Winter 2019 | Issue 52

Supporting and empowering you

Tidings

Colostomy UK

Coming together for World Ostomy Day

#SpeakingOutChangesLives

Inside

Colostomy UK's 2018 Round–up

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The elastic adhesive on all SenSura Mio is made from a special polymer blend that has twice the stretch of a conventional adhesive, so it fits snugly on contours. [1]

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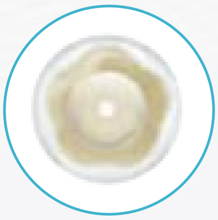

Fit Zones

SenSura Mio Concave has fit zones in the centre rim that increase flexibility so the stoma gets the necessary support and it increases the contact between the adhesive and curved body shapes. [3]

SenSura® Mio

SenSura® Mio Convex

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Brava® Elastic Tape

Brava® Protective Seal

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1. Coloplast, Product Evaluation, SenSura Mio, 2014 (VV-0197319)
2. Coloplast, Laboratory Report, Stretchability of SenSura Mio, (VV-0197750)
3. Comparison of SenSura Mio Concave and standard flat appliance.

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Dear readers

Cover picture
Ian Jackson
World Ostomy Day 6 October 2018

Wishing you all a happy New Year from everyone at Colostomy UK!

As I write this I am sitting amongst the remains of Christmas, wishing it wasn't over, but at the same time secretly looking forward to a house free of decorations and a return to normality! I'm sure many of you feel the same way. Of course, normality at this time of year means gloomy weather and little daylight. But it's not all bad news. I'm confident that the arrival of the latest edition of *Tidings* will put you in the mood for facing 2019! Before running through what we have in store for you, I thought I'd begin with New Year's resolutions...after all, its traditional isn't it? Mine's nice and simple: eat more, drink more and swear more. For once, I think I have a chance of success. Libby approaches the whole resolution thing much more seriously. This year she plans to start Pilates which, she hopes, will help to strengthen her shoulder – having dislocated this a grand total of three times.

This edition is something of a treasure trove. Our cover story (page 28) is all about how we marked World Ostomy day. You can probably see from the front cover that the weather wasn't very kind to us! This was one of our last big events of a busy year. In fact 2018 was such a success we've used this edition's news section to give you a summary of it. Of course, we couldn't have done this without all the kind support of people like you. Everyone at **Colostomy UK** (and that includes all our volunteers and fundraisers) is bracing themselves for a similarly frantic 2019. We also start the year with a slight change to our editorial team, as Ian Jackson has decided to step down. He is going to be missed by us all. Thanks for all your hard work Ian. And, I should add, that Ian is still very much a part of **Colostomy UK.** He is one of our trustees and active with all we do. This includes being an admin and regular contributor to the Facebook group and answering the Helpline.

As usual, Giovanni provides updates on our Active Ostomates project and has all the latest fundraising news. We also have Readers' letters and e–mails and our regular Irrigation slot. Unfortunately, we didn't receive enough questions to run Dear Nurse again, but don't worry as we have plans to run this slightly differently in future. In the meantime don't let this stop you writing! We do, however, have an article about a busy stoma care department in Wiltshire. We also have another piece from a healthcare professional. Rather than the topic being 'medical' Jeff, it's author, explains what inspired him to change career and start working in an acute surgical gastro–intestinal unit. We are very pleased too to be able to include the latest travel advice for ostomates, thanks to an article submitted by Sara Marchant who is an Accessibility Manager at Gatwick Airport.

Finally, there's our Real lives' stories. And what a great selection we have. Laura McKenzie explains how in the space of less than a year she went from having two stomas to travelling abroad and taking part in the 50K challenge. Vicki Smith tells us about her son Harry who was born with Hirschsprung's Disease and at six weeks old had a colostomy formed. Nicola Ridler talks with brutal honesty about the fears she harboured about having stoma surgery. We also have two interviews with ostomates. One is with Bernie MacDonald–Wilson who, since her stoma surgery, has been campaigning to improve accessible toilet facilities in her local area. The other is with Jeff Collins, who took part in a very special kind of bike ride and used this to raise awareness about stomas. Then, rather unusually, we have a story submitted by a stoma. I'll say no more on this one, but leave you to have a read on page 30.

Best wishes.

Libby

Libby Herbert
General Manager

Sarah

Sarah Squire
Trustee, Colostomate and Volunteer

Contents

We are **Colostomy UK.** Here if you have questions, need support or just want to talk to someone who lives with a stoma.

Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you; building communities to support you.

How to contact us

General Enquiries
0118 939 1537

24–hour free helpline (stoma care queries only)
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Social media:

Find us on Facebook

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

Cover story

Colostomy UK news

Real lives

Wellbeing

Fundraising

Support

New products

Donating to Colostomy UK

An annual donation of £20 (or whatever you can afford) allows us to produce *Tidings* and to continue our vital work, supporting, and empowering ostomates – see page 47 for donation form.

You can also donate via our website **www.ColostomyUK.org/donate** or by calling us on **0118 939 1537**

Colostomy UK: 2018 round–up

First some statistics, in 2018 we:

- Circulated approximately 88,000 copies of *Tidings,* with an estimated readership of 60,000 per edition.
- Sent out approximately 30,000 **Colostomy UK** leaflets and booklets to stoma care nurses, GP surgeries, support groups and care agencies.
- Responded to almost 6,000 telephone calls and e–mail enquiries.
- Membership to our closed Facebook group increased by 25%, reaching almost 6,500 people by October 2018.

Hopefully you're already slightly impressed, but if you still need some persuading then read on for a selection of the year's highlights…

Work with healthcare professionals, carers, local government and business leaders

- Attended the Association of Stoma Care Nurses' annual conference in Birmingham where we gave three papers about **Colostomy UK's** campaigns, projects and how we can work with healthcare professionals for the benefit of patients and people with stomas.
- Attended the Securicare Nurses' annual conference in Derby.
- Joined the South West Stoma Care Nurse forum.
- Visited 30 stoma care departments in the UK from Newcastle, Gateshead and Durham in the north right down to Cornwall in the south.
- Working in partnership with Wexham Park Hospital and Worthing Hospital to set up new support groups.
- Introduced a new dementia module to the care workshops that we deliver.
- Delivered 18 workshops to a combination of Local Authority Reablement staff, specialist day care staff, dementia support workers, care agencies and staff from nursing homes.
- Became members of, and contributed to meetings, at the transport forums and accessibility panels of the Civil Aviation Authority and a number of UK Airports.
- Worked with other charities at the UK Toilet Consortium.
- Continued to be a voice at the Patients, Industry and Professionals (PIPs) and Scottish Stoma forums with BHTA.

Support groups and open days

- Attended support group meetings across the country.
- Gave talks and presentations to 24 support groups about **Colostomy UK** , the support we offer and our campaigns and projects.
- Members of the team and volunteers represented **Colostomy UK** at over 100 open days.

Campaigns, Projects and Advocacy

Stoma Friendly Society and fighting the “Poo Taboo”

- Celebrated World Ostomy Day (see cover story page 28)
- Started discussions with the National Trust and the Royal Collection about their toilet facilities and signage.
- Attended and provided feedback on the Heathrow Airport Engage and Assistance events and the Manchester Central Training and Education Day.
- Began discussions with Sarah Newton MP, Minister of State for Disability People, Health and Work about public toilet provision (access, facilities and signage) and the need for government to support awareness campaigning.

Active ostomates

- Delivered 33 chair yoga sessions to 12 support groups.
- Piloted ‘Ostomate–only’ closed swimming sessions in Sheppey (Kent), Newcastle and Gateshead. See our article ‘Chlorine, the breakfast of champions’ in *Tidings* Summer 2018 edition for more.
- Ran the 50K Challenge, which saw 356 participants achieve over 69,000 km.
- Launched Team **Colostomy UK** Rugby League, with the team playing their opening fixture in July against Medway Dragons. Further fixtures have since been played against South London Silverbacks and PDRL United with further games scheduled for 2019.
- Launched our Creative Minds Art project in September 2018.

Phew… There’s lots more too, but we have run out of space!!!

My Mom – my rock, my hero.

Jeff Wills

I use these words to describe my mom, Connie Wills. Ever since I can remember she has been someone I have looked up to. She has always been my biggest supporter, even when she didn't fully agree with whatever crazy endeavour I was working on. I have also seen her face numerous life–changing challenges, when many would just give up. Not my Mom. She has always had this 'fight' about her. It has saved her life on many occasions. It's also because of her that I find myself working in a London hospital.

In the mid–80s Mom was diagnosed with Crohn's disease. To be honest, I was too absorbed in my own teenage antics to understand that she was sick. It wasn't until the early 90s when the Crohn's attacked her liver and we were told she would need a liver transplant that I realized just how sick she was. I was living in Los Angeles at the time and relocated back to St Louis to be closer to her. It was six months of pure Hell for everyone, especially Mom. Every time the phone rang I panicked thinking either a liver donor had been found or she had passed away. Luckily, we were able to find a support group for people who were waiting for transplants or had one already. This proved a great way for us to ask questions, express our fears and hear other people's journeys. In 1995 Mom had her transplant and came through with flying colors. In fact, just a few months later she was back on the stage singing her heart out. During this period, she was lead singer of a rock 'n' roll blues band. It was an incredible night seeing her onstage such a short time after getting a new liver!

In 1999 Mom became sick again, this time with cirrhosis of the liver which had affected her kidneys too. She underwent a double transplant in 2000. Again, the fear of her dying took precedence over everything. With her fighting spirit she pulled through and was back on stage again in just a few months. Her passion for life and her drive was (and still is) an inspiration to friends and family alike. It has also helped countless others as her story has been displayed in the transplant section of the Science Museum in St Louis. After both surgeries, she went back to 'normal' life: sang with the band, travelled, went shopping etc.

But everything changed on 18 November 2010. I was living in London at the time, was newly married and had just started a new job, when I received the terrible news that Mom had been in an horrific car accident. I flew back home that day and when I got to the hospital found her in a medically induced coma. She stayed like this for several months. At times they would bring her round and her hands would immediately go to where her transplant was. We found out that she was in extreme pain and while in the coma her intestines were dying. Over the next two months she had 20 operations and most of her intestines removed.

One day the doctor came in and told her only the option was a stoma. None of us really knew what this was. Mom was completely against the idea. All I cared about was her being alive so we would talk about it but still she refused. Her reluctance continued until November 2011. It was only after being told she was going to die that she reluctantly decided to go ahead. When mom woke up after surgery and looked at her stoma, wind came out with some stool. She screamed and cried. This was the first time I had ever seen my mom defeated. I had to put my own feelings aside so I could reassure her that this was the best decision, she was alive and was going to be OK. I knew it was absolutely horrible for her. I felt helpless but had to do my best to stay positive for her. This was difficult because I still had no idea what her life would be like. If she could even have a life. I remember crying and praying that she would pass away in her sleep so she wouldn't suffer any more. Thankfully, those prayers were never answered.

After about a year Mom was finally released from the hospital. Medically she was stable but now the emotional side took a turn for the worse. Once she got home, she became even more depressed. She wouldn't leave the bedroom let alone the house. She wouldn't eat. She even started abusing her pain medication so she could sleep. This was not my mom. I didn't know who this person was. I didn't know how to be supportive so I just let her do what she wanted. At this time, I was flying back and forth between London and St Louis. My work, marriage, finances and my own emotional stability started to suffer. I was in constant fear of losing everything. I was riddled with guilt about being away from my husband or being away from my mom. Luckily, I had the support of family and friends to get me through. Hiring a 24hr/day carer for Mom also alleviated some of the pressure on me and my brother.

Slowly, my mom started to 'return', wanting to venture out of the house. I heard she had been going to the grocery store and to a friend's house. One visit around Xmas time, we went to do some shopping. We were in a crowded department store when all of a sudden, her bag started to leak badly. She was covered in feces, it was all over the floor and the smell was terrible. People were crinkling their noses in disgust and making comments. I hate to say this but I was disgusted and embarrassed myself. I cry looking back on that now. There was my mom, crying in shame in front of a crowd of people and I did nothing but think of myself. Luckily my mom's carer took her to the bathroom and cleaned her up. I just stood there and watched the one person who had always been there for me reach the lowest point of her life and did nothing.

That moment changed my life. I became more involved in her care, learned how to empty/change her bags, helped her in her physical rehabilitation, worked on her diet and most importantly became the

supportive son I needed to be. Since that terrible day, I have seen my mom change and take back her life, doing almost everything she did before. She has even got remarried. SHE IS BACK!! My mom is my rock, my hero and my best friend.

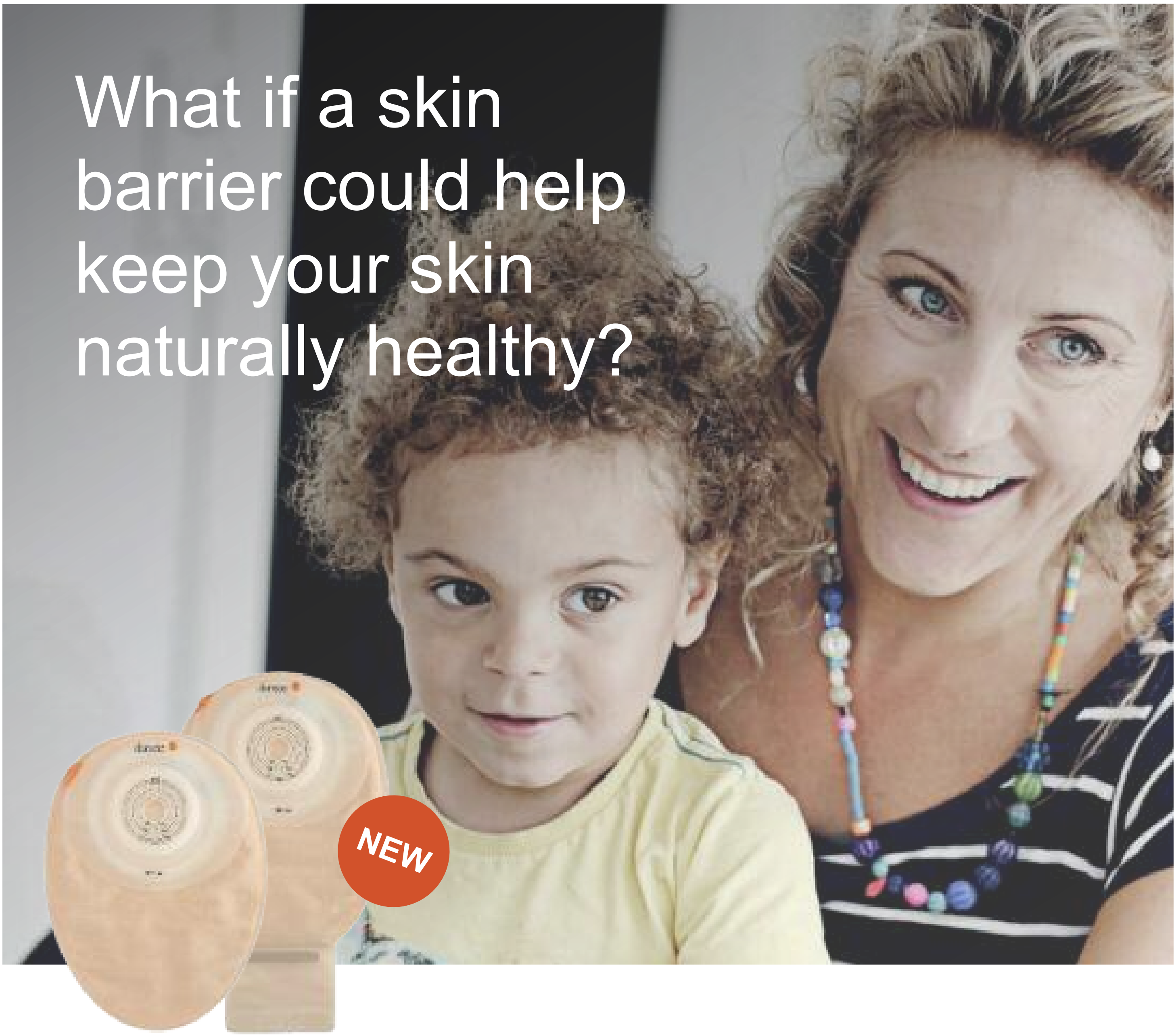
This experience led me to change career a year ago, going from event marketing to nursing. By chance or fate, call it what you like, I am now working as a nursing assistant in an acute surgical gastro–intestinal unit at a London hospital. Every day I talk to patients and family members going through similar situations to what my mom and our family went through. We have an amazing team of doctors and nurses who work on the medical side and do an incredible job teaching our patients how to manage their bags. However, we are unable to teach them how to LIVE with one.

