obtain one from the **Colostomy Association** (see form below). We can also supply a photo ID card, which confirms you are entitled to use

these facilities, in case you are challenged when entering or leaving the toilet.

It is, however, important to be prepared in case there is no accessible toilet nearby. A pouch change is possible in an ordinary toilet cubicle if you have some means of cleaning around the stoma. Wet wipes or cleansing gels which come in single use sachets are available from some ostomy manufacturers. The gel is squeezed out of the sachet on to a piece of toilet paper which is used to wipe around the stoma – wipe off the excess and allow the skin to dry before applying a clean pouch to make sure you get a good seal.

Disposing of the used pouch

Ladies can dispose of the used pouch in a sanitary bin. Men may find it best to use an accessible toilet as there is not always a bin available in Gents' toilets. The **Colostomy Association** is, however, currently working with other organisations to help improve toilet provisions across the country for ostomates. To find out more, read *Stoma Friendly Society* on page 31. ■

Photo ID Card

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

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

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

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

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

Please allow 10-14 days for delivery – thank you

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

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

(If you have any queries please contact the admin team at the **Colostomy Association** office via the following methods:

Telephone: **0118 939 1537** or Email: cass@colostomyassociation.org.uk)

National Key Scheme - Key and photo ID card purchase

Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

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

Signature of self or carer: _____



Please **tick** as appropriate:

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

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

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

Date: ____/____/2015

Peggy Farley



My story began a long time ago, in 1974, when we were involved in a terrible car accident on the M4. Thankfully my husband and three sons escaped with minor cuts and bruises. However, I was badly injured and spent two weeks on a ventilator in hospital. Once I was out of ITU and on a normal ward I noticed that everything I ate just wouldn't stay put, and when I enquired why my system was so upset I was told it was due to the trauma of the accident.

It took a year for me to recover with further treatments, but unfortunately I still had the problem of food passing through my body too quickly, and over the next few months it became steadily worse despite the various medicines prescribed. I eventually went to see a gastroenterologist who, after various examinations, diagnosed my condition as severe Irritable Bowel Syndrome (IBS).

My other problem was the fact that I'd had three very difficult childbirths which resulted in extensive internal stitching. I was eventually sent for various tests, and was told that my sphincter muscles were damaged and nothing could be done to rectify this situation. The gastroenterologist eventually said that I really ought to think of having a colostomy, as severe IBS with the absence of sphincter muscles just didn't make for a happy lifestyle. Of course he was quite right, but the thought of having a colostomy frankly horrified me, and so I decided to soldier on. Over the next few years I found my eating habits were minimal because my tummy would not accept a great many things. My diet was very restricted and if I was going anywhere I knew that I always had to have a loo in sight.

In 2005 I decided that after 30 years I just could not cope any longer, and went into hospital to have a colostomy. Of course it did not cure the IBS problem but at least I could go places, and join in outdoor bowls matches without wondering if disaster would strike. I didn't have many good days coping with the IBS and about five years ago started to have attacks of extreme stomach cramps followed by continual and severe bouts of diarrhoea. These attacks left me feeling exhausted, but nothing in the way of medicines helped and I couldn't trace it to any particular food in my meagre diet. I was just told it was part and parcel of my extreme form of IBS.

Two years ago I came across an article in *Tidings* which gave glowing accounts of colostomates who had successfully irrigated which aroused my interest. Because of the IBS problems I had tried everything I could think of to make life better, but I hadn't tried irrigation and decided that it was worth having a go. I went up to my local hospital one afternoon, with hope in my heart that a miracle could occur, and met up with two caring stoma nurses who spent a long time taking me through the procedure. Unfortunately the water that should have entered my colon seemed very reluctant to do so and only one attempt was partially successful. However, it was decided that I should go home and give it a real try which I did. Over the next week I struggled and only once did I manage to get my colon to accept the required amount of water – in fact most times I had more on the floor than inside me; it was so frustrating. At the end of ten days I decided that irrigation just wasn't possible for me and I reluctantly took all the gear back to the stoma clinic as I just couldn't face sitting on the loo for what seemed like hours every day without any result.

A year later In November 2014 I went into hospital for a parastomal hernia repair. Although the operation went well there were several weeks when I had bouts of continual stomach cramps and almost uncontrollable diarrhoea. It got to a point when I wished I had left the hernia alone. Ironically, although I didn't know it at the time, that operation changed my life.

At a subsequent appointment my surgeon told me that he'd had to take away about nine inches of colon during the operation as I had a large kink in it, which of course I hadn't known about. Over the next two weeks I thought about the kink factor and finally approached the same stoma nurse at the hospital and said I thought I knew why the irrigation did not work the first time and asked if I could have another try. She agreed that the kink could have been the source of the trouble and so I went up to the stoma clinic to go through the performance again. Although it was hit and miss to begin with, eventually all the required amount of water went in and irrigation worked.

Although once I was at home I was fearful that it just wouldn't work, it has been a success every morning since. I sit on the loo and watch with amazement the water level in the container quite rapidly reducing until the 1000ml level is reached. What was impossible the first time around is so simple now.

The benefit of irrigation has been two-fold for I can now eat food which before I would not even dare to look at. Because my colon is empty over the whole day I have now expanded my diet, and have been able to eat things like a salad meal and homemade cottage pie. Hopefully now I won't be a two meal cook, but I will be able to enjoy the lovely looking evening meals I have cooked for my husband all the time.

Irrigation does mean that I lose an hour of each day, although I am hopeful of reducing that time scale in due course, but the benefits are enormous. It is so comfortable just being able to wear a small cap all day instead of a bag and it is so much more hygienic as well. I would recommend anyone with severe IBS problems to have a go – for me it has definitely been a life changer, and it could be for you as well.

Before attempting to irrigate it is important to consult your stoma care nurse to check that this form of colostomy management is suitable for you.

For more information on irrigation see page 23.



What is Irritable Bowel Syndrome?

Irritable Bowel Syndrome (IBS) is the name health professionals give to a series of symptoms relating to a disturbance of the large bowel that cannot be explained by any other disease.

Symptoms of IBS can include:

- Abdominal cramps – often relieved by emptying the bowels
- Change in bowel habit; either diarrhoea or constipation or an alternating pattern
- Bloating and swollen abdomen
- An urgent need to go to the toilet
- A feeling of incomplete bowel evacuation
- Gurgling noises in stomach area
- Excessive wind
- Passing mucus from your back passage

People with IBS can also experience a variety of other unexplained symptoms including tiredness, backache, bladder frequency, indigestion, headaches, depression and anxiety.

What are the Causes of IBS?

There is no definitive cause of IBS but the bowel is often more sensitive and reactive to changes in food and mood. Factors that seem to make the gut more sensitive include troubling life events or situations and a bout of gastroenteritis. Symptoms of IBS are often triggered by a meal, but only very rarely due to a specific food allergy.

Diagnosis and Management

IBS should always be diagnosed by a healthcare professional, who will screen for other conditions that may give the same symptoms. They will often prescribe medications to reduce abdominal spasm and regulate the bowels.

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www.bladderandbowelfoundation.org

IBS (Irritable Bowel Syndrome) should not be confused with IBD (Inflammatory Bowel Disease) which includes Crohn's disease and ulcerative colitis, conditions where irrigation **cannot** be used for colostomy management.

A Better Quality of Life

Two readers whose colostomy was formed, not to save their lives, but to improve their quality of life tell their stories. For many years both suffered from IBS and incontinence due to childbirth damage. They eventually decided to have a stoma and now manage their colostomy by irrigation.

Carole Summer



For most of my adult life I have suffered from Irritable Bowel Syndrome (IBS). My GP prescribed Fibrogel and similar bulking agents but these simply increased my output and made matters worse. I was also suffering from an irritable bladder so you can imagine that I needed to know where the toilets were whenever I went out. Having had two children did not help as I tore badly during their birth and had lots of stitches. Eventually I had to wear incontinence pads which I hated.

My GP sent me to see a consultant about my bladder. He was so understanding and kind to me that I felt able to tell him that I had faecal incontinence as well and he gave me the name of another consultant who he felt sure would be able to help me. I was fortunate enough to have private medical insurance so made an appointment straight away. The consultant, Miss Karen Nugent, said I did not have any control over the muscles in my back passage, and suggested a colostomy but I said no, I could not bear that.

Then I went on holiday to Spain and had a very bad 'accident'; I had to hide in some hedges whilst my friend went back to the hotel to get me a change of clothing. On returning from the holiday I went back to

the hospital and an experimental treatment called Sacral Nerve Stimulation was suggested. I was one of the first to have this implant at my local NHS hospital. Following the surgery and just one night in hospital I was sent home with this gadget to try and control my bowels. I had to keep a chart of my output both before and after the surgery to compare the effectiveness.

After several weeks I went back to see Miss Nugent who was delighted with the result and, although I was not so impressed, I agreed to go ahead and have a permanent implant. However, while I waited for the NHS to give their funding it got to the stage that I could not even walk my dog without having an accident as any form of exercise would stimulate my bowel to work. Then I heard about irrigation and finally decided that if I could do that then I would agree to have a colostomy. I really could not believe that I had agreed to something so life changing.

When I got home after my colostomy operation I still had IBS. The output from my stoma was constant. My skin became very sore and I also had accidents at night. The stoma nurse came to show me how to irrigate. Irrigation was my saviour: doing this for about half an hour every other day meant that I had very little output. I also have six-monthly Botox injections into my bladder which has helped my urinary incontinence.

My life has changed completely: no more incontinence pants and accidents, I was able to have my life back. That was ten years ago and I am so glad to have been given 'George'. I cannot imagine life without him.

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Pathway to a Colostomy

Colostomy Association volunteer, Mike, writes about how diverticular disease led to a ruptured bowel and an emergency Hartmann's procedure to form a colostomy.

It all started in the summer of 1999 when my wife, Pam, and I were on holiday in Northumberland. While we were away I was severely constipated but I put this down to the change in diet etc. When we returned home I was more or less back to normal so I didn't worry about it unduly. Several weeks later I had abdominal pains on and off for several days which, despite taking indigestion remedies, failed to go away. As it was a Friday I decided to go home from work early and that I'd be better after a restful weekend.

Sadly this was not to be; by Sunday afternoon I was in agony, trying to ease the pain with warm water sitting in the shower. In hindsight this was a waste of time and later that evening when I began vomiting Pam insisted on calling the Out of Hours doctor. When he turned up at about midnight it didn't take him long to decide I needed to go to hospital. On a lighter note, our cat, Tigger, sensed I was not well and stayed curled up on my bed while the doctor examined me, but hastily fled downstairs when the ambulance came for me an hour later!

After an X-ray and an ultrasound scan at the Good Hope Hospital I was told that I probably had a burst bowel which they would fix with an urgent operation. The consultant told me that the worst scenario would be ending up with a colostomy bag. I had only a vague idea of what this meant. I saw a bag for the first time when I came round from the anaesthetic and cautiously looked under the bedclothes. There were lots of tubes stuck into my body and a large

bag on my left side. I didn't like the look of it but was assured that this was a post-op bag, different from what I would wear in the future.

I was told I had diverticulitis and the technical term for my operation was a Hartmann's procedure. I remained in hospital for about two and a half weeks and during that time I was shown very basically how to change my own bag. I remember being told before I left hospital that when I was fully recovered I would be able to go swimming, horse riding, skiing and hang-gliding. I thought this will be great fun and remarkable as I couldn't do any of these things before!

When I returned home it was a steep learning curve, but with the love and support of Pam and my son and daughter I went from strength to strength. It was during this time that I had my first experience of a discharge from my rectum. I was a bit alarmed as it was dark in colour and thought – silly in hindsight – that the internal connection hadn't been done correctly. My surgeon, however, reassured me that this was a normal post-operative occurrence due to blood residue etc. left inside and it would disappear in a few days, which of course it did. The stoma care nurses explained that I may also get a rectal discharge of clear or putty-coloured mucus; the production of mucus is a natural body function to lubricate the bowel. She encouraged me to do pelvic floor exercises to strengthen the appropriate muscles to control any discharge from the rectum.

I was able to return to work after about six weeks; part time was possible as I worked in the family's small wood turning business and could go home when I had done enough. I was able to increase my hours until I was back on full time, doing pretty

much everything I did before, both at work and socially. I was spurred on to return to normal in time to give away my daughter at her wedding in 2001.

There was a suggestion of having my stoma reversed in the future but I wasn't tempted for two reasons. Firstly, while on holiday before my operation, Pam and I had met a man in his forties who was due to have a reversal when he returned home. A year later Pam bumped into his wife in town and, on enquiring how her husband was, she was told that the operation had not been as successful as they had hoped. Secondly, I was back at work, had resumed my hobbies and I was used to wearing a bag and didn't fancy another operation and recovery period again.

I must have been given the British Colostomy Association (BCA) contact details when I left hospital as four or five years later I attended an Open Day in Walsall. There I met a lovely lady called Jackie Dudley who, after chatting to Pam and I, asked me if I would consider becoming a volunteer for BCA. I was very flattered to be considered suitable, but a bit hesitant. With some encouragement from Pam, however, I took the plunge.

After the usual checks and paperwork, I attended a volunteer training session and went on to help out at an Open Day. Then I was given a stand and a supply of leaflets etc and did my first Open Day on my own. From then on I haven't looked back and have enjoyed it all; meeting different people of all ages. Helped by the wonderful staff at the **Colostomy Association** in Reading, I will continue to be a volunteer for as long as I am able.

Mike



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

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

Fundraising Focus

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

Ordinary people doing extraordinary things

We're extremely grateful to a number of people who have broken the pain barrier to raise funds for the Colostomy Association in the last few months:

- ❖ In August 2015, Ian Scott swam, cycled and ran his way through the London Triathlon and raised a fantastic **£805.**
- ❖ In September, Stuart Vannet cycled 110 miles as part of the Pedal for Scotland event and managed to raise **£665.** Also in September, Sharon Burton ran the Worcester 10k and raised **£593.**
- ❖ October saw Iwai Simon (below) complete the Birmingham half marathon and raise **£392.**



Iwai Simon was motivated to run to raise funds for the **Colostomy Association** after seeing first hand how having a stoma can be daunting to both family and friends.

