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Colostomy UK's Award-Winning Magazine

Colostomy UK

Tidings

Supporting & empowering ostomates

"Seeing people like me succeed made me believe I could too"

Steph Taylor on overcoming the odds and living life to the full.

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Stoma reversal surgery - Former ostomates share their tips

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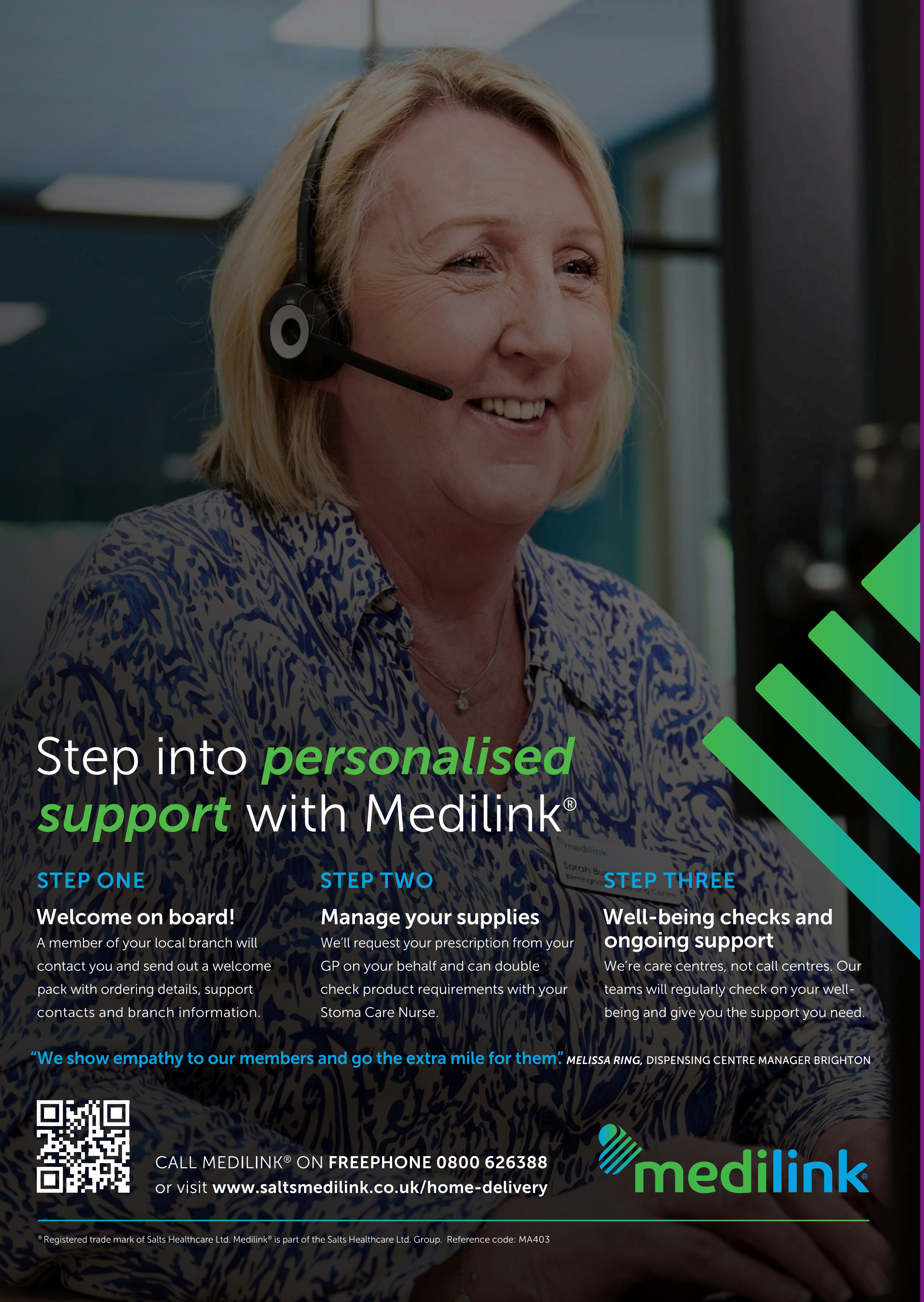
Debs Meredith on the five years that changed her life

**Real stories
Real people**



Colostomy UK

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Dear readers

It might be the autumn edition of Tidings, but this issue should be arriving in mid-August, when many of us will be coming and going from our summer holidays.