A few months ago I came up with the idea of starting a patient support group, bringing together people who are living with stomas and people who have just had stoma surgery. There was a sense of excitement when I contacted **Colostomy UK**, told them about my idea and I was informed that a young woman named Iffy was in the process of putting a similar group together at a nearby hospital. They thought it would be a fabulous idea to bring the two of us together. From the moment Iffy and I started talking on the phone about the work she had already done and her passion for this project, I knew I had met the perfect person to bring our joint vision to life.

The day of the first meeting was filled with excitement and trepidation…neither of us knew how it was going to turn out. Additionally, Iffy and I had never met face–to–face before. It was also the first time I had met anyone from **Colostomy UK.** Of course there had been numerous e–mails and phone calls beforehand, but that's never quite the same. But from the moment we all met it was like we had known each other for years! The first support group meeting was incredible. Along with Iffy, myself, and Libby and Giovanni from **Colostomy UK** we were joined by personal trainers, dieticians and healthcare professionals and, most importantly, ostomates and their friends and families. Everyone shared a little of their experience. There was laughter, joy, hope and a few tears. Most of all there was a sense of unity and support. It was an incredible experience seeing so many people come together and support one another.

Since then I have become more involved in the 'life' aspect of my patients' recovery. I still get asked the same questions and hear the same fears and concerns, but now I feel more equipped to help them. Before meeting Iffy, **Colostomy UK** and many other inspirational ostomates and their families, I only had my own experience to draw on and, as I'm sure you will agree, my experience was unique in many ways. That all changed when I walked into that first support group. I was no longer alone.

My mom, my family and myself went through this journey alone. There was no support. With the help of **Colostomy UK** I have dedicated myself to help those who are beginning this journey: someone that listens; a shoulder to cry on; a caring person with an honest and positive message – letting people know they are not alone. ■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Laura's Challenge

Laura MacKenzie

My Name is Laura MacKenzie. I am 41, I live in Wemyss Bay, Scotland and I am what is known in the ostomate community as a double bagger. This means I have two stomas; in my case a urostomy and a colostomy. I am writing this from my sun lounger in the Algarve, it's our first foreign holiday since my operation. By the time you read it, Christmas will have come and gone and the Colostomy UK 50K challenge will be over. The latter has been an inspiration to me. It's helped my recovery, both physically and mentally. The past year has been a challenge in many ways…

My stomas were created during a 12–hour operation for a total pelvic exenteration in November 2017. This was required after a stage 4 cancer diagnosis in the September. My first symptoms appeared in August 2017, when I started to pass faeces in my urine. I later found out that this was due to fistula caused by my cancer.

From August through to the main operation, I had various scans and procedures, including: CT, MRI and PET scans, a sigmoidoscopy and a cystoscopy. Initially I was admitted to hospital for three days as a blood transfusion was required. Then I went to the main hospital in Glasgow for nine days to stabilise my kidneys as these were only functioning at 60%. I also had two nephrostomies fitted. These artificial openings were created in my back to allow urine to be drained from my kidneys, thus bypassing my bladder.

At my first consultation at Inverclyde Royal, I was told that: "best case scenario, some radiotherapy would be required and worst case I would be seeing the senior consultant at the Glasgow Royal". It turned out to be the latter. Here I learned that radiotherapy was too risky and chemotherapy was not effective for my type of cancer. In addition, I was told that if the cancer had spread, then surgery wouldn't be an option either. Luckily the PET scans revealed that the cancer had not spread. Hence, the surgery that I went on to have literally saved my life.

With the support of my surgical team, friends, family and colleagues I made good progress after the operation. In particular, my husband – my rock and my best friend – was by my side every step of the way. I went home after 17 days in hospital. On 30 November, 29 days after the surgery, I got the all clear and so my husband and I went to our local hotel to celebrate. I went back to work part time at the end of January and was fulltime by mid–February. Since then I have continued to make a good recovery and continue to get stronger day–by–day.

What I went through both physically and mentally was massive, but I stayed positive and determined throughout the whole ordeal. Having two stomas is not without its challenges, but I make them work around my lifestyle and not the other way round. Holidays need more planning now but so far, apart from making sure I don't lift heavy items, there is nothing I can't do that I did before.

The support of organisations such as **Colostomy UK** has helped greatly as I adjusted to my new life. Back at the end of 2017, as I made my way home from hospital, I would have never believed that between April and October 2018 I would walk 1,431 km and raise £2,018.75 in the process! ■

Medical Terms Explained

A **nephrostomy** allows urine to be drained through a tube inserted through the skin on your back and into the kidney.

Total pelvic exenteration is an operation to treat cancer when the bladder, rectum and internal reproductive organs are removed.

Source: www.macmillan.org,uk

A **cystoscopy** is a procedure to look inside the bladder using a thin camera called a cystoscope.

Source: www.nhs.uk

A **sigmoidoscopy** is a diagnostic and screening procedure in which a rigid or flexible tube with a camera on the end (a sigmoidoscope) is inserted into the anus to examine the rectum and lower colon (bowel).

Source: www.surgeryencyclopedia.com

Colostomy

Most people think of colon or bowel cancer as an 'old' person's disease, so you can imagine my shock when I was told that I had stage four bowel cancer with liver metastasis. It was like a sledgehammer to the heart. Although I had numerous doctors' appointments in the lead up to this diagnosis, things were put down to IBS and food intolerances. How wrong this turned out to be. By the time I had my scan on the 14 August 2017, I was in a lot of pain. I was also needing to spend hours (if not days) on the toilet. When I did go out, worrying about the location of the nearest toilet was constantly at the back of my mind.

The consultant who reviewed my scan called and asked me to come back the same day to discuss the findings. It was suggested that the best route would be for me to have a colostomy the next day, followed by chemo, further operations, more chemo and more operations. I was told that without the treatment I might have six months left, but having it didn't come with any guarantee of a better outcome.

Now, you may think that making a decision at this point would have been easy. Surely surgery with just the possibility of living longer would be the only road to take? But for me this wasn't the case. I couldn't face the treatment as proposed, it was just not going to happen. Firstly, a colostomy – no way. I told my consultant I would rather be dead. Colostomies – they are definitely for old people (or so I thought at the time). At this point, ignorance led me to believe that having a colostomy was a life sentence. Even though my bowel was blocked and causing absolute agony I told him to think again, which he did. So off I went to have a stent inserted in my colon a few days later. They also took biopsies to confirm that the mass was a tumour.

Things went along swimmingly until December 2017. I remember getting back from work and having a bath then the pain started. It was like someone stabbing me in the guts, over and over again. My screams were so loud it really frightened my husband who called 999. I was rushed to hospital where it was confirmed I had a bowel perforation from another blockage. Again, I was faced with making a decision about having a colostomy. Again, I was told it was life or death. But I still couldn't do it. It was still not an option for me, so I was given 24–hours to live and taken to the Marie Curie Hospice. For anyone who has never been in a hospice I have to say this is the most comforting and amazing place you could ever wish to spend your final days. But I wasn't ready to quit so I fought back and like some kind of miracle I walked out of the hospice on the 29 December 2017. I had missed Christmas day but I was determined to see in the new year!

Fast forward to February 2018 and another blocked bowel and another stent, eating was so difficult, and the constant pain and toilet stops were getting way too much for me to bear. After a long hard think I decided that I was all out of options and if I wanted to live then I would have to take the colostomy route. I have to be honest, I found the prospect totally terrifying. But as I thought about it more, I came to realise that it was less terrifying than being given 24–hours to live or taken to a hospice and saying goodbye to all the people you love.

The only person I fully trusted was my consultant. Luckily for me, a cancellation meant that he and his team were available to do the operation. It happened on Valentine's day 2018. While most people were thinking about roses and romantic dinners, I was walking up the Heartlands corridor with my suitcase and pillow. My daughter dropped me off. At my request I was on my own, thinking life as I knew it was finally over. The rest of that day is a blur, bar my

on my terms

Nicola Ridler

memory of waking up from the anaesthetic. The pain was so bad I begged for morphine. At that moment I would have settled for a hammer to the head to make the pain go away! I remember thinking: "don't touch the bag, don't even think about it and definitely don't look at it". I'm not going to lie, I was absolutely terrified: lying in my hospital bed; the noise in the ward; my arms battered and bruised from all the drips and blood tests. I felt myself sinking into a very dark place and I hadn't even attempted a bag change. I just couldn't see a future or how I was ever going to cope.

The stoma nurse came around with a load of booklets, some supplies, and information about how I was going to have my supplies delivered. Nothing made any sense. Didn't they see that I couldn't do this? Obviously not, because within 24 hours I was up and told to get moving about. Getting out of bed was a challenge, even though I had had key hole surgery, the pain was intense. When Friday arrived it was time to leave. I really didn't want to go home because in hospital I had the security of people around me. Managing on my own was something I just couldn't comprehend in those early days. Eventually I had to deal with my bag. I didn't want to but there was no choice. It was like a mission, it took ages just to get everything I needed in the one place, let alone changing the bag itself. But slowly I started to get more confident. Luckily for me I have the most amazing husband who took no notice of my tears and my constant refusal to move. He simply put my feet in my shoes, laced them up, dressed me up like an artic explorer and that's when we started walking. To say I was slow is an understatement, we still laugh about those days now. Each day he set us a new target and by the end of a week I had made it half way round the block. I was very proud of myself.

Getting to grips with the bag became easier – yes it really does. After another check up with the stoma nurse I started to feel a lot more confident. It was still hard to comprehend that this was to be my life from now on, but as the days turned into weeks and the weeks turned into months, managing my stoma became second nature.

As a family we are very open about my colostomy. She also has a name, Beryl. I believe this has helped me to overcome the difficulties. I initially thought a stoma would stop me from being active again or being able to wear the clothes I like or really just being me. I am here to reassure you that yes it is scary, and yes there will be days when your stoma really gets on your nerves. Likewise you might not be able to eat the food you love without suffering afterwards, but that's just trial and error. My advice is throw all of that aside because if I can, you can. Take back control of your toilet habits and start living the life you want to. Ok, you might need to be a bit more organised and buy a bigger handbag to carry your 'to–go kit' but it works. Having my colostomy was the best Valentine's present I could ever have received, it's a gift for life and has given me a life.

I now openly discuss and show people who are interested in my bag. I talk to them about what it means to have a colostomy. Most people have never seen one or know anything about them. That's why we have to keep kicking this stigma into the long grass. If you are feeling overwhelmed then just stop, take a breath and start again. You will have bag leaks, you will have reactions to food, you will have days when you don't think you can get through, but you can because there are always better days ahead. My colostomy has not stopped me from doing what I want, I have been on a number of holidays, been swimming, sunbathed in a bikini, dressed up and gone to a ball and carried on living, I mean really living. ■

From ploughman's sandwich to local campaigner…

Bernie Macdonald-Wilson

Incredible as it may seem, our campaign to ensure that toilet facilities across the UK are stoma friendly is now in its fourth year. During this time we have focused on two things. Firstly, ostomates' requirements in relation to the facilities themselves. Secondly, raising awareness of 'hidden' conditions and disabilities. Sadly, we still receive reports of ostomates being challenged and even having to endure verbal abuse for using accessible toilets. Our campaign has involved urging organisations both to upgrade their facilities and display toilet signage that draws attention to the hidden nature of some conditions. We aren't so naïve as to think that the latter alone will end public ignorance, but we strongly believe it is a step in the right direction.

The restaurant chain Côte Brasserie were one of the first to come on board. Since then we have had lots more 'big names' join us. The INTU shopping centres at Bromley, Dundee and Cribbs Causeway, Bristol (combined footfall of 35.7 million pa) now display our toilet stickers (see below), as do a number of premier league football clubs. Most recently Sainsbury's began a nationwide roll–out, upgrading their customer toilets and displaying new signage. Naturally there is still lots of work to be done. Indeed, we see the campaign as one which will occupy us at **Colostomy UK** for the foreseeable future. Although we have had success with large organisations, we have yet to make much impact at a local level. Things, however, are changing.

If you live in Neston, Cheshire or surrounding area, then there's a good chance that you will have seen some of our toilet stickers. Since early 2018 they have been steadily breeding in this part of the world. Chester Sandwich Company has them, so too does The Deva Experience and the Grosvenor Hotel in Chester and the United Reformed Church in Neston. Slightly further afield they can be found in the Walker Art Gallery, Liverpool and the Lady Lever Art Gallery in Port Sunlight. If you are registered with Neston Surgery in Mellock Lane, then they are there now too, along with all the necessary shelves, hooks and mirrors in the toilets. We can't claim any credit for this. Instead, it's all down to our supporter and local campaigner Bernie MacDonald–Wilson, who you can see pictured opposite.

Bernie's formula for success is very simple. When she goes into a local business or organisation she asks to speak to the manager. She then talks about **Colostomy UK** and our toilet campaign and asks if they will display our stickers. As well as taking a supply of these, she also has a selection of **Colostomy UK** literature to hand. Of course, being an ostomate helps too, as Bernie can answer any questions and explain in detail why having a hook and shelf in an accessible toilet is particularly important for people with stomas. According to Bernie, most people she speaks with are more than happy to help. The warden at the church hall in Neston, went straight down to the DIY store for some wall hooks! Even when premises can't be changed (due to them being listed for example), she finds that owners are keen to do anything they can to help.

When I spoke to Bernie last, I asked what motivated her to campaign for us. To be honest, I wasn't expecting a ploughman's sandwich to feature in her explanation! Bernie is able to date the start of her story very precisely to July 2017, when she went out for a simple lunch with her sister. Shortly afterwards both became unwell. But, whereas her sister recovered, Bernie was admitted to hospital with a Campylobacter infection. It was while being treated for this, that a scan revealed a large pelvic mass. Initial thoughts were that it was cancerous. Surgery to remove it ended up being delayed until November, as Bernie had lost so much weight from the Campylobacter. She went into the operation knowing that a stoma was a possibility, but the likelihood wasn't discussed at length. As things transpired, an emergency end colostomy was necessary when it became clear that as well as having extensive endometriosis, part of Bernie's bowel and bladder had fused together.

L–R: Neston surgery staff – Helen Washington (Head Practice Nurse), Dr Vikki Arista (GP), Bernie, Heather Elkin (Practice Manager)

It was only when Bernie was in the high dependency unit that she became aware of what had happened. I'm sure many readers will identify with her initial reaction: emotional turmoil. She was very unwell, still didn't know if she had cancer and understandably concerned about what the future might hold, let alone dealing with the practical aspects of stoma management. Her state of mind was clouded further by the memories of her father who had had bowel cancer and a colostomy. At this point, she couldn't see a way forward. Matters weren't helped when two days after being discharged she had to be readmitted to hospital because of an infection and a break down in the skin tissue surrounding stoma leaving a gap to one side of it. It was while on the surgical ward that she heard patients coming round from bowel cancer surgery saying: "Thank God I didn't have to have a colostomy".