- ❖ Smurfits Unchained featured in the last edition of *Tidings* as they prepared to tackle the London to Brighton Bike challenge. We are glad to be able to report that the team of Ian Jackson, Nigel Goodger, Dave Paxman, and Duncan Taylor managed to raise a whopping **£2,362!**

Climb every mountain

Running or swimming 1,000 metres could be a fundraising challenge in its own right, but Sarah Gregory and Liam Gregory have decided that's not enough.



In August 2016 they will be attempting to climb the 1,344 metres that will see them reach the summit of Ben Nevis. They have already started training three times a week and the commitment levels will only rise as the event gets closer. We'll keep you updated on their progress, but more information can be found at:

www.justgiving.com/Sarah-Humphrey8

Knitted Delights

Margaret Whyte from Breaston in Derbyshire (pictured below) raised **£168** from the sales of cuddly toys that she knitted herself! Margaret spent nearly six months making them all and the result was that every one of them was sold at the St Michaels church craft fair. Fantastic!



Special thanks

Every year hundreds of people donate or raise funds for the **Colostomy Association** and while we can't publically acknowledge everyone we would like to say a special thank you to a few other people in this edition:

- ❖ David & Sandra Priestley donated **£125**, the winning proceeds from their local pub quiz in Kent.
- ❖ Ruth Gardner raised **£150** from a coffee morning in Birmingham.

CONTINUED ON PAGE 21, COLUMN 3

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Colostomy Association Calendar 2017



Bloomberg journalist, Kevin Young, walked away with a full-sized canvas of his winning photograph (kindly sponsored by Jessops) from last year's Calendar Competition.

Kevin's dramatic winning photo was of Rubjerg Knude Lighthouse in Denmark. The 2016 **Colostomy Association** calendar features 12 stunning photos from across the world; ranging from mountaintops in the Alps to colourful scenes in Turkey.

Speaking about winning the competition, Kevin said: "Thanks so much for the canvas – it's beautiful and it's a real honour to have won!"

Have your photos featured in our 2017 calendar

We are now looking for entries for our 2017 calendar and are searching for stunning landscape photographs from ostomates' journeys across the world: from exotic summer breaks to bustling cities and winter holidays to safari scenery.

If you would like a chance of your photograph featuring in our 2017 calendar then please email a digital copy of your photograph/s to the eMail address below

no later than **30 April 2016**. Make sure you bear in mind our specifications (see the box below) so that your photos will meet the printing requirements. Of the submissions received in 2015, many other excellent photographs were received that could have been serious contenders. Sadly, these could not be considered as they were not technically suitable, so please ensure your photograph/s meet the required criteria given below.

All proceeds from the calendars will go towards supporting vital **Colostomy Association** services such as our 24-hour helpline, range of literature, volunteers' attendance at open days, hospital visits and *Tidings* magazine. Send your entries to:

editor@colostomyassociation.org.uk

To enter our photographic competition and be short-listed to feature in our 2017 calendar, all photos must meet the following requirements:

- Landscape, not portrait.
- High resolution photos, where photos must be a minimum of 5,000 x 5,000 pixels to ensure they are high enough quality for print.
- **All entries must be received by 30 April 2016.**

CONTINUED FROM PAGE 19, COLUMN 3

Many thanks to all of you for your fantastic efforts to both raise funds for and spread awareness of the **Colostomy Association** throughout the United Kingdom. Many thanks also to everyone else who has donated and is not mentioned here.

Unity Lottery

The Unity Lottery has replaced the **Colostomy Association** 500 club, and we're pleased to say there's already been a **Colostomy Association** winner.

You can win up to £25,000 every week, with the chance to claim many other cash prizes as well! For more information on how to join see Page 12.

Not only does the winner receive the main cash prize, an additional donation of £2,500 goes to the charity you're supporting!!

Grants update

The **Colostomy Association** has benefited from a number of recent grants that will help us deliver an even better service to adults and children with a stoma, their carers and family members.

- ❖ Sport England have awarded our *Active Ostomates* pilot project **£3,639**



- ❖ The Big Lottery Fund have supported our *Caring for Colostomates* pilot project to the tune of **£8,824**



- ❖ The Morrison's Foundation has awarded us **£5,993** towards helping those who care for people with a stoma.



L-R: Giovanni Cinque, Morrison's Community Champion, Jo McKenzie

There'll be more information on our pilot projects in future editions of *Tidings*. ■

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- Psychological support
- Lifestyle information
- Holiday advice pack
- Pre-operation information



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Help when you need it

These resources are designed to help you through every stage of your care, including: advice, contact details, holiday tips, videos, FAQs, dietary advice and links to other resources.



Irrigation and you

Sarah Squire, Trustee writes: Irrigation is not an exact science. I wish it was – being a research scientist I went into irrigation looking for an exact protocol to follow which would tell me how to do the procedure and get the best results. Unfortunately we are all different, with varying length of colon, different diets and many other factors which make us individual. Dawn Starmer had similar questions to many of us when she began irrigating and explains her adventures with Penelope the stoma:

Dawn writes: It was like having a baby; you wake up and there it is, all red in the face with a sort of semblance of a smile, but its not a smile, more like an “oo”.

“Hello,” I said. “You do look a funny looking thing. I think I shall call you *Penelope*, you will be a good little girl won’t you?”

From that moment I became irrevocably attached to my little Penny. Nothing will ever separate us and I shall look after her like a mum should; she will want for nothing.

Of course I had had some insight of what to expect from the nurses as I had practiced with plastic replicas, but the real thing is nowhere near what I expected. At the start Penny developed a bit of a routine and changing nappies (pouches) was no problem. It was the irrigation thing that didn’t go so well.

I freely admit that as far as mechanics are concerned I am not the brightest star in the constellation, but to my mind this lot would challenge Isaac Newton.

So many questions: how much water, what temperature, how high up should the waterbag be, which way up should the flow regulator be, which end is off, what do I hang the water bag on, how do I get the air out of the tubing, how far in do I push the nozzle and how long should I wait for things to happen?

However, with a little technical support from my ever patient husband and many telephone calls to the nurses, after a few

weeks of trial and error it all started to come together. There were some unfortunate incidents; there had to be didn’t there? The hook holding a full water bag coming detached from the wall right in the middle of proceedings, the cone slipping out and soaking the nether regions et al, not having the valve closed when it should be and often getting myself and the toilet floor completely covered in water.

I was even getting a little blase about it all, then Penelope decided to strike and Good Penny became a very Bad Penny. No longer was she reliable and regular in her routine. Her moods became erratic and unproductive proceedings became the norm. The nurses and doctors did their best by suggesting various changes in diet and medication, but nothing seemed to work. I decided that I must be the problem and I would have to work it out for myself. So the saga continues.

The one much appreciated source of understanding and help has been from friends among the **Colostomy Association**. To them I say **Thank You** with all my heart.

As for Penny Dreadful, if things don’t improve I may even consider sending her back to where she came from! ■

To try and address some of Dawn’s questions:

When it comes to troubleshooting irrigation issues we can work through the basics but really have to learn what works for us over

time. Dawn had similar questions we hear a lot from new irrigators so I thought it might be good to cover these, as best we can seeing as we are all different.

- How much water is something almost every new irrigator will ask. Your stoma nurse will give you a guide when they teach you to irrigate but if things are not working the tendency is to assume more is better. This is not always the case though. Sometimes less water can give better results, and more water can lead to output a few hours later. Begin with the volume suggested by your stoma nurse and discuss with them how much is sensible to adjust that, up or down, if you are having difficulties. Personally I find after about 500ml I feel “full”, and that I need a second infusion of a similar amount once the first has expelled, to keep me clear for 24-hours.
- How warm should the water be? Literature states body temperature of 37°C is optimal but do bear in mind the water may be sitting in the bag for a few minutes cooling, and anecdotal evidence suggests that for some people water a little warmer is better. If it is too cool you may find you get stomach cramps or the colon will spit the water straight out. Too hot can of course cause damage to your colon so can be dangerous. Some irrigation kits come with a temperature gauge but if you can comfortably hold your hand in the water without it feeling

CONTINUED ON PAGE 25, COLUMN 1

Corsinel®

by **SUPPORTX™**

Introducing the **NEW** Easy Panel Belt

The Easy panel belt is a new innovation in belt design. The belt has been designed with an integrated support panel to offer firm support to the area around a parastomal hernia. Its unique support panel can be modified as required to allow the stoma pouch to come through fully or partly. No stitching is required as the panel is non fraying.

The belt offers two methods of bespokeing:

- **The Traditional Hole Cutting**
- **The New Half Slit Method**

The half slit method is a new innovation which offers superb stoma pouch drainage whilst still providing excellent support to the area around the stoma. This is especially useful where a parastomal hernia is present.



AVAILABLE ON NHS PRESCRIPTION

We offer a wide selection of hernia support garments, belts, girdles and a variety of made to measure supportwear.

To book a **FREE** fitting or for further information call

0800 917 9584

www.supportx.co.uk

CONTINUED FROM PAGE 23, COLUMN 3

too warm then you are on the right track. I have spoken to a number of people who are having problems and by slightly warming the water, much better results have been achieved.

- When it comes to the irrigation kit, they normally arrive in three or four pieces and can be a bit like a Krypton Factor puzzle to work out which bit goes where. You can almost guarantee I will put the flow regulator on upside down every time! I'd say it's a case of practice but I still struggle, but then it's only a few minutes of head scratching every few months! Advice says hang the bag around shoulder height and the first time I went solo at home I got into all sorts of bother as the handle I was using on a wall cabinet was too low. I had to shout for the poor hubby to hold the bag higher as I was getting backflow! Now I have a hook screwed up a bit higher and I'm sorted. I carry an 'S' hook when I travel which can be used over doors, mirrors, curtain rails in hotel bathrooms. I also take a sticky hook as a backup if there really is nowhere to hang the hook. So far I've never had a problem.

Once the kit is all set up and you are ready to roll it's important to get the air out of the tubing. This is simply done by running some water through and closing

the flow regulator. Introducing air to the colon is probably not a good idea – a little bit isn't going to cause any harm but it could be uncomfortable. The amount the cone goes into the stoma will vary person to person. I have a tiny stoma and only get about a centimetre of the cone in but I know some people who need the whole length in to stop water escaping. The important thing is not to push too hard. A gentle wiggle may help find the right direction but you shouldn't apply too much pressure or you could damage the delicate tissue of the bowel.

- Once you've infused the water how long to wait? Again a question we hear a lot, and again I'm going to give the same annoying line – we are all different. But what I will say is that you will learn how your body feels at different stages of irrigation and will hopefully learn to feel when you are empty. For some people the output is almost immediate, and

others may find it takes 10–15 minutes to start moving. You may find that pegging up the sleeve and having a potter round the house helps get the last output to come through, or, like me, if you prefer to stay in the bathroom a little tummy massage may help. Or, perhaps just relaxing and reading a book will work best for you. I find that every irrigation is a little different but I have become tuned in to how my body feels. Saying that the little so and so still likes to catch me out occasionally and spurt just as I've cleaned up and got a new bag on!

I've addressed Dawn's main questions here and I know there are lots more hints and tips out there. I would love to hear from irrigators with their own stories and experiences. I have been irrigating for eight years but still learn new things on a regular basis.

Sarah Squire

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

Colostomy Irrigation and You DVD

Order Form Colostomy Irrigation and You (Patients)

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

To obtain your single copy of *Colostomy Irrigation and You* at the special introductory price of £4.99 (inc postage and packing) simply fill in your details below and return it with your cheque made payable to the **Colostomy Association**, to:

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



Title: _____

Name: _____

Address: _____

Postcode: _____

Tel: _____

Email: _____

Please allow 30 days for delivery.

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



VOTE FOR YOUR 2016 STOMAHERO.

ConvaTec is delighted to announce that the Stomahero Award is now open for nominations. We know how important your Stoma Nurse is to you and this is your opportunity to say a big thank you!

ConvaTec is there for every person with a stoma throughout his or her entire journey and we recognise the crucial role of the Stoma Nurse throughout that process. The Stomahero Award has been developed to acknowledge the patient care and support delivered by Stoma Nurses across the country and to give patients the opportunity to nominate and say a huge thank you to their nurse for the continued support before, during and after surgery.

The Stomahero Award Nominations are judged by three patient associations, the Ileostomy Association, Colostomy

Association, Urostomy Association, together with an Amcare™ Group Stoma Nurse and an independent Stoma Nurse. Patients are invited to submit nominations via post and emails, all Stoma Nurses with more than one nomination are shortlisted to the judging panel.

The winner receives a £3,000 educational grant which can be redeemed against a stoma education course or an educational conference event, to help support the development of their stoma department and their own personal career development.

Nominating your Stoma Nurse couldn't be easier, simply visit www.stomahero.co.uk to submit your online nomination and tell us why they deserve to be the next winner.



"As a Stoma Care Nurse Specialist I was thrilled to receive this award. It makes it particularly special that the nominations came from patients."

Sharon Stopher

Stoma Care Nurse Specialist, Ipswich Hospital



/ConvaTecUKI



@ConvaTec_UKI



ConvaTecUKI

#stomahero2016



Full terms and conditions can be found online at www.stomahero.co.uk
For all ConvaTec product or service enquiries please freephone **0800 88 50 50**

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News From the Office



Stoma Aid is Live

— Give Someone
a Bag of Life!

It's incredibly exciting to start 2016 with the launch of one of our most anticipated new services – Stoma Aid.

In the UK, thousands of ostomy supplies are thrown away each month as they are no longer needed, sometimes due to a reversal operation or the loss of a loved one. They may no longer be suitable due to change in stoma size or skin problems and the NHS cannot accept unused supplies back into their own stocks and all of these unwanted products can end up going into UK landfill sites. Alternatively, they may be an end of line run of obsolete stoma pouches, direct from a manufacturer.

Meanwhile, in many developing countries, desperate ostomates are being forced to use bin bags, tin cans, bits of cloth, crisp packets and any other improvised items as stoma bags, due to the lack of supplies or their low income. Stoma Aid will provide a solution for both groups and give people a bag of life.