For some, this might mean big adventures in the rugged wilderness, or a chance to unwind on a sun-soaked beach. For others, the ideal trip might be a British-based jolly. Take for instance, the escapades of two of Colostomy UK's veteran volunteers, Sue Hatton and Jackie Dudley. The pair set off on a road trip to attend the highly successful open day of Shropshire-based support group, Bums on Tums (B.O.T.S) (page 45). Our very own CEO, Libby Herbert, had to chaperone just to keep a lid on their antics.

Whatever your preferred trip, living with a stoma often requires detailed planning ahead. Yet with so much to think about prior to travel, some of the essentials can easily slip the mind. As you might imagine, Colostomy UK's helpline is often busy with calls at this time of year from ostomates who have arrived on holiday only to find they have forgotten to bring enough stoma-care supplies. Happily, our Helpliner, Holly Broomfield, has plenty of useful tips for what to do in just such an emergency (page 13).

There is plenty more practical advice packed into this edition of Tidings too. This includes our Dear Nurse article in which nurse Jackie Mcphail talks us through irrigation as an alternative to wearing stoma bags for some ostomates (page 25), as well as a guide on how best to manage a stoma with bodily dips and creases (page 33). Our Q&A on stoma reversals looks at both the practical and emotional aspects of the procedure (page 27). The article follows up with two former ostomates at different stages of their journeys to get a sense of what others considering reversal surgery might need to consider.

Staying on the topic of emotions, ostomate and psychotherapist, Carrie Helman, addresses the complex thoughts and feelings which arise for some people following surgery. In particular, Carrie focuses on the sense of loss that some people living with a stoma experience (page 21). This sense of loss was keenly felt by Deborah Meredith, following major surgeries which required the removal of various organs and other body parts so as to live cancer free. Debs is one of very few people to have lived with all three of the main types of stoma as a result. You can read her incredible Real Lives story on page 37.

Like Deborah, Tony Knight had his stoma formed due to cancer. Tony talks us through the ten lessons he's learned about living with a stoma over the past twelve years, from initial post-op through to the present day - which even now is still full of surprises (page 8). Third in our Real Lives series is the story of Steph Taylor. Steph was born with numerous congenital conditions which, amongst other things, required her to have both a colostomy, and a lesser-known stoma, called a mitrofanoff, formed. Despite many setbacks, including intense bullying at school, Steph is now thriving in the world of arts (page 15).

Last but not least, we hear from Colostomy UK's outgoing Chair, Mandi Laing and incoming Chair, Matthew Pollitt, who look backwards and forwards respectively, as they pass the proverbial baton from one to the other. An apt way to mark the changing of the seasons once again.

Ross Othen-Reeves
Editor, Writer and Researcher

Colostomy UK is a National Charity that exists to make a positive difference for anyone impacted by any kind of stoma or stoma surgery.

Founded in 1967, we became a registered charity in 2006, and we maintain our original mission to this day: to support people with stomas and those who care about them.

We:

» Provide practical and emotional support and advice whenever it's needed.

» Run projects that empower and build the confidence to take on fresh challenges.

» Are a voice on the issues that matter, campaigning and advocating for ostomates' rights.

We want to live in a world where having a stoma presents no obstacles or barriers and carries no stigma.

A world where people can:

» Get the right information and advice, at the right time, at the right stage of their stoma journey.

» Have access to the facilities and resources they need when and where they need them.

» Live their lives to the fullest without fear of discrimination or prejudice.

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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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 24 for our donation form.
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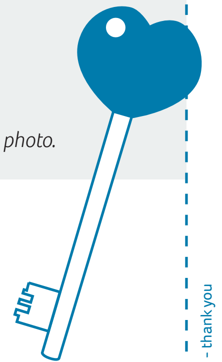

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Please cut along the dotted line and return to the address on this form - thank you

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Ask Jo!

Tidings' fitness guru and active ostomate, Jo Prance, answers your questions on how to get fit while caring for your stoma.

I go to Silver Swans ballet classes once a week (I am 63). After I have my surgery, when should I look at dancing again? Are there any ballet exercises I shouldn't do? (C.E)

Everyone's recovery is different, so the best time to return to dancing will depend on how you're healing and the advice of your stoma care team.

Let your dance teacher know that you've had abdominal surgery so they can help you adjust when needed. Try to avoid deep side bends, twists, or overhead reaches at first – especially if they involve forward folding.

Use a barre or chair for extra support and build back up to those movements as you start to feel stronger and more confident.

Begin with gentle warm-ups and increase the intensity gradually. Most importantly, listen to your body – if you feel any pain, pulling, or discomfort around your stoma, it's time to take a rest.