Moments like this can be a person's undoing. And, initially, they were for Bernie. Even when the histology results revealed no sign of cancer her feelings of fear and uncertainty about what lay ahead persisted. Still weak from the surgery and weight loss, Bernie spent the next couple of months at home, trying to make sense of what had happened. But, gradually, as she grew physically stronger and her stoma output normalised, her emotional state began to improve. She remembers an early trip out to the shops and afterwards taking her first 'conversation' with 'Bosie' her stoma. This marked something of a turning point, as for the first time she realised that he wasn't so bad after all. Indeed, she actually started to feel a little guilty about having hated his presence up until now. Shortly afterwards Bernie enrolled on a locally run 'Mindfulness' course where she openly shared her story with others. She also began to attend a support group run by the fellow ostomates in the local hospital's stoma care department. This was something that just months before she could not have envisaged would ever happen. The solace she drew from this added to the kind attention and support she received from the department's stoma care nurses.

It was around this time that Bernie joined **Colostomy UK** and started to read *Tidings.* She had been given a copy of the latter when she was in hospital, but had thrown it away, along with the various information booklets she was given too. As she said, back then it was just too much to take on board. Now however, things were different. Bernie says that *Tidings* quickly made her realise that colostomies weren't just an 'old people' thing, nor were they life limiting. Instead from this point onwards, she began to regard a stoma as something that gives life. With this new sense of acceptance Bernie got active and embraced her stoma. She contacted the local council who, on hearing of her medical needs, arranged for two additional bins. She phoned a number of underwear manufacturers for samples and organised some prescription underwear from her GP. She also started to reflect more on her journey. She thought about all the amazing and brave people she had met in hospital and what they had had to cope with. Ultimately, it was this that inspired her. She wanted to do something tangible to help new and existing ostomates and, knowing how important toilet facilities are for people with stomas, saw getting involved with our campaign as the best way to do this. The rest is history. As a measure of how far Bernie has come, she is not sure whether she would go ahead with a reversal should it transpire this is possible. As she says, her and Bosie are now quite a team and they are looking forward to further adventures together. In fact, by the time you read this, they will have celebrated his first birthday which, I understand from Bernie, is going to involve a cake, candle and party with friends and family at a local restaurant!

Everyone at **Colostomy UK** is really grateful for Bernie's efforts. If you have been inspired by Bernie's story and would like to campaign with us, then please drop us an e–mail or give us a call. ■

Written by
Richard Biddle

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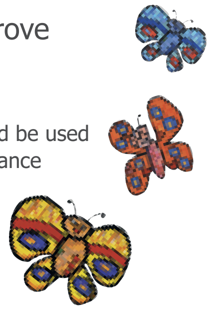

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Ostomates share their experience of leakage

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I have had my colostomy for over 25 years. I had a couple of leaks soon after my stoma was formed, probably my fault for not making sure that my bag was securely in place. The contents of the bag started to seep out under the flange on one side. I was at home at the time so the problem was easily solved, but it taught me to be prepared when I went out.

Now I always check my bag is secure before I leave the house and, if necessary, change it for a fresh one. Even if I am only going out for a short time, I make sure I take my emergency kit with me: a couple of spare bags, sachets of adhesive remover and cleansing gel, a disposal bag and a couple of flange extenders in case there is need for an emergency temporary repair. They take up very little room in a zip compartment in my handbag. I have only had to change away from home on rare occasions but it is reassuring to have everything with me should the need arise. For years I don't remember having any leaks, probably because my stoma was well away from my scars so there was a smooth surface to give a good seal between the flange and the skin.

Then a year or so ago, the situation changed. As I got older, I gained a bit of weight especially around my middle and the slight indentation to one side of the stoma became more pronounced. When I sit down a crease forms on the right–hand side of my stoma which occasionally forms a channel for the bag contents to leak out beneath the flange.

On the odd occasion this has happened, I usually get a warning: a slight whiff or a feeling that something's not quite right. From experience I have learnt not to panic and get to the loo as soon as I can. The first thing I do when I get there is make sure I have a clean bag and a disposal bag within easy reach, and I remove any clothes that might get in the way. Before I take a look, I stand next to the toilet – seat up – with the bag area just over the bowl, just in case there are any drips when I remove the bag.

This strategy has stood me in good stead in coping with the few leaks I've experienced over the last year. At one time I had no hesitation in going anywhere with a stoma – holidays abroad, long haul flights or staying with family or friends – but now I have become a bit more anxious. What if my stoma becomes very active on the flight and the "fasten your seatbelt" sign is on, or there is a long queue for the toilet.

I told myself not to be silly, not to worry about something that might never happen; instead to "Be Prepared": I always have my emergency kit handy in my handbag under the aeroplane seat, not in the overhead locker. I always change my bag just before boarding the plane and stick extenders (some stoma care nurses call them "bananas" because of their curved shape) around the flange to increase the area of adhesion and allow more time to get to the toilet.

I have experienced a leak in the night at home, and worried that this might happen in someone else's bed. When on holiday I always check my bag before going to bed and if necessary change it, to be sure the filter will release any wind so that the bag does not inflate while I sleep. Depending on how my stoma is behaving at the time and where I am staying, for extra security at night, I might use flange extenders, wear pants beneath my pyjamas, or place a cot–sized bed–protector (available as complimentary items from some ostomy delivery companies) over the bottom sheet, just in case.

To date, that leak aboard a plane or in a foreign bed that I have spent so much time worrying about has never happened! My holiday confidence has increased.

It's now quite a while since I had a leak, but what of the future? I still have a few other strategies up my sleeve. If it starts happening again, I could try another bag

CONTINUED ON PAGE 21, COLUMN 1

BEYOND DEFINITION

www.beyonddefinition.co.uk

CONTINUED FROM PAGE 19, COLUMN 3

that might have a more secure flange. I could try washers, also known as seals, rings or "doughnuts" to create a better seal; they can be moulded to shape and stuck around the stoma, before applying the flange. If, heaven forbid, I put on any more weight and my stoma becomes recessed or flat to the skin, I'll ask my stoma care nurse about bags with convex flanges designed to make stomas protrude above skin level. It's always best to get expert advice on these as in the past convex flanges were rather hard on the skin, but I believe the more recent soft convex flanges are less of a problem.

I like to think that whatever the future may bring at least, as far as my colostomy is concerned, I'm prepared.

Rosemary Brierley

I often hear leaks described as explosions, "the bag burst" etc. but it has never been my experience that a bag has burst. They are made of stout stuff.

Leaks for me tend to be more insidious, more about 'seepage', which is nonetheless distressing and potentially embarrassing.

What happens is that the flange/the base plate comes away from the skin. The bag – I have a two piece – remains attached to the flange and the leak comes from under the flange.

There is no rhyme or reason to a leak. One time I had the flange on for a good seven days, during which time the outer, sticking plaster element of the flange had quite come away and the flange was only being held on by the hydro colloid in the centre. And there was no leak, no smell, nothing. I changed the flange because I thought it was risky to continue like this.

I do use a convex inner ring which does help to reduce leaks, or seepage.

But what I do get and again for no rhyme or reason is 'Erosion'. You notice erosion because of the smell. There is a nasty niff coming from the area of my colostomy. I have a look, hoping that it is because I have not clipped the bag to the flange properly, as this is an easy fix and on occasion this is the case. More often than not I will see a brown spot on the flange. Something is trying to get through from underneath. This brown spot can be at the bottom of the flange but equally and confusingly it can be above the stoma. Gravity is not involved where erosion is concerned.

The minute I am aware of the smell and see the brown spot I need to change the flange. I know I am the closest person to the smell emanating from my stoma and I may be over sensitive but I would be too embarrassed if others were to notice it. I was always embarrassed by farting, both the noise and the smell. Others I know enjoy a good fart, the louder the better. Not me.

And the funny thing about erosion is that it is not something that happens over time, not something that will occur after a few days wearing the flange. No, it can occur moments after I have just put a new flange on. Most odd.

Still, it requires immediate attention.

My fear is not so much leaks, which I have had and which are a nightmare to deal with if you are out in public – will anyone notice after you return from the loo that you are no longer wearing a shirt under your pullover as you had to throw it in the bin – my fear is the smell from erosion and noise. I am standing in front of a group of people presenting to them and my stoma makes a noise. Everyone has heard. But they are confused. This noise has just come from my chest. And I am trying to cover up the noise by coughing. And there's another noise and again more coughing from me. Notice I cough after the noise, not at the same time, obviously as I can only react to the noise. By now people are looking at me, oddly. I say nothing and carry on. It's what you have to do.

Duncan Wells

Photo ID Card

The **Colostomy UK** photo ID card can be useful if challenged when using accessible toilet facilities.

To apply for a Photo ID card, complete the form opposite and return it to the **Colostomy UK** for processing with the enclosures listed below:

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

***Note:** Credit card payments can be taken over the telephone if preferred, ensure the above are sent in the post in advance.

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

Allow maximum of 10–14 days for delivery.

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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 UK.** Return all required items to:
Colostomy UK, Enterprise House, 95 London Street,
Reading, Berkshire, RG1 4QA

(If you have any queries or would like to pay by credit card, please contact **Colostomy UK** office: Telephone: **0118 939 1537** or Email: **info@ColostomyUK.org**)

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 accessible toilet facilities. The key is for the personal use of the above named and their designated carer only.

Please **tick** as appropriate:

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

☐ I would like to receive a **photo ID** card for **£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 UK.**

For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received.

Signature of self or carer:

Date: / /2019

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

Behind th

Have you ever wondered what life is like in a busy stoma care department? Well towards the end of last year I took the opportunity to find out and interviewed Judy Pullen who is the clinical nurse specialist in charge at the Great Western Hospitals NHS trust in Swindon. Judy trained as a nurse back in the 70s and has been working in stoma care since 1991. As you can imagine, with almost 30 years' in the field, there is very little that Judy doesn't know about stomas…albeit she was at pains to point out that even for someone with her experience it was important to keep her knowledge base up–to–date with the latest research and evidence–based practice. During her career, Judy has seen the massive changes that have taken place in stoma care and stoma management (including the many developments in bag 'technology'). Between 2012–2016 she was the inaugural chair of the Association of Stoma Care Nurses UK. She lectures to student nurses and junior doctors and is currently involved in the CIPHER study, which is a national, multicentre research project, investigating the prevention and treatment of parastomal hernias.

Judy's department is located within a District General Hospital with 500 beds (as opposed to a tertiary centre or specialist centre). The trust's catchment area includes part of Wiltshire and extends westwards as far as Chippenham. In population terms this equates to around 1.3 million people. As stoma care departments go, Judy describes hers as 'reasonable' in size. It has four stoma care nurses, a healthcare assistant and a secretary. They also provide placements for students from Oxford Brookes University doing adult nursing degrees, with

e scenes at a stoma care department

Richard Biddle
Writer and Researcher
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students spending up to three months of their training with the stoma team. In a normal week the department sees an average of 40 patients in stoma clinic. Patients follow a set pathway. These 'pathways' are common across the NHS but vary in their detail between departments. They are also reviewed regularly to make sure that they continue to meet patient needs. In Judy's department, patients are seen a week after surgery, they then have two, one month follow–ups. They are then seen three months later, then six months and annually thereafter. Additionally, patients are seen as emergencies, with a slot kept available for this each day. Patients are able to self–refer. Judy's team also keep a list of ex–patients who will happily talk to new ostomates, and make use of us at **Colostomy UK** from time–to–time too. Judy says that regular appointments usually last around 30 minutes and cover everything from dietary advice to ongoing management. First post–op appointments take longer. This is because as well as covering all the issues around stoma care, the stoma care nurses also undertake some of the functions previously done by district nurses, such as removing sutures. I asked Judy about the size of the department's caseload. She thinks this is around two thousand patients at any given time, but explained it was difficult to be precise because some patients move away from the area after their surgery, while others move in etc.

The patients that Judy's department sees are split roughly 50/50 between permanent and temporary stomas. Not all of these patients have had their surgery locally. Southmead Hospital in Bristol performs the Trust's urology surgery. People with spinal injuries are operated on in Salisbury. Some patients have their surgery in Oxford. In total she estimates that they have around 200 new patients each year. Judy said that awhile back, it was anticipated that surgical advances would lead to less stomas being formed. However, rather interestingly, Judy said the opposite has happened. This is largely down to the fact that advances mean that surgeons can now operate much lower down in the colon than ever before. This has led to an increase in temporary stoma formation to protect anastomosis (join in the bowel). She said that the increase has been influenced by other factors too. For obvious reasons the introduction of the bowel cancer screening programme has had an impact, so too has the nation's ageing population. Quite simply, as people live longer they have more time to develop things like bowel cancer. In Judy's area, an increase in the population has also led to a rise in their patient numbers.

Like hospitals, clinics and GP surgeries up and down the country, Judy's department has issues with patients not turning up for appointments. Understandably this is something that she finds very frustrating. Not only is all the pre–appointment preparation time wasted, it also means that another patient has been denied the opportunity of seeing a stoma care nurse. Judy emphasised a number times the importance of ostomates having regular reviews. When I asked why, Judy said it was all about prevention. Changes in weight for example, can lead to changes in stoma size and if the hole in the baseplate or flange are not then cut to the new size, skin problems can result. As Judy explained, getting on top of these sorts of issues quickly was vital. She was also keen to point out that her advice about reviews was something that applied to even the most experienced ostomates. She said it is fairly common for patient's to say: "I've had my stoma for 15 years I don't need a review" only to then end up in the department as an emergency case a couple months later. As she put it: "the 4:00pm panic call on a Friday because a bag won't stick or no longer fits".

As you would expect ostomates visit the department with all sorts of issues and enquiries. Judy said the most common that they see are peristomal skins problems, parastomal hernias, ulceration, pancaking and granulomas. She also said that recently they have started to notice an increase in the number of enquiries about irrigation. When she said this, I wondered whether our regular slot on irrigation and all the irrigation stories that we share in *Tidings* might have had something to do with this! Judy sees this growing interest in irrigation as a positive development as she, along with her colleagues, firmly believe that patients should take responsibility for their health. That said, she also is fully aware that patients are often unsure when to seek medical help and sometimes delay doing so because they are worried about wasting the time of a healthcare professional. It was with this in mind, that her department put together a leaflet called 'THINK' which they give to patients. This is based around a simple traffic light system which aims to help patients seek advice at the appropriate moment and in a timely fashion. Her hope is that the leaflet will help patients to understand what they can expect and also prevent problems escalating.

I finished by asking Judy what areas of stoma care she would focus on if money and the time resources of her department were no object. This was followed by a long pause before Judy outlined her wish that she and the team could be more proactive, getting out into the community and educating GPs and patients, around issues such as wastage and appropriate prescribing. This was a topic that I wrote about back in the Spring 2018 edition of *Tidings* and it's clearly still very much on the NHS agenda. Judy said that her team try to think in terms of 'necessity' or 'unnecessary accessory'. She gave the example of an air freshener. Even though a patient might be entitled to have one of these on prescription doesn't mean they should have one! As she said: "When I need an air freshener for the toilet I go and buy one. Ostomates are no different!"

I hope you have found this 'behind the scenes' insight interesting. I would like to thank Judy for taking the time to talk to me about her department and all the hard work that she and her team do. ■

Colostomy UK
Purple Iris Stoma Care Award

The Colostomy UK Purple Iris Award recognises outstanding stoma care in community and clinical settings.

If your stoma care team has gone above and beyond in their care of you, a family member or a friend, then why not nominate them?

The 2017 recipients of the **Purple Iris Award** were the stoma care team at **King George Hospital in Essex.**

Nominations are now open for the **2019 award,** and we welcome nominations for stoma care teams who:

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

A representative from the winning stoma care department will be invited to attend our **Open Day dinner in 2019** when an official presentation will be made by our President.