Supplies can now be donated to our warehouse in Bolton, kindly sponsored by Stone Logistics Ltd/PRS Ltd. From there the items will be sorted, packaged and labelled, before being collected by reputable UK based charities who will ensure they reach those most in need in parts of Eastern Europe, Asia and Africa. The links with these charities are now well established and they already have thousands of recipients urgently waiting for supplies, including babies and children.

Frank Healy, **Colostomy Association** Trustee and main organiser of Stoma Aid, says: "This project has the potential to change thousands of lives across the world. With the help of charities such as Hospices of Hope, Smile International and Wantok Support these supplies will directly reach desperate recipients in developing countries. It is thanks to grants, fundraising and the kind donations of many of our supporters that we are finally able to launch this much-needed service."

CONTINUED ON PAGE 29, COLUMN 1

OPEN ALL HOURS

www.colostomyassociation.org.uk/shop

NEW! Colostomy Association Online Shop

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

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

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

of the facilities being in a usable state.

Product

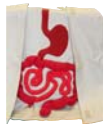
(prices inclusive of VAT & p+p)

Unit Price

Quantity Required

Sub Total

Anatomy Aprons £157.50



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

Lapel Pins £3.00



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

Irrigation and You DVD £4.99



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

Note: Not all colostomates have the potential to irrigate. It is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

CA Wristband £2.00



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

202mm x 12mm x 2mm. Sold individually

Coasters £3.50



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

Pens £1.50



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

NKS – RADAR Key £3.50



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

Product

(prices inclusive of VAT & p+p)

Unit Price

Quantity Required

Sub Total

CA Umbrella £11.50



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

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

Running Vest £12.49



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

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

Sizes available (inches):

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

T-shirt



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

T-shirt designs with the following words:

#1 Living life (with a colostomy) and proud of it

#2 Living life (with a stoma) and proud of it

#3 I failed my English I didn't have a colon – my stoma saved my life



T-shirt size

Unit cost

Design

Size

Colour

Quantity

Sub total

S (35-37), M (38-40), L (41-43), XL (44-46)

£17.49

2XL (47-49), 3XL (50-52)

£18.49

5XL (56-58)

£19.49

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

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

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

Women's size guide:

S 10 M 12-14 L 16 XL 18

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

Please send me the above marked items. I enclose a cheque for £ made payable to: **CA Commercial Ltd.**

Title:

Name:

Address:

Postcode:

Tel:

Email:



CONTINUED FROM PAGE 27, COLUMN 3

To donate your unwanted supplies, please post them to the following address:

**Dean Philp
Stoma Aid
c/o Stone Logistics Ltd/PRS Ltd
Lorne Mill
Lorne Street
Bolton
BL4 7LZ**

Please help make this service a success, but ensure only unwanted supplies are sent and not existing useful supplies that would waste valuable NHS funds. While syringes, sprays, deodorants, aerosols, prescribed medications or drugs of any kind cannot be accepted, Stoma Aid will gratefully receive donations of the following items:

- Colostomy, Ileostomy and Urostomy bags (closed, drainable, convex, two piece as paired items – both parts to be supplied, leg bags, night bags, paediatric bags, etc)
- Drainable bag clips
- Seals
- Flange extenders
- Adhesive removers (wipes only, not sprays)
- Pastes (must not be out of date)
- Barrier creams (must not be out of date)
- Wipes and cleansers
- Disposal bags
- Bandages
- Dressings
- Incontinence pads
- Support belts

Please ensure any two piece pouches have both the pouch and the matching flange/base plate included.

Unfortunately, the collection of items is not possible but postage should only amount to around £5 or so for a parcel. Please consider how much even one person's life would be drastically improved for the better by your kind donation so please pay for the postage and help make this worthwhile project a success.

In future editions of *Tidings*, genuine life changing stories will be included clearly demonstrating what a difference Stoma Aid has made to people living in developing

countries. If you have any questions about Stoma Aid then please call Niall Norbury or Giovanni Cinque at the **Colostomy Association** offices on **0118 939 1537**.

Stoma Aid has come into being courtesy of the generosity of our supporters and grant-making trusts, as well as a financial commitment from central **Colostomy Association** funds and the kind support of Stone Logistics Ltd / PRS Ltd. So far approximately £20,000 has been donated and ring-fenced for this cause but the aim is still to raise £150,000 which will ensure that this worthwhile project will last for many years and can be spread to more developing countries. In the meantime, the **Colostomy Association** Trustee Board has agreed to bear half the running costs and has provided £10,000 of the total funds so far.

However, ongoing fundraising efforts are continuing through other avenues such as approaching UK Rotary Clubs and hopefully, applying for a global grant. We intend to work with the local Rotary clubs overseas too (where a UK based charity does not exist), to ensure that the goods get distributed to those that need it most and at a negligible cost. If you can offer any help with fundraising please liaise with Giovanni Cinque or, if it involves a local Rotary Club or other similar service organisation in your area, please contact Niall Norbury who will then pass on your contact details to Alfred Levy, **Colostomy Association** trustee, as Alfred has kindly agreed to take a major role in this specific fundraising campaign.

Our special thanks go to Stone Logistics Ltd/PRS Ltd for use of their staff and warehouse storage space, to the Hilden Trust for their £5,000 grant, the C.B & H.H Taylor 1984 Trust for their £3,000 grant, and to our valuable supporters who have given so generously for the benefit of fellow ostomates in developing countries. Thank you all for making Stoma Aid a reality and helping the **Colostomy Association** give thousands of people a bag of life.

Ostomates in Kosovo have already benefited from Stoma Aid. Working in partnership with the Kosovan Embassy in London, Nine boxes of supplies have already been despatched to the Kosovo Stoma Association. ■

Why choose? Get them all



Get yours from:
colostomyassociation.org.uk/shop

Update on stoma care products and services

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

SUPPORTXTM NEW!

Suportx are proud to launch a new range of premium Corsinel support belts.



The New Easy Panel belt is unique and a first for the UK. This garment received a very positive response from most stoma care nurses at the ASCN nurses conference that took place in October 2015.

The Easy Panel belt has a built in support panel that can be easily modified to allow the whole or part of a stoma pouch to be outside of the belt. The slit system is new and is offered exclusively on the easy panel belt. The slit system is an ideal solution to enable good drainage of the stoma pouch, whilst still supporting the area around the stoma to assist in hernia prevention or support of existing parastomal hernias.

Also available in the new Corsinel range of belts is a tube belt with a shaped back, this belt offers maximum comfort, support and a clean line so can be worn with utmost discretion.

Please refer to **page 24** for our main advert. Or call **0800 9179584**

New LBF Sterile Barrier Film Spray to help prevent sore skin

LBF Barrier Film Spray has evolved into the improved LBF Sterile Barrier Film Spray, meaning it can now safely be used on broken skin too.

LBF Sterile Barrier Film protects skin from bodily fluids and the sticky adhesive on stoma pouches, which can cause skin to become red, sore and sometimes damaged.

FREE SAMPLE

Call the
CliniMed Careline
0800 036 0100

or email:
enquiries@clinimed.co.uk



New Aura Flushable



Aura Flushable is the next generation of stoma pouch in CliniMed's innovative flushable range for colostomates. The inner liner can be flushed with or without the flange as both are fully biodegradable. In addition, Aura Flushable offers the comfort of medical grade Manuka honey.

FREE SAMPLE

Call the
CliniMed Careline
0800 036 0100

or
clinimed.co.uk



Stoma Friendly Society



Having a stoma should not prevent anyone from living a full or active life, but there are some challenges unique to ostomates. It is estimated that almost 1 in every 500 people in the UK live with a stoma which is why the **Colostomy Association is committed to creating a stoma-friendly society, such as by campaigning to improve the attitudes of the general public and to improve toilet facilities.**

Ostomate Friendly Loos

Calls are frequently received on our helpline from people wanting to know where their nearest accessible toilets are located or raising complaints about disabled toilet facilities in their area. To improve toilet facilities across the country we have been:

- ◆ Writing to the UK network of train providers asking them to include hooks in their toilet cubicles on all platforms.
- ◆ Consulting with Hitachi whose new fleet of trains for 2017/2018 will have toilets which are suitable for those living with a stoma.
- ◆ Attending the annual Loo of the Year Awards to put forward the case for ostomate-friendly toilets.
- ◆ Forging links with the British Toilet Association.
- ◆ Encouraging our supporters to contact their local MP to stress the importance of ostomy-friendly loos.
- ◆ Joining the 'Changing Places' campaign with Mencap.

Since launching in 2006, the Changing Places campaign has led to the creation of improved 'Changing Places toilets' which meet the requirements of all people who need accessible toilets.

Among their comprehensive list of requirements is the inclusion of a shelf for people with a stoma to change their bag, sanitary bins in each cubicle for disposal and now to include a hook on the back of the door, thanks to our contact with

Changing Places as part of our campaign. By working with Changing Places we hope not only to improve facilities for those with a stoma, but for all users of accessible toilets. A full list of Changing Places toilets is available on their website at: www.changing-places.org

Our collaboration with the Changing Places campaign led to a recent debate in the House of Commons about accessible toilet facilities where Dr Philippa Whitford – MP for Central Ayrshire – specifically raised the needs of ostomates.

Rossanna Trudgian, co-chair of the Changing Places Consortium, said: "We are delighted that the **Colostomy Association** are supporting the work of the consortium. Some Changing Places toilets have a colostomy bag shelf in recognition of the additional needs of people with a stoma which we thoroughly recommend. There are still many large public places across the UK that lack Changing Places toilets and therefore deny people's rights. With the help of our fantastic campaigners, we will continue to fight to make sure every single one of the 1/4 million people in the UK who require a Changing Places toilet, can access one."

The **Colostomy Association** has three main recommendations to make a loo ostomate-friendly:

- 1 A shelf or countertop for changing of appliances.
- 2 A hook for hanging clothes and bags.
- 3 A waste-bin in cubicles for disposal of used pouches.

These additions to toilets are both easy to implement and fairly inexpensive. Making these changes can not only improve the quality of life for people living with a stoma, but improve general cleanliness for all users.

Ostomate Friendly Attitudes

Our campaign for a stoma-friendly society also extends to the treatment of people

with a stoma in airport security. Everyone understands the need for heightened security checks due to the threat of terrorist attacks and that some people with a stoma bag may have to be searched. However, it is vital that anyone with a stoma is treated with respect and dignity. To tackle this, we have contacted airports across the country to offer training to their security staff to help improve their understanding of what a stoma is, what a pouch/plug looks like and how people wearing a stoma bag should ideally be treated.

This campaign extends far beyond airport security staff to the wider general public, as we are hearing from more ostomates who have been challenged for using accessible toilets or being refused help from shop staff when a toilet is urgently needed. This, sadly, is becoming far too common.

Our aim is to educate the public about the rights of people with a stoma to use accessible toilets and to improve public perceptions. To date we have responded to your negative experiences by:

- ◆ Writing to a well-known supermarket chain after a customer was treated rudely and refused urgent access to a toilet. A suitable apology ensued along with the promise of improved staff training.
- ◆ Writing to a Council to successfully lobby against the closure of a public toilet facility.

The **Colostomy Association** will continue to champion the rights and issues of ostomates in the UK. If you would like support or assistance in improving the toilet facilities in your local area or if you need help canvassing a business which has left you feeling embarrassed, then please get in touch with Niall Norbury, our Marketing Communications Officer by telephoning:

0118 939 1537 or by email: niall.norbury@colostomyassociation.org.uk

Together we are stronger and together we will achieve a stoma friendly society! ■

A Day in the Life



Jackie Dudley, former Colostomy Association Trustee, writes about her work as a volunteer at Colostomy Association head office and her role in supporting ostomates at Open Days and at her local support groups.

Many years ago, I attended a coffee morning held by a stoma care nurse. It was the first time that I had met anyone with a stoma and it was a real eye-opener. The hints and tips that I received about living with a stoma proved to be invaluable and the warmth of the friendship I was offered was awesome.

At that meeting, I met a young lady from the British Colostomy Association (BCA) who suggested that I might like to visit their headquarters in Reading and see for myself the work carried out to support, advise and help other colostomates.

That was the day I became a volunteer.

I started out in 2002 by becoming a 'post lady' helping with the stacks of parcels, packages and letters that had to be sent out

to hospitals, nurses and the general public. At that time this was carried out twice a week and so I worked on a Thursday and I loved it. I felt that I was part of helping others who, like myself, needed the support that the association was offering.

It was in 2005 that the British Colostomy Association ceased and we became the **Colostomy Association**. A team of volunteers became the Board of Trustees that allowed the charity to continue supporting ostomates throughout the UK and sometimes those from abroad. I was one of the new Trustees that worked under the guidance of the charity commission to form the new and exciting **Colostomy Association**. Macmillan Cancer Support was very supportive and we were able to stay in the "old" offices in Station Road and have access to the database of our BCA supporters.

When we moved from Station Road to new premises I went too! The paid team was very small and my contribution to the work that the association was doing became very

varied and always enjoyable. It has been amazing how the **Colostomy Association** has expanded and we now have over 19,000 supporters – all receiving support, advice and help from the association. The number of volunteers has increased and we now have over 100 trained volunteers throughout the country.

As the years went on, I continued to work in the office and attend Open Days so that I could make contact with other volunteers that were spreading awareness of the **Colostomy Association**. Taking along the banner plus literature and setting up a stand is an important part of being a volunteer; raising awareness for the association and encouraging others to join is very rewarding.

This is also a wonderful way of meeting the representatives of the many companies that supply and deliver our products. It is a two way street as they benefit greatly from our presence at their Open Days. The volunteers get the opportunity to meet the many ostomates that attend and answer their

e of a Volunteer



questions and encourage them to live life to the full.

Ten years ago on July 4th 2005 I started a support group in Bracknell, and later took over the support group in Reading, from a retiring stoma care nurse. Both groups are still running. They are small social groups that offer support to the ostomate, family member and carers.

They are lively meetings and I encourage the members of the Bracknell group to run the meetings. In this way, we have new and innovative ideas making each weekly meeting different. Speakers are invited to come along to talk to the members and I have received full support from the manufacturers whose representatives come along to demonstrate their products.

In 2015 I resigned from being a Trustee to allow others to come in with fresh ideas but I keep in touch fully and I continue to support the Association in any way I can. I still work in the headquarters of the **Colostomy Association** in Reading and love being in the hub of such a busy office.

