Autumn 2022 | Issue 67 | £6.25

Colostomy UK

AWARD-WINNING

# Tidings

Supporting & empowering ostomates

## Will you Step Up For Stomas this September?

PAGE 32

Judy Colston Retires after 25 Years as a Volunteer

PAGE 43

Crafting Kept Me Sane and Slim!

**Real stories Real people**

Colostomy UK

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# Dear readers

**As I write this it is early July. I'm in the International Conference Centre in Edinburgh with Cameron, our public relations and engagement manager, attending The Association of Coloproctology of Great Britain & Ireland's annual conference.**

We got here yesterday evening, having braved the chaos at Heathrow, and on arrival were struck immediately by how cold it was! This didn't stop us taking a stroll along the Royal Mile. I have to admit it is my first ever visit to Scotland. Edinburgh castle was as impressive as I was expecting, perhaps more so in fact, looming as it did against a grey and overcast sky. You can read more about the conference and why it's important for us to attend such events in Colostomy UK News (pp. 6-7).

This edition has the usual mix of regular features and articles. Ambra Bertinara, who is a senior stoma care nurse specialist and also on the Tidings editorial board, has written our Dear Nurse, which looks at the issue of rectal pain and discomfort after surgery. We receive many calls about this on our Stoma Helpline. We have an interesting piece from our volunteer Katie Sainsbury, about purple urinary bag syndrome. The IBD Registry, who are a not-for-profit organisation, give an overview of their work and explain how by collecting patient data, they can help hospitals to treat their patients more effectively. Finally, there is an article on crafting, from Shirley Jones, who contributed to our lockdown memory quilt, and a short biography of Libby Herbert, Colostomy UK's Chief Executive Officer.

Two of our three real lives stories diverge slightly from the norm. In the first, Stewart Russell reflects on the issue of body image, thinking about how this can be affected by stoma surgery and how he has come to accept the way he looks and feels. In the second, Linda Boulter uses a short story to examine how ignorance about stomas can negatively impact ostomates. Although this is a piece of fiction, you will quickly pick up that it is written from a position of experience. For me, it has an all too familiar ring and encapsulates perfectly why Colostomy UK's StomaAware campaign is and will continue to be important for the foreseeable future. Our third story is about Judy Colston who, after many years as a Colostomy UK volunteer is retiring. As you will see, in the time she has been with us, Judy has helped ostomates in lots of different ways having been driven to volunteer after going through stoma surgery herself in 1996.

I wanted to finish on a more sombre note. As I am sure you are well aware, organisations across the world are having to deal with rising costs. Sadly, Colostomy UK has not been immune to this. Tidings in particular has suffered, with the cost of paper and printing (driven by rocketing energy prices) rising by over 20 per cent between the winter and spring editions alone. Thankfully, due to the generosity of people like you we can keep producing our much-loved magazine, but your ongoing support is now needed more than ever before!

Best wishes,

Richard

Richard Biddle
Editor, Writer & Researcher

Colostomy UK

**Colostomy UK** is a national charity that offers support and advice to people living with a stoma, their families, carers, and friends. We're here if you have questions, need support or just want to talk to someone who lives with a stoma.

We also run projects to **EMPOWER** ostomates to return to sports, hobbies and other interests and give them the confidence to take up fresh challenges. We are advocates for ostomates' rights and their voice on the bigger issues. Our campaigns raise awareness and encourage organisations to make their facilities more inclusive. **SUPPORTING** and enhancing ostomates' wellbeing is at the core of everything we do.

**How to contact us**

**Stoma helpline for:**

Emotional support, experience-based advice and guidance from a volunteer.
**0800 328 4257**
24 hours a day and completely free.

**Adminline for:**

Information packs, ID cards, RADAR keys, travel certificates and Literature.
**0118 939 1537**
If we're not in, just leave a message.
**hello@ColostomyUK.org**

**To request (or cancel) your quarterly copy of Tidings call 0118 939 1537**
**hello@ColostomyUK.org**

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**Join our 'private' 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!

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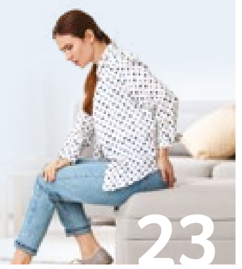
# Contents


10


16


23

27


41

## Colostomy UK News

6 Colostomy UK: **News**
13 **Volunteers**
20 **Active Ostomates**
39 **A Short Biography of Libby Herbert, Colostomy UK's CEO**

## Real Lives

10 **The Day Katie Spoke Out About Hidden Disabilities** – By Linda Boulter
16 **If I Were an Antique Vase…** – By Stewart Russell
32 **Judy Colston Retires after 25 Years as a Volunteer** – By Richard Biddle

## Wellbeing

23 **Dear Nurse** – By Ambra Bertinara
25 **Could Your Health Data Help Improve IBD Treatment and Care?**
40 **What is Purple Urinary Bag Syndrome? (PUBS for short!)** – By Katie M Sainsbury
43 **Crafting Kept Me Sane and Slim!** – By Jacqui Ramsey

## Fundraising

27 **Will you Step Up For Stomas again this September?**
36 Colostomy UK: **Fundraising**

## Support

47 **Your Letters and Emails**
51 **News from Support Groups Across the UK**

**Donating to Colostomy UK**

An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 45 for our donation form.

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

Colostomy UK

# news

**Libby Herbert**
General Manager
Libby.Herbert@ColostomyUK.org

## *Welcome to the* TEAM


**Nicola Kendall**

**Nicola Kendall joined Colostomy UK in June 2022 as Finance Manager bringing with her a wide variety of finance experience ranging from water companies to pub chains to schools.**

Her CV also includes time working as a chocolate taster. We didn't realise you could be paid for that! Outside of work Nicola enjoys spending time with her family including lots of walks with their new puppy, going to exercise classes as often as she can motivate herself to and singing in a local choir.

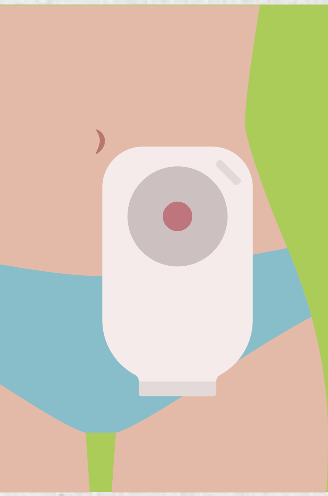
## Changes to the Board of Trustees

**At our AGM in July, we said goodbye to David Buchan, our Secretary and Governance Trustee and thanked him for all his hard work over the past few years.**

David has been replaced by Matthew Pollitt. Matthew has been aware of us since becoming an ostomate ten years ago and was thankful for the help we gave him. Matthew has over 30 years' experience working in various charities in roles ranging from HR to finance and legal services and is pleased to use his skills in the service of Colostomy UK.


**David Buchan**


**Matthew Pollitt**



## Research

**In the past few years Colostomy UK has had more involvement with stoma-related research. Indeed, if you are a member of our Private Facebook Support Group, then you may have seen posts asking for ostomates to participate in studies.**

Last year we supported a funding application for a project led by Keele University, aimed at developing resources and training to better support young adults with stomas. The application was successful, and we were very pleased to be asked to sit on the research steering committee. The first meeting was in late May, and Richard (editor of Tidings!) represented Colostomy UK.

# OUT & ABOUT

## The Annual Meeting of the Association of Coloproctology of Great Britain and Ireland

**Richard and Cameron were lucky enough to attend this event in Edinburgh.**

Despite some initial problems getting exhibition materials delivered, they were able to talk with many surgeons and colorectal nurses and let them know how we can support their patients. Events like this are a great opportunity to raise awareness about Colostomy UK amongst healthcare professionals and tell them all the charity does.

## Call to Action!

**On 20 July, as part of a joint initiative with Coloplast UK and Ireland, The Ileostomy and Internal Pouch Association and the Urostomy Association, we ran in a relay race to Parliament to launch a new 'Call to Action' statement.**

Developed by ostomates, this sets out the changes and improvements that are needed for people with stomas to access optimal care and live life to the full after their surgery. The relay started at a London hospital and ended directly outside Parliament, with a reception where all those involved handed their message or 'baton' to policymakers!

## Trip to Coloplast

**In early June, Coloplast held two Innovation Days which involved tours of their headquarters in Peterborough.**

Cam represented Colostomy UK and found it an insightful and worthwhile trip. He was shown around a call handling office and distribution centre for ostomy products. The latter he found especially awe inspiring just from its sheer scale. As our Public Relations and Engagement Manager, developing good relationships with the stoma industry is vital and Cam was able to make some useful contacts over the two days.

## Summer Nursing and Midwifery Conference

**Jo, Angela and Jacqui from the office team ran the Colostomy UK stand.**

It was the first time we have attended this event and we were very glad that we did. As you will know from previous editions of Tidings, we have begun to talk more about stomas and childbirth trauma, so it was a great opportunity to let midwives and nurses know what we can offer their patients if the need arises.

Colostomy UK

# Annual Prize Draw

Dear Reader

**In past years your copy of Tidings included a book of raffle tickets for our annual prize draw.**

The amount raised each year from the prize draw makes a significant difference to Colostomy UK and helps to run our support services including our stoma helpline and produce this magazine.

We are running the draw as usual this year but in a slightly different way. Rather than having a book of tickets, we are using the entry form you can see on the opposite page.

To enter the prize draw you just need to complete the form, selecting the number of entries you would like to buy (each one costs £1), and then return it to us with your payment.

Your unique draw numbers will be allocated to you on receipt of your entry. Let us know if you would like to receive an email confirming these.

**So why are we changing things?**

Quite simply, it's to reduce costs so that more goes towards supporting the ostomate community. With the old way of doing things we had to pay to produce the raffle tickets. There was also an insertion fee for the magazine. Changing to the new way of doing things removes both these costs!

If you have any queries, please email **GetInvolved@ColostomyUK.org**

Colostomy UK

## Would you like **more**?

**More** news from Colostomy UK direct to your inbox.

**More** information about the latest stoma product updates.

**More** opportunities to take part in surveys and have your say on the future of stoma care in the UK.

**More** access to our support literature and factsheets about all aspects of living with a stoma.

**Get more from Colostomy UK by signing up to receive our monthly e-newsletters. Just visit www.ColostomyUK.org and click on the 'e-newsletter' tab**

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Colostomy UK

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You can also order your draw entries online at **colostomyuk.bigcartel.com**

No tickets may be sold by or to anyone under 18 years. No tickets may be sold on the street. Promoter: Mr Giovanni Cinque, Colostomy UK, 100 Berkshire Place, Winnersh, Berkshire RG41 5RD. Please return no later than Friday 21 October 2022. Late entries will be treated as donations. Winning numbers will be selected by random number generator and notified by telephone, email or post and announced in the Spring 2023 edition of Tidings. Colostomy UK is a charity registered in England and Wales No: 1113471. Lottery Licence no: LOT000141

T67

# The Day Katie Spoke Out About Hidden Disabilities

BY LINDA BOULTER

> **"I'm afraid we will have to operate, and you will have a permanent stoma."**

A few minutes later Katie, holding her husband Chris's hand, replied: "If that's what keeps me from dying and gives me longer with Chris and my family, that's fine."

The consultant raised his eyebrows, probably in amazement that Katie remained so matter of fact about the shocking news.

"Will I lose my hair if I need to have chemotherapy afterwards?" she asked.

The Macmillan nurse sitting opposite her smiled, maybe with amusement that Katie seemed more concerned about losing her naturally blonde hair, which would grow back, than having a stoma. She joined the conversation:

"Let's not worry about that yet, you may not need chemotherapy."

"Okay, that's fine, what happens next?" Katie looked at the consultant, then the Macmillan nurse for more information.

The next few weeks were a whirl of scans and appointments leading up to operation. The operation was then followed by gruelling treatments. Katie had no problems adjusting to life with a colostomy, but more importantly, the treatments did not result in any hair loss!

Over the following years, Katie recovered as much as she could and family and working life resumed. Her first recollection of 'bags' was when she was a young child. She had barged into the spare bedroom forgetting a relative was stopping over, only to find him changing his bag. Not knowing anything about bags, it played on her mind afterwards. This was made worse by her mum's response. When she rushed downstairs and said she was frightened, her mum put her finger over her mouth saying:

"Shush Katie, go outside and play."

Back then the stigma of 'having a bag' was far greater than now. Thankfully, things have since improved. Prior to having her operation, Katie had participated in Colostomy UK's 'Step Up For Stomas' challenge, because one of her friends had an ileostomy. So, when it was her turn, she already knew people who had 'bags', which is probably why she was able to cope better with the news she was to have one. Not once had Katie thought, "Why me?".