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

Purple Iris Stoma Care Award – Nomination Form

Your details

First Name: ______________________ **Surname:** ______________________

Address: ____

______________________ **Post code:** ______________________

Telephone Number: ______________________ **Email:** ______________________

Nomination details

Name of team/department: ____

Name of hospital/community setting: ____

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

____

____

____

Additional Information

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

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

Signed: ______________________ **Name:** ______________________ **Date:** ____________

Please return this nomination form to: **Giovanni Cinque, Colostomy UK, Enterprise House,**
95 London Street, Reading, RG1 4QA by 30 April 2019.

Your letters and e–mails

Dear Editor

In May 2016 I was left with a permanent colostomy due to bowel cancer. I named him horrid Henry and started irrigating as soon as possible. This gave me confidence, freedom and control over Henry.

In July 2018 this all changed. I broke my right wrist very seriously. Because of this I was in hospital for three weeks with a metal fixator in my arm and an open wound. I was not able, or allowed, to change Henry so had to rely on nurses. It amazed me at how little the staff knew about stomas and nothing about irrigation. They were very good and I used to talk them through the procedure, but irrigation was out of the question. Not the nurse's fault but they didn't have the time to do it.

When I came out of hospital, because of living on my own and my need for the fixator and antibiotics, I had carers coming in daily. They were to change Henry for me morning and evening. This would have been ok if Henry behaved all the time but he didn't. With the help of a very good friend who helped at times, I was coping.

However, one night I had no option but to change him myself. I had a little think and then managed to do it with one hand and no accident. This made life a little easier as I didn't have to wait for people to come and possibly be too late.

After eight weeks the fixator came out, leaving a very stiff and useless hand. Then I started intensive physio. I was still changing Henry but at the beginning of October I decided it was time for me to be in control of him and try irrigation again. I have managed this, three times now, every other day and no accidents. It is a challenge but I am getting better at it and feel so much more confident and in control again, particularly if am going out.

Hopefully this will encourage others to try irrigation or start again if they have had a setback.

Regards, Janet

Dear Editor

Safety measure for leaking stomas

Most of us have suffered embarrassing leaks, just when we really didn't want it to happen. However, much as we hope the adhesive will stick securely and we can have a day out and be relaxed and forget that anything maybe going on in the stoma bag area – it is always a worry.

I have had my stoma for 20 years, a colostomy and irrigated, and then due to pre–cancerous polyps, an ileostomy. Whichever stoma I had, there have been times when I have had a stressed tummy, been unsure about surroundings etc. and had an unfortunate, embarrassing leak.

So, I have found my security blanket. It is...a puppy training pad!

You can buy them from Amazon, a blue square waterproof pad. It is light and when folded into a square, oblong or whatever shape fits you, will tuck between your stoma bag and your pants, knickers, whatever your underwear is – don't think teeny weensy thongs could be tucked into!

So, if you are experiencing unexpected leaks and you have ensured that your stoma is fitted correctly – well just have a pack of these training pads handy and tuck them in and relax a bit!

Sue Hatton

Dear Editor

In her article in the last issue of *Tidings,* Pamela Wickham asked for "tips for long stays away" with a stoma. I go away for three months at a time – a couple of which have been on world cruises – so I hope these may help.

For a month I counted how many bags I used, doubled the amount and added one box (for luck), black bags and wipes too. If you swim include small bags, and a few drainable bags are handy for those moments when you have a dodgy tummy. Your supplier will help. Remember, when in hot countries you will need to change a little more often, as the heat can affect the flange. I took bags out of boxes for easier packing in a holdall which I carried with me at all times to keep safe whilst travelling to and from the ship.

Everybody is different, I know, but I found if I was up front with my fellow passengers that I had a colostomy, then if I suddenly got up and left the room there was a reason for it! (And blame your husband if 'it' breaks wind!)

Enjoy your cruise, best wishes
Barbara Brown

Please note:
Before acting on suggestions from other ostomates regarding medication or treatment you must check with your doctor or stoma care nurse that this course of action is suitable for you.

We look forward to hearing from you, our readers:

Send an e–mail to: **editor@ColostomyUK**

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

Please make sure you include your full name and contact details, and confirm that **Colostomy UK** has permission to publish your letter. Also indicate whether you would like us to use your full name or just your first name. If you do not give us permission to use your name we will publish only your initials.

New 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.**

BEYOND DEFINITION

New!

Beyond Definition offer a range of ostomy cases designed to enhance your changing experience and blend into your lifestyle. For more information visit our website. See our main advert on p20

www.beyonddefinition.co.uk

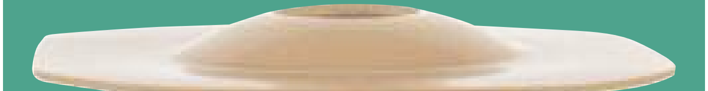
SenSura Mio® Convex – new sizes now available

Coloplast have extended the SenSura Mio Convex range to now include cut to fit sizes of 10–43mm for Light and Deep convexity.

Available in closed and drainable options. Visit **www.coloplast.co.uk** for more information and to request your free sample.

See our main advert on p2

DID YOU KNOW?



You can **interchange** our **new Combimate Soft Convex Flanges** with your *ConvaTec Natura* Pouch* or our **new Fleximate Soft Convex Flanges** with your *Coloplast Assura*** or *SenSura** Pouch*

Call **Freephone 0800 652 0424 to experience Combimate** and **Fleximate Soft Convex Flanges**

See our main advert on p18

Convex products should be used upon the guidance of a Stoma Care Nurse

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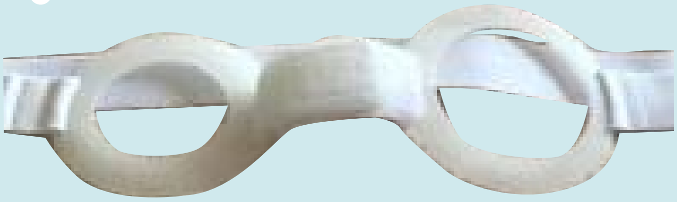
SASH Est. 1972

New!



Great news for 'Double Baggers'!

Following the success of the Double Stoma Hernia and Support Belt, SASH Medical Ltd is now able to supply a Double Security and Leakage Belt. The belt is fully adjustable for waist size and separation of the two stomas.

www.sashstomabelts.com **See our main advert on p30**

Air Travel: latest advice

Sara Marchant

As you know, Colostomy UK is working with the Civil Aviation Authority and UK airports to improve the airport experience for ostomates. We were therefore delighted to receive the following 'top tips' from Sara Marchant, who is an Accessibility Manager for Gatwick Airport. The advice she gives applies to airports across the UK.

Airports can be complex, busy, confusing places at the best of times. For passengers who have a hidden medical condition, the prospect of going through security can be particularly concerning. By following a few simple "top tips" it doesn't need to be a stressful experience.

All airports are required to screen passengers entering the departure lounges to be certain that nothing dangerous can be carried on to an aircraft. There are no exemptions to this rule, meaning everybody has to be screened.

There are things that you can do to make your journey through security as simple and stress–free as possible so here are a few pointers.

- Arrive in plenty of time. If you are rushed, it is easy to forget and leave things such as liquids in your hand luggage which will mean it is selected for search.
- Make sure you know which terminal you are flying from. Planning ahead can save you considerable time and effort.
- Check the website of the airport you are flying from. There is a wealth of information on there, and lots of additional help and advice.
- Have your boarding card ready as you arrive at security. You don't need your passport at this point.
- Some airports offer a "Family and Assistance" lane and some have a "Premium" security lane. Both these options are available to you, although there may be a charge for Premium. Of course, you can go through the main security area as well. It is your choice which route to take, but the officers on the Family and Assistance lane will be expecting to see passengers who have mobility issues, hidden disabilities and non–visible medical conditions.
- Most airports offer a *Hidden Disability Lanyard* which acts as a discreet signifier to staff that the person wearing it or somebody in their party has a hidden condition and may need a little more help or time. These are available from the Special Assistance desks and some airports can also post them out to you (see websites for more information). The staff will know that the person wearing the lanyard has a hidden condition, but not what that condition is and so you can choose to share as much or little information as you want to. They are of course entirely optional, but do give some people a bit more confidence.
- Make sure you have removed all liquids, gels, pastes and creams from your hand luggage and placed them in a clear 20cm by 20cm plastic bag. Liquids must be no larger than 100ml, and they must fit inside the bag which must be sealed. There is a limit of one bag per person. Remember, this applies to all liquids and will include things such as make up, toothpaste, perfume and foodstuffs.
- If you have prescription medication that you need on the flight, you can take it even if it is larger than 100ml, provided it has the prescription label on it or GP headed medical authorisation paperwork. It will be subject to non–invasive testing by the security team. It too, needs to go in a clear plastic bag.
- Take your laptop, kindle or other large electrical devices out of your bag. They need to be screened separately (they can go in the same tray as your bag though).
- Remove your coat or jacket and put them in the tray along with your other belongings.
- If you are picked for a search, you can ask the officer to have the search undertaken in private. You will be able to take a witness with you, and the officer will do likewise. You will be able to go to a separate room, where the search can be undertaken discreetly. If you are in any pain, inform the officer prior to the search.

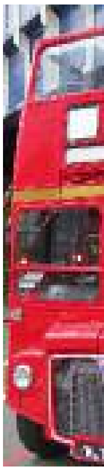
Travelling by air should not be a stressful experience provided you plan ahead and give yourself plenty of time. If you have any issues on the day, just speak to a member of staff who will be happy to help you.

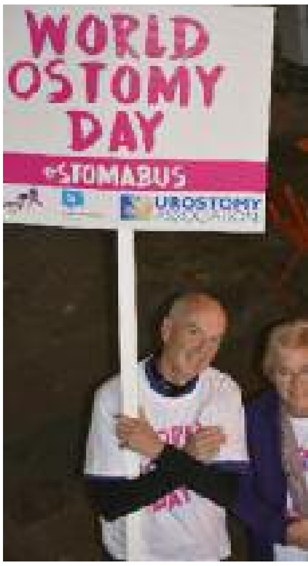
Sara Marchant
Accessibility Manager
Gatwick Airport

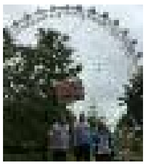
World ostomy day – destination awar

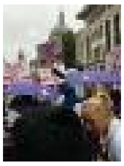
Raising public awareness about stomas and the needs of ostomates is something that everyone connected with the stoma world feels passionately about. But, as we are all too well aware, there is still a long way to go before we break the 'poo taboo'. Luckily, at **Colostomy UK** we are here for the long haul. A large part of what we do each year is aimed at realising our vision of a stoma–friendly society. This sees us trying to tackle practical issues, such as air travel and campaigning for improvements to toilet facilities, as well as sharing stories of ostomates across social media and writing articles for mainstream publications about what it is like to live with a stoma. We also run an annual Colostomy Day every October. Support for this has steadily grown and in the last couple of years the focus that the day brings has allowed us to reach tens of thousands of non–ostomates through things like Facebook and Twitter.

Last year was slightly different however, as on 6 October it was World Ostomy Day. This awareness day takes place once every three years and sees people across the globe running events and generally making lots of noise about all things stoma. World Ostomy Day started back in the 1990s…1992 to be exact. I'm sure of this date, not because I googled it, but because it has special significance for **Colostomy UK.** It was us, along with the Ileostomy Association and the Urostomy Association, that set up the committee which organised the first ever World Ostomy Day. Last October we joined together again and used our collective voices to raise awareness. The theme and hashtag for the day was #SpeakingOutChangesLives. Hopefully, you caught wind of it during your travels on the ether. If you were in London, then you might even have seen us as we made our way across the capital en route for Speakers' Corner. A big, red, open top double–decker bus packed with noisy ostomates dressed in white t–shirts and carrying 'World Ostomy' banners is difficult to miss at the best of times, particularly when it is pouring with rain. Indeed, I have it on good authority from volunteers

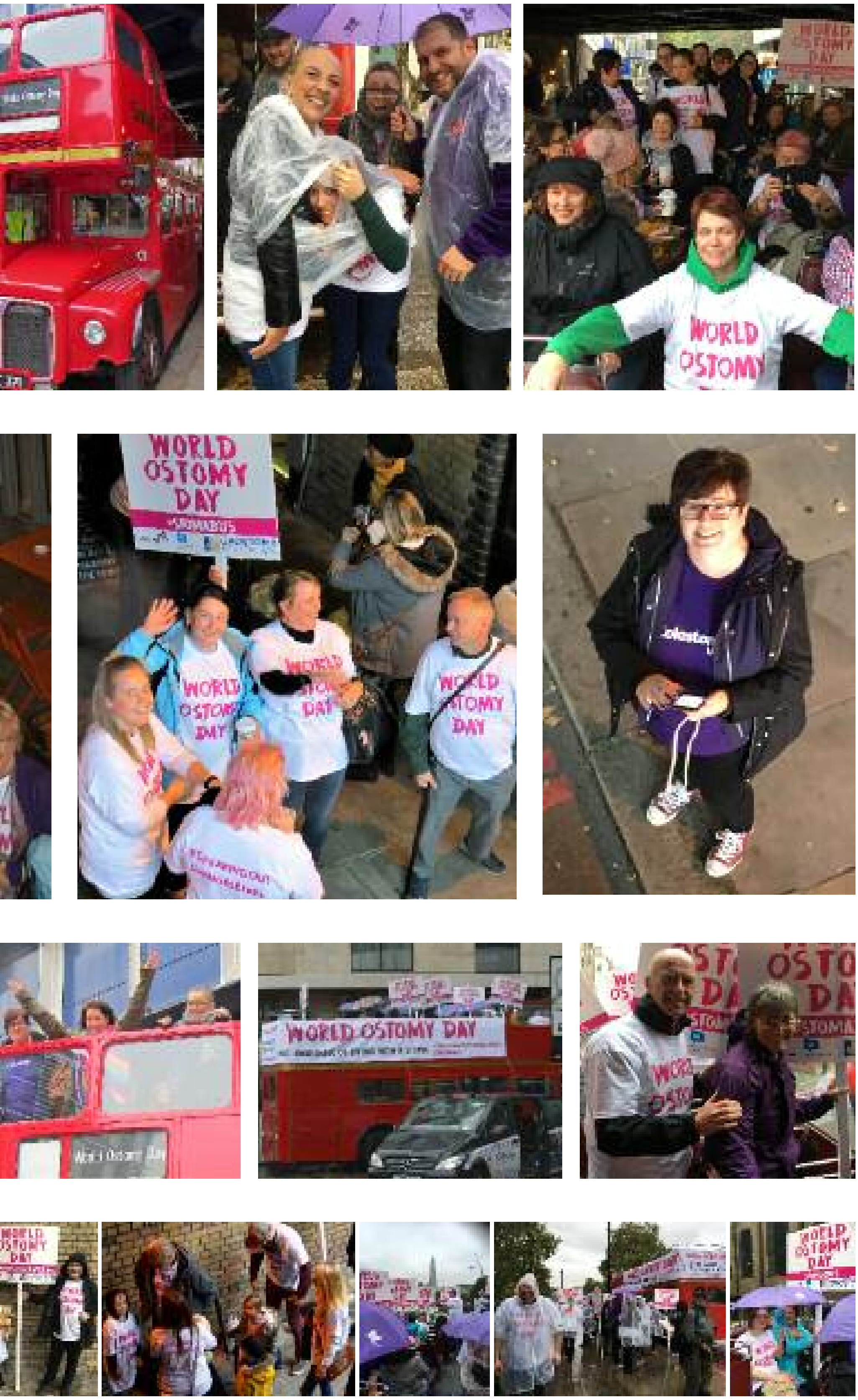








eness!



who attended, that some passengers even started to query the merit of hiring an open–top bus in October. If you didn't see the bus, then perhaps you caught the competition for space at Speakers' Corner, once everyone had 'debussed'? As luck would have it, the bus arrived at the same time as a large group of Zombies, there to celebrate World Zombie Day. The positive side to this chance encounter was that it afforded the opportunity to raise awareness of stomas with the undead!