A typical day's work would include:

Mailshots

Manufacturers and suppliers of ostomy appliances etc often ask the **Colostomy Association** to send out information to our supporters. These are usually invitations to Open Days to be sent to ostomates who live in specific areas. The **Colostomy Association** never discloses details about our supporters on our database to others. The companies therefore send the envelopes containing their information and I and other volunteers stick on the address labels and the stamps. This is an important way of raising funds for the association.

General office work

This includes working on the computer to update spread sheets and the database. I keep the many pigeon holes topped up with leaflets and booklets from the store cupboard. I will type, copy and scan letters and other information and willingly take on any other task that I am asked to do.

Packaging ready for postage

I pack up **Colostomy Association** information packs ready to send to new supporters and also the bulk orders of our booklets, leaflets and other literature to send to our volunteers, hospitals, stoma care nurses and health centres. Recently I have also been packaging the many items now being purchased from our On-line shop.

Fundraising

I cut the stamps off all the envelopes that arrive in the office. These are then forwarded to a company that pays £10 a kilo to the **Colostomy Association**. This is an important fundraiser for the charity.


My work as a volunteer is so enjoyable and being part of the wonderful team that looks after thousands of ostomates is so rewarding.

Jackie Dudley




SAVE OUR SKIN

You'll find everything you need to protect vulnerable skin from the harmful effects of bodily fluids and adhesives with the LBF Sterile Barrier Film and LBF Barrier Cream product range. Choose from a variety of convenient presentations including the market leading LBF Sterile Barrier Film Wipes, and the new LBF Sterile Barrier Film Spray with no touch application perfect for sore and damaged skin. Contact us today to receive your free sample.

 Careline: 0800 036 0100

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PID 2310

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Unbeatable protection for
even the most sensitive skin

A carer's perspective

Mack and his wife Dian



In the summer issue of Tidings you may remember a suggestion that we include a section where carers can share experiences and exchange ideas. We contacted Mack who wrote the letter and asked him to write the first article.

I am very pleased to have been given this opportunity to express my views on what it is to be a carer. When you mention the word carer to anybody, they immediately assume you are talking about a person who is trained to make house calls on the elderly and infirm, or perhaps works in a care home, or just maybe a stay at home person who has taken on the responsibility of looking after a member of the family who needs help with the day to day things in life, like washing and feeding.

I am not that type of carer; I am like hundreds, if not thousands, of other people who support somebody who, for no fault of their own, have to live with a medical problem. I have no training or NVQs, what I do is give support to my wife, an ostomate, because we care for each other. Some people have had an opportunity to ask questions before their loved ones went under the knife, but I was totally unprepared for what my wife had to endure because the procedure was a matter of life or death.

I am there to laugh with her, give her a shoulder to cry on when she feels low and show her that I really do care. When an ostomate first arrives home after their

surgery, be it elective or an emergency, they have left the comfort of the medical support team that is the hospital; they are now in a new world, metaphorically speaking, and this is where the carer comes in.

The first thing was to reassure my wife that I was with her all the way, no matter what the future holds, be it leaking pouches – not often now, thank goodness – or embarrassing sounds that can occasionally sound like an out of tune barrel organ. When we are in the privacy of our home we just have a laugh at it and let it pass. If we are out in public we do what others do, that is to look around with an inquisitive look of who's to blame for that; who knows there could be another person who is in the same situation and they think it's them.

A person who has a colostomy is always concerned that other people can see the bulge in their clothes, or detect an unpleasant odour from the pouch. This is the point when I try to reassure my wife that all's well and not to worry or if there is a problem let her know in a caring way so as not to cause more upset, whilst at the same time distracting the attention of others from the situation.

After any person has undergone major surgery on the abdomen, they are told to let the muscles heal before they lift anything heavy, so as to avoid a post operative hernia. This again is the point where I came in, doing all of the lifting and carrying, bending down to pick things up,

all the things that prior to her operation my wife did for herself.

At some time or other, the subject of what the stoma looks like and how to change or empty the pouch will come up. This was tackled when we were both in a relaxed mood and under no pressure. It is not voyeurism to find this out and watch the procedure, but essential if you are ever called upon to help at some later date. Should your partner have an accident that leaves them with limited, or indeed no, use in one arm or hand then you, like me, the carer will have to step up to the line and give assistance, and it is better to know what to do in a planned way rather than in a state of panic.

Whatever you do, or how you handle the situation, always remember that no matter how liberal your sex life, your wife/partner is going to feel uncomfortable with the situation. It is the same in the early days when the body is coming to terms with the changes in shape and behaviour that a leak can sometimes occur. I tried to show my wife that I was there to assist. When she got into the shower I cleaned up, changed bed sheets, found clean clothes etc.

After all of these little problems, I hope you will be like us, and find it has drawn you both closer together and given you a few good laughs along the way.

Mack



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Changing lives:

How
this is
achieved by the
colostomy  **association**
Helping ostomates since 1967

2015 was an incredibly positive year with our 10th anniversary celebrations and increasing demand for our services from ostomates, carers and medical professionals.

We are extremely proud of what was achieved with your support last year and, as explained by our President, we plan to do even more in 2016. What's more, in 2017, our focus will be on our original roots – going back 50 years to the Colostomy Welfare Group which was set up in 1967!

As a charity, we are committed to being transparent and ensuring that our supporters know how any money they donate or raise for us is spent. Here's a snippet about our services, activities and staggering levels of support provided each year:

1 Unique support

The knowledge, reassurance, empathy and advice ostomates can provide one another cannot be over-estimated. As a result, many of our services enable those living with a stoma to be helped by those who have been in a similar situation to them.

Our 24-hour helpline is unique and it is one of our most-needed services. It provides vital support at any hour of the day and on any day of the year. On

average, over 3,000 calls are made to our helpline each year.

Our closed Facebook Group is another invaluable service, with over 3,700 members using the group as a safe space for advice, information and assistance. Despite its large size, it's administered by only a handful of dedicated volunteers who monitor hundreds of posts each day, almost every hour of the day!

Our Junior Ostomy Support Helpline (JOSH) provides an important lifeline to parents or carers of children with bowel or bladder dysfunctions. JOSH enables mums, dads and carers to speak with their peers about topics of concern, giving them emotional support and reassurance at a time when they are often feeling totally isolated. This helpline makes a very real difference to people's lives, whether their child is only a few days old or in their teens.

Whether it's online, on the telephone or in person, the **Colostomy Association** is committed to providing unstinting support whenever people need it.

2 Information

The **Colostomy Association** has become a vital source of information for healthcare professionals, students,

carers, members of the public and people living with a stoma. Traffic on our website has grown by 20% in the past year with over 40,000 visits each month.

Tidings magazine continues to grow in popularity as more and more people discover it to be a vital source of life stories, inspiration and information. Over 19,000 people now receive the magazine and in total up to 84,000 copies of *Tidings* are sent out each year.

Our literature on topics ranging from caring for colostomates to healthy eating is very popular with nurses, patients and other agencies. In the last year, the **Colostomy Association** issued over 20,000 booklets to individuals and hundreds of parcels of leaflets were delivered to hospitals.

It is essential that anyone, regardless of background or financial situation, is able to find the information they need. As a result, our website, magazine and range of literature are completely free to receive (although donations are always welcome to help cover the costs).

3 Local impact

Although we are a national charity, we aim to improve the living situation of ostomates in their own communities.

CONTINUED ON PAGE 38, COLUMN 1

Changing lives:

CONTINUED FROM PAGE 37, COLUMN 3

The past year has seen a growth in our local services as well as the launch of new projects and initiatives.

In 2015, we trialled **Pouch Craft** – a local competition where children were encouraged to draw on and decorate stoma bags. The purpose of the activity was to introduce the topic to young people in a way that was accessible and fun. The scheme proved to be incredibly popular with adults and children alike, with our charity receiving plenty of positive press attention focusing on the support we provide.

Our team of nationwide volunteers are vital in ensuring we reach communities across the length and breadth of the UK. They attend hundreds of open days up and down the country each year, run support groups and provide one-to-one support to patients before and after surgery.

Coming up in 2016, more local pilot projects will be launched focused on

improving the knowledge of carers and care agencies in parts of the country as well as initiatives to help people living with a stoma become more active.

Local support can make a real difference to people. We would like to reach those who struggle to find out about our 24-hour helpline or visit our website so that we can make a positive impact in the community where they live.

4 National debate

As well as providing individual support, the **Colostomy Association** is campaigning to improve public attitudes, as well as facilities for ostomates throughout the UK. We are working harder than ever to champion the concerns of those living with a stoma and we are creating a national debate about what it means to live with one. Further information about our Stoma Friendly Society campaigns can be found on page 31.

Thanks to a boost in staff, volunteers and funds and by proactively lobbying, we will succeed in changing public perspectives.

5 New opportunities

Our plans are to offer more services and launch more projects by finding new and exciting ways to provide better support to larger numbers of people living with a stoma. With your assistance, we hope to reach and support every single person with a stoma who needs our help. ■

Colostomy Association – in numbers:

3,000+	calls received each year
3,700	members of our Facebook Group
19,000+	registered supporters
20,000	booklets and factsheets delivered each year
40,000	hits to our website each month
84,000	copies of <i>Tidings</i> sent out each year



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Employee of the Year Award

The **Colostomy Association's** senior administrator, Jo McKenzie, was recognised for years of hard work and dedication after winning Employee of the Year at the Pride of Reading Awards in the autumn.

The annual awards recognise the best and brightest individuals, companies, charities and groups in Reading. Jo received her nomination from the **Colostomy Association's** General Manager, Sue Hale, for going the extra mile to ensure that vital services such as the **Colostomy Association's** 24-hour helpline, attendance at open days and range of free literature remain accessible for as many people as possible.

Jo initially joined the British Colostomy Association back in 2003 and has been a member of the **Colostomy Association** team for over a decade. As senior administrator, Jo's duties include supporting a team of over 100 volunteers nationwide, managing the 24-hour helpline, overseeing volunteers' attendance at open days, organising volunteer training sessions, as well as dealing with our online and telephone enquiries on a daily basis.



L-R: David Woolford, Jo McKenzie, Chris Tarrant

Speaking about receiving the award, Jo said: "This is an amazing thing to happen for me and the charity. I was totally shocked. It is wonderful being able to help so many people – and everyone who works for the charity loved the opportunity to benefit from the positive publicity."

The entire team at head office is extremely proud of Jo and everyone is delighted to see her formally recognised for years of hard work and service for the charity.

Jo is pictured above with Chris Tarrant (from ITV's Who Wants to be a Millionaire) and David Woolford from the award sponsor, Magal Engineering Ltd based in Reading.

500 Club September 2015 Draw Winners!

Anonymous	£ 362.00
Anonymous	£ 181.00
Anonymous	£ 72.40
Mrs Moody	£ 72.40
Mr Saunders	£ 72.40
Anonymous	£ 36.20
Mrs Hensman	£ 36.20
Miss Holcroft	£ 36.20
Anonymous	£ 18.10
Anonymous	£ 18.10
Mr Newton	£ 18.10

NOTE:

The following people also kindly donated all or part of their winnings back to the Colostomy Association: Miss Holcroft donated £36.20; Mr Saunders donated £10.00; Anonymous donated £15.00; Anonymous donated £15.00.

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



Each year, the **Colostomy Association** attends the annual conference for the Association of Stoma Care Nurses (ASCN) to help spread awareness of the services, information and support the **Colostomy Association** can provide patients.

Held in Birmingham in 2015, the ASCN's annual conference brings together around 500 stoma care nurses, stoma product manufacturers as well as other organisations and charities for three days to share information and gain knowledge.

Representing the **Colostomy Association** were Sarah Squire, Rosemary Brierley and Niall Norbury who were kept busy talking with stoma care nurses about our services, networking with other organisations and

individuals, as well as attending some insightful topical talks on developments in stoma care.

There was a great deal of interest from nurses in both our **Colostomy Irrigation DVD** and our Junior Ostomy Support Helpline (JOSH). Additionally, the **Colostomy Association** delegates were able to establish and build on contacts with nurses, companies and other organisations in attendance, as well as potential contributors to Tidings.

The conference is the main annual gathering for the Association of Stoma Care Nurses – a national organisation originally established as part of the World Council for Enterostomal Therapists (WCET) which became the ASCN

UK in 2013 to promote collaboration between stoma care nurses and the development of stoma care within the UK.

Speaking about the event, Marketing Communications Officer for the **Colostomy Association**, Niall Norbury, said: "This year's ASCN annual conference was a great opportunity to let both healthcare professionals and the stoma industry know about the wide range of services and support that the **Colostomy Association** provides. Additionally, the contacts made and information we learned from the annual conference will help enable the **Colostomy Association** to champion the voices of people living with a stoma in the coming months." ■



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Get Involved with

the colostomy association

Helping ostomates since 1967

Would you like to help out with tasks such as promotion, lobbying, giving talks, fundraising or administration? Helpers are needed for the following specific activities:

Local promotion Could you help spread the word about the **Colostomy Association** in your local area? We are looking for volunteers who can contact their local GP surgeries, stoma care team, hospitals, libraries, and pharmacies to display **Colostomy Association** literature, *Tidings* magazines or general advertising posters. Alternatively, perhaps you could provide us with the contact details for the editor of your regional community magazines so that we can send them future event information. Please contact Niall Norbury if interested.

Local campaigning Perhaps you'd like to help us by lobbying your local MP about specific **Colostomy Association** campaigns or topics of concern. Please consider joining our 'campaigners' database so you can

proactively assist us when the need arises! Please contact Niall Norbury if interested.

Giving talks to Rotary/Lions Clubs Would you be able to give a talk on Stoma Aid to clubs in your local area? Perhaps you enjoy public speaking and can travel easily to several nearby clubs. The presentation slides and script will be provided and we'll even make the initial approach for you! Please contact Niall Norbury if interested.

Fundraising As an independently funded charity we rely heavily on donations, grants and the efforts of fundraisers to continue our range of free services. If you'd like to hold a cake sale, run a marathon, 'go purple' or organise another activity to raise funds please contact Giovanni Cinque.