Having now lived with her bag for five years, the one thing that still irked her though, was when she overheard people saying things like: "Did you know (so and so) has a bag?" or "Don't you feel sorry for (so and so)? they have a bag!". To her this revealed that there was still a level of ignorance out there. It was something she had thought about a lot recently and in doing so had to admit that prior to her surgery, she too had been guilty of making such comments. At the time, it had never occurred to her to question whether all those people with bags (permanent or temporary) might not want sympathy. She had just assumed that having a bag was bad news, forgetting in the process that for many people, that bag was responsible for saving and restoring their life.

She had also done a lot of thinking about disabilities and hidden disabilities. In some ways Katie wished she had made a career in some kind of healthcare work. But it was too late now, she had spent her working life in retail and this was what she knew. Besides, changing paths would cost money to retrain, and she needed this to help with the bills, not spend on herself. It was good to dream about what might have been, but Katie enjoyed her job at the city department store regardless. She loved the hustle and bustle of the branded clothing department where she worked and had many good friends.

When Katie returned to work after her operation, her bosses were supportive and made reasonable adjustments to accommodate her needs, which from a practical point of view made her feel comfortable to be back. She worked three long days each week, including one day on alternate weekends. Apart from her bosses and a couple of work colleagues who she worked closely with, no-one else at work knew she had a colostomy. To Katie's mind, there was no need for anyone else to know. She didn't keep it a secret, but she didn't broadcast it either.

One day this all changed, when Katie overheard snippets of a conversation while she was on her morning break. It was just after eleven o'clock and the canteen was packed. She didn't see anyone she knew so sat on the only empty chair she could find at the end of a long table. It was a big department store with lots of staff all working different shifts and because of this she recognised people's faces but rarely knew their names or went further than a polite good morning. It happened while she was sipping her coffee and replying to a text message from her daughter:

"Do you know when Kay is coming back?" said one woman.

"No, I spoke to her husband, and he thinks it could be a month or so," replied the other.

"I heard she is having a bag. That sounds horrible, bet she won't be able to come back with one of those"

If that wasn't enough for Katie, the two women both pulled a face. Although she was normally quiet and reserved, Katie felt her temperature rising. Reacting to this red flag, she suddenly found herself standing up and glaring at the two women. What followed surprised her even more, as she heard herself shout:

> **"I have what you call a bag. If I didn't, I would be dead."**

As an awkward silence descended on the canteen, Katie grabbed her belongings and headed, blushing, to the toilets. Inside, she splashed cold water on her face, doing her best to compose herself before returning to her department. She tried to put the whole incident out of her mind and thanked her lucky stars that after today she wasn't back at work until the weekend.

Despite being busy at home over the next few days, her mind kept returning to the incident. She had mentioned it to Chris at tea one night and his reply was, "Good for you!". It was so out of character for her to speak up like that. She felt bad about eavesdropping, but the women had been so loud, and it was offensive, particularly the way they pulled faces at each other. To make matters worse they were chatting in public about their friend and work colleague's personal business, someone who had clearly been through such a lot.

So much was going on in Katie's mind and for once she was not looking forward to going in to work. But once back it was business as usual. Katie's only remaining concern was bumping into the two women. When it reached late morning, her boss rang down and requested to have a word with her at two o'clock. Katie decided to go out at lunchtime for a walk as she felt anxious about the meeting. When it reached two o'clock a nervous Katie knocked on her boss's door.

"Come in."

Katie walked in and to her surprise the two members of staff who made the comments in the canteen were sitting on chairs next to her boss's desk, both looking a little sheepish. Her boss swivelled her chair around and welcomed Katie:

"Katie, Helen and Julia have something to say to you."

"Both Julia and me are very sorry, Katie. We didn't realise how hurtful what we said was. To be honest we are a bit ashamed. We have got you these flowers and hope you will accept them."

"You are both forgiven," a shocked Katie replied.

"Let's just learn from it, I have… I shouldn't have been eavesdropping on your conversation. Thanks so much for the flowers, they are beautiful."

With that, the two ladies left the office, leaving Katie with her boss.

"Someone reported to me what happened. Thank you for accepting their apology. Obviously, I knew you had a stoma, but I guess not everyone does. I hope you didn't mind me calling you in like this?"

"No not at all, it's not a secret, but just something I don't go round broadcasting… well not normally!" Katie laughed.

"Well I wondered if you would consider this? We are in the process of doing our new promotions brochure. How do you feel about modelling some sportswear with another staff member from our London store? He has a stoma too. Our new lines of sportswear are suitable for people with stomas and hernias."

"Wow, I like the thought of being a model especially if it raises awareness. Anything that reduces the stigma of a stoma can only be good." Katie smiled. "I also think that I will treat myself to some fancy unique cover for my bag!"

They both laughed.

Katie went back to her section. Her worries lifted. She smiled to herself, amused at the thought of modelling sportswear! Maybe a celebratory take-away was in order tonight!

**Editor's note:** For me, the most important message this story conveys is how damaging lay perceptions of stomas and bags can be for people. I think the author did well to capture this through such a simple scenario. **This is why awareness matters**. Imagine if the conversation had occurred on Katie's first day back at work after surgery and the impact this might have had on her recovery. And sadly, though a fictional account, it has an all too familiar ring.

# Colostomy UK volunteers

**Maxyne McGinley**
Volunteers & Community Manager
Maxyne.Mcginley@ColostomyUK.org

### A message from Max:

In a couple of months, I will be celebrating my first anniversary with Colostomy UK. I can't get over how quickly time passes here. I think it's because life as the Volunteers & Community Manager is always so busy! So far this year we've already managed to deliver twelve training sessions for new volunteers, many of whom are now up and running.

What's been nice also, is that we have started to see more younger people volunteering. This is really important for us, because not only do they bring fresh ideas and a new perspective, but they also connect well with the many younger ostomates who contact us for support.

Traditionally, charities (including Colostomy UK) have thought in terms of volunteer roles, e.g. helpline volunteer or hospital visitor. But the more I work with our volunteers, the more I realise that we need to think broader and tap into their wealth of skills and experience. This was never more evident than when a call from St Mark's Hospital in London led us to discover that our volunteer Merv Quick, who we thought of as an 'open day' and 'telephone' volunteer, was also a consummate speaker…

## Volunteering: Not Always about Handling Phone Calls

By Merv Quick


Merv Quick

**For many, the thought of being a volunteer means manning a phone to answer questions and provide support to those with or about to have a stoma. There are many other ways that a volunteer can help Colostomy UK.**

Recognising that some ostomates are concerned about travelling, particularly overseas, I wrote an article for Tidings: Travelling with a Stoma.

I thought this contribution was then done and dusted, and hopefully had achieved its goal. However, life has many surprises. It transpired that a consultant stoma nurse at St Mark's Hospital in London was planning to give a presentation at the World Conference of Enterostomal Therapists in Texas, on travelling with a stoma. Having read my article, she contacted Colostomy UK and asked if I could assist with her presentation. Naturally, I was only to pleased to help.

After some discussion, we decided that at the end of her formal presentation, I would talk through my journey as an ostomate taking on the new changes of travelling with a stoma. Unfortunately, I didn't get a free ticket to Texas, but instead we made a video that she played. Feedback from the audience was, apparently, very positive and having a formal presentation followed by input from a live ostomate (as it were!) was a format that was appreciated.

This is probably one of the more unusual ways of helping as a volunteer, but there are many other opportunities where your time and input can help those struggling with both the changes and the trauma of living with a stoma.

If you would like to find out about volunteering for Colostomy UK, please get in touch. And remember, volunteering doesn't have to be an onerous commitment. It's about what works for you. Maybe you can spare a couple of evenings each month or the odd weekend to take calls on our Stoma Helpline, or perhaps you have some IT or design skills that you are happy to volunteer for specific projects… Either way, I can't wait to hear from you.

Max

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1. Coloplast, Product Evaluation, SenSura Mio, 2014 (VV-0197319). 2. Walker et. al. Raising the bar: new flexible convex ostomy appliance – a randomised controlled trial. WCET supplement 2016. 3. Laboratory Report: TM7064 Leakage test of Confidence Be from Salts and TRE from Dansac, compared to SenSura Mio from Coloplast, Coloplast, Data on file, VV-0283269 and VV VV-0294078

Coloplast

# If I Were an Antique Vase...

BY STEWART RUSSELL

**I guess we all do that body image thing from an early age. How can I be more like my hero? I suppose it starts in school where there's always somebody who has something that you wish you had, whether it's something material, looks or personality. Then it moves onto a pop star, a film star, a footballer, or maybe even a politician!**

So here I am, an old man with a stoma and slightly overweight. Old in the - being in my late sixties - sense. Overweight in the - medical healthiness - sense. And with a stoma in the permanent sense, as in the - had my anus removed so no alternative - sense.

Having massive surgery in your sixties means you are perhaps more aware of how your body is changed by the surgery. You've had plenty of time to get used to how it was. I think you do become conscious of body image under the circumstances. And realistically, life's 'best times' that seemed completely dependent on body image have passed.

Or perhaps those times were dependent instead on what I hoped would be someone else's perception of my body image? Actually, the most important part of your body image as you get older isn't what you can do with your body, it's what you can do with the bit between your ears. I think as a youngster I wouldn't have realised that.

Of course, I had a head start in the body image game. I was badly scarred from a very young age. My first steps were very nearly my last as I reached out for balance and pulled a boiling pot of tea over myself. Skin grafts and six weeks in hospital followed. So, I have never known flawless skin because it happened before I remember anything. And oddly enough I don't really remember even being aware of it at all until I was about six or seven years old. That's when you ask your parents, "What's this all about then?".

Happily, it hasn't put me off tea; I can drink it in copious amounts. But when you're in a PE vest at school and they ask you about it, "I pulled a pot of tea over myself when I was a baby," seems a bit lame somehow. So, I began to make up outrageous stories about how I'd ended up scarred. Fighting with lions or alligators was an early one. Rescuing someone from a burning building was a favourite, unless it was an attractive girl who had asked, in which case I was rescuing someone's pet cat. Eventually I had been a racing driver in a bad crash, the car burst into flames, and I couldn't face racing anymore.

Then I remember being in a football changing room and spotting a large mark on a team-mate's left shoulder blade. A familiar-looking wound. We compared notes. What was fascinating was that as babies we'd both had grafts of skin taken from the top of the inner left thigh. In babies the top of the inner thigh tends to be a smooth and delicate thing, but in an adult male it is often a rough and hairy thing. He and I are still the only two people I've ever known of with pubic hair on their shoulders. Because it had always been there, it never bothered me. The only time I really noticed it was when I had a physical job that required a lot of lifting, and as my arms grew stronger the grafted skin tightened across the muscles. But the muscles only grew so much, and the skin stretched in good time, so it wasn't a problem.

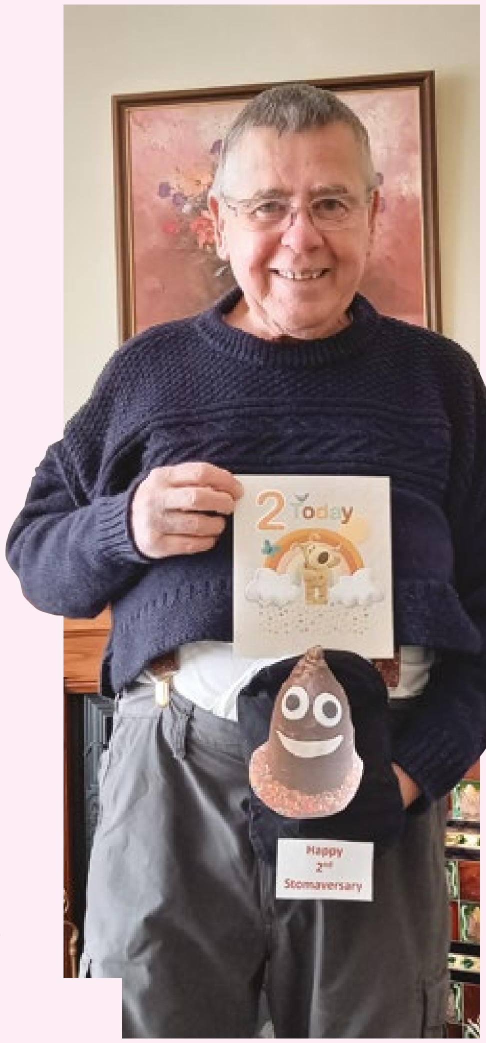
My body image might be intertwined with my philosophy on life, or vice versa. I've always been able to put bad things behind me. Once something unwelcome or unfortunate has happened, you can't make it un-happen. Because the image that my body shell projects has always been one of being 'slightly damaged goods', I've had to just get on with it. So, I've gone through life with an attitude towards happenings of 'Repair it, if possible, remember it and what caused it, and carry on.'

When prostate cancer came along, I didn't want to hear it. I was told I should have done something about the symptoms I'd been experiencing a year ago. But I couldn't un-happen it, so just had to deal with it and follow the treatment plan. This led to medically induced changes to my body again:

- superficially cosmetic in that I acquire three tiny tattoos for radiotherapeutic triangulation
- internal changes in that my prostate gets blasted by thirty-seven concentrated and focused blasts of radiation
- hormone treatment that makes me menopausal and sweat profusely, which doesn't help with my body image.