I'm 12 weeks post-op and have been trying to get out walking every day. Is it ok to start rebounding for extra movement and to try and tone up? Eventually I want to get back out running, and figured rebounding would be a good way to do cardio without the ground-impact that running causes.

Rebounding is a low-impact exercise usually performed on a small fitness trampoline. Gentle rebounding can be safe with a stoma, providing you've healed, wear stoma support, and have no complications like a hernia.

Start slowly, keep movements light, and stop if you feel any discomfort, pulling, or pressure around your stoma. Over time, you might gradually reintroduce walking interspersed with light jogging to build back up to running.

I'm seven months post-op. I started back at the gym in January, and go 4 - 5 times a week doing 30 minutes on a stairmaster, treadmill and weights, but I have avoided lifting Romanian Deadlifts (RDLs), etc. Is it safe to do these types of lifts if I start light? (T.M)

RDLs are a complex exercise that involve holding a weighted bar or dumbbells at hip height and hinging forward from the hips, lowering the weights toward your knees. Because RDLs challenge your core, it's essential to use good technique to avoid placing excessive strain on your lower back or through the abdominal wall – especially if you've had stoma surgery. RDLs are not advised if you have a parastomal hernia, as they may increase strain on the abdominal wall and worsen the condition.

If you're unsure about how to execute them safely, seek guidance with a fitness professional.

If you're thinking about trying RDLs, here are few things to keep in mind:

- **Start light:** Use a dowel, broomstick, or no weight at all, while learning the movement.
- **Engage your core gently:** Avoid holding your breath and wear your stoma support wear or belt.
- **Watch for warning signs:** If you feel pain, pressure, or notice bulging around your stoma, stop immediately.
- **Keep it controlled:** Modify how far you go or use support like a chair or wall if needed.
- **Progress slowly:** Only add weight gradually and when everything feels good. There should be no discomfort, pulling or pressure around the stoma.

Take your time, move with care, and always listen to your body.

Learning to Live with a Stoma

TONY KNIGHT
EDITED BY JILLIAN MATTHEW

Tony Knight shares his top ten lessons (plus one bonus tip!) from his 12 years as an ostomate – from his initial post-op days through to today, where he is once again living life to the full.

In the summer of 2013, I received a diagnosis of bowel cancer. This is my journey and what I have learnt since then.

1 Getting a diagnosis

What my GP initially diagnosed as piles, turned into an urgent referral to the Colorectal Unit when I saw a locum who was suspicious of my symptoms. Within a week, I had an interim diagnosis of bowel cancer, low down near the anal sphincter. An appointment was made for admission for surgery after a planned two-week holiday, which I was encouraged to still take.

Before the surgery I was expecting a reversable stoma procedure. Nine hours later, and after some difficulty in bringing me round, I had received a total abdominoperineal resection. So, the stoma would be permanent. I found this out, during the surgeon's rounds the following day – not surprising without a rectum and anus!

So far, I had learnt that a healthy scepticism was necessary to deal with the sometimes vagaries of the medical profession's diagnoses.

> Prepare for the worst and hope for the best perhaps. I did, however, have confidence that I would survive!

Determined to try to leave hospital as soon as possible, I pushed myself to complete the tasks required of me prior to discharge. Four days after surgery, sporting my brand new stoma, I was discharged home complete with catheter having an unsuccessful 'trial without catheter' (TWOC).

2 Post-surgery follow up care

The next learning was not to rely solely upon the system for follow up home care. A few enquiries via a district nurse friend produced a home visit from a nurse who knew her stuff. My urine bag, which kept detaching from the catheter, was replaced with a flip-flow valve. The instruction given was to wait until you really felt you needed a pee and then to open the valve by the toilet and make like you were having one normally. Astonishingly, having been advised that my catheter might be permanent, I partially passed the next TWOC.

3 Humility

It was then I learned the delights of intermittent self-catheterisation, where I was shown how to insert a catheter into my bladder myself.

> My third lesson was not to stand on one's dignity. Being instructed 'hands on' in the procedure by a nurse in her office was a surreal experience.

4 Eating with a stoma

I had been well instructed in how to manage my stoma by the stoma care nurse in the hospital, and I was getting the hang of it literally and metaphorically. I was careful with my diet as advised but couldn't resist some lovely new corn on the cob at our village market. I loved it, but it not me. Of course, everyone is different and it's a case of trial and error. I found a drainable bag to be a useful tool for the problem which then ensued, lesson four.

5 Stoma nurse support

So, lesson five was go to the stoma care nurse with your problems. It might have been a delicate drive sitting on my newly crafted bottom, but I was rewarded with helpful tips, information and a sympathetic ear.