Admin Perhaps you'd like to assist in our head office with mailings, research, putting welcome packs together, parcelling up literature for nurses and other office tasks. For more details about the work of a **Colostomy Association** admin volunteer,

read Terry's story (below). If you live in or near Reading and are interested, please contact Sue Hale.

Other skills or useful contacts?

If you have a different skill, expertise or a useful personal network/contact you think may also be of benefit, please let us know. We're always interested in exploring new ways of reaching and supporting more people!

If you have a few hours to spare on a fairly regular basis and believe your skills could be of use, please get in touch:

Niall Norbury – Marketing Communications Officer
niall.norbury@colostomyassociation.org.uk

Giovanni Cinque – Development Officer
giovanni.cinque@colostomyassociation.org.uk

Sue Hale – General Manager

cass@colostomyassociation.org.uk
 Alternatively, call the **Colostomy Association** office on **0118 939 1537**.

Thank you so much.

Without our wonderful team of admin volunteers we would be unable to offer the range and quality of services that people with a stoma require and expect from us. Their impact on our day to day work ensures our quarterly magazine and range of literature reach as many people as possible.

A typical case is Terry Bryant. Terry lives in Reading and he has been volunteering in the office for more than three years. Terry was 72 when he had his stoma operation and he called us for advice. A year later Terry decided that he wanted to give something back; to help other people with a stoma get used to the changes in their lifestyle. Terry joined us as an admin volunteer in 2012 and he helps out with a variety of tasks in the office on a regular basis.

Most of Terry's time with us is spent dealing with a large number of postal mailings but he also helps the admin team pack up and send out orders from ostomates, nurses or support groups. Terry was also on hand at our 10th anniversary open day to meet and greet attendees.

Terry finds volunteering with us rewarding as his contribution is making a real difference.

If you're interested in joining as an admin volunteer, please contact our General Manager – Sue Hale – via telephone **0118 939 1537** or email **cass@colostomyassociation.org.uk**



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Junior Ostomy Support Helpline (JOSH)

Are you the parent or carer of a child with bowel or bladder dysfunctions/diversions? The **Colostomy Association's** specialist parent helpline, JOSH can provide you with the support you may need.

JOSH was launched by **Colostomy Association** Trustee, Wendy Hetherington, at the end of 2014 as a much-needed service for parents of children with bowel and bladder conditions. The helpline is staffed by trained volunteers who have all experienced the same issues and challenges as their callers. Two JOSH volunteers in their early 20s have J-pouches themselves and are happy to talk to teenagers about their own experiences.

To be put through to a JOSH parent, please call the **Colostomy Association** helpline and ask to speak to someone from JOSH. Our admin team will take down your details and find a helpline who best matches your situation who will then call you back at a time that suits you.

Call JOSH today on **0800 328 4257**

JOSH parents receive further training

Parent helpline for the JOSH have received further training in the past few months to help them provide even greater levels of support to callers.

In November 2015, seven JOSH parents and our junior ambassador, Aled Griffiths, attended a CliniMed sponsored training session on Neuro-Linguistic Programming (NLP). The course provided helpline with additional knowledge and skills on effective and empathetic communication.

Additionally in November, JOSH volunteers took part in an IPSEA law training course to help them navigate the new legal framework for children with special education needs and disabilities. As a result, our helpline will now be able to assist callers to make sure their children get the right educational support to meet their needs.

Why I became a JOSH parent

Aled's mum, Gaile, writes about how she became a JOSH volunteer:

Aled was born with an imperforate anus and a neuropathic bladder, neither of which I had heard of before. His first operation was to form a colostomy and was carried out when he was one day old. He only weighed four pounds which caused lots of problems; the colostomy bags were as big as he was. Over the next few years we did a lot of research into

his problems so that we could ensure that he received the help that he needed. As I was part of a charity for children with a similar condition to Aled this knowledge was shared with other parents and they in turn passed their hints and tips on to me.

In May 2014 I heard that a new helpline was starting up and that they were looking for parents of children with stomas; this was just the sort of thing that I could do. In September I was invited to participate in the

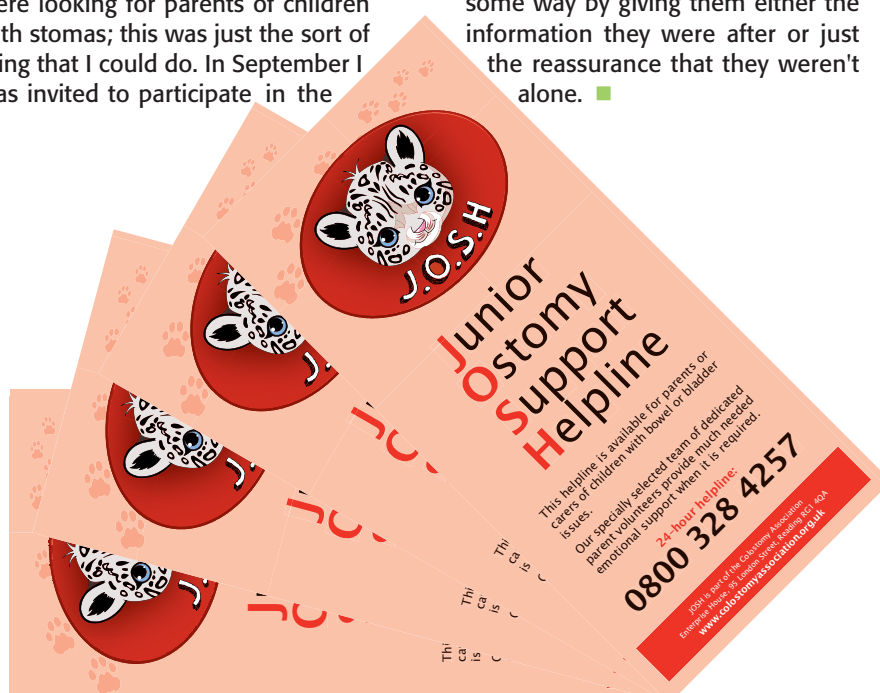
first training course for the new JOSH helpline. It was an exciting time. I met

other parents dealing with a range of bowel issues as well as learning how to answer a call.

My first call was quite a nerve racking experience. I wanted to make sure that what I said would help the caller; I didn't want to put my foot in it. A short time into the call, however, it all became natural, and I remember feeling really proud that I had been able to provide the caller

with useful information.

Since that first call I have had numerous other calls. Some have been for information for example about coping with a stoma while aboard an aeroplane. Others have been from parents with children who were about to have stomas. Each time I was able to help the caller in some way by giving them either the information they were after or just the reassurance that they weren't alone. ■



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Facebook Group

Scottish Mini Meet-Up in Glasgow

Wednesday 16th September 2015

One morning, after a restless night, I decided to visit the CA Facebook group to see if there was anyone interested in having a mini meet in Perthshire.

By coincidence, Jo Jones posted at the same time asking if anyone was interested in a meet up for coffee in Livingston in Mid-Lothian! Great minds and all that. I got no response for Perthshire, but Jo got some takers for Livingston. While chatting to Jo I asked how she felt about travelling to Glasgow and discovered that this was fine with her as Perth and Glasgow are about the same distance from where she lives but in opposite directions, so this seemed like a possibility. Next step was to have a look at Ian Jackson's members' map of the Facebook group. This showed a bigger cluster of members who could access Glasgow reasonably well and, hey ho, off we go.

I posted an initial enquiry on the Facebook group to see if there was any interest and was so pleasantly surprised by the response. Not just from members wanting to join in but lots of support from members in other areas who have organized similar meet ups and had such a great time. That really encouraged me to get on with it.

We settled on the date and booked a convenient restaurant which was reasonable and cheerful. When it came down to the final count we had 14 members all willing to travel to meet up with each other, which I thought was absolutely brilliant. Not only that, but there were lots of others who were sorry they couldn't make it but wanted to be kept informed of any future meet-ups or events.

The day before the event I got everything organized (or so I thought!) checked the booking, wrote sticky labels as name tags for everyone, even doing one for Tomas, the CA Facebook group bear who was very graciously joining us courtesy of Margaret Smith from Edinburgh who 'adopted him' recently when she won him in a raffle at the

Colostomy Association open day in Reading.

I set my alarm for an early start and thought that was that! I left in enough time so that I could get to the venue early to greet everyone, but due to various hiccups like forgetting the batteries for my hearing aids (had Hubbies of course, but not mine) so I had to go back! Then back on the road again, I got held up with a tractor and a spilled load and, of course, it was blocking the dual carriageway at a point I couldn't get off and around it! I eventually arrived a very flustered 15 minutes late instead of early, but, lovely ladies that they are, they had all organized themselves at the table, introduced themselves to each other and were in the middle of telling each other their particular stories! There was so much chat and laughter going on that I almost felt I should just go home and leave them, but it looked too good not to join in!

The whole afternoon seemed to fly by very quickly and we all declared what a great time we had all enjoyed, and when were we going to do it again? Think that tells you what a success it was and we will definitely be organizing another one so keep an eye on the closed Facebook group for any updates as to the next one.

Many thanks to Jo Jones for all her help and particularly as our designated photographer.

We might even get enough support to make a weekend out of it!

Una Campbell

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

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Legacy donation A gift in your Will

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

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

We're busy looking forward to our tenth birthday celebrations in 2016. It's amazing to think that an idea that Julie had one evening has grown and become so successful. Looking back at the children that came to the first Breakaway weekend it's wonderful to see how well they have done, and how they really haven't let their stomas hold them back.

We've lots of exciting things planned to celebrate, and we'd love it if some of you could join us. It all starts with our 10 Year Anniversary Gala Dinner on Saturday 7th May at the National Brewery Centre in Burton-on-Trent. Tickets are £40 a head which includes a three course meal with wine. We are also having an auction and raffle, and are delighted that Duncan Wells has agreed to be our master of ceremonies.

We are still on the lookout for some more fantastic auction and raffle prizes, so if you are able to help us, or know someone who can please do get in touch. If you would like to buy tickets, please email us at info@breakawayfoundation.org.uk

Our May family weekend is being held at a new venue, and it's in Scotland! This is the first time that we've had a family weekend north of the border, and we are really looking forward to it. Our families have been telling us that they'd really like a weekend in Scotland as there's a lot of them living there, so we hope that lots of them will be able to join us. It is the 27-30th May, at the Belmont Outdoor Centre, Meikle, near Blairgowrie. If you are in Scotland and have a child aged up to 18 with a stoma and you'd like to join us, please do email for a booking form.

SUPPORT YOUNG OSTOMATES

July sees our 10th Birthday Family Fun Day on Saturday 9th July at Beaumanor, Leicestershire. The team at Beaumanor have been involved with Breakaway for the last nine years, and we're delighted to be able to have our family fun day with them. There will be all sorts of activities, from craft, facepainting, zip wire, high ropes, cannons, rocket building, bouldering, hide and seek in the cellars, and there will also be an exhibition from all the major stoma care manufacturers. Tickets are £5 per person and can be booked via the Eventbrite link on the Breakaway website.

And then in August we have our second family weekend of the year, from the 26-29th August at the YHA National Forest in Moira, Derbyshire. The YHA is a great venue, with en-suite rooms and a bar on site! We'll be at Beaumanor for the activities, which will include things like canoeing, team games, climbing wall, and the zip wire and high ropes for the older children.

So it's really going to be a busy year for Breakaway, but one that we are really looking forward to.

Sue Blackwell
Breakaway Trustee

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Ever thought of making your own pouch covers?

Wendy explains how

Wendy began making pouch covers when she had problems with soreness around her stoma. She found that cotton was best against her skin, but the covers available on-line were not quite what she wanted and rather expensive. So, not having picked up a needle since primary school 45 years earlier, she set out to experiment.

It was October 2011 when Wendy had her colostomy due to bowel cancer. She says that the first year of having a stoma, whilst being a learning curve, presented no issues. At the beginning of 2014 she had a parastomal hernia repair and the following July she decided to put her health first and resigned from her job. Now fourteen months later she knows she made the right decision. Wendy lives in Norfolk and enjoys walking, swimming, Tai Chi and Pilates.

These days Wendy wears the pouch covers just for fun. She was invited by her stoma care nurse, to come along and exhibit her covers and demonstrate the process of making them at a recent Stoma Open Day in Norwich.

Wendy's instructions of how to make pouch covers are available by contacting the **Colostomy Association** on **0800 328 4257** or to download from www.colostomyassociation.org.uk



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

I was told today that I will need an operation to form a colostomy. The doctor said he would arrange for me to see a nurse who would explain all about it. But I need to talk to someone now. I don't know much about colostomies except that my grandmother had one; she never went out, and it used to smell.

Last week I had a colostomy formed due to Crohn's disease and have only just come home from hospital. When I take a shower, should I leave my bag on or can I take it off?

I ordered my supplies last week and they still haven't arrived. It's the weekend. I only have a couple of bags left. What shall I do?

Is it OK to go swimming when you have a stoma?

The **Colostomy Association's** helpline is one of our most-loved and most valuable services. Anyone in need can call **0800 328 4257** at any hour of the day to be put through to a member of our staff or someone living with a stoma.

If you dial **0800 328 4257** during office hours on a weekday, your call will be taken by one of the staff at the **Colostomy Association** office. They will be able to answer your questions, or point you in the direction of someone who can. The office staff can also provide practical advice and send out any leaflets which might help (or suggest you download them from the **Colostomy Association** website). If it is appropriate they will ask if you would like to speak to someone else who has a stoma and if you agree they will take your telephone number and details of when you are likely to be in to take a call. This information will then be passed on to one of our 100 volunteers who will call you as soon as they can.

When **Colostomy Association** office closes at 5pm the helpline is transferred to one of our helpline volunteers, who will keep the line until 9am the next morning when it will be transferred back to the office. Similarly anything from one to four volunteers will man the line in shifts over the weekend. These volunteers will be at home getting on with their normal evening, Saturday or Sunday activities, be it watching the television, weeding the garden, surfing the net or walking the dog. They will, however, be happy to stop what they are doing and listen to your concerns, answer any questions or give non-medical advice on coping with a stoma. What they can't do is give medical advice and if this is required they will suggest you contact your stoma care nurse or GP or, if the problem cannot wait until they are available, dial 111.

We receive thousands of calls each year on a huge range of topics and issues. Take a look behind the scenes of one of our flagship services and find out why our helpline is so valuable for people in need.