Then I developed a leaky bum, which wasn't piles as first suspected, but a mucus leak caused by a cancerous growth at the exit point. It turned out I had a four-centimetre-long tumour, which had grown into the wall of my back passage. Once again, I couldn't un-happen it. I was told I would need my anus removed and it was pretty clear that the operation was a matter of life or death and had to be carried out within a few weeks. On top of this I would also need a stoma! Perversely, I think it helped that there was a lot of death in my family at the time. It took my mind off my own potential misery. I had two funerals to attend, the second of which I had to arrange. With one dying from a secondary cancer diagnosis and the other from a massive stroke, I was actually well motivated for the surgery, looking forward to it in fact.

After my surgery, my stoma **'Zeppy the Zeppelin'** seemed completely unexceptional. I did my first couple of bag changes in the hospital, under supervision. It was quite easy, and of course the nurse didn't see anything odd or unusual about me pooing out of my belly, so why should I think it unusual or odd? Why should anyone think it was odd? It was great that I found my friends rallied round, although I was exhausted by the visits they made once I had got home. I recall one afternoon when three of them turned up independently and stayed for over an hour and a half.



During my first tentative game of golf, a very gentle stroll around a nine-hole pitch and putt, I was so conscious of the bump of my bag showing. But I was told it wasn't noticeable. With a support belt on, it is only really me who notices it under my clothing. Gradually getting myself back to fitness and finally playing walking football again, I ended up getting changed in the changing room with the rest of the team. Rather like in the film 'Crocodile Dundee' where he says, "That's not a knife, this is a knife!", I was bragging, "That's not a scar, this is a scar!".

I have no control over what Zeppy does, I just get on and deal with it, and so do people around me. I try to find humour in it. As I wrote this he was intermittently blowing into the bag, living up to his name of Zeppy the Zeppelin. My preferred footballing position is as a defender, and one of the footballers that I play against quite regularly in training sessions likes to back into opposing defenders. I tell him he'd best not back into me against my bag!

Physically I seem to be doing well. My footballing stamina has certainly improved recently, and my golf game is almost back to pre-operation levels. My partner of 37 years says she still fancies me. She's only ever known me with scars, what's a few more? After all this, it turns out I'm still me. Just a bit more battered around the edges, a bit older, probably no wiser.

**If I were to think of myself as an antique vase, my value at auction has probably gone down because of a few more chips and cracks, and the paintwork has faded a bit, but I am still more or less watertight. But that's fine, I am what I am.**

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# Literature range

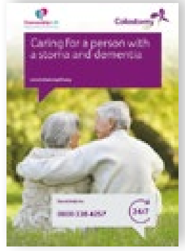
**Have you seen our extensive range of support literature? To order your complimentary copies, please download them from our website or contact us by:**

**Admin line:** 0118 939 1537 | **Email:** hello@ColostomyUK.org | **Website:** ColostomyUK.org/information

Active Ostomates sport and fitness after stoma surgery

Campaigns and Projects Flyer

Caring for a person with a stoma



Caring for a person with a stoma and dementia

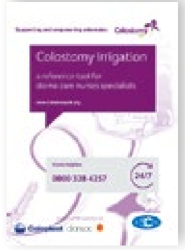
Colonoscopy through a stoma

Fundraising Pack

Healthy Eating

Helpline Cards

How will a stoma affect me?



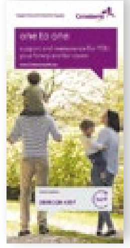
Irrigation Booklet

Irrigation DVD (nurses)

Irrigation DVD (patients)

Legacy Flyer

Living with a stoma



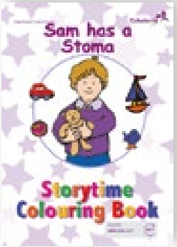
One to one

Ovarian Cancer and stomas

Pain and discomfort

Parastomal hernias

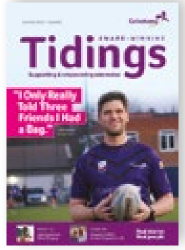
Rectal discharge



'Sam has a stoma' colouring book

Stoma friendly toilet guideline and stickers

Stoma reversal



Tidings magazine

Travel advice

Travel certificate

Tri-Charity leaflet

Welcome pack

#ActiveOstomates

# active ostomates®

**Giovanni Cinque**
Fundraising & Campaigns Manager
Giovanni.Cinque@ColostomyUK.org

## In with the new

**Although on the face of it society has returned to a certain level of pre-pandemic normality, research from Sport England and others has recently highlighted that physical activity levels amongst people with long term health conditions are not increasing at the same levels as the rest of the population.**

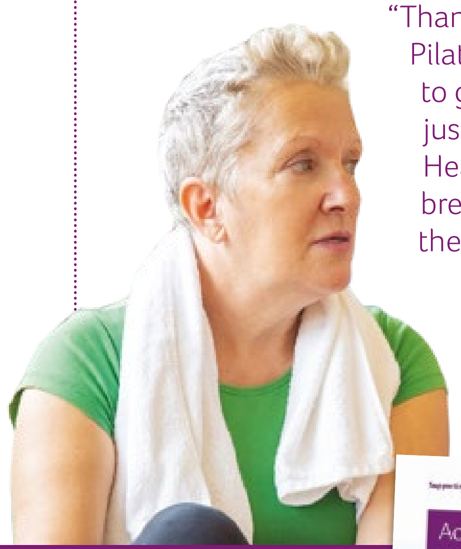
In response to this we will be launching several new Active Ostomates activities in the new year that will focus on providing safe and suitable activities, while also aiming to tackle challenges around loneliness and isolation, which have also increased in the last two years.

To keep up to date with all our new activities please email **getinvolved@colostomyuk.org** with 'Active Ostomates' in the title.

## Active Ostomates: at Home continues

**Our summer classes have now finished. We've had a really good response to our Yoga, Mindfulness & Meditation, Chair Yoga, and brand-new Pilates classes, with over 300 registrations and some great feedback too.**

They'll all be back again from the autumn so keep an eye on our website (**www.ColostomyUK.org**) and our monthly e-news for details of the start dates for new classes.



"Thank you for organising Pilates. It was fabulous to get back to it and just to focus on what Heather was saying, breathing through the movements and stretching my muscles. Such a big step in recovery!"

If you're looking to return to being active after stoma surgery, why not pick up a copy of our 'Sport and Fitness after stoma surgery' booklet? It is full of great tips for exercises you can do at home, and advice around how you can get back to playing team and individual sports. It also has details of some of the great community activities we provide.

If you would like us to send you a copy, please email **hello@colostomyuk.org** or call us on **0118 939 1537**. You can also download a copy at **www.ColostomyUK.org**

## Team Colostomy UK update

**Our Rugby League team had a brilliant couple of weeks towards the end of spring with lots of media coverage and new relationships developed as part of our game against the British Asian Rugby Association (BARA). This took place late May in Batley, West Yorkshire as a curtain raiser to the match between Batley Bulldogs and London Broncos. The idea behind the game was to help Colostomy UK reach South Asian communities in the UK so that people from these communities are more aware of who to turn to if they need support.**

In the build up to the game we met with Kim Leadbeater who is the Member of Parliament for Batley & Spen. She attended the game and, along with Ralph Rimmer, the Chief Executive of the Rugby Football League, met the team before kick-off and then got the match underway. Kim is also keen to support us in the future.

The buzz from both teams after the game was electric. There was a genuine camaraderie, and we all knew we'd been part of something special. Players from both sets of teams also came together to take part in a podcast on men's mental health led by BARA player and recording artist Saqib Murtza.

We had some great chats with both Ralph and Kim after the game, which left us feeling quite enthusiastic for the future, and had amazing support from everyone at Batley Bulldogs too. There was a genuine interest in wanting to find out what we do and the reasons behind it.

Back in the Colostomy UK office on the Monday morning after the long drive back down south it didn't take long before the first benefits from the game materialised. Thanks to Kim's support a telephone conversation with Rugby Football League's (RFL) head of legal Richard Yates, led to an invitation to present to the All-Party Parliamentary Rugby League group this autumn. We've also arranged an initial chat with the new RFL head of inclusion Ben Abberstein. All exciting stuff.

Later the same morning we received a call from one of our players who is a custody sergeant to say that he had just spoken with a South Asian solicitor who had recognised him from the media coverage he'd seen about the game!

The day after Radio 5 dedicated much of their day's content to stomas. This was after Radio One DJ Adele Roberts' recent surgery for Bowel Cancer. Fortunately host Naga Munchetty expressed her disbelief that someone with a stoma could play rugby. This led to a flurry of messages and calls, and an hour or so later we were live on air putting her right! While it was great to get the opportunity to be on the show, it also revealed that there's still a long way to go in tackling that stigma.

The teams next outing is on 17 July against the London 9s in Chiswick. This is just before Tidings goes to print, so I won't be able to tell you how we got on until the winter edition. But you still have two more opportunities to watch Team Colostomy UK tackling the stoma stigma this year. On 3 September we will be travelling to Lancashire to take on a Chorley Panthers Select side, and on 16 October the team will be in Newcastle for the 'Squads on the Tyne' festival. This is being played to coincide with the opening weekend of the Rugby League World Cup which sees both England vs. Samoa, and Scotland vs. Italy taking place in Newcastle.

If you're on social media, you can keep up to date with the latest news by following the team on Twitter or Instagram. Just search for the handle **@teamcolostomyuk**.

Colostomy UK

# dear nurse

**Ambra Bertinara**

Senior Stoma Care
Nurse Specialist

## Rectal Pain and Discomfort after Bowel Surgery

**Once recovered from stoma surgery, some ostomates experience pain and/or discomfort in the rectal or perineal area. The causes and treatment vary depending on the type of surgery that was performed and whether or not the rectum was removed.**

### Bowel surgery where the rectum is intact

#### What are the causes of rectal pain?

If you had a bowel surgery with stoma formation and the rectum is intact, you may experience pain and/or discomfort in the rectal or perianal area. You may continue to have the sensation of needing to pass a bowel motion, as the muscles and nerves in the rectum may still function as before the surgery.

The bowel also produces a lubricant called mucus, which helps food pass through the system. Even though the rectum is now redundant, mucus may still be produced. This can either be passed through your anus (back passage) or dry up and become difficult to pass, causing pain.

#### What can you do to alleviate the pain?

Sitting on the toilet can help. Gently bearing down as if you were opening your bowels may help to expel mucus. Doing this everyday can reduce the build–up of mucus too.

#### When should you seek medical help if you have rectal pain?

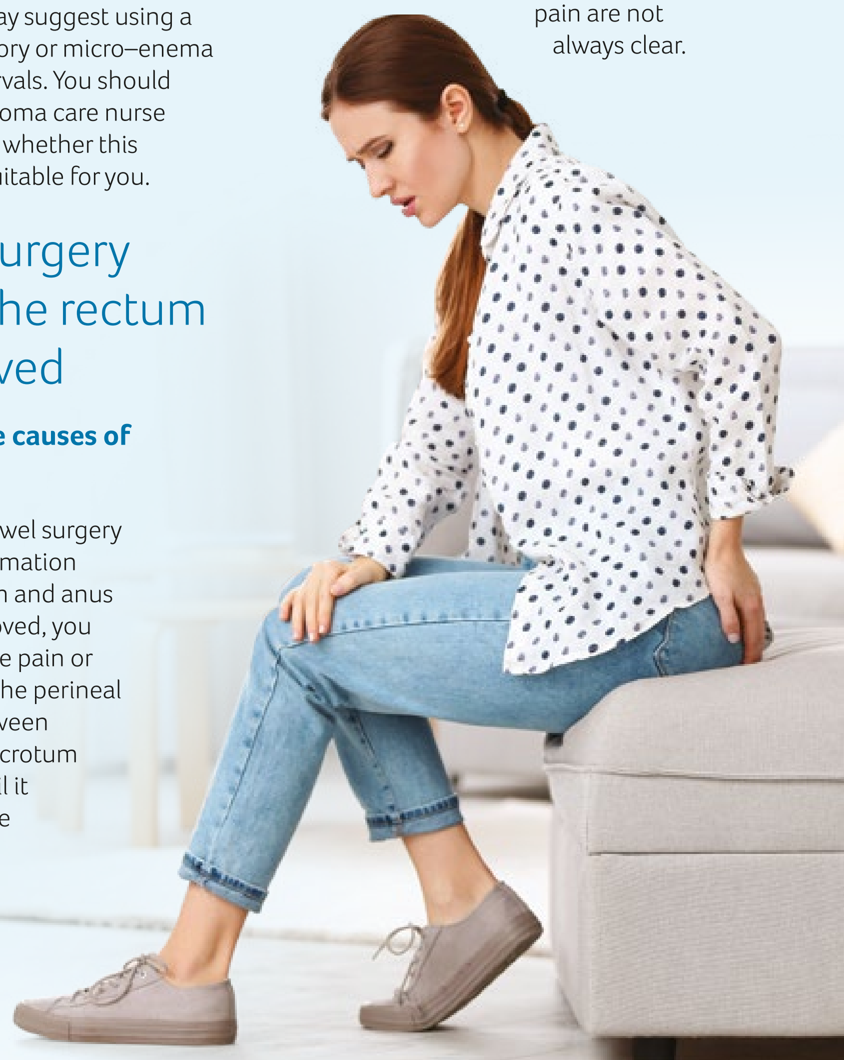
If you are unable to pass mucus naturally then your stoma care nurse or GP may suggest using a mini–suppository or micro–enema at regular intervals. You should consult your stoma care nurse or GP to check whether this treatment is suitable for you.