Talking to people who attended, it was clear that the whole day was a great success. Rather than being a hindrance the rain seemed to have the opposite effect. To begin with, it really added to the feeling of solidarity between all those on the bus. Sarah Squire (who you will know from her regular articles on Irrigation) said: "we were wet to the skin and cold to the bone but had an amazing day". Bobby Minshull, one of our long standing volunteers, echoed Sarah's sentiments, adding that just being on a bus with lots of ostomates was, in itself, inspirational. The other 'good' thing about the rain, was that it really drew attention to the bus (as you can see from the pictures on the left). As Sarah went on to say: "it was incredible to see so many people reading the banners and asking what a stoma was". In this regard, I can't finish without making special mention of Ian Jackson. He is the rather soggy looking figure on the front cover of *Tidings.* Despite the weather, he remained on the top deck throughout, proudly displaying his World Ostomy banner. Many commented on this. Some (who wish to remain nameless, but fulfil the role of our senior support co–ordinator) said he was bonkers, others thought that by the end of the day he looked like Rose from the film Titanic (I've been advised not to liken him to Leonardo DiCaprio). Ian, however, just brushed aside such remarks and is reported to have said: "Nothing can stop a determined ostomate".

Roll on the next World Ostomy Day. We hope you like the photos!

Written by
Richard Biddle

Herbert's t

Dave Smart

The year is 1977, James Callaghan is Prime Minister, the F1 grand prix at Silverstone is won by James Hunt in a McLaren–Ford, Red Rum wins the Grand National for the third time and our Queen becomes a grandmother for the first time when Princess Anne gives birth to a son.

14 November 1977 was when I first saw the light of day.

Hi, my name is Herbert and I am a stoma peeping out of the belly of this 33–year old bloke called Dave. My mate the rectum has gone, pity I was quite attached to him. He is probably in a jar of alcohol on a laboratory shelf somewhere.

Why Herbert you ask, well I was named thus by a lovely New Zealand matron on the ward at the Royal Berkshire Hospital (RBH) in Reading. Every day she would come to see how I was getting on, raise the bed sheet and say how's Herbert doing today mate, and the name stuck.

Unfortunately I wasn't doing too well. Christmas dinner went down and promptly came up again, apparently something had stuck to something else and on 1 January 1978 they had to open us up again. Dave is down to 52.6kg (8st 4lb) from his usual 66.7kg (10st 7lb) self.

However, the second op was a success and we continued to improve. After six weeks in the RBH we were transferred to a cottage hospital in Henley–on–Thames for a week's convalescence. Dave will tell anyone who will listen, and those that won't, how he proudly walked down to the local shop to buy chocolate (his weakness) and thinking, here I am out and about with a colostomy and no one knows!

He had mixed feelings when told we could go home, after seven weeks in hospital. I think Dave was starting to get institutionalised. However everything was fine and he continued to grow stronger and gain weight. By June he returned to work, (he is a Clerk of Works on construction sites). To celebrate Dave bought himself a motorbike and on the first ride out he didn't wrap me up, not even a bag cover, so I got really cold.

He got a nice lady to make me a couple of bag covers, one with a double layer of material on the outside with an open end at the bottom so one can slip in a piece of

ale

windproof material. It works a treat, ideal for cold days out.

Life continued, with work, holidays, motor biking, days out etc, everything was going along fine until…

The year is 2004, Tony Blair is the Prime Minister, the F1 grand prix at Silverstone is won by Michael Schumacher in a Ferrari, double Olympic gold medalist Kelly Holmes is named as this year's BBC Sports Personality of the Year and the first Harry Potter film is shown on BBC One.

On the 24 July we were back in the RBH with our second dose of cancer and another big operation. This time my mate the colon was reduced to about 200mm long.

By 3 August we were home, no seven weeks stay this time. At age 60, it took Dave a while to get over this op, fortunately his employer paid generous sick pay and Dave returned to work part–time after six months, he recalls getting home at lunchtime and promptly falling asleep!

He returned fulltime by mid–March, still tired, but on the road to full recovery. He bought himself another motorbike, a Triumph this time, but it wasn't fast enough so it went. By the age of 65 and a bit he retired to enjoy a life of rebuilding old motorbikes, holidays, days out and volunteering at a local railway museum.

So what has he learned after 40+ years with a colostomy:

- Ensure that the bag is warmed up to make it softer and pliable. This can be done by placing it close to, but not on, a radiator or, failing that, place it under your armpit until it warms up.
- Ensure that the skin around the stoma is clean and dry.
- Smear a smidge of vaseline inside the bag to help the contents slide down and prevent pancaking. This is best done by wiping a finger around the jar then transferred into the bag.
- A few squirts of a lubricating deodorant in the bag via the outlet once the bag is on, helps to tackle odours. He uses the above in the day and a few drops of Eucalyptus Oil at night instead; it keeps the cost down for the NHS.
- If you are concerned about possible leakage around the flange, try using 25mm wide tape, half on the belly and half on the flange at the point where it might start to leak.
- A bag cover is a good idea, as described above. ■

Colostomy UK kit and merchandise

All profits raised from the following items help us to support and empower ostomates.. Order online at **www.ColostomyUK.org** or complete the order from below.

Team Colostomy UK Baseball cap

£8.99
Shipping £1.99

100% soft touch acrylic. Embroidered Team Colostomy UK logo on front. One size fits all.

Qty required: ....

Team Colostomy UK Beanie hat

£5.99
Shipping £1.99

100% cotton drill. Rip–strip size adjuster. Embroidered Team Colostomy UK logo on front and colostomyuk.org on back. One size fits all.

Qty required: ....

Colostomy UK Logo T–Shirt

£11.50
Shipping £2.99

Stand out from the crowd and show your support for **Colostomy UK** in our brand new logo T-Shirt. 100% heavy duty cotton.

Sizes available (inches):
Small (34"/36"), Medium (38"/40"),
Large (42"/44"), XLarge (46"/48")

Qty required: Small ________ Medium _________
Large ________ XLarge ___________

Team Colostomy UK RL Hooded sweatshirt

£31.99
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Team Colostomy UK Rugby League Hooded sweatshirt Acrylic/Cotton/Polyester mix. Features printed Team Colostomy UK and Masters Rugby League logos on front and #ActiveOstomates on back.

Qty required: Small ________ Medium _________
Large ________ XLarge ___________

Anatomy aprons

£156.00
Shipping £4.95

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

Qty required: ....

Team Colostomy UK Hooded sweatshirt

£34.99
Shipping £2.99

45% acrylic, 30% cotton, 15% polyester, 10% mixed fibres.

Embroidered Team Colostomy UK logo on left breast, and Printed logo on back.

Sizes available (inches):
Small (34"/36")
Medium (38"/40")
Large (42"/44")
XX Large (50"/52")

Qty required:

Small ....

Medium ....

Large ....

XX Large ....

Otto ostomy anatomy model

Standard **£1,020.00**
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Shipping £4.95

An excellent teaching resource. Using a simple colour–coding system for the various organs, Otto can help patients better understand the workings of their digestive system and urinary tract. An end or loop colostomy and ileostomy can be demonstrated, along with a urostomy and gastrostomy tube replacement.

Standard Model	**Advanced Model** as standard model plus:
Stomas:	**Stomas:**
7/8" Diameter stoma	3" Diameter stoma
2" Diameter stoma	Loop without rod
Loop with rod	Double barrel stoma
Urostomy with 3" stents	Oval stoma
	Granuloma stoma
	Necrotic stoma
	Mushroom stoma
	Prolapsed stoma
	Ischemic stoma
	Flush stoma
	In–skin fold stoma
	Parastomal hernia stoma
	Mucocutaneous separation stoma
	Recessed stoma

Additional parts included in both models:
small intestine segment, ileostomy loop adaptor,
colostomy loop adaptor, ileal conduit.

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

Please send me the above marked items. I enclose a cheque for £ made payable to: **Colostomy UK.**

Title:

Name:

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Do you irrigate? **If not, are you interested in trying? If you feel you would like to try irrigation you should first contact your stoma nurse to see if you are a suitable candidate. If you get the go ahead they will then arrange a time to teach you. For more information see the Colostomy UK website or purchase the Irrigation and you DVD using the form overleaf.**

Irrigation and you

Sarah Squire
Trustee and Co–Editor
E: Sarah.Squire@ColostomyUK.org

If you have any questions, comments or experiences of irrigation you'd like to share please send an e–mail to: **sarah.squire@ColostomyUK.org** or write to me at **Colostomy UK**.

Thank you all so much for the letters and e–mails you've sent in. It's great to hear irrigation stories from or readers. In this article, Trevor Williams an experienced irrigator, shares the method he has devised over the last 20 years

I am a 78 year old retired chartered accountant. I became an ostomate in January 1998 due to bowel cancer and since then have also suffered further illnesses.

Like Steve in a previous edition of *Tidings,* I am a keen sportsman. Golf is my main interest; I still manage to get on the course twice a week, all year round. Back in 2000, I was captain of my golf club and played over 100 rounds in that year. I'm also keen traveller. Since having my colostomy I have visited 20 of Europe's capital cities, including Reykjavik, Moscow, Madrid, Lisbon and Paris. Along the way I've also managed to play some golf, enjoying courses in France, Italy, Spain and Portugal. However, I can say confidently that none of this would have been feasible without irrigation.

When I had my colostomy surgery back in 1998, very little was known about irrigation in the UK. Researching my condition and requirements on the internet I found two useful websites, one in America, the other in Australia. Both had member forums and specialised in irrigation experiences and problems. An aspect of irrigation which I find interesting is the development of the variety of methods and equipment available to ostomates. With this in mind, I hope that readers will find useful information in my method of irrigating. It is something that I have developed through trial and error over the past 20 years.

When I started all those years ago I irrigated every day, usually between 8:00am and 9:00am. A few years later I found out that some ostomates only irrigated every other day and others claimed that they irrigated every third day! I started to go every 36 hours for several months and thereafter to 48 hours. I eat and drink everything including meat, fish, curry, Chinese, beer and wine. However, I do wear a pouch and very occasionally there may be some small discharge during the second night. The method I use is as follows:

- I start by arranging everything I need. You can see things set out in plate 1 (right). Everything is there, including my electric water pump (obtained on prescription). You can also see the fold out chair I use (together with towel for comfort!), placed between the toilet and sink.
- Next I fill a jug with 900ml with warm water and use the hot and cold taps to get a temperature of between 38.4°C to 38.6°C (measured with a thermometer). I pour the water into either the water reservoir or pump then re–fill the Jug with hot water for cleansing use later on.

CONTINUED ON PAGE 34, COLUMN 1

Plate 1 L–R:
Back *– 2 storage trays, Deodorant Spray, Adhesive removal spray, Pouch, Electric water pump with Tube to right with nozzle attached above.*
Front *– Adhesive removal wipes, blue disposal bag, Thermometer, Water Jug with Litre measures, Sleeve with elastic waist belt and clip at bottom.*

CONTINUED FROM PAGE 33, COLUMN 3

- I then remove most of my clothing and move the chair adjacent to the toilet.
- Still standing I remove my pouch and clean around the stoma with a wipe.
- I now attach the Hollister sleeve by means of the elasticised belt and position the sleeve over the stoma. I close the sleeve by folding the top and secure by means of the plastic top. It would be easier to attach to the abdomen with an adhesive sleeve but the only ones I have seen so far are too long and wide.
- Holding the nozzle of the pump over the toilet, I allow water to flow through to the nozzle to remove any air and then turn off the pump. Then I insert the nozzle into my stoma making sure that it is fully fitted and flush to my abdomen. I then infuse the water. It takes about five minutes to empty 900ml. I check that the water is flowing by keeping an eye on levels in the pump/bag. If these don't change, I remove the nozzle and clear any obstruction.
- Next, with my chair as close to the toilet as possible, I sit down, holding the nozzle firmly in front of me.
- There is normally an instant return of water. After a delay of a few minutes the faeces starts to flow into the sleeve and then the toilet. I encourage outflow by lightly massaging my abdomen on the right of my stoma. After about 25–30 minutes around 90% to 95% has moved from the colon to the toilet.
- As body movement is useful to get to 100%, I now stand up, pour water down the sleeve to cleanse and then use clip to close bottom of sleeve. I put on my underwear and dressing gown.
- I then shave, clean my teeth, wash the nozzle and tidy the bathroom.
- If any residue has entered the sleeve, I remove the clip, pour water from jug down sleeve and then remove to disposal bag.
- I then shower and get dressed including putting on a pouch.

During the last 20 years I have experienced several mishaps caused by diarrhoea or constipation. As a result, I always travel with a 'changing kit'. I suffer constipation more often than diarrhoea. The first time the former occurred I was treated in hospital, where the consultant advised me that if it reoccurred I should take 10ml of laxative and then irrigate with water at 39.0ºC to 40.0ºC temperature. It has worked each time! ■

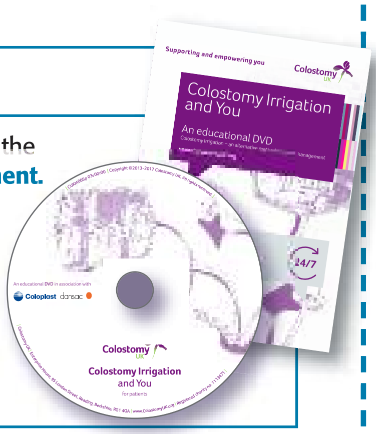
Trevor Williams

Please remember this experience is personal to Trevor. Before acting on any suggestions from other ostomates you are advised to check with your stoma care nurse that this course of action is suitable to you.

Plate 2 L–R:
Back – *Adhesive spray and Wipes, Deodorant spray, Brush for nozzle cleaning, Water pump.*
Front – *Blue disposal bag Large pouch, Small pouch, Plug.*

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 UK** to raise awareness about ***colostomy Irrigation* as a method of bowel management.**
Note: Not all colostomates have the potential to irrigate. It is therefore essential in the first instance to consult your Surgeon/Stoma Care Nurse as they will advise as to your suitability.

To obtain your single copy of *Colostomy Irrigation and You* at the special price of £1.99 (incl postage and packing) simply fill in your details below and return it with your cheque made payable to the **Colostomy UK,** to:
Colostomy UK, Enterprise House, 95 London Street, Reading, Berkshire, RG1 4QA

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Name:

Address:

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Tel:

Email:

Please allow 30 days for delivery.

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

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


Harry

Harry's Story

Vicki Smith

Harry was born in York Hospital, on 6 February 2018, following an otherwise healthy pregnancy. We were overjoyed to welcome him as our second child, but within 48 hours, we knew something wasn't quite right.

Soon after he was born Harry passed meconium (the dark tar–like poo that healthy babies pass after birth) and that is what made his eventual diagnosis even more surprising to doctors. He did, however, spend a lot of time sleeping and was disinterested in feeding. The small feeds he did manage, he brought back up, so on Day 2 he was transferred to the Special Care Baby Unit (SCBU).

His abdomen was distended and an x–ray showed free air in his bowel. Unfortunately, York hospital did not have the specialist doctors they felt were required to help diagnose his condition. Therefore, on Day 4, EMBRACE – the Yorkshire and Humber round–the–clock transport service for critically ill infants and children – transferred Harry and me to Hull Royal Infirmary, 40 miles away.

Harry was admitted on to the Neonatal Intensive Care Unit (NICU). As he was having problems feeding, the doctors decided to pass a nasogastric tube in to his stomach, and to provide the required fluids intravenously. His consultant paediatric surgeon informed us that she suspected he had a condition called 'Hirschsprung's Disease'.

Hirschsprung's Disease is a rare condition that causes faeces to become stuck in the bowel. The nerves that control the movement to push faeces through the bowel, are missing from a section in the lower bowel. One of the main signs of Hirschsprung's Disease is failure to pass meconium following birth. Given that Harry had passed meconium, doctors hadn't initially considered this diagnosis. However, not feeding well, intolerance to feeds, distended abdomen and failure to consistently pass faeces, were all pointing towards Hirschsprung's Disease. In order to diagnose this condition, a sample of tissue is taken from the bowel and a histopathologist has to determine whether there are nerves present. These nerves are also known as 'ganglion cells'.