Typical calls

Q: *I was told today that I will need an operation to form a colostomy. The doctor said he would arrange for me to see a nurse who would explain all about it. But I need to talk to someone now. I don't know much about colostomies except that my grandmother had one; she never went out, and it used to smell.*

A: Like yourself, many of us facing stoma surgery are concerned that their life will never be the same but in most cases we find we can do everything we did before we had a colostomy; return to work and resume our normal activities and hobbies. However, you will need to give yourself time to recover from the operation and get used to managing your stoma.

Ostomy care has moved on since your grandmother's time. Stoma pouches are now small and discrete and have special filters to ensure there is no odour. There are about 120,000 people who have a colostomy or other type of stoma in this country. You will have passed them in the street, sat next to them, spoken to them and never guessed they were wearing a stoma bag. So no one will know that you have a colostomy... unless you choose to tell them. And today more and more people are choosing to speak out and increase public awareness.

You will no doubt think of more questions over the coming weeks so we will send you a copy of our leaflet *How*

will a Colostomy affect me. Please feel free to ring our helpline at any time either before or after your operation; out of office hours ie in the evening and at weekends, it will be answered by a volunteer. All our volunteers have a colostomy themselves and we can also arrange for one of us to visit you at home or telephone you at a prearranged time.

Q: *Last week I had a colostomy formed due to Crohn's disease and have only just come home from hospital. When I take a shower, should I leave my bag on or can I take it off?*


A: Water will not harm the stoma and cannot normally enter the body via this route so you can bathe and shower with the pouch off. However, it would be best to leave the bag on for the first few weeks until healing is complete and the stitches have dissolved.

After that it can be a pleasant, clean feeling to bathe or shower while not wearing a bag, and it is also beneficial for the skin. When you have become more confident in managing your stoma and have developed a routine you will be able to identify the times when the colostomy is unlikely to be active, for example before rather than after a meal, and plan to have a bath or shower then.

Q: *Is it OK to go swimming when you have a stoma?*

A: Yes, swimming is excellent exercise for an ostomate. If you are worried that your bag will come off in the water, then don't be. The adhesive is designed to be waterproof and all that will happen is that if you are in the water for a long time it might become a little bit soggy around the very edge of the flange, but it will not come off. Semi-circular

The Colostomy Association Helpline



shaped pieces of adhesive called *flange extenders* can be stuck around the flange to give you added confidence the first time you venture into the pool or the sea.

Maybe you are worried that other swimmers will notice the outline of your bag beneath your costume. They won't, but, if you are concerned, you can always choose a patterned costume or wear a support waistband beneath it. There are companies that make swimwear specifically designed with extra support or with an internal pocket for ostomates and we can send you a list of contact details if you wish.

While in the water you may prefer to use a smaller version of the pouch you normally use or a stoma cap. A plug which can be worn for a short time by some colostomates is also available but you need to check with your stoma care nurse that this is suitable for your type of stoma.

Unless your pouch is empty it is best to change it just before going in the pool. It is a good idea to have one of the sticky patches, which you will find in your box of supplies, over the filter while you are in the water. This will prevent the filter getting wet which can make it less effective in releasing any wind later on.

Food entering the stomach stimulates the gut into action, so for everyone, not

just ostomates, it is best not to go swimming too soon after a meal.

Q: *I ordered my supplies last week and they still haven't arrived. It's the weekend. I only have a couple of bags left. What shall I do?*

A: Is there a possibility that you might have put some bags in the car, just in case, or perhaps in a handbag that you don't use very often? Do you take drainable bags with you on holiday and bring them back unused? If you can't find any bags you've forgotten about and you can't contact your supply company then the best thing to do is to ring the local hospital. If you had your operation there then ask to be put through to the ward where you were an inpatient. Otherwise ask for the colorectal or surgical ward. Explain your problem and ask if they could let you have a few bags to tide you over. They may not be the type of bags you normally use and you, or a relative or friend, will have to go to the hospital to collect them. Another option is to try contacting a local support group as one of their members may have a few suitable pouches to spare.

Delivery companies now have to receive your prescription before they are allowed to send out stoma supplies. This means that, especially if the delivery company request the prescription, it can take two weeks or more from making a request to receiving your supplies.

Therefore ostomates are advised to place a new order as soon as they get down to three weeks supply.

Q: *A friend had an operation for cancer a few months ago and will shortly be coming to stay with me for a few weeks. She now has a colostomy so I was wondering about meals and what she will be able to eat and if there is anything I should do to make her stay more comfortable.*

A: There is no special diet for people with a colostomy and as your friend had the operation a few months ago she is now probably enjoying the same foods that she ate before she had the operation. It would probably be best to ask her if there are any foods that do not agree with her so you can avoid them while she is staying with you. Many ostomates find that eating regular meals helps to regulate their colostomy and some find it best to have their main meal at midday rather in the evening so you could ask your friend about her normal eating pattern.

Your friend will probably need to dispose of her used appliances, wrapped up in special disposal bags she will bring with her. If you have a bin with a lid in the bathroom she could use that, or alternatively she may prefer to take them outside and put them straight into the dustbin. ■

Dear Nurse

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



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

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

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

Q: *I had an operation for bowel cancer on the 29th June and joined the **Colostomy Association** when I returned home from hospital. I have found the articles in the *Tidings* magazine very useful and was especially interested in the article about irrigation and pancaking. As I suffer from pancaking I am contemplating irrigation. I am concerned that using irrigation could cause an infection in the stoma. Have any osomates had any problems relating to infection?*

A: Infection with the use of stomal irrigation is unusual. It is a clean procedure and as long as the equipment is cleaned and stored in a clean area and that you wash your hands before and after the procedure you should not have any problems. I would suggest seeing your local stoma care nurse to discuss the benefits of stomal irrigation. If they feel it is suitable for you then they can order the equipment and arrange to see you to train you in the technique. I have several patients who use this very successfully. Good luck.

Q: *In March 2003 I had a resection of the rectum after being diagnosed with bowel cancer. As a result, from that time I have had a colostomy bag. From a*

which was acceptable to me. This was via a TENS pain relief unit which brings some relief, but only for 20 minutes or so after a 30 minute session.

*The purpose of this email is to see whether the **Colostomy Association**, with its wide experience, can offer any suggestions to resolve or at least alleviate my two problems, in particular the discharge?*

A: These are common following the sort of surgery you have had. Most people manage to control the pain with different medication or treatments to a level that they find able to live with. If you have not reached this stage with regard to the pain it may be worth discussing other options with your consultant. A further review with the Pain Management Team would also be of use.

With regard to the rectal discharge this is something that again people manage in differing ways. Some people find it happens so infrequently that they can manage without any treatment at all. However, if it is troublesome then it may be that using a glycerine suppository on occasion to clear the back passage would be of benefit. This can be through your GP. If the discharge is frequent some patients find the use of the *Coloplast Anal Plug* useful but this must only be used once you have been reviewed by your local stoma care nurse to see if it is suitable for you and many patients find that the feeling of fullness in the rectum that it causes is as uncomfortable as the discharge. Another solution is to see your consultant and to see if he can prescribe some steroid suppositories or enemas in case this is proctitis in a defunctioned rectum, or if he would consider removing the rectum completely and making it a permanent colostomy. This last one is a very final solution and needs to be considered carefully.

Q: *A year ago I had a fall and hurt my pelvis. On examination they found a hole in my bowel which they said needed an operation. When I came round from the operation I found I'd had a Hartmann's procedure.*

I have constantly had this pressure as if I want to poo all the time. The only time I have any freedom from it is if I lay down which I cannot do for 24 hours. I have had a sigmoidoscopy which found nothing wrong. On further investigation the gastroenterologist said the pressure feeling I am getting from the rectum is likely to be from my abdominal organs. Unfortunately this cannot be resolved and I do not know what to do.

cancer point of view the operation was successful, but there have been two particular ongoing problems, which have proved impossible to deal with effectively; discharge from what remains of my backside which has continued intermittently in varying quantities over the last 13 years, and pain from the area that was operated on for the same period.

As to the discharge, my consultant tells me when I raise the matter on an annual basis that nothing can be done and I just have to put up with the problem and manage it as best as I can. As to the pain, three years ago I saw a pain management consultant who offered a number of options, only one of

I have seen many doctors and therapists. It's alright saying that I have to put up with it but they won't have to put up with it for the rest of their lives. Can you please try and help me. Could a hypnotist or acupuncture help, because I have tried loads of medication, suppositories etc to no avail?

A: Obviously without access to your medical records it is difficult to be able to offer any advice or solutions. Have you discussed your concerns with your local stoma care nurse or your consultant? They may be able to advise as to alternative treatments or to offer you some hope or a referral to another consultant for a second opinion. I'm really sorry I cannot offer much in the way of advice, I presume you are managing with the stoma without any problems as you do not mention any in your letter. Good luck and I hope someone is able to offer you some hope to solve the distressing problems you are experiencing.

Q: I was diagnosed with colon cancer in 2009 and had an operation in May of that year (Anterior resection – rectal carcinoma). Since then I have suffered with pain in my bottom. I have read letters from other readers of the magazine who feel pain when they sit down whereas I experience the pain when I am standing up.

I have tried numerous pain killers. I am currently taking Oxycodone, Tramadol and Paracetamol.

These help a bit but the pain is always there, except when I sit down. I have tried acupuncture and electric shock treatment with no improvement.

I went to see a surgeon in Bristol who specialises in the pelvic area. He says that it would be too risky to carry out an operation because of the operations I have had in that area. I had my bladder removed about three years ago. I can't have an MRI scan because I have a pacemaker fitted. The surgeon doesn't think he would learn anything from it any way.

The question is – has anybody else experienced the same problem and if so have they been successfully treated for it?

A: You have obviously done a lot of research and seen several people in an attempt to find a solution for your problems. It is difficult for me to comment on any individual case as I do not have access to your medical records.

You do not mention any other problems such as bleeding or discharge from the rectum but if there are any then I would suggest you get a medical review to see if this has any cause.

A referral to a specialist with an interest in pelvic floor may also be useful as there are many things now which can be used to treat Anterior Resection Syndrome and your GP can arrange this. I also wonder if the use of special support to provide a pressure pad in the rectal area would be of use as you say when you sit down the pain and discomfort disappears. If this is an area you wish to explore then a company called CUI International can make bespoke supports. I hope you manage to find a solution for your problems.

Q: In the autumn edition of Tidings a couple of people have written in about trouble with blockages caused by adhesions.

I had bowel cancer two years ago and ended up with a colostomy. In the last two years I have been admitted to hospital four times with blockages. The only treatment is pain relief and hydration through a drip as I am unable to drink fluids because of the vomiting. I find that there is not a lot of knowledge about blockages and the working of the digestive system out there.

Some stoma nurses advise that I should be able to eat normally but the last time I was advised to have a low fibre diet. This appears to work for me; my last blockage was March this year. Fingers crossed. I am writing as anyone in a similar position might want to try a low fibre diet.

A: Thank you for your comments about your experiences with bowel blockages. I hope you have found the solution which works for you. It is always good to speak to people like yourself who are the true 'experts', living with a stoma on a day to day basis. Some people who have had blockages do find that a low fibre diet works for them and it is always worth trying but the solutions are often found on a patient by patient basis. Some patients find dietary changes help, others find the problem settles with intravenous fluids and nil by mouth (obviously if the blockage keeps recurring then this is not a long term solution) and some people find surgery to relieve the cause of the obstruction is necessary. Good luck for the future and hopefully you have found your solution. ■

What kind of stoma do you have?

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

Five facts about an ileostomy

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

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

Five facts about a colostomy

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

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

Editors Comment

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

If so, write in and tell us:

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

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

Readers' writes



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

Rosemary Brierley

Dear Editor

I was interested in the article in Issue 39 of the *Tidings* about pancaking and decided to try the stoma bridge product suggested by BM. Opus Healthcare kindly sent me a few samples of the small size. However, I found difficulty in positioning the stoma bridge in the pouch with my chubby fingers so I decided to use tweezers.

Firstly, hold the stoma bridge with the tweezers and pinch in the sides. Second, remove the backing paper exposing the sticky side. Next open the pouch and with the tweezers position the stoma bridge to the side of the pouch. When in the right position, press firmly on the pouch to secure the stoma bridge with the tweezers still holding the bridge. Withdraw the tweezers and repeat the process on the other side. Finish by pressing down firmly on the pouch so that both stoma bridges are secure.

I hope this tip will help fellow users of stoma bridges.

Regards
Mike Lansdall

Dear Editor

In the Autumn 2015 issue of *Tidings* the article *From One Ostomate to Another* discussed Pancaking. Good ideas were suggested, including Ian Jackson's list of 5 top answers.

One big help I find for pancaking and stoma management overall is a glass of prune juice with breakfast. Tesco have the cheapest, but most supermarkets stock it. The quantity required will depend on ones diet at the time – small amounts for vegetarian or healthy diet, more for a higher fat content diet.

This reduces solidity, increasing fluidity, making the bag contents much more mobile and it is easier to empty the bag. Get to diarrhoea symptoms and you've had a little too much prune juice.

Hope that this helps – I suffer immediately when the dose of prune juice is missed.

Regards
PH

Dear Editor

I was advised to consider irrigation by my stoma care nurse. It is the best thing I have done. I have had my stoma bag for over 18 months and have always felt uneasy at going out to social events, even lunch, in case it performed and needed attention. Since I started irrigation I have enjoyed life to the full again.

With the help of my stoma nurse, I am trying, to set up a local group within a 20 mile radius of the Royal Surrey Hospital. Any help would be appreciated.

Thanks
RY

Dear Friends

This seems a good place to air two difficulties which I encountered before and after my stoma surgery in July of this year.

Firstly, an information book of colostomy hints and tips produced by a manufacturer of stoma appliances carried an unfortunate story of an ostomate who had all kinds of post op complications. He couldn't sit for six months, required three further ops etc I read this book the evening before my operation and it did NOT fill me with confidence or add anything positive to my experience – quite the opposite. This sort of information can be given as required by the surgeon as he outlines the procedure to the individual, should he need to.