### Bowel surgery where the rectum is removed

#### What are the causes of rectal pain?

If you had a bowel surgery with stoma formation and the rectum and anus has been removed, you may experience pain or discomfort in the perineal area (area between anus and the scrotum or vagina), until it is healed. Some ostomates find that sitting for long periods is too uncomfortable, in particular in the first four to six weeks after surgery. The pain can be constant or intermittent. The adjectives used most frequently to describe it include: sharp, shooting, stabbing, burning or a throbbing sensation. Most ostomates find that the pain and sensation of needing to pass a bowel motion gradually diminish over time and then disappear.

The causes of pain are not always clear.



They can include scar tissue, where the surgical scar becomes hard and thickened. This is more likely to occur if the wound was slow to heal or the tissues were damaged by radiotherapy. The bowel or other organs in the pelvis pressing down on this scar can lead to a feeling of fullness where the rectum used to be. Another cause of pain is nerve damage (neuropathic pain). It is possible for nerve damage to be sustained during surgery, from radiotherapy and chemotherapy treatments, and from an infection.

### What can you do to alleviate the pain?

Sitting on the toilet and going through in your mind the process of opening your bowels can help to relieve the feeling of wanting to pass a motion.

For more persistent pain or discomfort, some ostomates report that tilting the pelvis reduces the pressure on the perineum. This can be achieved by lying on your back and placing a pillow under your bottom.

### When should you seek medical help if you have rectal pain?

Over the counter pain killers can help, but you should not use these without first speaking to your stoma care nurse or GP. This is because some can cause constipation, which might lead to problems with your stoma.

To obtain your copy of Colostomy UK's booklet please email: **hello@ColostomyUK.org** or call us on **0118 939 1537**.


Supporting and empowering you

Colostomy UK

Pain and discomfort

following stoma surgery

www.ColostomyUK.org

Stoma helpline:

0800 328 4257

24/7

# Could Your Health Data Help Improve IBD Treatment and Care?

People with IBD can now join the IBD Registry to help improve services for patients and support vital research.

### What is the IBD Registry?

We are the national database for Crohn's disease, ulcerative colitis and other types of inflammatory bowel disease (IBD). Our purpose is to help achieve better health and quality of life for people with IBD by collecting and analysing health data. We use this valuable information in different ways, such as:

- finding patterns and trends that help hospital teams improve IBD care
- monitoring how IBD is treated to support safe and effective medications
- supporting new research projects investigating IBD.

The IBD Registry is a not-for-profit organisation owned by the British Society of Gastroenterology, the Royal College of Physicians and Crohn's & Colitis UK.

Anyone in the UK diagnosed with IBD can join the Registry to help improve treatment and care and support vital research. Currently we are focusing on adults, but we are hoping to invite children and young people with IBD to join us later in the year too. You can find out more about how to join the IBD Registry, and how this helps people with IBD, in this article.

### How does the IBD Registry collect data?

The IBD Registry has been collecting data from hospitals for many years, creating a database of more than 85,000 patient records.

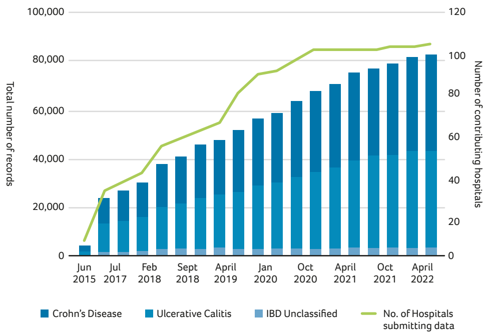
More than 100 hospitals across the UK work with us to share carefully selected information that can help improve care and treatment for people with IBD. This includes information about:

- diagnosis
- types of medications prescribed
- how long a patient takes a medication
- how active a patient's disease is
- details of hospital admissions
- surgeries a patient has had
- other information such as age and sex.

We have permission from the UK Government to receive this information in order to support better treatment and care for people with IBD. We do this by analysing the data so we can share useful insights and statistics with IBD hospital teams and researchers.

People with IBD can join the Registry using our online consent form, to tell us more about how they would like us to use their data, and to share information about their health with us directly.

Combining information provided by patients with data collected from hospitals creates a more complete picture of IBD care in the UK. Collecting and analysing this information on an ongoing basis means we can provide hospital IBD teams with a better understanding of the standard of care they provide, and how they can improve this for their patients. We can also look at how a person's IBD changes over time and how this is affected by their treatment. This information, used anonymously, can be really helpful for doctors and researchers working to make IBD treatments more effective.



People with IBD can maximise the value of their health data by allowing us to use it for research. If you're particularly interested in research and you have joined the IBD Registry, you can also give us permission to contact you about relevant studies you may want to take part in.

**1300+**

**patients have signed up to the IBD Registry's new research database.**

Figure based on IBD Registry consented database as of 25 July 2022

### How does the IBD Registry keep patient data safe?

We make sure that any data we collect is transferred to us securely and held within carefully controlled electronic databases in the UK. Any research that uses IBD Registry data is done in a secure digital space where only approved researchers and analysts can access the data. This is called a Trusted Research Environment.

Approved IBD researchers can apply to use our data, which is de-identified before analysis or research can take place. This means we protect your identity by removing information which could identify you, such as your name or NHS number.

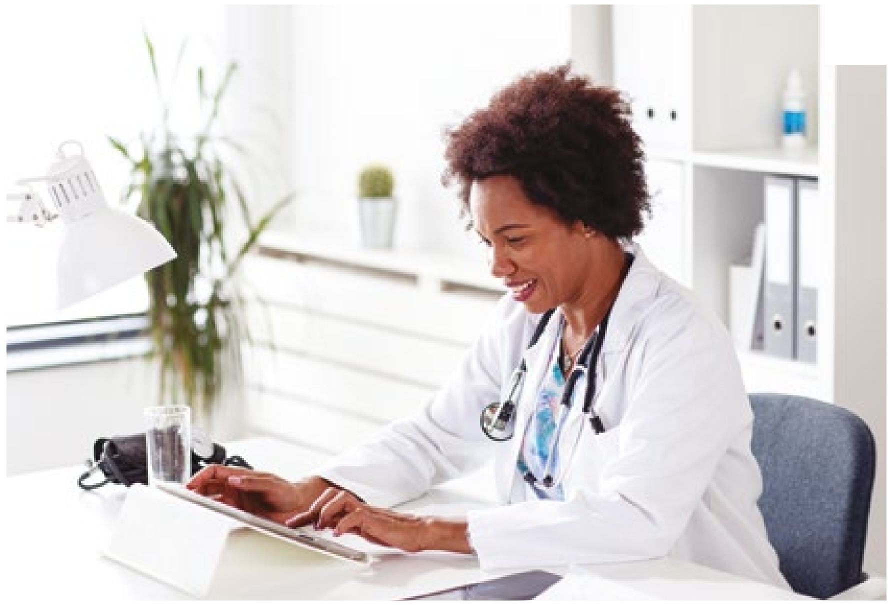
### How does our data support people with IBD?

By looking at data shared with the Registry by hospitals and patients, we can see how different treatments are being used over time, and how well they are working for patients. This helps us to check whether hospital teams are prescribing medications such as biological therapies and steroids in the most effective way for people with IBD.

For example, there are national treatment guidelines about how long people with IBD should take steroids for and how many courses can be taken within a 12-month period.[1] By analysing the information that hospitals share with us, we can provide a report to them about how their prescribing of steroids match these guidelines. This helps hospitals to treat their patients more effectively.

Some people with IBD will also have to switch biological treatments a number of times to find what works for them. We have started to look at whether our data can be used to understand more about which medications are being prescribed in which order, and how well they are working for patients. We hope this will help hospital IBD teams provide earlier effective treatment by reducing the number of times a person has to switch to a new medication.

We also know that the way IBD care is provided has changed since the start of the COVID-19 pandemic, with more people having appointments over the phone or on video call. We are supporting a study looking at whether people with IBD prefer virtual or face-to-face appointments, and the different factors that might be linked to those preferences, such as age and whether someone's IBD is active or not. This study aims to help shape future services that suit patients' preferences and lifestyles.



### How do I join the IBD Registry?

We're delighted that so many people with IBD have already joined the IBD Registry to help improve treatment and care, and support research. The more people who join, the more value this combined health data has for hospitals and research teams working to improve the lives of people with IBD.

Deborah (pictured above) has ulcerative colitis and joined the IBD Registry as she wanted to try and make a difference to others with IBD. She said: "At times my ulcerative colitis has made me extremely poorly and by being part of the IBD Registry, I hope to make research accessible to all patients – something that I didn't think I could be a part of before."

If you have IBD, you can visit **ibdregistry.org.uk/join** for more information about our work and how to be part of this valuable resource for research. If you have trouble accessing the internet, you can ask someone to download a paper form from our website or contact us on 020 3393 3969.

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[1] https://www.bsg.org.uk/clinical-resource/bsg-consensus-guidelines-on-the-management-of-inflammatory-bowel-disease-in-adults/

Step UP FOR STOMAS

THE 39 CHALLENGE

# Will you Step Up For Stomas again this September?

**Last September's campaign challenged people to take 160,000 steps in order to raise funds for Colostomy UK and spread the word about all we do to support people with stomas.**

It was a brilliant success, raising **over £50,000!**

This year it's The 39 Challenge! But why the number 39?

**Because every 39 minutes someone in the UK has stoma surgery**

In 2021 it was 160,000 steps, one for every person in the UK who has a stoma. This year we're asking people to take on a challenge or activity based around the number 39 (or 3 and 9) because as you may have seen from our adverts in Tidings and on social media, every 39 minutes someone in the UK has stoma surgery. The challenge will run for 39 days (September 1st to October 9th) and we'd love it if you got involved.

**Register for Step Up For Stomas – The 39 Challenge**

It's really easy for you to take part. All you need to do is go to Colostomyuk.org, click on the Step Up For Stomas link on the home page and complete the online registration form. You just need to leave your name, email, and contact number.

You'll then receive an automatic confirmation email which will include links to a challenge guide and details on how to set up a fundraising page. You can also use the sponsorship form on page 30 to raise funds.

**39 Ways to Take Part in the 39 Challenge**

We recognise that not everyone can or wants to take on a physical challenge, so we have come up with a list of diverse suggestions to inspire you to give our fundraiser a go. You can of course come up with your own idea or event.

**Create, Craft or Entertain**

- Juggle for 39 minutes
- Write 39 lines of short story
- Learn a Tik Tok dance challenge in just 3.9 minutes
- Karaoke 39 different songs
- Build a 3.9-metre-high tower of Lego
- Bake cakes or biscuits for 39 friends and family members
- Toss a pancake 39 times without dropping it
- Complete 39 crosswords or Sudoku puzzles
- Get crafty and make something to sell for £3.90 or £39 each
- Wear your favourite sports team's (full) kit for 39 hours!
- Organise a virtual raffle with 39 tickets at £3.90 each
- Challenge 39 friends to donate to Colostomy UK
- Ultra-challenge! Do 39 hours of an activity in relay with your housemates/family! 39 hours of yoga? Painting? Knitting? Whatever you love doing!

## Get Active

- Walk, crawl, or jog 39 Kilometres (51,181 steps), or 390 kilometres (511,811 steps – or 13,100 a day)
- Swim 39 kilometres (1k a day)
- Perform 39 skips a day without stopping
- Cycle for 3.9 kilometres a day or 39 kilometres over the period of the whole challenge
- Do 39 press ups
- Take your dog for a 39 minute walk each day
- Dance for 39 minutes a day
- Jump 39 times on a trampoline each day
- Row 39 miles
- Hop 39 times a day
- Hula Hoop 39 times a day
- Do 39 star jumps a day

## Try a Brain Teaser

- Complete 39 puzzles
- Host a quiz night with 39 questions
- Learn how to say thank you in 39 different languages
- Test your resolve and give up something you love for 39 days
- Stay silent for 39 minutes a day

## Set up a Social

- Hold a coffee morning and charge people £3.90 to attend
- Organise a 39-item treasure hunt and charge people £3.90 or £39 to enter
- Host an online yoga/dance session

## Kick Start your Fundraising!

Whether you decide to put your baking skills to the test or don your dancing shoes for 39 minutes a day, the money you raise will help us to keep supporting ostomates and those who look after people with stomas.