A suction biopsy was carried out by Harry's consultant and we had to wait 48 hours for the results. When we got the results, they

CONTINUED ON PAGE 37, COLUMN 1

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50p From every £1 goes to Colostomy UK

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D.O.B.:
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How many entries would you like each week? ☐

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How often do you want to pay? (please tick payment frequency and write amount in box)			
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	☐	Every 26 wks	£26
	☐	Every 52 wks	£52

→ ☐

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Total Payable ☐

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Branch Sort Code: ☐☐ ☐☐ ☐☐
Bank/Building Society account number ☐☐☐☐☐☐☐☐☐☐

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

unity Instruction to your Bank or Building Society to pay by Direct Debit **DIRECT Debit**

Service User Number 4 2 1 1 0 2
Reference: ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

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

Signature:
Date:

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

Signature:
Date:

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

Detach the form, put it into a stamped envelope and return to **Unity** at the address shown on the right. They will notify you of your **Unity** lottery number.

Post this form in a stamped envelope to:

The Unity Lottery
Furness Gate
Peter Green Way
Furness Business Park
BARROW-IN-FURNESS
LA14 2PE

For office use only:

T52

The Unity Lottery, Furness Gate, Peter Green Way, Furness Business ParkBarrow-in-Furness | T: 0370 050 9240 | E: info@unitylottery.co.uk
Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 – www.gamblingcommission.gov.uk

The promoter of this Unity lottery is Colostomy UK, Enterprise House, 95 London Street, Reading, RG1 4QA | Registered with Reading Borough Council Registration number: LOT000141

CONTINUED FROM PAGE 35, COLUMN 3

were inconclusive and his biopsy had to be repeated. Again, we waited for 48 hours. The results showed 'immature ganglion cells'.

Harry's consultant wasn't happy with the results from the biopsy and she requested a barium x–ray. This showed what was described as a 'typical Hirschsprung's diseased bowel' and it was clear to see that there was an obstruction of faeces in Harry's bowel. However, barium x–rays alone cannot diagnose Hirschsprung's Disease; it has to be proven through biopsies and analysis by a histopathologist.

Harry was managing to pass some faeces whilst in NICU and he had begun to tolerate feeds. After 10 days, we were finally allowed to take him home. Unfortunately, within 36 hours we had to return, as Harry had failed to pass faeces and was in terrible pain. His consultant gave him an enema and we were sent home. This became a frequent occurrence until Harry was five weeks old, when his consultant decided to do a 'full thickness biopsy' under general anaesthetic. A full thickness biopsy is different to a suction biopsy, as it takes samples from deeper and further in to the bowel. The results, however, were inconclusive and we were sent home.

Harry continued to have problems passing faeces and when he was six weeks old his consultant made the decision to create a colostomy. During the operation, they took frozen cell samples from his bowel. The frozen cell samples finally confirmed that Harry did not have ganglion cells in his rectosigmoid colon and that he had Hirschsprung's Disease.

Once the colostomy had been created, Harry went on to thrive. We were told that his colostomy would be reversed when he was ten weeks old and the section of bowel that didn't have ganglion cells, would be removed. They would then bring the remaining functioning bowel back down to his rectum and re–join it.

Life with a colostomy bag wasn't always easy. Before Harry had his operation, I was given a doll with a fake stoma to practise putting on a bag. While he was in hospital, I only changed his bag once and then we were sent on our way. Over time I became more confident and a dab hand at changing his bag. We used Salts neonatal bags until Harry was four months old then changed to a bigger bag as he grew. We were relatively lucky in relation to leaks, but we did experience a few!

I sought help from members on the Colostomy UK Support Group page on Facebook. I shared Harry's story and the members fell in love with Harry and gave me the support I needed to help me through a difficult time. I asked for advice when we experienced a spate of his bag leaking continuously and when Harry suffered from trapped wind. What members on this page don't know about coping with stomas isn't worth knowing! I also met other mums whose children have stomas. I helped out one lady who had been left in the lurch without any neonatal bags for her baby.

Harry had his colostomy reversed and his bowel resected when he was six months old. He is continuing to do well and we will be celebrating his first birthday next month. I will remain on the Colostomy UK Support Group page on Facebook, as I've made some good friends through the group and everyone loves to see his progress.

Vicki's tips for Mums who have a baby with a stoma

- Don't stress, it's only poop!
- There aren't any nerves in the stoma, so your child cannot feel pain if you touch it.
- Leaks aren't always obvious. If your child is in distress and you don't spot a leak, change the bag anyway.
- Poo can cause sore skin and pain for your child when the bag leaks.
- Use a barrier when needed. We were advised to always use a barrier, but this made it trickier to stick the bag. Harry never experienced sore skin, so we clearly did something right!
- Empty air out of the bag. They're no fun when they go pop in the night!
- Make sure the skin is dry before you apply the bag.
- It's fine to bath the baby with the bag still on. In fact, it's less messy. I always changed Harry's bag after his bath, to ensure it didn't become unstuck.
- Let babies have time without the bag on. Lay them on a towel or mat.
- If you think you're ready to cry, ask for help! There's always someone that can offer advice on the Colostomy UK Support Group page on Facebook. There's also your stoma care nurse and the **Colostomy UK** helpline, manned by volunteers who can arrange for a parent in similar circumstances to telephone you. Remember it's OK not to be OK.

For more information about Hirschsprung's disease visit: **https://www.nhs.uk/conditions/hirschsprungs-disease**

Your travel checklist

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

The ostomate needs to remember to:

☐ Pack sufficient supplies for your stay. At least twice the normal usage at home.

☐ Take all supplies and travel stoma kit as hand luggage.

☐ Ask the airline in advance if you need extra hand baggage for your supplies.

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

☐ Pack all your normal medications and any that may help an upset stomach.

☐ Pack some form of electrolyte replacement solution in case you become dehydrated.

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

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

☐ 'Check in' online 24 hours before departure to secure your preferred seat.

Remember:

❖ You can request **not** to go through a body scanner but if you do, you WILL be subjected to a full search.

❖ Most UK airports now operate a hidden conditions lanyard or bracelet scheme. These are available from assistance reception areas. Wearing them identifies you to staff as having additional needs.

❖ If you need assistance on your flight you should advise your airline at least 48 hours before your departure date.

❖ You should AVOID requesting the presence of a healthcare professional if you are searched. Airports do not generally have such staff on standby and the likelihood is that you will miss your flight.

❖ You can only take more than 100ml of liquids in your hand luggage if there is a prescription label on said item.

❖ You should expect to be treated the same as everyone else. Having a stoma does not exclude you from any security checks.

Supporting and empowering you
Colostomy UK
Travel Advice
Having a colostomy should not prevent you from travelling at home or abroad
Freephone helpline:
0800 328 4257
24/7

Supporting and empowering you
Colostomy UK
Travel Certificate
for people with a colostomy
24/7

General Enquiries:
0118 939 1537
Monday to Thursday
9am – 5pm and
Friday 9am – 3pm

or

E-mail:
info@ColostomyUK.org

Website:
www. ColostomyUK.org

What’s so good about the Colostomy UK closed Facebook group?

Sarah Squire
Trustee and Co–Editor
E: Sarah.Squire@ColostomyUK.org

It was back in 2012 that **Colostomy UK** made its Facebook support group ‘closed’. Within a year it had 1,000 members. By the Spring of 2017 the figure stood at 4,500. Now, over 6,500 people are part of this vibrant and ever–growing community. So what makes the group so good? Well rather than us waxing lyrical about everything it has to offer, we asked its members to tell us what the group means to them. We were overwhelmed by the response, so much so that we don’t have space to print all the feedback we received. In fact, there probably wouldn’t have been enough room if we had devoted an entire edition of *Tidings!*

So, instead, we’ve printed a representative selection below. As you’ll quickly see, the themes of support, understanding and friendliness are common to them all:

Firstly, not feeling alone. Others personal experiences are a great source of support. I’m very thankful for this group 😁 **LC**

Post op 6 weeks and was feeling down the night I joined, but within 2 hours I was feeling inspired by the support I was getting from people telling me my life was just starting again and not over as I was fearing **George Reid**

Such a friendly group of people and everyone there offers advice. Takes a lot of pressure off… **MB**

I couldn’t have got through everything without this group… I also love being able to talk to a range of ages that have gone through the same as me…it’s fantastic **Kimberly Tipling**

It’s like a family that picks you up when feeling down **Jay Kirk**

It stops us feeling alone **Alastair Jamieson**

I learned to live again from the wonderful people in this group **Jennifer Lynn**

I love this group, I have learned so much from it 😘 😘 **NA**

Everything fell into place when I read this group’s stories xx **NQ**

The humour is tremendous too 👍 💩 Thank you all 😘 **Gillian Wood**

This group has literally taken me from not knowing anything to being a volunteer and trustee of Colostomy UK… **Ian Jackson**

If you’re not already a member of the group, then hopefully reading these words from some of its members will encourage you to join. It’s very easy. Just search for ‘Colostomy UK Support Group’ on Facebook, choose the group and you will see a tab to click to join. Once you’ve requested to join, one of the admins will greet you. We hope to see you soon! ■

Colostomy UK: active ostomates

Giovanni Cinque
Fundraising and Development Manager
E: Giovanni.Cinque@ColostomyUK.org

Welcome to the regular update page dedicated to our 'Active ostomates' project.

'Active Ostomates' supports your wellbeing with a range of programmes. Some are delivered through support groups; some can be done in your own home; others you need to sign up for. We will also be promoting activities and events that can help everyone work towards having a more active body and mind.

Creative minds

Being active is not just about physical exercise. It's also about exercising those grey cells too. Both are important to health and wellbeing.

Here at **Colostomy UK** we are always looking for new ideas and initiatives that could benefit and improve ostomates' quality of life. With this in mind, last September we launched our new 'Creative Minds' art project.

Aimed at stoma support groups and delivered free of charge, the sessions last from one and a half to two hours and enable participants to explore their creativity and create wonderful artwork with the support and guidance of an experienced artist.

Delivered in partnership with a social enterprise of the same name, the sessions have many proven benefits for participants such as boosting self–confidence and esteem, increasing cognitive stimulation, and improving dexterity and motor skills.

All artists are fully trained to ensure that they deliver the best service. Each artist has an enhanced DBS check, public liability insurance and provides all of the art materials and equipment needed to deliver the sessions. Every session delivered is adapted and accessible to all participants, to ensure that everyone can take part and enjoy the session.

If you are involved in a stoma support group and would like to take part in our free Creative Minds project please email **Giovanni.Cinque@ColostomyUK.org** or call **0118 939 1537.**

Team Colostomy UK Rugby League update

On Saturday 10 November Team Colostomy UK Rugby League took part in a world first match when we joined with Physical Disability Rugby League (PDRL) United to raise awareness of Living with a stoma, and Physical Disability Rugby league. The game took place at Post Office Road, the Iconic home of Featherstone Rovers.

Aptly for what was a wonderful day and experience, the final result was an 8–8 draw.

After the game there were also various talks on **Colostomy UK,** Physical Disability Rugby League, and Mental Health awareness, while a significant sum was raised for both the Poppy Appeal, and **Colostomy UK.**

Further fixtures are being planned for this year. If you're interested in playing or helping out in other ways please email **Giovanni.Cinque@ColostomyUK.org** or call **0118 939 1537.**

#ActiveOstomates

50K CHALLENGE



On 31 October after six months of inspirational stories and a few broken pedometers along the way, the **Colostomy UK** 50K challenge finally reached the finishing line.

All of us at **Colostomy UK** would like to say a massive **THANK YOU** to everyone who took part.

356 participants achieved an amazing 69,739 kilometres and raised nearly £10,000.

Every penny will be invested in our Active Ostomates project encouraging more people to be active.

Keep an eye on future *Tidings* and our website as we'll be launching our 2019 challenge soon.

Revised and updated *Sport and fitness after stoma surgery* booklet available

We have distributed over 6,000 copies of our *Active ostomates: sport and fitness after stoma surgery* booklet since its initial launch in 2016.

The newly revised and updated version is now available which includes new sections on modified sports and updated advice and links to numerous activities you can try.

To get hold of your copy either download it for free on our website, call us on **0118 939 1537** or e–mail: **info@ColostomyUK.org**

Supporting and empowering you

Colostomy UK

Active Ostomates:
Sport and fitness after stoma surgery

www.ColostomyUK.org

#ActiveOstomates

Freephone helpline:
0800 328 4257

24/7

Why not also grab a copy of our *Healthy eating* booklet too? This gives useful guidance on how to achieve and maintain a healthy diet.

Chair Yoga expanding in 2019

Our Chair Yoga project is now entering its fourth year. The aim is to deliver a gentle level of physical activity which is suitable for people of all ages. The focus is on balance and coordination, relaxation, and breathing techniques.

Hundreds of ostomates from nearly twenty different support groups have benefited from our sessions and we are pleased to say that we are now able to offer them on a regular basis to support groups in Lancashire and Yorkshire. If you run a support group and would like further information, or book a taster information please call Giovanni on **0118 939 1537** or email **Giovanni.Cinque@ColostomyUK.org**

Fancy a dip?

As part of Active Ostomates we work with support groups to provide free ostomate–only swimming sessions. We are looking for more groups to partner with throughout the UK to enable us to reach even more people.

In 2018 we held sessions in Sheppey, Newcastle–upon–Tyne, Gateshead, and County Durham and are looking to further expand these this year

If you are involved in a support group and are interested in our swimming activity please call Giovanni on **0118 939 1537** or email **Giovanni.Cinque@ColostomyUK.org**

The Tour de Stoma

Geoff Collins

On the 9 June 2018 around a thousand cyclists took to the streets of London as part of the 15th Annual World Naked Bike Ride. This fun and popular protest, which is now a familiar sight in cities across the globe, aims to raise awareness about global oil dependency, car culture and the vulnerability of cyclists on city streets. It is also a celebration of body freedom. Full or partial nudity is the order of the day with many participants decorating themselves with body art and body paint. Some wear fancy dress too. At last year's event, cyclists could choose from seven routes, all of which ended at Hyde Park Corner. Geoff Collins, at the time an ostomate of just six months, who had only recently finished chemotherapy, opted for the one which took in major tourist spots like Piccadilly and Trafalgar Square.

So what made him do it? I was certainly intrigued to know. The cycling bit I could understand. And, to be that active so soon after surgery is obviously impressive, but naked? Isn't that just attention seeking? I have to admit that this was going through my mind when I called Geoff. In fact, if I'm being brutally honest, I was expecting him to be a bit of a weirdo…but I couldn't have been more wrong. Instead, I found a courageous and inspirational man who, despite the shock of bowel cancer, has remained positive as well as determined not to let a stoma define him or his life.

Geoff retired from teaching French and IT at secondary school in September 2017. At age 60 he conducted the standard bowel screening test, which came back all clear. But, in October 2017, although feeling fine in himself, Geoff noticed a change in his bowel habits. Luckily he didn't delay visiting his local GP surgery where he was referred for a colonoscopy. It was while waiting for this appointment to come through that the symptoms worsened. To begin with it was constipation, but as time progressed Geoff started to experience vomiting after eating. Matters came to a head in late October when, having been to bed early one night because he felt so bloated, Geoff woke up in such pain that his wife rushed him to hospital. Here, he was admitted to a surgical ward, where a CT scan revealed his bowel was blocked. If the need for emergency surgery wasn't shocking enough, the surgeon also told Geoff that he would have to have a stoma as well. So, with no time to prepare, Geoff found himself on the way down to theatre. He woke later to discover that the obstruction in his bowel had been caused by cancer. He started a six–month course of chemotherapy in December 2017.