Secondly, although well prepared by the stoma nurse, it was still not a pretty sight to stare solemnly post op at this transparent, bloody bag on top of a cherry coloured lump, over which I had little control. When faeces came in this became brown. I cannot describe my feelings to have all of this so visible. Ever practical, I would like to make a suggestion to be adopted in hospitals. I recognise the need for staff to monitor the contents of the bag and colour of stoma etc so the bag needs to be transparent. Could I suggest a detachable, opaque sort of hot water bottle cover which could easily be

Readers' writes

removed for inspection? This would tick all the boxes, I think.

Many thanks.

Yours sincerely
MRC

Dear Editor

With regard to the Autumn 2015 issue no. 39 article: *Prescription Review*.

I read this article with interest as my husband has had his stoma some 27 years, and with the excellent guidance of his stoma nurse, post operation choose the product that suited him and to this day it still does. He orders his equipment as required because, as you'll appreciate, the function of the stoma and his health, determines how many bags and seals he goes through in any given month. Therefore he does not stockpile, indeed we would not have the room to accommodate more supplies.

I don't know if any of your readers or stoma nurses have encountered this but the company we use, who are good, have taken to ringing to ask if he needs supplies, can they put him on an automatic renewal system. He declines as this would mean for him that he felt less in control and it would not meet his changeable needs and could/would result in stockpiling.

I just felt the need to bring this to your attention as on first observation this offer from the company would appear to be most helpful, which I am sure for some ostomates it is. However, it can encourage stock piling.

With kind regards
Sue Smith

Dear Editor

I have read your article *Prescription Review* (*Tidings* Autumn 2015). As a member of the PRG (Patient Reference Group) at my GP surgery and as someone who follows closely the work of the CCG (Clinical Commissioning Group) in the area in which I live, I found it very interesting.

Although I have had a stoma since May 2009, I had not really felt the need to make contact with a stoma care nurse for more than five years. I did some research on the trust with reference to stoma care and found from a published freedom of

information request that the trust had not employed any stoma care nurses in any of the last four years. Further research revealed that a contract for stoma care had been awarded to one of the stoma product delivery companies.

I decided to try and speak to the stoma care department at the hospital which was responsible for my original diagnosis and surgery and was delighted to be contacted by one of the stoma care nurses with whom I had dealt in 2009, and who in fact had done the original home follow up after my discharge. At this time she was employed by the NHS Foundation Trust albeit with some financial support from suppliers. She confirmed that she and her colleagues in the trust are now all employed by a delivery company. She had also read the article and agreed that a great deal of over prescribing does take place especially in such items as adhesive removers and barrier products. She also advised me that the stoma care team of which she is part offer a service to GP surgeries where they can assess all of the patient records within a practice where stoma care products are prescribed and identify the possibility of over prescribing.

From my own personal point of view there are two things which I find disturbing. Firstly I find it difficult to accept that any company with a commercial interest in supplying goods would want to be proactive in reducing the quantity of such supplies, and secondly that so many patients receive supplies on a regular basis without having to request same. This must surely lead to over prescribing as to avoid any problems such a prescription must have sufficient quantity to avoid running out during any given period.

I, like many patients request my supplies through a delivery company which then requests a prescription from my GP surgery. On my repeat prescriptions list there are just two items, pouches (which are on every request), and adhesive remover wipes which I have only requested once in the last six deliveries. The last time I ordered something outside of these items it was questioned by the delivery company and subsequently confirmed by my GP surgery, surely this is the way to deal with all such requests and therefore cut down on over prescription?

Kind Regards
John Constable

The Editor

I read with interest the article in the Autumn edition of the magazine, and saw with horror (but not undue surprise) the photos of wastage at the end of the article.

Recently I had cause to visit my local stoma clinic at Hythe near Southampton and, piled high in a corner, was a mound of returned, unwanted stoma bags. When I commented on this to the nurse, she said that occasionally they were collected to send to a needy country. I said that I knew of a lady at my local church, who would soon be going to the Ukraine. I asked if it would be feasible for them to go there and, on making further enquiries, was told this was alright. My friend said they would be very gratefully received there, so my husband and I filled two large black bin bags with the bags which we had taken from their boxes.

I know the bags will be used with gratitude, but surely it would have been better if the bags had not been ordered or prescribed in the first case and thus avoided any unnecessary cost to the NHS.

Concerned
WH

Dear Editor

Firstly I would like to say a big thank you to all the wonderful people who give their time so there is always help out there, and for publishing *Tidings* which I love to receive and read from cover to cover.

The story from Tim Harvey really touched me in the fact that he could not talk about it.

I myself am quite open about the fact I have had three different cancers: breast, skin and bowel with very many other operations: varicose veins stripped, gall bladder and appendix removed, full hysterectomy and I suffered infection in all my ops until I started taking antibiotics prior to the op.

However, my biggest problem now is not my colostomy as I am happy with my pouch but I am so unfortunate that the mesh that was supporting the remaining bowel has collapsed and I have a parastomal hernia which is so uncomfortable. I am 85 years old or should I say young!

EML

CONTINUED ON PAGE 55, COLUMN 1

Helpful Ostomy Support Groups & Organisations

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

Stoma Care Patient Open Day event dates

For a comprehensive list of Patient Open Days events, visit the CA website.

Listings are updated throughout year.

If you are not online contact CA on:

0118 939 1537 to find out if there is an event near you.

Note: The Colostomy Association full contact details can be found on Page 5.

SASH

Freephone
0800 389 3111



Ref. No. HB102

Stoma Support & Hernia Belt Ref. No. HB102

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

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

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

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

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

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

Stoma Shield Ref. No. SS104

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

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

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

Web: www.sashstomabelts.com



Ref. No. SS104



Ref. No. SR103

"The ring of confidence"

Security & Leakage Belt

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

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



Readers' writes

CONTINUED FROM PAGE 53, COLUMN 3

Dear Editor

I would like to make a reply to *Readers' Writes* in the last *Tidings* about disabled toilets.

I do agree that able-bodied people should not use a disabled toilet. I say that, I have a colostomy and always use disabled toilets. Important things that have not been mentioned include the need for a tap and basin with running water also soap – I have been in disabled toilets where there is no soap. Also a large mirror hung on the wall and plenty of shelving.

Thank you for all your good work. I do enjoy reading every word in the *Tidings* mag.

JW

Dear Editor

I recently visited Australia for a month's holiday. Whilst in Melbourne I went to the main information centre as I have a permanent colostomy and needed to use the toilet. An assistant told me the nearest toilet was the other side of the square. When I pointed out they had disability facilities nearby and showed my disability rights card, she inferred that I needed to be in a wheelchair to use these facilities.

Needless to say I made my way across the square and changed myself with great difficulty. I was very disappointed with the attitude of the assistant.

Yours sincerely
JM

Sadly, many members of the public believe that accessible toilets are only for those with mobility issues when they are actually for use by people with a variety of conditions. While the Colostomy Association cannot campaign for improved facilities or attitudes abroad, we are currently championing the rights of ostomates to live in a stoma-friendly society. For more information please read our article on the topic which can found on page 31 in this issue of Tidings.

Dear Editor

In the Autumn *Tidings* there was a letter from Donna Ashbrook asking for advice if you forget to take your supplies with you or run out of bags whilst away on holiday.

It is easy – if you get your equipment from a supplier delivered to your door (I use

Medilink) they only need a phone call and they will deliver wherever you are (even abroad). No more worries when going away. I go away for three months at a time each year knowing that, if I have miscalculated, they will get them to me.

Regards

Barbara Brown

It is a good idea to take your delivery company's contact details with you if you are going on holiday. However, the Colostomy Association recommends that you plan adequately before you leave and not rely on receiving supplies while abroad as this cannot be guaranteed, even if your delivery company is told about your trip in advance. If you are going abroad for an extended period and are unable to carry all your supplies with you, it might be worth asking your delivery company if they are able to send your supplies in advance. If you are staying with relatives or friends this would give you the opportunity to check that they have arrived before you leave.

Dear Tidings

In Issue 38 of *Tidings* I was drawn to an article by Jennie Burch on *Prolapse and Retraction*. As I read I realised that I was one of the 3% having a prolapse! In fact, since my successful bowel cancer operation a little over four years ago, I have had three prolapse revisions – the most recent, and final, in late August.

I had lived quite comfortably with my stoma and the first two minor corrective operations but the third developed into a semi-emergency. My stoma had extended to over four inches and I could not manipulate it back inside my body. The tip was black and enlarged – just like the picture in the article. My stoma nurse quickly arranged an appointment with my hospital oncology department. The consultant told me that the main body of the exposed colon was very healthy but the end had "died".

I was admitted to hospital that same afternoon and I was operated on the following morning. Forty-eight hours later I was home again, somewhat the worse for wear. I had hoped that the operation would have involved only minor external attention to my stoma (as had happened on the two previous occasions) but a full body incision had to be done to sort everything out. It is now two months since my discharge and I am almost fully recovered with, so far, a neat and manageable small protrusion!

Although I am 80 years old I lead an active life and in normal circumstances my colostomy does not interfere with my day-to-day activities. I even manage to volunteer my services at **Colostomy Association** Head Office to help with urgent mailings!

Michael Weller

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

Thank you for your letters and e-mails. Space permitting, we will print your contribution in the next issue of *Tidings* or we may hold it over for a future issue.

To contribute to the Readers' Writes page:

e-mail:
editor@colostomyassociation.org.uk

or write to:

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

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

Editing may be required for reasons of clarity or space.

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If you have a product to sell, an event to advertise or a message to communicate, you can place a small advert for as little as £65. Stoma care nurses, if you would like to promote your Stoma Care Department, its services and events for FREE, then just get in touch; Contact – editor@colostomyassociation.org.uk



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Pelican Healthcare Exclusive Meeting

The Quay Arts Centre, 15 Sea Street,
Newport, Isle of Wight PO30 5BD
Jan 19th 2016 – 11:00am – 2:00pm
Tel: Kacie Morgan 0800 318 282

Inaugural Meeting

Stoma Support Group

Ivy Bush Royal Hotel,
Carmarthen, SA31 1LG
Mar 7th 2016 – 7:00pm
Tel: Iris Williams 01267 227 916

Coloplast Event

Bankfield Hotel,
Bingley
Jan 26th 2016 – TBC
Tel: Karen Sutcliffe 07469 144 054

Salts Coffee Morning

The Library, 96 Shenley Road,
Borehamwood, Herts, WD6 1EB
Jan 28th 2016 – 1:30pm – 3:30pm
Tel: Barbara Milleret 07741 606 360

Cambridge University Hospital

The Hexagon – The Frank Lee Centre at
Addenbrooke's
Apr 23rd 2016 – 10:30am – 2:30pm
Tel: Stoma Care Team 01233 216 505

Friarage Hospital

Mowbray Suite, Golden Lion Hotel,
Northallerton, DL7 8PP
May 17th 2016 – 11:00am – 2:00pm
Tel: Stoma Care Team

Coloplast Event

The Bentley Hotel, Newark Road, South
Hykeham, Lincoln, LN6 9NH
Feb 22nd 2016 – 11:00am – 2:00pm
Tel: Carline 0800 220 622

Coloplast Event

Kettering Park Hotel, Kettering Park Way,
Kettering, Northamptonshire, NN15 6XT
Mar 12th 2016 – 11:00am – 2:00pm
Tel: Carline 0800 220 622

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ALWAYS MENTION TIDINGS WHEN CALLING.

Contact – editor@colostomyassociation.org.uk



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





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Thank you for your support

Regular donation

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

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

Note:

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

My Details: Title:

Name:

Surname:

Address:

Postcode:

Telephone (home):

Mobile:

Email:

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

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

Bank Address:

Postcode:

Name(s) of Account holder(s):

Account number:

Sort code:

I would like to make a **regular donation*** of ☐ £15 ☐ £20 ☐ £25 ☐ £50 or other amount (please state) £
☐ **monthly** ☐ **quarterly** ☐ **annually starting on the** ☐ **1st** ☐ **15th** ☐ **25th of month:** **year:**

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

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

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

Name: (IN CAPITALS)

Signature:**Date:** / / 2015


Thank you for your gift

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

☐ I would like the tax to be reclaimed on this donation and any eligible donations that I have made in the last four years or will make to the Colostomy Association until further notice. I confirm that I pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

Signature:**Date:** / / 2015**Optional Information:**

Date of Birth:

Stoma Type: Colostomy ☐

Reason for your stoma:

(Please tick) Ileostomy ☐

Year of operation:

Urostomy ☐

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

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

Thank you for your support

Single donation

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

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

Note:

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

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

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

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

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

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

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

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

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

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

giftaid it

Thank you for your gift

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

☐ I would like the tax to be reclaimed on this donation and any eligible donations that I have made in the last four years or will make to the Colostomy Association until further notice. I confirm that I pay an amount of Income Tax and/or Capital Gains Tax at least equal to the tax, not including Council tax and VAT, that the Colostomy Association and other charities and CASCs reclaim on my donations in the appropriate year (currently 25p for every £1 donated).

Signature:

Date: / / 2015

To make a single donation... Please fill in the form, check your details are correct, then return this page to the Colostomy Association - thank you



Oldham Stoma Support Group

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.



Oldham Stoma Support Group

June Wilde, Chair of the Oldham Stoma Support Group, describes herself as a 75 year old tap dancing grandma to four wonderful great grandchildren. She writes about how she came to have a colostomy and founded the group 16 years ago.

In 1998 I had a hysterectomy and over the next five months I went progressively downhill. Eventually a surgeon decided to look at me under anaesthetic and when I awoke I was told I had an abscess. This later burst and left me with a fistula between my front and back passage.

The only solution was to have a colostomy. I was told I could have a reversal but I decided not to because it would involve at least two more operations and I really wanted to carry on enjoying life. I went back to my job which I really enjoyed as manager for the customer service department of a mail order company. Then, as I was approaching sixty, I was offered a retirement package and I decided to take it.

Soon after the local stoma care nurses from the Royal Oldham Hospital held a meeting to see how many people would be interested in attending a support group. They knew I had been in a managerial position and was quite used to talking to people and organising events so I was

asked if I would set this up. As I was taking my daughter and two grandsons to Australia for five weeks – my retirement present to us all – I said I would start the group on my return.