You can set up your Step Up For Stomas 39 Challenge fundraising page on JustGiving, Go Fund Me and/or Facebook. You can also print and use the sponsorship form overleaf.

JustGiving™

**Just Giving:**
justgiving.com/campaign/StepUpForStomas

**Facebook**: facebook.com/ColostomyUK

Look for the **'Create a fundraiser'** page and click on the link.

## Fundraising Top Tips

### Set a Target

Fundraising pages with a target are 75% more successful than those without one! We recommend setting your initial target at a level you're comfortable with. If you meet this target before completing the challenge you can, of course, increase it! This will also give you some good news to share with your friends, family and colleagues to inspire them to donate.

### Seed Donations

Pages with a few donations give potential donors confidence, lend legitimacy to your fundraiser and help you to achieve further donations. Put an initial donation on your page if you can afford to do so yourself, and approach two or three people personally to ask for donations before you share your page with the rest of the world.

### Shout on Social!

Tell people on social media what you're doing and don't forget to tag us in! Your friends and family will be proud of you for undertaking this challenge. Each share could encourage another person to donate (or get involved). People often need to be asked a few times before they donate. Post on Facebook, Twitter and Instagram and put your fundraising link in your page's profile, bio or status. Check out and use our downloadable social media graphics, tell people why raising money for Colostomy UK is so important to you and keep your pages updated so people can follow your journey.

### Match Funding

Some companies offer to match charity donations up to a certain amount. This can come in the form of a one-off donation, or even go as far as matching everything that you raise. If you're an employee, why not ask if your company will support you?

### Get Your Merchandise

Look the part and order your Step Up For Stomas gear to help you shout about the fantastic challenge you are undertaking and raise awareness about stomas at the same time. T-shirts are available in sizes S - XXL and just £17.99 plus p&p. Hoodies are £35 plus p&p. **To place your order visit: colostomyuk.bigcartel.com**

## Step Up For You

Did you know there are some surprising benefits to taking on a fundraising challenge for a charity?

### Improve your health

We all know that physical challenges have a positive impact on our health, but we're happy to report that raising money for charity and helping others increases our overall wellbeing. Knowing that your efforts help improve the lives of others is empowering and in turn, promotes feelings of happiness and fulfilment, often referred to as the 'helpers high'.

### Forge new friendships

Taking part in a charitable fundraising challenge can give you a sense of belonging and purpose because it allows you to meet and connect with like-minded people. It's easier to make new friends when you have shared interests and goals. You may even find you have other interests in common allowing lasting friendships to flourish.

### Gain new skills

Practice makes perfect as the adage goes. Repeating an action 39 times will enhance existing skills or allow you to develop a new one. By the time you get to the 25th bake, that soggy-bottomed cake will be a work of art. How good is that!

## Step Up For Ostomates

Colostomy UK is a self-funding charity so every £1 we raise really matters! As part of this challenge we would also love it if you could try to raise as much as you can. All funds generated will go towards supporting our key projects and services, including our 24-hour Stoma Helpline, our Befriending Service, and the continued production of Tidings magazine. It will also allow us to train more volunteers, encourage more ostomates to get active, and help us to campaign for a more stoma aware United Kingdom.

The money you raise will help us to support people like Alice:

"I underwent emergency surgery at the end of last year that left me with a stoma which has been difficult and challenging and something of a complete lifestyle change. Without the support of Colostomy UK, I would not have had access to nearly so much information, equipment and community support and I am incredibly grateful for their work."

## Frequently Asked Questions

### Do I need to prove I've achieved my challenge?

This is your challenge so you don't need to send us proof that you have reached your goal. We do however recommend posting about your progress on your fundraising and social media pages to let all your friends and family know how you're getting on with your challenge.

### What happens if I miss a day?

If you've picked a challenge that you aim to complete on consecutive days, don't worry if you miss a day. We appreciate that with the best will in the world sometimes life gets in the way! You can resume the challenge the minute you are able, or team up with friends or family to help you achieve your 39 Challenge goal.

### What happens if I don't reach my target?

Not a problem at all! We are grateful for your support and will appreciate whatever you manage to raise. Every single pound counts!

# Sponsorship Form

Date of event:________________________ Sheet number: _____ of _____.

We wish you every success with your fundraising activity. Please remember to return this form to our office with any money raised, otherwise we will be unable to claim gift aid. The donors full name, address and postcode are needed in order for us to claim gift aid. You have a legal responsibility to ensure all sponsor money is paid to the Colostomy UK. Please print another copy of this form and number it, if you need additional pages. Cheques should be made payable to Colostomy UK. Thank you for your support.

| **Title** | **First Name** | **Last Name** | **Address** | **Postcode** | **Amount** | **Paid** | **Gift Aid*** |
|---|---|---|---|---|---|---|---|
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*I want to Gift Aid my donation and any donations I make in the future or have made to Colostomy UK in the past four years. I am a UK tax payer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of the Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference (currently 25p for every £1 donated).

**Please return completed form to: Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD**

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# Judy Colston Retires after 25 Years as a Volunteer

BY RICHARD BIDDLE

**If it wasn't for a volunteer, we wouldn't exist. Colostomy UK is what's termed a volunteer-centred charity. The seeds of today's charity were sown in 1963.**

What started as an experiment with a volunteer ostomate visiting stoma patients on the wards, quickly developed into something much bigger. By 1967 we were a registered charity (called the Colostomy Welfare Group) and by the late 1980s we had become truly nationwide, with a network of volunteers across the country, supporting ostomates face-to-face and also producing a range of literature. When MacMillan stopped providing financial support to associated charities in 2005, it was volunteers who came forward and saved us, forming the Colostomy Association. It is for these reasons and many more that the first week of June each year figures prominently in my diary and the diary of everyone else who works for Colostomy UK.

This is because it's Volunteers' Week. For us, it's all about recognising our volunteers and saying thank you. But how do people come to volunteer in the first place, what drives them?

Judy Colston, who has been with us for the past 25 years, recently retired as a volunteer. During this period, she has given her time freely to the cause and along the way helped and supported countless ostomates. After so many years, it was only fitting that I told Judy's story, as a way of thanking her on behalf of us all. When I spoke to her, I also used the opportunity to find out a little more about why she decided to volunteer in the first place and what kept her coming back for more, year after year after year!

It all started for Judy with reading The Mail on Sunday, where she chanced on an advertisement for half price private health screening at any Nuffield Hospital. It covered a multitude of tests, including one for bowel cancer if you were aged 50 or over. Judy was 50 in May 1996 and so decided to book an appointment for the screening, a few days after her birthday. As I'm sure you've already guessed, she ended up with the kind of birthday present nobody wants… Following a rectal digital examination and test of a stool sample, the doctor told her there and then that she thought Judy had cancer and referred her back to her GP. Judy was understandably shocked, particularly as earlier in the year her doctor had told her not to worry about the intermittent rectal bleeding she had been experiencing, suggesting it was likely to be haemorrhoids. Things moved quickly. Within four weeks she had seen a surgeon and in June 1996 had a colostomy and Abdominal Perineal Resection (APR) followed by radiotherapy.

Judy says she adapted to life with a stoma quite quickly at home but faced more challenges when she returned to work. At the time she had an administrative role in the NHS. This meant attending meetings, where Judy got embarrassed by the unpredictable noises her stoma made. She remembers clutching her stomach and praying 'no'! Her stoma care nurse suggested irrigation. This was something that had been mentioned to Judy just before she was discharged from hospital. However, as many readers will know, there is so much to take on board in the aftermath of stoma surgery, that things get easily forgotten. Judy agreed to give it a go and never looked back. In Judy's words:

**"It changed my life completely, gave me the confidence I needed, and I was happy".**

It was around this time that Judy met Robin Mills, who was a volunteer and also trustee of the British Colostomy Association (as we were then known). Robin supported Judy as a new ostomate and then later put to her the idea of becoming a volunteer. Judy says that the thought of helping and encouraging people with stomas really appealed to her, especially knowing just what a difference Robin had made to her. Hence in 1997 she put herself forward and was accepted as a volunteer.

Judy remembers attending a training course before she was let loose. This involved looking at the sorts of questions people asked and problems they faced, as well as learning about representing us at open days and working on the telephone helpline. Of course, since then the range of support services we offer has increased substantially, but ostomates needs haven't changed. I'm sure if Judy was to attend our volunteer training today, she would recognise many similarities with how it was when she joined.

There was no stopping Judy after this. In the decades she has been with us, she has undertaken a wide range of volunteering roles. She has been a regular on our Stoma Helpline and says she was always amused when callers in the evening would say things like: "Oh, you're a real person, I was expecting an ansaphone". For Judy, this was a great icebreaker and made the whole process of putting the caller at ease simpler. Judy says she found being on the helpline very rewarding. Over the years she found that helping people with even the smallest of things could go on to have a big impact. In her view (and we agree totally!): "Just listening to people when they are feeling down means a lot to them".

Judy also represented us at Open Days. She enjoyed these a great deal and loved being able to talk with people face-to-face, especially if the conversation could be turned round to irrigation. Judy was (and still is) passionate about this and says she was delighted if someone said they would consider giving it a go after a conversation with her. As a Colostomy UK volunteer Judy was one of our 'irrigation' team and spoke to many ostomates about this method of stoma management. She is also in our Irrigation DVD, demonstrating what's involved. The other big plus point to open days, or what we might call a volunteer perk… was that many of the manufacturer's open days used to be held at prestigious venues. Judy has

happy memories representing us at events at Luton Hoo, Hampton Court and Woburn Safari Park.

Finally, Judy had a spell as a trustee, starting when we were called The Colostomy Association through until we became Colostomy UK. Try as I may, I was unable to get Judy to give away much about the other trustees on the board at the time. All she would say was that one in particular would appear to be asleep in board meetings, but when asked a question would rouse immediately and give the impression that they had been closely following the discussion all along. To this day, she can't work out for sure if they were in fact asleep. Much to my disappointment she wouldn't name names!

Two words capture Judy's reflections on Colostomy UK and how it has developed since 1997: Progress and Change. When Judy started there were just a handful of staff working from a small office in Reading. Judy has seen more employees and volunteers recruited and with it she believes, much more capacity to support, help and campaign on behalf of ostomates.

She has witnessed the start and development of our stoma-friendly society and now StomaAware campaign. She has experienced first-hand how Active Ostomates can positively affect people's physical and mental wellbeing after surgery. She has enjoyed watching Tidings' transition over the years into the magazine it is today and has appreciated our ever-growing range of support literature. Judy says that in 1997 none of this seemed possible, in fact, she says it never crossed her mind that Colostomy UK would grow in the way it has.

But to my mind, the progress and change that Judy spoke of, simply would not have been possible without Judy and all the other hundreds of volunteers that have worked with us the past five decades. Like so many volunteers before and after her, Judy got involved because she wanted to help. She wanted to ease the worries and burdens and the challenges that people face after stoma surgery. She wanted to use what she learned for the benefit of others. Hence, this article is a thank you to Judy, but it's also a tribute to our volunteers more generally. We couldn't do it without you!

# Christmas cards

Spread the festive cheer this winter with our Colostomy UK Christmas cards. These biodegradable cards picture a quintessentially English village snow scene, with a classic red post box and robin. The message inside reads "With best wishes for Christmas and the New Year". Our cards come in packs of 10 and 100% of profits from every purchase goes towards helping ostomates.

So, make someone feel special this Christmas by sending them a handwritten card and support Colostomy UK at the same time.

## Order form

Colostomy UK Christmas Cards (pack of 10 biodegradable cards with envelopes) £4.50

**Postage and packaging**

Please add the following contribution for card orders of:

Orders up to £5 - £1.50

Orders between £5.01 & £10.00 - £2.95

Orders between £10.01 & £20.00 - £3.75

Orders between £20.01 & £50.00 - £4.95

Orders in excess of £50.00 - £6.50

**Number of Packs**

**Sub Total - £** ______________________

**UK P&P - £** ______________________

**Donation (optional) - £** ______________________

**TOTAL - £** ______________________

**Personal details**

Title: ______________________

Name: ______________________

Tel: ______________________

Email: ______________________

Address: ______________________

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

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

**Paying by cheque**

Cheques should be made payable to Colostomy UK and sent to:

Colostomy UK, PO Box 280, Weston super Mare,
North Somerset BS22 9ZD

**Paying by card**

Card number: ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐ (Maestro only)

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Issue No. (Maestro only) ☐☐

Signed: ☐

Dated: ☐

**Gift Aid Statement:**
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 purchase 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.