Geoff was determined to get up and about just as soon as his body would let him. In hospital he was encouraged to take gentle walks around the ward. Once home, he built on these by walking up and down the garden. On 12 November, eight days after discharge, his step count breached the 5,000 mark. On 16 November, he took his first trip away from home and clocked just over 10,000 steps. By 22 November he was at 20,000 steps and has managed to achieve this every day since. As Geoff told me these statistics I was somewhat aghast. I even began to question whether I should make more of an effort myself! I'm pretty sure that many of you reading this, while marvelling at Geoff's achievement, might query doing so much exercise so soon after surgery. This was certainly my initial reaction. As we know, although exercise is vital to post–op recovery and ongoing physical and mental wellbeing, it's also very important not to over exert yourself in the early days. But, we have to understand Geoff's levels of activity in the context of a man that had been very active all his life. And, I might add, Geoff's definition of active is almost certainly different to yours and mine. From age 40 onwards he had cycled the 50 mile round trip to work every single day! As Geoff explained, it was an encounter with paraganglioma (a form of cancer) back in the 1980s that provided the initial impetus for doing this. He hoped that getting fit would help him to fight the heart and blood pressure problems that are known to accompany the condition. Thus, having been so active for so many years, he was absolutely desperate to get out and about again. By mid–December, six weeks

after his surgery, Geoff had started running again. It was about this time that he remembers posting the message 'I'm back' on the family WhatsApp group. He is also convinced that doing the things he loved was a tonic in its own right. The sense of being on the road back to 'normality' made him feel good.

As I mentioned earlier, Geoff has something of a history where cycling is concerned. Post surgery, he delayed getting back in the saddle until the December. However, once the chemotherapy started, cycling became more problematic as, like many people, he suffered the side effects of neuropathy. For those readers who are unfamiliar, this is peripheral nerve damage, that can manifest itself in many ways, including numbness, increased sensitivity and a tingling or burning sensation. It wasn't until April 2018 that he had re–started cycling 'proper'. This brings us neatly back to the subject of the Naked Bike Ride. Geoff's participation last June, was not his first. In fact, he started attending the annual protest in 2007 when he was cycling to work each day. He initially decided to get involved as he was keen to raise awareness about cyclists as road users and draw attention their vulnerability. As he said, when cycling to work in all his cycling gear he sometimes felt he was invisible to motorists. Conversely, cycling in the nude he found that there wasn't a single road user that failed to notice him! As he explained, during the Naked Bike Ride, motorists hoot their horns and wave with encouragement, rather than with anger and irritation.

Geoff, of course, still feels passionately about the safety of cyclists, but his reasons for taking part in last year's ride were slightly different. It was while in hospital that one of the stoma care nurses mentioned to him and his wife that many people with stomas suffer from problems with their body image. At **Colostomy UK** we are only too well aware of this and the social isolation it can lead to. Geoff's ride in 2018 was therefore driven (or should I say pedalled?!) by the desire to demonstrate that having a stoma is fine; it's not a barrier. He wanted to show the world that he and not his stoma was in charge of his life. He also hoped that other ostomates would draw strength from what he was doing. I asked Geoff about the reactions he received. Geoff said that his perception was that while some people noticed his bag, that was as far as it went; they noticed it, but didn't dwell on it. To his mind, the wearer is more conscious about the presence of a bag than anyone else. There was one specific incident though, that he does recall very clearly. This occurred when he stopped by another cyclist who appeared to have a slow puncture. The man's girlfriend was there and remarked on Geoff's bag. She said that her Dad had one too and that she was going to tell him she had seen Geoff, because his confidence had suffered so much since the surgery. Admittedly, this is just a single incident, but from where I'm standing, even if Geoff's ride brings hope to just a single person, then it was worthwhile! ■

Written by
Richard Biddle

It is with great sadness that I must report that just as we were going to print, Geoff's wife Debbie contacted me to say Geoff's cancer had returned and that he died suddenly in October 2018. She explained that in true Geoff style, he fought to the bitter end and, as a final mark of his determination not to let his illness define or control him, he had continued to visit the gym until his last days and insisted on walking to hospital the day he was admitted.

Colostomy UK: focus on fundraising

Giovanni Cinque
Fundraising and Development Manager
E: Giovanni.Cinque@ColostomyUK.org

Get involved!

Are you interested in fundraising for us? A successful event doesn't need to raise huge amounts of money. Rest assured, whether it be £5 or £500, **Colostomy UK** will put it to good use. We've got plenty of fundraising ideas to help get you started. If you would like one of our brand new fund–raising packs, which also includes lots of hints and tips about organising an event, then call us on: **0118 939 1537** or email: **fundraising@ColostomyUK.org**

easyfundraising
feel good shopping

Easy fundraising is a website which allows you to donate to **Colostomy UK** at no extra cost to you while you shop, with hundreds of the UK's top high–street brands.

All you need to do is:

- Register as a supporter on the Easy fundraising website and
- Make sure that **Colostomy UK** (Colostomy Association) is added as your supported cause.
- You can then accumulate donations while you shop with any of their partner retailers.

For more information or to register just visit:
www.easyfundraising.org.uk/causes/colostomyassociation/

Keith's Walkathon

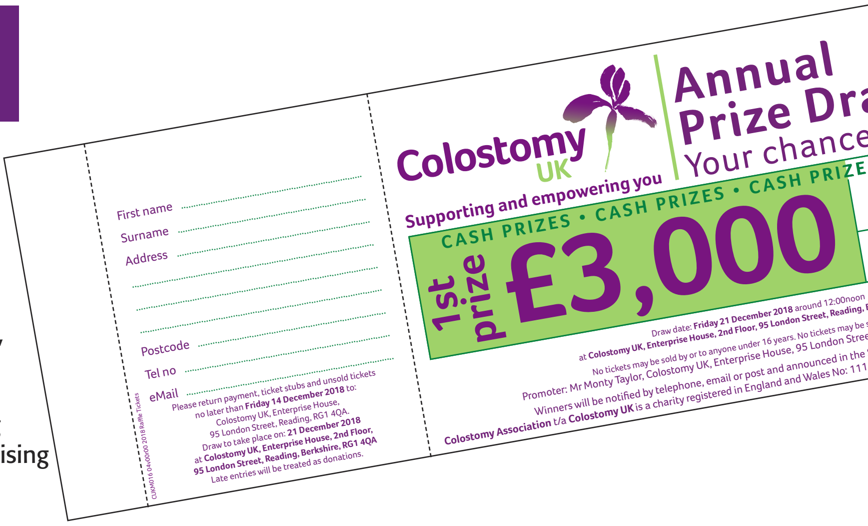
Last November Keith Thorogood took on the amazing challenge of walking from the Royal Devon & Exeter Hospital to St Mary's Hospital Paddington with a target of raising £50,000 for **Colostomy UK.**

His route took him through Yeovil, Stonehenge, Basingstoke, Reading, Maidenhead, and Chiswick before finally completing a walk through all the London Underground Mileage Lines.

We're hugely grateful to Keith for taking on this momentous challenge and for the funds he is raising for us.

You can still donate in support of Keith's Walk by sending a cheque or postal order made payable to **Colostomy UK,** to:

Colostomy UK, Keith Thorogood Challenge,
Enterprise House, 95 London Street,
Reading RG1 4QA



First name ....
Surname ....
Address ....
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Postcode ....
Tel no ....
eMail ....

Please return payment, ticket stubs and unsold tickets no later than **Friday 14 December 2018** to: Colostomy UK, Enterprise House, 95 London Street, Reading, RG1 4QA.
Draw to take place on: **21 December 2018** at **Colostomy UK, Enterprise House, 2nd Floor, 95 London Street, Reading, Berkshire, RG1 4QA**
Late entries will be treated as donations.

CUKM016 04v00r00 2018 Raffle Tickets

Colostomy UK
Supporting and empowering you

Annual
Prize Dra
Your chance

CASH PRIZES • CASH PRIZES • CASH PRIZE

1st prize £3,000

Draw date: **Friday 21 December 2018** around 12:00noon
at **Colostomy UK, Enterprise House, 2nd Floor, 95 London Street, Reading,**
No tickets may be sold by or to anyone under 16 years. No tickets may be s
Promoter: Mr Monty Taylor, Colostomy UK, Enterprise House, 95 London Stree
Winners will be notified by telephone, email or post and announced in the
Colostomy Association t/a **Colostomy UK** is a charity registered in England and Wales No: 111

2018 Raffle

The winners of our 2018 raffle have been drawn and contacted. Due to print deadlines they will be announced in the next issue of *Tidings.*

Thank you to everybody who purchased tickets. All proceeds will go towards supporting our core services, projects and campaigns, so by purchasing a ticket you are making a difference.

Than

Unfortunately we don't have the space to thank everybody who has made donations to **Colostomy UK** since the last issue, but we would like to acknowledge a few people and organisations who have been busy raising funds for us:

Mr Barry Parkyn has do

Andrew Hewitson raise
in the Great North Run.

Wayne Love is raising funds for **Colostomy UK** at his Pet Store 'Fluffy's' in Watford New Market.

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e to win
£1
Ticket
5 per book
S • CASH PRIZES
2nd prize £500
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Spring 2019 edition of *Tidings*
Lottery Licence no: LOT000141
3471

Grants and Trusts

We're grateful to the following Trusts and Foundations who have supported us recently following successful applications for funding: Swire Charitable Trust, Tay Charitable Trust, The Weinstock Fund, The Persula Foundation.

Textgiving

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

Whatever mobile network you're on, simply text our unique code **CASS01** followed by a space, and your chosen amount to **70070.**

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

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

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

kyou!

nated **£500.**

d **£160** by competing

Vicki Smith has set up a Just Giving page to support **Colostomy UK** due to the support she received when her son had a temporary colostomy. At the time of writing she has raised over **£350**. You can read all about Vicki and her son on pages 35.

Graham Wells raised **£563** by playing in our Team Colostomy UK Rugby League debut game against Medway Dragons last July.

Unity Lottery

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

Members have the chance of winning a main prize of £25,000 each week (plus a £2,500 donation to **Colostomy UK**), as well as smaller prizes of 5 free draws, £25, and £1,000. Entry is only £1 per week and we receive 50p for every £1 ticket sold. You can join by completing the form on page 36 or online by visiting **www.unitylottery.co.uk** Just remember to link to **Colostomy UK!**

WHAT WILL YOUR LEGACY BE?

Giving in your will is a truly special way to make a lasting difference. It will help the ostomates of tomorrow, their family members and carers, receive life-changing support from Colostomy UK.

What your gift means

Legacies large and small can have an extraordinary impact for all the people we help and support. They can:

- Ensure there is always a voice at the other end of the phone.
- Train volunteers to provide support at open days and in hospitals.
- Fund our campaign for a stoma friendly society.
- Help support our 'Stoma Friendly Society' campaign or our projects including 'Active Ostomates' and 'Creative Minds'.

How to leave a legacy

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

Your solicitor will need the following information:

Name: **Colostomy UK**

Registered address: **Enterprise House, 95 London Street,**
Reading RG1 4QA

Charity Commission registration number: **1113471**

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

Colostomy UK

Do something amazing!

Join Team Colostomy UK.
Together we can make a difference.

Whether you run 5K, complete a marathon, skydive or swim the channel. Do it as part of Team Colostomy UK!

fundraising@ColostomyUK.org
0118 939 1537

Make a donation

Colostomy UK

Without **donations** from people like you, **Colostomy UK** could not continue its vital work **supporting** and **empowering** ostomates. Thank you for supporting us.

My Details: Title: Forename: Surname:

Home address:

Postcode:

Telephone (home): Mobile:

Email:

Date of Birth: Month and year of operation:

Reason for your stoma: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy

Tick as appropriate: I would like to be kept informed by: ☐ Post ☐ Email ☐ Telephone. Please tick if you would like a receipt ☐

I would like to receive information about: ☐ Tidings magazine ☐ Bag and product manufacturers ☐ Colostomy UK, the work it does, including training, conferences, volunteer opportunities and fundraising.

We will never sell or swap your information with other organisations. You can change how we communicate with you at any time.

Call us on: **0118 939 1537** or email: **info@ColostomyUK.org**

I would like to make a donation of:

☐ £20 ☐ £30 or whatever you are able to give £

☐ I enclose a cheque or postal order made payable to **Colostomy UK**

☐ Please debit my Visa/Mastercard/Maestro Card with the amount specified

Card number (Maestro only)

Expiry date / Security code (Maestro only) Start date / (Maestro only) Issue No.

Signed Date D D M M Y Y

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 £20 becomes £25 with gift aid, at no extra cost to you.

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

Signature: Date: / / 2019

I would like to make a regular donation – 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 ☐ £20 ☐ £30 or other amount (please state) £

☐ monthly ☐ quarterly ☐ annually starting on the ☐ 1st ☐ 15th ☐ 25th of month: year:

thereafter until further notice. (Please cancel any previous standing order in favour of this beneficiary).

*Please allow one month's notice to ensure donation processes through banking system and state your donation amount in words:

Please pay: NatWest Bank, Market Place, Reading, Berkshire, RG1 2EP

Account name: **C.A. Ltd** Account No: **88781909** Sort code: **60-17-21**

Name: (IN CAPITALS) T52

Signature: Date: / / 2019

To donate, please fill in the form, check your details are correct, then return this page to Colostomy UK – thank you.

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

Registered Charity No: 1113471

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News from support groups across the UK

L–R: Tracy Moore, Ruth Maher, Alison Teed, Carolyn Hodge, Giovanni Cinque, Isabel Pena Barrientos

New stoma support group set up in collaboration with Colostomy UK and Wexham Park Hospital Stoma Care Department.

Liz Harris and Laura O'Mahoney, Stoma Care Nurses at Wexham Park Hospital in Slough felt that there was a lack of support in their area for people living with a stoma. They approached **Colostomy UK** and asked for our help in setting up a support group to cover their community (East Berkshire and South Buckinghamshire).

In their opinion a local support group for the residents of East Berkshire and South Bucks would be hugely beneficial. At present the nearest one is in Bracknell which is some distance to travel for people living in Maidenhead, Windsor, Ascot, Langley, Slough and environs. Collectively these areas have over one million inhabitants.

While **Colostomy UK** don't 'run' support groups in the traditional sense we are able to offer a wide range of support to both new and existing ones. We therefore agreed to take on the task of recruiting and training volunteers, putting the initial plans and structures in place, and taking a 'hands on role' at the early meetings. Once the committee is confident in their ability to run the group, we will step back, but acting as mentors when needed.

We had a great response to our request for volunteers in *Tidings* and on our Social media feeds, and in July 2018 had our first volunteer meeting at the Harte & Garter in Windsor. Six enthusiastic people attended who brought with them a wide range of skills and experiences.

The initial conversations were based around the name of the group, where it would be based, how often it would meet, how we would attract members, and how the group would be funded. The second meeting took place in September 2018 and ended with us agreeing to the name: **WAMS (Windsor, Ascot, Maidenhead, and Slough) Stoma support group.**

The group will meet monthly between 19:00 and 21:00 on the first Monday of each month, starting in March 2019. The venue is to be confirmed, please e–mail us if you are interested in attending the support group.

We have a great committee in place including Carolyn Hodges, Ruth Maher, Giovanni Cinque, Alison Teeds, and Isabel Pena Barrientos, and look forward to supporting the ostomate community in East Berkshire and South Bucks from March onwards.

Giovanni Cinque

If you would like to set up a support group in your community or if you're interested in volunteering please email **info@ColostomyUk.org** or call us **0118 939 1537** and speak to Giovanni or Libby.

Shropshire B.O.T.s (Bums on Tums) 3rd Open Day

Another successful Open Day with in excess of 100 people attending.

We were delighted to welcome **Colostomy UK's** Giovanni Cinque who came to join us and give a talk on the work of **Colostomy UK.** Also speaking was Jo Jones from Birmingham Airport who gave a very lively and entertaining talk on how the airport security works and how to ensure a speedy and trouble free passage through. Next year's Open Day will be in the same place on 3 October 2019, and the BOTs look forward to welcoming you. **Irene Constable**

Staffordshire support groups

HELLO – all members who live in the south of the county.