We have now been in existence for 16 years and from the first meeting we have gone from strength to strength. I still run the group with the help of a secretary and treasurer. There are usually 30 or so members at each meeting. Some of them are from the original first group meeting – sadly one or two are no longer with us but not forgotten.

Our meetings are bi-monthly, in February, April, June, August, October and December on the first Tuesday of the month. They are held at Oldham's Link Centre, a purpose built venue for people with disabilities to hold meetings and social events. At first we used to meet in the afternoon, but now we have found that the evening is more convenient for most people so our meetings are from 7pm till 9pm and we will have a bite to eat and maybe a glass of wine.

I try to organise a supplier to come along to each meeting so that we can keep up to date with new products. We have speakers, for example someone from NHS came along to explain the changes to how supplies were ordered and a surgeon took



June Wilde (centre) and The Tappers

us through the procedures of a colostomy operation, which was interesting, but scary. Sometimes we just have an open meeting where we talk over problems. There have been many trips out over the years including several to chocolate factories (yummy) and breweries, canal boat trips and many more.

Aside from this, my wonderful members support developing countries by recycling bras, which are sent abroad by my church and spare appliances and other stoma items which a friend takes to Jacob's Well in Beverley when she visits her son.

Our December meeting was a Christmas party and the entertainment included a Mr & Mrs game and a music quiz. The highlight of the evening was the surprise visit from my tap dancing club and our performance of a tap dance routine to the song, *Hit the Road Jack*.

After all that I must say to anyone thinking of starting a group – Go for it. The rewards are far greater than you think. You will make wonderful friends and enjoy your meetings.

Best wishes to you all.

June Wilde

For more information about the Oldham Stoma Support Group:

Telephone June on **0161 312 5538**

If you would like to see your support group featured here, please telephone the Editor on: 0118 918 0500 or send your article and photos by post to: Editor, Colostomy Association, Enterprise House, 95 London Street, Reading RG1 4QA or if you prefer email your article and photos to: editor@colostomyassociation.org.uk

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

Stoma support groups in your county

England

B

Bedfordshire

Saturday Social Club
Karen Richards: 0123 479 2278

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652
Reading Bowel Cancer Support Group
Ted Wingrove 0118 961 8297 or 07974 790 558
W.B.O.C (West Berkshire Ostomy Club)
Jackie Dudley: 0134 442 6652

Bristol

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

Buckinghamshire

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

C

Cambridgeshire

Connections Cancer & Colostomy Group
Bev or Sue Scott 0135 386 0356 / 0776 695 8811 or Barbara Hunt 0135 386 2133
Peterborough Stoma Support Group - Ostomistics
Alan Wright 0135 465 3290 / 0783 666 1102

Cheshire

Countess of Chester Hospital Stoma Support Group
Stoma Nurses 0124 436 6170
Stockport Support Group
Angela Simpson: 0161 320 9400 / 0800 652 6667
Stoma Support Group
Catherine McIntosh: 0147 753 5071
Warrington Ostomy Support Group
Jane Shaw: 0192 566 2103

Cleveland

Oops Group
Julie Morrisroe/Carol Younger: 0128 728 4113

Co. Durham

Bishop Auckland Stoma Care Group
Betty: 0138 881 4535
Darlington Support Group
Sister Jacqui Atkinson: 01325 743005

Cornwall

Cornwall Bowel Cancer Support Group
Keith Anderson: 0182 225 8618, cbcsginfo@gmail.com or website www.cornwall-bowel-cancer-support-group.co
Cornwall Ostomy Support
Ken Jones: 01872 863 106 or www.cornwallostomysupport.org.uk
Ostomist and Carers Support Group
Christine Davey: T: 016370 850 895 E: chris.davey28@gmail.com or Mandy Rowe: 01726 832 642

Cumbria

Grange Cancer Support Drop in
Marie: 0153 953 3279

D

Derbyshire

Diverted Local Stoma Support Group
Diane Manning: 0128 354 1311

Devon

Mid Devon Ostomy Support Group
Janice: 0136 377 6417 or jdkelly234@gmail.com
North Devon Bowel Cancer Support Group
Karen Day: 01271 322 464

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Jenny Pipe: 0120 274 0440
Colostomy Urostomy Pouch Ileostomy of Dorset (CUPID)
Beryl Andrews 0120 248 3303
Colostomy, Urostomy, Pouch & Ileostomy of Dorset - CUPID (West Dorset)
Colin Clare - 0130 585 3238

E

East Midlands

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

Essex

Connect
Lin Hart 0127 950 5273
Mid Essex Stoma Support Group
Paul Foulger: 0124 522 4374, Jeanette Johnson: 0137 651 1862
N.E.S.S (North Essex Stoma Support)
Secretary: Brian Waller: 0120 654 0449
Optimistic Ostomates
Carol Booth: 0170 238 5510 or Angela Taylor: 0170 238 5509
Redbridge Ostomists Club
Stoma Nurses - Chris/Lisa: 020 8970 8321
STEPS
Jackie: 0126 845 1937

G

Gloucestershire

Ladies Big Op Group
Gill Hopkins: 0300 422 4363. Please Note: For ladies with one or two permanent stomas
Vale Stoma Support Group
jfn.dursley@gmail.com or text 0794 182 7393

H

Hampshire

Solent Ostomates Support Group (New Forest Branch)
Ron Lever 0238 089 3949 / rdlever@sky.com
Solent Ostomates Support Group (S.O.S.)
Carole Summer: 0752 770 7069
Southern Ostomy Group
Caroline or Karen on: 07756 819 291 southernostomygroup@hotmail.com
Wessex Urology Support Group
Adrian Kuczyński: 07910 786 978

Herefordshire

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

Hertfordshire

Colonise
Anastasia 0172 776 0981
Hertford Stoma Support Group
Ralda: 0199 253 5311
Stevenage Ostomistics
Judy Colston: 0143 835 4018 / neilcolston@btinternet.com or Alfred: 0176 731 6958

I**Isle of Man**

IOM Bowel Cancer Patient and Carer Group

Heather Norman: 07624 480 973

Stoma Support Group

Carole Cringle stoma nurse: 0162 465 0212

Isle of Wight

Optimistics

CNS's Andie Coates & Amanda Broadbridge 0198 353 4009

Semi-Colon Club

Tony Crowson on 01983 559 326 or Cancer Clinical Nurse 01983 534 180

K**Kent**

Ashford Stoma Support Group

Carole Hobbs: 0130 381 4014 or Margaret Webb 0123 362 8807

Atoms Support Group

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

Dartford Ostomy Group Support (DOGS)

Tracey, John or Sue: 0794 897 4350 or dogs-uk@hotmail.com

Dover Stoma Friends Group Support

Julie Bell: 0777 134 5703 or Ros Marshall: 0130 482 2696 or June Golding (Organiser): 0130 482 2696

M.O.G.S (Medway Ostomy Group Support)

Helen Or Tracey: 0777 360 5534

Maidstone Stoma Support Group

Judy/Kirsty: 0162 222 4305

Royal Tunbridge Bowel Cancer Support Group

Bronwen Tetley CNS: 0189 252 6111 x 2287

Thanet Stoma Buddies Support Group

Phil (Secretary) 0184 358 7769

L**Lancashire**

North Manchester and Bury Stoma Support Group

Julie Meadows (SCN) 0161 720 2815 or 0784 120 6910

Oldham Stoma Support

June Wilde: 0161 312 5538

Tameside Ostomisticks

Paul Seavers on 0777 135 9046

Trafford Bowel Care

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

Leicestershire

Kirby Ostomy Support Group.

Colostomy, Ileostomy and Urostomy in Leicestershire

Janet Cooper: 0116 239 2844 / kosg2013@btinternet.com

Lincolnshire

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

Grantham Support Group

Bobbie/Rachel: 0147 646 4822

March Group

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

Sutton Bridge and Long Sutton

Ostomy Group

0140 635 1617

London

Bowel Cancer Newham

Scyana: 0208 553 5366
scyana@tiscali.co.uk

ESSence (Ealing Stoma Support Group)

Wendy Hetherington: 0771 733 5884

Homerton Hospital Bowel & Stoma Support Group

Angela Davy: 0208 510 5318 or 0208 510 7599

Rectangle - Colorectal Cancer Support Group

Regina Raymond 020 7472 6299

South Woodford Support Group

Nurse Christina and Lisa: 020 8535 6563

St. Thomas' Hospital

CNS: 020 7188 5918

Surrey & South London Bowel Cancer Support Group

Sue Berry: 0173 755 3134 or John Amos: 020 8668 0796

M**Merseyside**

I.C.U.P.S

SCN: 0151 604 7399

St Helens Cancer Support Group

Office: 01744 21831, Denys Floyd: 01744 884097 or email: contact@sthelenscancersupportgroup.org

Middlesex

Inside Out

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

Semi-Colon Club

Pat Black or Kathryn Foskett on 0189 527 9391

N**Norfolk**

Kings Lynn Ostomy Friendship Support Group

For more info please call 0155 369 1370 / 768271 / 775698

Stars

Anne Browne: 0160 366 1751

Northumberland

Berwick Ostomy Support Group

Bobbie Minshall: 0771 447 9320

Hexham Ostomy Group

Judith on 0796 792 7286

Northumberland Cancer Support

members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group

Tore and Nicky Norman: 0177 371 5460

Nottingham Colostomy, Ileostomy & Urostomy support group

Rosemary Brierley: 0115 982 6691

Nottingham Stoma Support

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

O**Oxfordshire**

Oxfordshire Ostomy Fellowship

Pat Longworth: 0123 552 4163

S**Shropshire**

B.O.T.S. (Bums on Tums)

Irene Constable on 0169 123 8357

Somerset

Devon IA

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

Staffordshire

Outlook

Moiria Hammond 0778 840 2195

Suffolk

East Suffolk Ostomy Group

Marion Fisher: 0147 331 1204

James Pagett Ostomy Support Group

Sandra Hutchings: 0150 258 5955

West Suffolk & District Stoma Group

Jessica Pitt stoma nurse: 0163 851 5525

Surrey

Epsom and District Stoma Support Group

Lindsay, Trevor or Sheena: 0137 273 5925

Sussex

Brighton & District Support after Stomas (SAS)

Sylvia Bottomley: 0127 355 4407

Chichester Stoma support Group

The Stoma Care Team 0124 383 1527

The Ostomy Friends Group

Jane Quigley: 0132 341 7400 ext 4552

West Sussex Princess Royal Stoma Support

Tina Walker: 0144 444 1881 ext 8318

T**Tyne & Wear**

Gateshead Stoma Patient and Carer Support Group

Stoma Care Nurses: 0191 445 3152 or email stuart.sutcliffe81@yahoo.com

NHS Molineaux Centre

Gordon Weatherburn: 0191 234 1109

Royal Victoria Infirmary Support Group

Gordon Weatherburn: 0191 234 1109

W**West Midlands**

Coventry Stoma Support
Martin: 0794 738 5643

Wiltshire

Swindon IA
www.swindon-ia.org.uk

Wessex Stoma Support Group

Michael Slater:
wessex.stoma@yahoo.co.uk or on
0172 274 1233

Worcestershire

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

Y**Yorkshire**

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

Airedale Stoma Support
Sue Hall: 0153 521 0483

Barnsley Bottoms Up Stoma Support Group

Stoma Nurses 0122 643 2528 or Celia
Utley (Chairman) 0122 628 4262

Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)

Stoma Care Nurses: 0148 435 5062

Dewsbury & District Ostomy

Janet Edmond: 01924 512 041 or
01924 512 072

Leeds Bowel Cancer Support Group

Lynda Castle (Colorectal Nurse
Specialist) 0113 206 5535

Rotherham Ostomates Caring Support

Karen Kilford: 0788 057 5758

Scarborough Stoma Support Group

Sister Jean Campbell: 0172 334 2388,
Amanda Rowe: 0172 334 2446

The Hull and East Riding Colostomy Support Group

Pete Smith: 0798 956 5335 or Pete
Rennard: 0793 951 8642 / 0148 279
3966 or Rosanna Grimsby: 0148 280
1575. www.hercosg.org.uk

Scotland**Ayrshire**

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 0129 222 0945

Stoma Care And Recovery (SCAR)

Maggie: 0129 427 1060/ 0781 773
6147 maggie13@sky.com or
Rhona: 0129 455 7478

Fife

Fife Ostomy Support Group
Ishbel Barr: 0159 277 2200

Lanarkshire

G66 Support Group
Les Ireland 0141 776 3866

Glasgow Stoma Support group
Chairperson: Maureen O'Donnell:
0123 643 6479

Scottish Borders

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

Stoma Support Group

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

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Wales**Bridgend**

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

Carmarthenshire

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

Denbighshire

North Wales Ostomy Support Group
Debi Devine 0787 676 2503 / Hazel
Duke 0797 681 7246 / Email:
devinetherapies@btinternet.com

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 0187 385 2672 After
6pm

Cwmbran Ostomy Support Group (COSG)

Philippa Lewis: 01633 791 339 /
07504 713 069

Mid Glamorgan

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

Pembrokeshire

PSA (Pembrokeshire Stoma
Association)
Roy Whitfield 0143 776 0701

Powys

The Bracken Trust Cancer Support
Centre
Helen Davies: 01597 823646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support
Group
Domenica Lear 0144 344 3053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 0179 241 8245

Channel Islands**Guernsey**

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

Northern Ireland**Co. Antrim**

Colostomy Association Volunteers
Northern Ireland
Chris Wright: 0772 071 7771
Mater Hospital
Karen Boyd - Stoma Nurse: 0289 074
1211 Ext 2329
Royal Victoria Hospital - Belfast
Sarah Haughey/Audrey Steele: 0289
024 0503 Ext 3483

Co. Armagh

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

Co. Down

North Down Stoma Support Group
Adrian Ewing on 0785 074 1511
Ulster Hospital
Hazel/Martina: 0289 055 0498

Co. Fermanagh

Erne Hospital
To be confirmed

Londonderry

Causeway Support Group
Mary Kane: 0287 034 6264

Republic of Ireland**Co. Mayo**

Mayo Stoma Support
Marion Martyn: 094 902 1733

Dublin

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

France**Provence**

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

Kosovo**Kosovo**

Kosovo Ostomy
Arta Uka: kosovoostomy@gmail.com

Spain**Alicante**

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

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