# fundraising

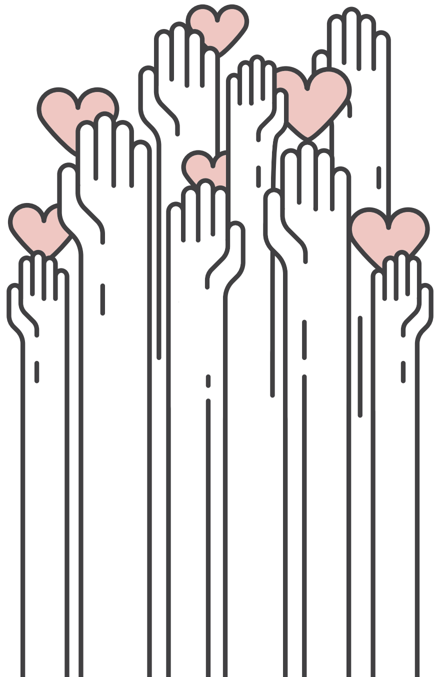
**Giovanni Cinque**
Fundraising and Development Manager
Giovanni.Cinque@ColostomyUK.org

## Supporting Colostomy UK

**Every month dozens of people hold events, take on challenges, or ask for donations to support Colostomy UK. As a self-funding charity, we rely on this help. Without it, we wouldn't be able to support people with stomas in nearly as many ways as we do.**

Please consider raising funds for Colostomy UK, and don't worry - you don't need to even think about running a marathon or swimming 5K if you don't want to! There are loads of other ways to fundraise. You could host a coffee morning or a cake sale, or perhaps run a quiz night.

Visit **www.colostomyuk.org/get-involved/fundraising** for details of how you can make a difference. Every £1 you give really does help!



## Thank you

**We don't have the space here to personally thank everyone who has supported us recently, but we'd like to give a shout out to the following individuals and organisations:**

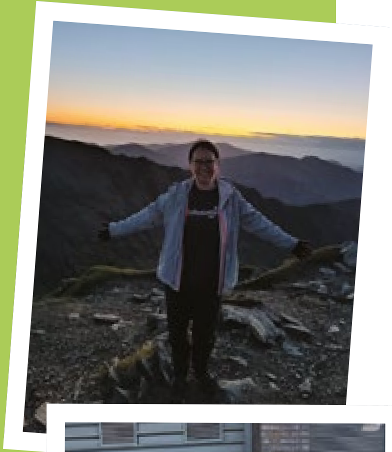
Alice Navarro (pictured) raised a brilliant £500 from climbing Snowdon with her sister Elizabeth.

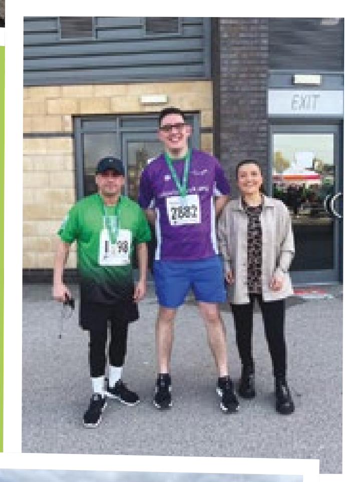
Thomas Lliffe raised £500 and generated lots of media coverage on ITV through taking part in the Derby 10K.

Stourport Swift's Juniors FC (pictured) raised £1053 for us as part of their charity Football Weekend.

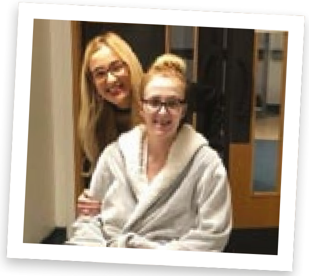
SPUK Sports and social raised £545 from proceeds of parking at Leeds United home games and donated the funds to Team Colostomy UK.

Thank you also to the following charitable trusts whose donations will help support the continued delivery of our services: William and Able Morris Charitable trust, Jules Thorne Charitable trust, Joseph Strong Fraser Trust, Childwick Trust, Colefax Charitable Trust, David Family trusts.





## Team Thrive take on the Yorkshire Three Peaks!



**A massive thanks to Zoe Webb and 'Team Thrive' who at the time of writing have raised well over £1000 for us by climbing the Yorkshire Three Peaks.**

In Zoe's words, this is why they've done it:

"On Saturday 13th August 'Team Thrive' are taking on the three highest peaks in Yorkshire, climbing a total of 2,136 meters and walking 24.5 miles in 12 hours, all to raise money for Colostomy UK.

Three years ago to the date of our climb, my twin sister Hannah had an emergency operation that saved her life.

Hannah's bowel perforated due to a severe infection from food poisoning. This was from a simple curry on a night out in Swindon. This incident of food poisoning led to her having her bowel removed, her life was changed forever.

She spent the next two weeks in ICU and hospital recovering, before she was back home to start living life with her stoma.

To be told your twin nearly didn't make it was the worst day of my life and I'll never forget it. She's only a minute older (she reminds me all the time) and the stronger one of us two, but it was now my turn to be strong for her.

Hannah's strength and determination has filled me and everyone else who knows her with nothing but pride. She's an inspiration and I'm lucky enough to call her sister.

Living with a stoma has its constant challenges which Hannah has taken like the true champion she is, she has overcome so much and is living life in a way we couldn't even imagine doing.

Colostomy UK support people living with stomas, helping them to navigate the many challenges, it is a charity close to several of our hearts who are taking part in the climb."

If you'd like to donate to their fundraising page, you still can do here: **https://gofund.me/b91f203d**

## Legacy

**Leaving a gift in your will to Colostomy UK will make a real difference to the support we are able to give to the ostomates of today and tomorrow.**

If you'd like further details of leaving a gift to us, please see the flyer included with this copy of Tidings.

Colostomy UK
Help us support the people with stomas of today and tomorrow
Will you consider leaving Colostomy UK a gift in your Will?

## Clothing Collections

**Thank you to everyone who donated their unwanted clothing and other items to Colostomy UK through our partnership with ICollect Clothes.**

Don't forget, if you're planning a clear-out, then as well as clothes you can also donate your unwanted paired shoes, linen, bedding, towels and curtains too. It all generates much needed funds for Colostomy UK! ICollect Clothes also collect accessories (bags, belts, hats, scarves), books, DVDs, CDs, soft toys, electronics, and small domestic appliances.

If you live in London and the South, The Midlands, North West, or North East you can book a collection online at **icollectclothes.co.uk/donate/colostomy-uk** or by calling **0344 879 4417**.

For all other areas give them a call and they will be able to advise when they will be collecting near you.

From the Masai Mara to Winnersh Triangle:

# A Short Biography of Libby Herbert, Colostomy UK's CEO

BY RICHARD BIDDLE

**If you have been following developments at Colostomy UK, then you will know that we have recently finished an internal restructure and recruited some new people. With the likes of social media becoming ever more important it is vital that we move with the times and have the right foundations in place to keep on supporting ostomates and campaigning on their behalf. Now that the dust has settled, I caught up with newly promoted Libby Herbert, Colostomy UK's Chief Executive Officer, and asked her to tell Tidings' readers a little about herself. Libby has been with us for almost five years now, starting as general manager.**

As you might have guessed from the title, Libby was born in Kenya. The family moved there after her father was offered a job in Nairobi. She is youngest of four children (three brothers). Libby has fond memories of Africa, with holidays on the coast to Mombasa and Safaris in the vast expanse of the Masai Mara. It was a time of adventures, getting into mischief and competing with her brothers in a way that only a younger sister can do.

The family returned to the UK in 1983 when Libby was seven. She can still recall getting off the plane and thinking the fog was down everyone in England smoking! For the first three years the family lived in London with her grandma. It took Libby a while to adjust. She found accents hard to understand and missed the green spaces of Kenya. School was challenging. The food and customs were alien and there weren't any baboons in the trees to greet her as she walked to class.

Libby has had a wide-ranging career, which I'm sure has prepared her for the challenges she faces as Colostomy UK's CEO. To give you a flavour… she met her husband while she was a hostel manager on Phillip Island in Australia; he was working for board and lodgings. This takes fraternising with customers to a new level! She has also worked for First Choice in Portugal, in sales for Toshiba and for a company called Bakehouse, where she managed teams and office operations. More recently she was with a start-up company. On the face of it, her experience sounds rather eclectic, but I would describe it as ideal for a small charity with big ideas.

When I posed the question 'Why Colostomy UK?' her answer was immediate: "I knew I wanted to work for a charity when I left the corporate world. My Dad was a recovering alcoholic, and because of bladder cancer needed a urostomy. It seemed like a good fit, and I felt that if he was alive today, he would be part of our volunteer team."

I asked Libby to round things off by telling me about the lessons she has learned in her varied life and how they will help her at the helm of Colostomy UK. She emphasised the importance of teamwork. She spoke about making time for people, building relationships, listening, and seeking and valuing their input. But to me something else shone through and that was her passion for helping people. There was an aura of energy and drive about her, which makes me feel comfortable that our charity is in safe hands.

# What is Purple Urinary Bag Syndrome?

## (PUBS for short!)

BY KATIE M SAINSBURY
BSc (Edin) BA (Open)

**If you wake up one morning and find that the urine in your catheter or night drainage bag has suddenly turned purple it can be very alarming.**

So…we thought it would be a good idea just to outline what Purple Urinary Bag Syndrome is and what it may mean if your urine bag suddenly becomes purple overnight!

### What is PUBS?

Purple Urinary Bag Syndrome was first reported in the medical literature in 1978. It is an uncommon (some say rare) condition occurring in people who may be catheterised or who have other forms of urinary diversions where the urine is drained into a drainage bag.

### So…why does the urine appear to turn purple?

The purple colouration is the result of the breakdown, through the digestive system, of a building block of protein called tryptophan (found in a range of foods including milk, fish, chicken and turkey). In certain situations, a resultant by-product of the metabolism of tryptophan, indoxyl sulphate, reacts with bacteria in the urine to produce two pigments: indigo (blue) and indirubin (red). We know from our childhood paint box that red and blue combine to make purple. Hence the purple colour!

Interestingly it is not the urine itself that is purple. The bag or catheter turns purple when increased levels of these pigments react with the plastic to produce the purple discolouration.

### Why does it only happen sometimes and just to some people?

In the medical literature a number of risk factors for this syndrome have been identified, which may include:

- A urinary tract infection where there may, or may not, be any UTI symptoms. PUBS does not seem to be associated with any particular bacteria. In their paper 'Purple Urine Bag Syndrome: More Than Eyes Can See' the authors identify over 20 different bacteria which have been associated with UTIs relating to PUBS, including E.coli, Proteus mirabilis and Pseudomonas aeruginosa.
- An alkaline urine (although there have been a few reports of PUBS where urine is acidic)
- Constipation
- Catheterisation or other urinary diversion
- Use of a polyvinyl chloride urinary catheter or bag

### Treating and preventing PUBS

PUBS is usually associated with a UTI so the steps that can be taken when it is seen include:

- Deciding whether to treat any underlying UTI with antibiotic
- Treating the constipation
- Maintaining good personal hygiene
- If an indwelling catheter is present - change it regularly
- If urinary drainage bags are used - change them regularly.

**Important to remember:**

If you suddenly wake up and see purple urine…
**Don't panic!!**

It is not, in itself, a serious condition but it can point to an underlying UTI, so do make sure you seek medical advice to ensure you can get the correct treatment.

Sabanis N, Paschou E, Papanikolaou P & Zagkotsis G., (2019) 'Purple Urine Bag Syndrome: More Than Eyes Can See' Current Urology, Vol 13 (3), 125-132

McDonnell D, & Aldridge A., (2019) 'Urine Bags Syndrome masquerading as a bowel obstruction' Clinical Microbiology and Infectious Diseases, vol 4, issue 2.

Dilraj S. K, Ward J, Lee R, & Handa, A., (2017) 'Purple Urine Bag Syndrome: A Rare Spot Diagnosis' Disease Markers.

Previously published in the Urostomy Association Journal Winter 2021

# Crafting Kept Me Sane and Slim!

BY JACQUI RAMSEY

**Crafting has long been recognised as a form of therapy. As well as bringing about a sense of control and empowerment, there is the self-expression involved in choosing materials and designs, and then the necessary focus required. Many find it a potent stress buster.**

It certainly proved the case for Shirley Jones, a retired staff nurse who lives in Aberystwyth with her partner, John.

"I'd always done knitting of some sort since my early childhood until life got in the way. I was working full time in our local hospital and with a family, and mine and my partner's parents close by, I never had the time," she says.

Then, life took an unexpected turn for 69-year-old Shirley when she became seriously ill with sepsis. While visiting her mother who suffered from vascular dementia, she was aware of an abdominal pain.

"I put it down to my hernia. I had been so busy taking care of my mother that I'd not looked after myself and I'd put on weight," Shirley explains.

The pain worsened and Shirley went to A&E where doctors admitted her to hospital. Days later she underwent a mesh repair to her hernia. However, it soon became clear Shirley was developing further problems and an investigation revealed her bowel had perforated.

Within a fortnight of admission, in October 2016, Shirley underwent emergency stoma surgery for a permanent ileostomy.

Faced with months of recovery in hospital, and at her daughter's urging, Shirley turned to crochet to help fill the hours during her seven-month hospital stay.