We have started a County Stoma Group and will meet on **26 January** at **The Round House on Sidney Ave, Stafford, ST17 4EL** at **2:00pm.** Please contact **Christine Bryden** on **07757 911 726** or email **countystoma@yahoo.com** for updates about this group.

Outlook, The North Staffs Ostomy Support Group

L–R: Dave Berry, Julie O'Rourke, Joan Buck, Graeme Kassell, Tina Collins, Stan Collins, Moira Hammond, Christine Bryden, Julie Rust

Outlook held its Annual Open Day on 27 October and as always, we had a steady flow of visitors who enjoyed the opportunity to meet, as well as see manufacturer's products. There were also representatives from the national support groups and our Stoma Nurse, Julie Rust was kept busy chatting to patients. For more information about the group and our programme for next year, please contact **Moira Hammond** or **07788 107 937** or **cm.hammond@ntlworld.com**

We look forward to welcoming new members to all our meetings – do come along. **Moira Hammond**

Stoma care open days

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

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

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

James Paget University Hospital
Stoma Care & Colorectal Open day
The Wherry Hotel, Oulton Broad
(Brown Boat Suite)
Lowerstoft, Suffolk, NR32 3LN
14 February 2019 1pm–5pm
E: molly.eaglen@jpaget.nhs.uk
T: 01493 452 427

Royal United Hospital
Stoma Care Open Day
Bath Racecourse & Conference Centre,
Lansdown, Bath, BA1 9BU
04 April 2019 10:00am–2:30pm
Stoma Care Dept: 01225 824 056

National support organisations

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

UA Urostomy Association
www.urostomyassociation.org.uk
Telephone 01386 430 140
e–mail
secretary@urostomyassociation.org.uk

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

IOA International Ostomy Association
www.ostomyinternational.org

Junior Ostomy Support Helpline (JOSH)
via the **Colostomy UK** 24–hour free
helpline 0800 328 4257
e–mail info@ColostomyUK.org

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

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

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

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

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

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.

If, you are thinking of starting a support group in your local area, or are perhaps about to take over the running of an existing one, then please don't hesitate to get in touch with us for advice,
Tel: 0118 939 1537 or e–mail: info@ColostomyUK.org

Stoma support groups
in your county

Channel Islands

Guernsey

Guernsey Ostomates
Luci Deane 01481 236 077 / lucideane58@gmail.com

Jersey

Jersey Ostomy Society
Fiona Le Ber: 01534 445 076 or jerseyostomysociety@gmail.com

England

Bedfordshire

Saturday Social Club
Karen Richards: 01234 792 278

Berkshire

E.B.O.C (East Berkshire Ostomy Club)
Jackie Dudley: 01344 426 652

Reading Bowel Cancer Support Group
Ted Wingrove 0118 961 8297 or 07974 790 558

WAMS (Windsor, Ascot, Maidenhead & Slough) Stoma Support Group
If you are interested in joining then please please e-mail info@ColostomyUK.org or call us on 0118 939 1537

Bristol

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

Buckinghamshire

High Wycombe Stoma Support Group
Jan Peacock telephone 01494 715 139, e-mail peaky461@gmail.com

Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary) mkssg.sec@gmail.com 01908 567 091

You Are Not Alone Stoma Support Group
Carla 07846 354 918 e-mail: carla_wright@sky.com

Cambridgeshire

Peterborough Stoma Support Group - Ostomistics
Alan Wright 01354 653 290 / 07836 661 102 http://www.ostomistics.org/

Cheshire

Countess of Chester Hospital Stoma Support Group
Stoma Nurses 01244 366 170

East Cheshire Stoma Support Group
Catherine McIntosh: 01477 535 071

Stockport Support Group
Marion Caulfield: 0161 320 9400 / 0800 652 6667

Warrington Ostomy Support Group
Jane Shaw: 01925 662 103

Cleveland

Oops Group
Julie Morrisroe/Carol Younger/Alison Hall-O'Donnel: 01287 284 113

Co Durham

Bishop Auckland Stoma Care Group
Mrs Maureen Davison tel: 01388 818 267 email: trebornosivad@tiscali.co.uk

Darlington Support Group
Sister Jacqui Atkinson: 01325 743 005

Durham Stoma Support Group
Sister Maxine Santana 0191 333 2184

Cornwall

Cornwall & Plymouth Bowel Cancer Support Group
The Secretary: 01872 241 145, cbcsginfo@gmail.com or website www.cornwall-bowel-cancer-support-group.co.uk

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

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

Cumbria

Grange Cancer Support Drop in
Marie O'Connor 015395 33279

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

Derbyshire

Diverted Local Stoma Support Group
Diana Manning: 01283 541 311

Devon

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

Mid Devon Ostomy Support Group
Janice - janice234ford@gmail.com

Plymouth & District Bowel Cancer Support Group
Wendy Wilson - Facebook: Plymouth Bowel Cancer

Dorset

Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Bournemouth)
Beryl Andrews 01202 483 303

Colostomy Urostomy Pouch Ileostomy of Dorset - CUPID (Poole)
Jenny Pipe: 01202 740 440

Colostomy, Urostomy, Pouch & Ileostomy of Dorset - CUPID (West Dorset)
Colin Clare - 01305 853 238

Essex

Connect
Lin Hart 01279 505 273 email: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group
Paul Foulger: 01245 224 374

N.E.S.S (North Essex Stoma Support)
Brian Waller- 01206 540 449

Optimistic Ostomates
Angela Taylor 01702 385 510

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

STEPS - Stoma Essex Patients Support
01268 451 937 or email- stepsessex@gmail.com

Gloucestershire

Vale Stoma Support Group
jfn.dursley@gmail.com or text 07941 827 393

Hampshire

Replummed stoma support group
www.replummed.me

Solent Ostomates Support Group (S.O.S.)
For information tel. 07527 707 069 or solentostomates@hotmail.co.uk

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

The Hampshire Ostomates Support Group
Contact Nicki Beare on 07771 558 458 or Nichola0405@yahoo.co.uk

Waterside Stoma Support Group
Hazel Derham: 023 8089 1934 or hayjuder@sky.com

Wessex Urology Support Group
Mrs Jo Stacey: 07910 786 978

Herefordshire

Herefordshire Stoma Support Group
Carol Steele 01432 880 656 or email: carolsteeleglo@gmail.com

Hertfordshire

Colonise
Anastasia 01727 760 981

Ostofriends Support Group
Peter Lannen ostofriends@gmail.com 07501137511

Stevenage Ostomistics
Judy Colston: 01438 354 018 / neilcolston@btinternet.com

Isle of Man

IOM Bowel Cancer Patient and Carer Group
Heather Norman: 07624 480 973

Stoma Support Group
Carole Cringle stoma nurse: 01624 650 212

Isle of Wight

Optimistics
CNS's Sarah Capon & Sarah Varma 01983 534 009

Kent

Ashford Stoma Support Group
Carole Hobbs: 01303 814 014 or Margaret Webb 01233 628 807

Atoms Support Group
Maria Culleton, SCN: 01227 769 679 or 07827 997 424

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

Dover Stoma Friends Group Support
Julie Bell/Ros Marshall: 01233 616 646 and Support Group Organiser June Golding: 01304 822 696

GOGS (Gravesend Ostomy Support Group)
Tracey, Helen or John
on 07948 974 350

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

Maidstone Stoma Support Group
Judy/Kirsty: 01622 224 305

Tunbridge Wells Stoma Support Group
Cathy Chitty/Mags Donovan 01892 632 323

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

SWANS Stoma Support Group
Heather - 07711 445 312

Thanet Stoma Buddies Support Group
Kathy 01843 291 825

Lancashire

North Manchester and Bury Stoma Support Group
Julie Meadows (SCN) 0161 720 2815 or 07774 263 563

Oldham Stoma Support
June Wilde: 0161 312 5538

Phoenix Bowel Cancer Support Group
Sandra Peet: 01772 683 790,
www.phoenixgroupbvh.com
or eMail: sandrapeet7@aol.com

Kangaroo Klub, Blackpool stoma support group
For further details please contact the stoma department at Blackpool Teaching hospitals, Tel: 01253 956 620 or e-mail crc-stomanurses@bfwhospitals.nhs.uk

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 Williams - 01205 724 120,
Sheila - 01205 364 493

Grantham Support Group
Bobbie/Rachel: 01476 464 822

London

Bowel & other Cancer Support Newham
020 8553 5366

London

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

Rectangle - Colorectal Cancer Support Group
Regina Raymond 020 7472 6299

South Woodford Support Group
Nurse Christina and Lisa: 020 8535 6563

Surrey & South London Bowel Cancer Support Group
Sue Berry: 01737 553 134
or John Amos: 020 8668 0796

Time 2 Talk
Ifrah Mohamed - 07463 838 718
mybodysauthor@gmail.com,
Viki Palmer - 07894 276 986

Merseyside

I.C.U.P.S
Sue: 07742 237 013

St Helens Cancer Support Group
01744 21831,
Denys Floyd- 01744 884 097

Middlesex

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

Norfolk

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

STARS (SToma And Reconstructive Surgery social support group)
Sylvia Hughes 01263 733 448
sylvia.ruth.hughes@gmail.com

Norfolk Ostomates Support Group (on Facebook too)
Barbara Harris 01603 417046 07789 581 312

James Pagett Ostomy Support Group (Afternoon Meeting)
Vicki Blackwell on 01493 663 363

James Pagett Ostomy Support Group (Evening Meeting)
Sandra Hutchings: 0150 258 5955

Northamptonshire

Northampton Ostomy Support Group
07801 316 403 (evenings)
or Trish 07703 188 386

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull: 07714 479 320

Hexham Ostomy Group
Judith on 07967 927 286

Northumberland Cancer Support
members@northumberlandcancersupportgroup.co.uk

Nottinghamshire

North Notts Stoma Support Group
Tore & Nicky Norman: 01773 715 460

Nottingham QMC Stoma Support Group
Rosemary Brierley: 0115 982 6691

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

Shropshire

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

Somerset

Stoma Heroes Support Group
Shane Green 07802428074
Shane@stomaheroes.com

Staffordshire

Outlook The North Staffs Ostomy Support Group
Moira Hammond 07788 402 195 or e-mail: cm.hammond@ntlworld.com

County Stoma Group
Christine Bryden 07757 911726 or e-mail: countystoma&yahoo.com

Suffolk

East Suffolk Ostomy Group
Marion Fisher: 01473 311 204

L.O.G.S (Lowestoft Ostomy Group Social)
Mandy O'Shea: 07899 913 617 or
Bruce Pollard: brucepollard@me.com

West Suffolk & District Stoma Group
Jessica Pitt stoma nurse: 01638 515 525

Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor
or Sheena: 01372 735

Normandy Colostomy Support Group
Marina Harkins: 01483 233 126 or 07852 554 049 or Jackie Sanders: jackie-sanders@hotmail.co.uk or 07815 603 742. Website: http://www.normandystomagroup.wordpress.com

Stoma Support Group
Robin Young: 01428 723 255

Sussex

Brighton & District Support after Stomas (SAS)
Sylvia Bottomley: 01273 554 407

Chichester Stoma support Group
The Stoma Care Team 01243 831 527

The Ostomy Friends Group
Jane Quigley: 01323 417 400 ext 4552

West Sussex Princess Royal Stoma Support
Tina Walker: 01444 441 881 ext 8318

Tyne and Wear

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

NHS Molineaux Centre
John Burchell 0191 265 1047

Royal Victoria Infirmary Support Group
John Burchell 0191 265 1047

Sunderland Support Group
Michele Downey 07704 949 30
email: micheledowney@outlook.com

Warwickshire

Warwickshire Stoma Support Group
nuneatonstoma@aol.com
or Bob: 07564 680 803

West Midlands

Coventry Stoma Support
Martin - 07947 385 643

Wiltshire

Swindon IA
www.swindon-ia.org.uk

Wessex Stoma Support Group
Michael Slater: wessex.stoma@yahoo.co.uk or on 01722 741 233 www.wessex-stoma.co.uk

Worcestershire

Kidderminster & District Collossus Support Group
Brendon Drew: 01299 400 843

Yorkshire

Acorn Ostomy Support Group
07580 693 155 (After 6-00pm)

Airedale Stoma Support
Sue Hall: 01535 646 373

Barnsley Bottoms Up Stoma Support Group
Stoma Nurses 01226 4325 28 or Celia Utley (Chairman) 01226 284 262

Behind You (Calderdale & Huddersfield Bowel Cancer Support Group)
Stoma Care Nurses: 01484 355 062

Bottoms Up (for urology and colorectal cancer patients)
John Whelpton 07974 657 146 email: midyorks.bottomsup@gmail.com

Dewsbury & District Ostomy
Janet Edmond: 01924 512 041 or 01924 512 072

Hambleton and Richmondshire Ostomy Support Group
Stoma Nurses - Judith Smith and Mary Hugil 01609 764 620/07736 295 131

Harrogate Stoma Support group
Stoma department office Nurse Gill Wilson/Fiona Holtham 01423 555 786

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

Scarborough Stoma Support Group
Stoma Care Team: 01723 342 388

The Hull and East Riding Colostomy Support Group
Pete Smith: 07989 565 335 or Pete Rennard: 07939 518 642 / 01482 793 966 or Rosanna Grimsby: 01482 801 575. www.hercosg.org.uk

Northern Ireland

County Antrim

Colostomy UK Volunteers Northern Ireland
Chris Wright: 07720 717 771

Belfast City Hospital Stoma Nurses
Audrey Steele, Karen Boyd, Kirsty Niblock, Annette Lambert, Emma Dunn tel 028 9504 5941

County Armagh

Craigavon Area Hospital
Claire Young/ Lynn Berry/ Tanya Garvie 028 3756 1845 (Direct Line)

Daisy Hill Hospital Support Group
Bernie Trainor: 028 3756 2932 (Direct Line)

County Down

North Down Stoma Support Group
Adrian Ewing on 07850 741 511

Ulster Hospital
Hazel/Martina: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane: 028 7034 6264

Republic Of Ireland

Dublin

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

County Mayo

Mayo Stoma Support
Marion Martyn: +353 94 902 1733

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Jim Krasewitz: 01292 220 945

Stoma Care And Recovery (SCAR)
Maggie: 01294 271 060/ 0781 773 6147 maggie13@sky.com or Rhona: 01294 557 478

Fife

Fife Ostomy Support Group
Ishbel Barr: 01592 772 200

Lanarkshire

Glasgow Stoma Support group
-Morag Sinclair 0141 779 1322 or Jackie McChesney 01505 324 052

Moray

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

Scottish Borders

Stoma Support Group
Nancy Fraser: nancyfraser@talktalk.net or 01450 374 012. Fiona Gentleman: r.gentleman@sky.com or 01450 371 063

West Lothian

GOSH (West Lothian)
Scott Pattison: 07502 163 644

Bring Your Own Bag Stoma Support Group
Western General Stoma Team 0131 537 1000

Wales

Aberystwyth

West Wales Stoma Support Group
Shirley Jones: shirleyejones78@gmail.com

Bridgend

Bridgend Ostomy Patients Support Group
Anita Brankley (Secretary) 01656 645 602 or bridgend.ostomy@gmail.com

Carmarthenshire

W.O.W.S. Wales Ostomy West Support
Judi Hopkins 01267 237 847 or Julian Boswell 01554 772 877

Conwy

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

Gwent

Blaenau Gwent Self Help
Celia McKelvie: 01873 852 672 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
Chair person 01685 877144

Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Roy Whitfield 01437 760 701

Powys

The Bracken Trust Cancer Support Centre
Helen Davies: 01597 823646

Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear 01443 443 053

Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins: 01792 418 245

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