"I started with granny squares. You can't go wrong; you can pick it up and put it down again easily," she enthuses, "Crocheting provided a welcome distraction and gave me something to do."

Back at home, and when Shirley felt well enough, she joined a knit, crochet, and natter group in the autumn of 2017. "I knew I had to get out and meet people. After such a life-changing experience it helped me to feel 'normal' again," she says.

The crafting group was a tonic in healing the psychological wounds Shirley suffered as she came to terms with her changed body. "All the lovely ladies so warmly welcomed me. I felt accepted; if I couldn't go to a meet-up, they sent me lovely messages.

"And though they would ask me how I was, the group were more focused on what I was crafting. They treated me as one of them and not as someone out of the ordinary, which is how I had felt when I had my ileostomy.

"I was frightened when I first got home, and there was not much that I could do apart from try to recover. I recognised that I needed something constructive to do, something that was pretty and feminine.

"As I'd no choice in having my ileostomy, I felt a sense of control from crafting."

Since her surgery Shirley has lost ten stone. Prior to the operation, the pounds had piled on while she had been caring for her sick parents and Shirley admits that she did not eat healthily during that time.

The dramatic weight loss, a welcome side effect of her stoma surgery, is something that Shirley wanted to maintain, and crafting provided the perfect tool to help her stay trim.

"It was so easy to overeat, especially when feeling stressed which I had been a lot of the time, but when you are making something you're unable to do anything else. It's relaxing and keeps you calm."

Shirley continued to attend the knit, crochet, and natter group until the first lockdown in 2020. Though it was a blow not to be able to meet her crafting friends she determined to continue with her crochet and beavered away in the evenings, making inroads into the extensive stash of wool she had collected over the years.

Crocheting bonnets for babies for a national charity and making celebratory blankets and cushion covers for friends, kept her busy through the pandemic. A mood blanket based on colours that Shirley assigned to emotions such as orange for happiness is her bed cover-up over the winter months.

One item that she is particularly proud of is the 'thank you' iris that she made using a latch hook technique for Colostomy UK.

"I would not be here without Colostomy UK," she says, "My daughter contacted the charity first off, because she felt she needed to find out about stomas and how she could best support me."

"My journey has been full of complications but at least I can tell members of the Facebook support group I have come out the other side. You can give other people hope and encourage them to keep going."

Locally, Shirley has become something of a cause celebre on the crochet front, taking orders from various friends and extended family members. And all for the love of it!

Her neighbour, Tom, sports a crocheted beanie in all weathers; the one she made in two nights with wool, hook, and happy application. A resounding crochet success we believe!

---

# Please support Colostomy UK

**Your donation to Colostomy UK will make a real difference and help us to better support more people living with a stoma, like you. Please consider supporting us by setting up a regular direct debit (see reverse page), or a one off gift by debit /credit card or cheque. Thank you.**

Colostomy UK

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

## My Details

(Please complete in **BLOCK CAPITALS**)

Title*: First name*: Last name*:
Address*:
Postcode*: Phone Number:
Email*: Date of birth:
Gender: ☐ Male ☐ Female ☐ Other, please specify:

If you are new to **Colostomy UK**, how did you hear about us?
Are you: ☐ An ostomate ☐ A carer ☐ A healthcare professional ☐ Family or friend
☐ Other, please specify: Stoma type: ☐ Colostomy ☐ Ileostomy ☐ Urostomy
Date of surgery: Reason for surgery:

**Tick as appropriate:** I would like to be kept informed by: ☐ Post ☐ Email

*You are in control of the information you receive and can change your options or unsubscribe at any time.* I would like to be kept informed and receive (please select and tick the box):

☐ Monthly **Colostomy UK** support e–newsletters
☐ Post from carefully selected third parties (eg about open days or offers)
☐ Emails from carefully selected third parties (eg about open days or offers)

Any other details you would like to share with us

**Data Protection: Colostomy UK is registered under the The Data Protection Act 2018. The data we hold is managed in strict accordance with the Act. We do not disclose any information supplied by you to any third party organisations. (However, we may send you their promotional information, which we think may be beneficial.)**

## My one-off donation

☐ £25 ☐ £30 ☐ £50
☐ Other amount (please state) £
☐ 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**

T67

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.

Signed: Date: / / 2022

Please fill in this form to make a donation. Check your details are correct, then return the completed form by post to: **Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD.**
Telephone: **0118 939 1537** if you have any queries.

Registered Charity No: 1113471

Registered with FUNDRAISING REGULATOR

**Charity Name:**

**Colostomy UK**

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

**Name and full postal address of your Bank or Building Society**

*To: The Manager*

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*Address*

*Postcode*

**Name(s) of Account Holder(s)**

**Bank/Building Society account number**

**Branch Sort Code**

**Service User Number**

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| 6 | 9 | 1 | 2 | 1 | 3 |

*CAF, Kings Hill, West Malling, Kent, ME19 4TA*

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Signature(s)

Date (DD/MM/YYYY)

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*This is not part of the Instruction to your Bank or Building Society*

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☐ *Mr* ☐ *Mrs* ☐ *Ms* ☐ *Other (Please Specify)*

*Address*

*Postcode*

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*I would like to make a regular donation of* **£**

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Please notify us if you want to cancel this declaration, change your name or home address or if you no longer pay sufficient tax on your income and/or capital gains.

☐ *Tick to apply*

*This guarantee should be detached and retained by the Payer*

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DIRECT Debit

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- If an error is made in the payment of your Direct Debit, by Charities Aid Foundation or your Bank or Building Society, you are entitled to a full and immediate refund of the amount paid from your bank or building society - If you receive a refund you are not entitled to, you must pay it back when Charities Aid Foundation asks you to
- You can cancel a Direct Debit at any time by writing to your Bank or Building Society. Written confirmation may be required. Please also send a copy of your letter to us.

# Your Letters and Emails

**Editor's note:**
Thank you to everyone who has dropped me a line. As you will see from the selection below it was a mixed bag this time round. Please keep those letters and emails coming!

**Dear Editor,**

I have been in touch with a hospital dietitian who works in the colorectal department.

She has suggested I try flaxseed and linseed to cut down on wind. For diarrhoea she suggested live active bio yoghurts, bio peanut butter, cutting down on carbs, having more protein and reducing my use of laxatives. Following her advice does seem to have calmed my bowel down from all the craziness I have suffered for almost 20 years. I hope some of your readers will find this useful.

*Shirley*

*Editor's note: You should check with your stoma care nurse before following Shirley's tips. The important thing to note though, is that taking and following dietary advice can help resolve bowel issues.*

**Dear Editor,**

I enjoy reading Tidings so much, but the part I enjoy most are the stories of how people came to have a stoma.

At age 80 I started to suffer from a lot of wind in my stomach, then I went for a week without emptying my bowels at all. The chemist gave me a suppository, but this didn't work. The health centre prescribed another the day after and also suggested I call the doctor.

The doctor visited me and sent me to hospital. They kept giving me opening medicine, which again didn't work. By this time, I couldn't eat at all, but was not in pain, just bloated. After a few days I had a CT scan which showed I had a blockage. They decided to operate the day after.

When I woke up, I had a stoma bag on. The specialist who visited me told me it was cancer. I was in hospital three weeks. The district nurse then visited me for a month afterwards to dress it and show me how to deal with my stoma.

After three months I went back to hospital. The specialist said they thought they had removed all the cancer, but it was my decision whether to do nothing or have a 30-week course of chemotherapy. As I was almost 81, I told them I didn't want to put myself through chemotherapy and I would take my chances.

I am now 96 years old and still here. I consider myself very lucky. My stoma works well most of the time and as I am now housebound if I do have problems, I can easily deal with them.

*Thank you, M P*

**Dear Editor,**

Many thanks for introducing my great-grandson, age six, to stoma bags.

He noticed, and then asked about all the ladies showing their bags on the front cover of the magazine (Stoma Squad, spring 2022 edition), so it was not a problem to tell him all about me being poorly when he was born. It was the same night I went in for my operation.

*Thanks again, Mrs Brenda M*

**Dear Editor,**

I had my bowel cancer surgery 20 years ago and compared with today's waiting problems I was lucky.

I saw my doctor and had my operation a couple of weeks later. My tumour was caught before it spread so I didn't need chemo. My reversal was done five months later but I had problems afterwards. These went on for five years. I dare not go out for a meal as I didn't know at what point I would have to rush for the toilet. It was worse at night: I could be up 8-10 times and would often have to change my sheets.

My luck came back when I saw my doctor again and said I'd like a bag back as I couldn't cope anymore. She sent me to see Evette Wright at the Norfolk & Norwich, who asked if I would try rectal irrigation. I told her I would try anything once. Well thanks to her I got my life back. I will be forever grateful to her and my doctor. What I would like to say is, why isn't more said about this option in Tidings?

Having finished reading the latest Tidings and Dorothy Ternent's letter about air travel, I thought I would tell you what happened to me on a recent trip to France. I have a card which says what I have to do and the equipment I use but the French custom officers still held up my irrigation equipment for all to see! If they thought I would be embarrassed, they were wrong. I didn't tell them (I don't speak French) where it had to go and where it had been… so I was able to leave them, chuckling to myself!

Thank you for your magazine - it is interesting how people cope.

*Regards Valerie Crofts*

**Dear Tidings,**

I read with interest Dorothy Ternent's letter (summer 2022).

I have also suffered more than once from appalling treatment by staff at the airport. I sent the airport management at Manchester a letter asking for an explanation but never got a reply. I have been through airports abroad and have never been treated in the same way. I am due to fly in October, and I am already getting stressed about being in a packed immigration hall and hearing staff shout across the crowd asking for suitable staff to carry out a search. They do not allow my husband to accompany me, so he is left hanging about without knowing how long this is going to take.

Please are you able to get any explanations from management that will give us some hope of not having to endure this indignity.

*M S*

## We look forward to hearing from you, our readers:

Send an e–mail to: editor@ColostomyUK.org

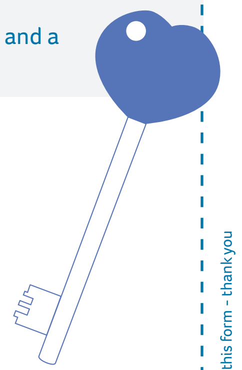
Write a letter to:
The Editor, Colostomy UK, 100 Berkshire Place,
Winnersh, Wokingham, Berkshire, RG41 5RD.

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.

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

Ensure you always have access to a toilet by purchasing a Radar Key and Photo ID card. Through the National Key Scheme, Radar keys open the doors to over 9,000 accessible toilets in the UK in places like shopping centres, pubs, cafés and department stores. A Colostomy UK Photo ID card, which is endorsed by Disability Rights UK (and displays their logo), can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

To order a Photo ID card you will need to include a copy of your prescription or delivery note as proof of eligibility and a passport-sized photo.



To obtain a **key or a photo identity card** please **complete the form and declaration below,** or visit:
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Title: ______________________
Name: ______________________
Tel: ______________________
Email: ______________________

Address: ______________________
______________________
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Postcode: ______________________

**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.

Signature (or carer signing on behalf of the person named above): ☐ Date: ☐

Please **tick** as appropriate:

☐ I would like to receive a Radar Key for £4.50 (inc. postage and packing).

☐ I would like to receive a photo ID card for £6.50 (inc. postage and packing) and enclose a passport photograph.

Return all required items to: **Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD. Cheques should be made 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. (If you have any queries or would like to pay by credit card, please contact **Colostomy UK** office: **0118 939 1537** or **hello@ColostomyUK.org**).

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

## 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 Colostomy UK to raise awareness about colostomy Irrigation as a method of bowel management.

Note: Not all colostomates can 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 Colostomy UK, to:

Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD
or you can purchase online at: www.ColostomyUK.bigcartel.com

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Issue No. (Maestro only) ☐☐

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**Please allow 30 days for delivery.**
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Halfx3 10v00r00 DVD Patients order form | Date of Publication: December 2020 | Copyright ©2018-2020 Colostomy UK | Registered charity no.1113471

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

# News from Support Groups across the UK

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

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 email: **hello@ColostomyUK.org**.

INSIDE OUT
Stoma Support Group

## Inside Out Stoma Support Group

Are holding a Stoma Information Day on **Saturday 17th September.**

**Level 3 Central Middlesex**
**Hospital, LONDON, N10 7NS.**

Doors open at 10:00 am
Free entrance.

Come and meet our company reps and listen to our speakers. All are welcome. Call **07811 084514** for further information.

## Mid Devon Ostomy Support Group

We are a friendly group who have four meetings a year. We welcome anyone with any type of ostomy, as well as their partners.

I've been running the group for ten years, during which we've enjoyed talks from many speakers, on everything from how laughter is the best medicine, to one from the Devon Freewheelers charity. Stoma reps attend to show their latest products. We usually have a stoma care nurse in attendance and are grateful to them for giving up their Saturday afternoons! Amanda Gunning, Lead Stoma Care Nurse at the Royal Devon & Exeter Hospital, has given many informative and amusing talks.

As a group we have enjoyed chair yoga, which was provided by Colostomy UK. At our last meeting we had a 'travel special' which got everyone talking, sharing their experiences of travelling with a stoma.

We have help in the kitchen from Pat who makes cakes to go with a cup of tea or coffee. Mark runs around selling raffle tickets, the proceeds of which, along with the tea money, pay for the hall.

Support groups are invaluable in getting people to meet others who have a stoma and helping one another in an informal way. If you live in Devon, feel free to join us. Contact Janice for more info: **janice234ford@gmail.com** or **07923 975 051**.

## North Notts Stoma Support Group has moved to a new home

Having had our monthly meetings at King's Mill Hospital, Sutton in Ashfield for a number of years the decision was taken in 2021 to seek an alternative venue.

We didn't have to look far and found a very suitable place at **Harwood Court Community Centre, Harwood Close, off Skegby Road, Sutton-In-Ashfield NG17 4PD.**

We've been there almost a year now and it has proved ideal, with one large room suitable for up to 40 people, an up-to-date kitchen and an accessible toilet.

For more information about our support group, contact Tore and Nicky Norman, T: **01773 715 460**.

## Stoma Support Group in Cumbria

We are pleased to announce the re-start of support group meetings:

**Stoma Support Group**
**Harraby Community Centre,**
**Edgehill Road, Carlisle,**
**Cumbria CA1 3SN**

11am- 12noon. Every 3 months. Please contact stoma nurses on **01228 814179** for dates.

## Channel Islands

### Guernsey

Guernsey Ostomates
Luci Deane
T: 01481 236 077
E: lucideane58@gmail.com

### Jersey

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

## England

### Berkshire

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

WAMS (Windsor, Ascot, Maidenhead & Slough) Stoma Support Group
T: 0118 939 1537
E: wamsstoma@gmail.com

### Bristol

Bristol Ostomy Self Support (BOSS)
Pat T: 07855 449578
E: info@ostomy.org.uk
W: www.ostomy.org.uk

### Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

Milton Keynes Stoma Support Group (MKSSG)
Morag Harvey (Secretary)
E: mkssg.sec@gmail.com
T: 07843 768 386

You Are Not Alone Stoma Support Group - Chesham
Carla T: 07846 354 918
E: carlawright0502@gmail.com

### Cambridgeshire

Peterborough Stoma Support Group - Ostomistics
Alan Wright
T: 01354 653 290 or 07836 661 102
W: www.ostomistics.org

### Cheshire

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

Crewe & District South Cheshire Stoma Group
Venue phone number: 01270 560471

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

Warrington Ostomy Support Group
Louise or Joan T: 01925 454 813

### Cleveland

Oops Group
Julie Morrisroe/Carol Younger/
Alison Hall-O'Donnel T: 01287 284 113

### Co. Durham

Bishop Auckland Stoma Care Group
Mrs Maureen Davison
T: 01388 818 267
E: rdavison816@gmail.com

Darlington Support Group
Margaret Clothier
T: 0191 333 2184

Durham Stoma Support Group
Lynn Ridley
T: 0191 333 2184

### Cornwall

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

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

### Cumbria

Grange Cancer Support Drop in
Marie O'Connor T: 01539 533 279

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

### Derbyshire

Diverted Local Stoma Support Group
Diana Manning T: 01283 541 311

F.I.S.H.Y.S. (Friendship, Information, Support & Help for Young Ostomates (age 18-45)
E: fishysderbyshire@gmail.com

Mercia Inside Out Stoma Support Group
Sally Chester T: 07500 441 442
Jackie T: 07919 002 612
Gary T: 07779 218 245

### Devon

Devon IA
E: devon@iasupport.org

Mid Devon Ostomy Support Group
Janice T: 07923 975 051
E: janice234ford@gmail.com

Plymouth & District Bowel Cancer Support Group
Rita T: 0785 557 1840
E: admin@plmdistbcsg.com

### Dorset

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

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

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

### Essex

Connect
Alan Marshall T: 01279 411830
E: comeconnectwithus@gmail.com

Mid Essex Stoma Support Group
Paul Foulger T: 01245 224 374

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

Optimistic Ostomates
Angela Taylor T: 01702 385 510

STEPS - Stoma Essex Patients Support
T: 01268 451 937
E: stepsessex@gmail.com

### Hampshire

Replummed Stoma Support Group
W: www.replummed.me

Solent Ostomates Support Group (S.O.S.)
T: 07527 707 069
E: solentostomates@hotmail.co.uk

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

The Hampshire Ostomates Support Group
Nicki Beare T: 07771 558 458
E: hampshireostomatesgroup@gmail.com

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

Wessex Urology Support Group
Mrs Jo Stacey T: 07910 786 978

### Herefordshire

Herefordshire Stoma Support Group
Carol Steele T: 01432 880 656
E: carolsteeleglo@gmail.com

### Hertfordshire

Ostofriends Stoma Support Group (Potters Bar)
E: ostofriends@gmail.com
T: 07596 748 376

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

### Isle of Man

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

### Isle of Wight

Optimistics
CNS's Sarah Capon & Sarah Varma
T: 01983 534 009

### Kent

Ashford Stoma Support Group
Carol Hobbs T: 01303 814 014
Treasurer, David Christian
T: 07970 220 773
Secretary, Maureen Curnow
T: 07989 773 332

Dartford Ostomy Group Support (DOGS)
Tracey or John: T: 07779 155 846
T: 07948 974 350
E: dogs-uk@hotmail.com

Dover Stoma Friends Group Support
Carolyn Fullager T: 01304 821 132

GOGS (Gravesend Ostomy Support Group)
Tracey T: 07779 155 846
Helen T: 07710 780 958

Maidstone Stoma Support Group
Judy/Kirsty T: 01622 224 305

M.O.G.S (Medway Ostomy Group Support)
Tracey T: 07779 155 846
Helen T: 07710 780 958
E: mogs-uk@hotmail.co.uk

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

SWANS Stoma Support Group - Swanley
Heather T: 07711 445 312
E: heather601@virginmedia.com

Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825

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

### Lancashire

Kangaroo Klub, Blackpool Stoma Support Group
Blackpool Teaching Hospital
T: 01253 956 620
E: crc-stomanurses@bfwhospitals.nhs.uk

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

Phoenix Bowel Cancer Support Group
Sandra Peet T: 01772 683 790
E: sandrapeet7@aol.com
W: www.phoenixgroupbvh.com

### Leicestershire

Kirby Ostomy Support Group. Colostomy, Ileostomy and Urostomy in Leicestershire
Janet Cooper T: 07464 957 982
E: kosg2013@btinternet.com

### Lincolnshire

Grantham Support Group
Bobbie/Rachel T: 01476 464 822

### London

Bowel & Other Cancer Support Newham
T: 020 8553 5366

Homerton Hospital Bowel & Stoma Support Group
Irene Fernandes and Glyn Fountaine
T: 02085105318 or 07785971120

Newham Stoma Support Group
Contact Lauren King T: 020 7055 5576

Rectangle - Colorectal Cancer Support Group
Regina Raymond T: 020 7472 6299

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

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

Time 2 Talk
Ifrah Mohamed T: 07463 838 718
E: mybodysauthor@gmail.com
Viki Palmer T: 07894 276 986

### Merseyside

Bowel Cancer and Stoma Support Group (BeCauSe Group)
T: 07948 120 955

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

St Helens Cancer Support Group
Bob Martin T: 01744 345 365
E: contact@sthelenscancersupportgroup.org.uk

### Middlesex

Inside Out
Sarah Varma T: 0208 235 4110
Bob T: 020 8428 4242
Barry Caplan (Chair) T: 07811084514
E: abmc23@virginmedia.com

### Norfolk

Kings Lynn Ostomy Friendship Support Group
T: 01553 775 698 or 01553 674 962
or 01553 768 271

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

### Norfolk

James Paget Ostomy Support Group
Sandra Hutchings T: 01502 585 955

### Northamptonshire

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

### Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas T:07941 433 600

Northumberland Cancer Support
E: members@northumberlandcancersupportgroup.co.uk

### Nottinghamshire

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

Nottingham QMC Stoma Support Group
Robin Ford T: 0115 778 6463
E: hello@nottingham-stoma-support-group.uk

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

### Shropshire

B.O.T.S. (Bums on Tums)
Irene Constable T: 01691 238 357

### Somerset

Stoma Heroes Support Group
Shane Green T: 07802 428 074
E: Shane@stomaheroes.com

### Staffordshire

County Stoma Group
Moira Hammond T: 07788 402 195
E: cm.hammond@ntlworld.com

Outlook The North Staffs Ostomy Support Group
Moira Hammond T: 07788 402 195
E: cm.hammond@ntlworld.com

### Suffolk

East Suffolk Ostomy Group
Ian Denison T: 01473 684865

### Surrey

Epsom and District Stoma Support Group
Lindsay, Trevor or Sheena
T: 01372 735 925

Normandy Colostomy Support Group
Robin Young
E: robin.young11@btinternet.com
T: 01483 417 610
W: normandystomagroup.wordpress.com

Stoma Support Group
Robin Young T: 01428 723 255

### Sussex

Brighton & District Support after Stomas (SAS)
Virginia Keefe T: 01273 723775

Chichester Stoma Support Group
The Stoma Care Team T: 01243 831 527

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

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

### Tyne and Wear

Gateshead Stoma Patient and Carer Support Group
Stoma Care Nurses T: 0191 445 3152

South Tyneside Hospital and Community Stoma Support Group
Jane Barnes, Amanda Logan:
stoma care nurses

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

### Warwickshire

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

### Wessex

Wessex Stoma Support Group
Karen Berryman
T: 01980 590 599
E: info@wessex-stoma.co.uk
W: www.wessex-stoma.co.uk

### West Midlands

Coventry Stoma Support
Martin T: 07947 385 643

### Wiltshire

Swindon IA
W: www.swindon-ia.org.uk

### Worcestershire

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

### Yorkshire

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

Airedale Stoma Support
Sue Hall T: 01535 646 373

Barnsley Bottoms Up Stoma Support Group
Stoma Nurses T: 01226 432 528
Celia Utley (Chairman) T: 01226 284 262

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

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

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

Dewsbury & District Stoma Support Group
June T: 07884 003 945
E: dews.ssg@gmx.com

Hambleton and Richmondshire Ostomy Support Group
Stoma Care Nurses,
Judith Smith and Mary Hugil
T: 01609 764 620 / 07736 295 131

Harrogate Stoma Support Group
Stoma department office.
Nurse Gill Wilson/Fiona Holtham
T: 01423 555 786

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

Scarborough Stoma Support Group
Stoma Care Team T: 01723 342 388

Second Chance Ostomy Yorkshire
Jackie Butterworth
T: 07544882353
E: secondchanceostomyyorkshire@gmail.com
W: www.secondchance-ostomyyorkshire.org

The Hull and East Riding Colostomy Support Group
Pete Smith T: 07989 565 335
Pete Rennard T: 07939 518 642 or 01482 793 966
W: www.hercosg.org.uk

## Northern Ireland

### County Antrim

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

Colostomy UK Volunteers Northern Ireland
Chris Wright T: 07720 717 771

### County Armagh

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

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

### County Down

North Down Stoma Support Group
Adrian Ewing T: 07850 741 511

Ulster Hospital
Hazel/Martina T: 028 9055 0498

### Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

## Republic of Ireland

### County Mayo

Mayo Stoma Support
Marion Martyn T: +353 94 902 1733

### Dublin

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

## Scotland

### Ayrshire

Ayrshire & Arran Stoma Support Group
Hugh Strathearn T: 07837 464 376

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

### Fife

Fife Ostomy Support Group
Ishbel Barr T: 01592 772 200

### Lanarkshire

Glasgow Stoma Support Group
Morag Sinclair T: 0141 779 1322
Jackie McChesney T: 01505 324 052

### Moray

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

### Scottish Borders

Stoma Support Group
Fiona Gentleman T: 01450 371 063
E: r.gentleman@sky.com

### West Lothian

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

## Wales

### Aberystwyth

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

### Bridgend

Bridgend Ostomy Patients Support Group
E: bridgend.ostomy@gmail.com

### Carmarthenshire

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

### Conwy

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

### Gwent

Cwmbran Ostomy Support Group (COSG)
Philippa Lewis
T: 01633 791 339 or 07504 713 069

### Mid Glamorgan

C.A.S.S Colorectal and Stoma Support Group
Chairperson T: 01685 877 144

### Pembrokeshire

PSA (Pembrokeshire Stoma Association)
Rosemarie Rees Paton T: 01437 532 473

### Powys

The Bracken Trust Cancer Support Centre
Helen Davies T: 01597 823 646

### Rhondda Cynon Taf

Royal Glamorgan Stoma Care Support Group
Domenica Lear T: 01443 443 053

### Swansea

Swansea Ostomy Self Help Group
Glynis Jenkins T: 01792 418 245

## Fundraising

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