6 What to wear with a stoma

Initially I changed from a belt to braces for my trousers and low-cut underwear that fitted below my stoma. I eventually found German cut trousers that had a higher waistline and a longer zip so that I could resume wearing a belt with the waist sitting above the stoma. I changed to looser shirts and woollies with bolder patterning which help to distract the eye from the bulge that I was left with post-operatively. In general, most people around me had no idea about my new body. All good until I used a radar key to gain access to a disabled toilet when an urgent change became necessary.

> A good phrase to use: "not all disabilities are visible". I just gave the statement to the challenger, accompanied by a Paddington Bear hard stare!

7 Ballooning

I have never found a pouch that could address my problem with wind. I can control it by eating very carefully but I do give in, from time to time, to a nice fruitcake, ratatouille, a crisp rose-red apple, BBQ pork in sauce and so on – you've got the picture. The valve seldom does its job. I found that gently slipping a finger down from the top of the wafer towards the stoma opens up a re-sealable gap to allow the gas to vent off.

> A sort of self-controlled fart without the noise, but time and place is rather important. As is being able to do it swiftly and confidently.

Fumbling self-consciously with one's clothing near to the stoma tends to arouse suspicion. Admiring a view leaning on a wall with no one down-wind works well, or just nipping outside (and out of view) to check something. Or, of course, a visit to the loo hoping you can open a window or that no one follows in soon after.

8 Carrying stoma supplies when out and about

From carrying around a suitcase full of stuff everywhere I went in the first few weeks, I have now got this down to a small, zipped bag (around 16 x 13 x 3cm). I prepare two pouches, a drainable or closed pouch each packed within one of the free disposal bags containing: adhesive remover wipe, skin protect wipe, two cotton wipes, four sheets of toilet roll and another disposal bag. In the zipped bag: an adhesive remover spray and a RADAR key, along with the two carefully folded packs. I can slip this into a capacious pocket in a coat or jacket, but I also use a 'man bag'. I found that the weight of things in my pockets tended to pull my belt down over the stoma over time when out and about. All I then need is a drop of water, though in emergencies I have made use of the spray and wipes.

9 Coping with leaks

I have had few 'poonamis', both at home (easier to deal with), and out and about. If I know I am to be away from civilised loos, I tend to have a spare pair of pants, shorts and T-shirt in the car. I carefully take off soiled clothing and do without until I get to the car or somewhere better equipped. The spare bags in my zipped pouch can come in handy here. I have had to rinse stuff out at a sink and put clothes back on just wrung out. I rather think we can be more conscious of our predicament than many around us and anyway what's the worst that can happen if they do notice? The 'hard stare' comes in useful sometimes.

I have discovered on occasions, when my insides empty out completely, that it can take around 36 hours or so before output resumes. I'm not advocating taking purges, but it might indicate that irrigation could be an option if the fear of embarrassment when out and about gets in the way of having the best life you can.

10 Travelling with a stoma

There is good advice about flying. I have made several long-haul flights without incident. Latterly, I have made use of improved airline assistance to secure an aisle seat not too far from a loo. Also, a fast pass-through passport and luggage inspection just in case I need a loo but am stuck in a long queue. I am very careful about what not to eat before flying and always have an empty pouch before starting. My confidence has extended to using a closed pouch, but I started out with a drainable just in case. Over the years I have a good mental record as to what I can eat, the likely transit time before it appears at the stoma end and in what form the output might take. I avoid diuretic drinks e.g. caffeinated or fizzy ones, unless it is airline champagne offered free and I'm seated ready to go!

Bonus Tip! Don't be afraid to try something different

A few weeks after initially drafting this article, I plucked up the courage to change to a new pouch advertised in Tidings. It has been transformational. No seepage under the wafer at all, and therefore no leaks. Plus a vent that actually works well, so no ballooning either. So after 12 years, I have been able to add back into my diet all of those foodstuffs that I have avoided because of the difficulties they caused. All without any adverse effects on the condition of my skin around the stoma.

> So if there is a final lesson learnt, it would be "don't be afraid to try something different".

Having done so, I went to see my stoma nurse for the first time in 12 years and she happily endorsed the new solution and changed my prescription. So there was no problem with my GP practice or re-ordering either.

Colostomy UK

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Help! I've Run Out of Stoma Bags…

Ever wondered what to do if you run out of bags while travelling, or even whilst at home? Never fear – Colostomy UK volunteer, Holly Broomfield, has you covered.

It's 8pm on Friday, on a bank holiday weekend, and Colostomy UK's stoma helpline rings. One of our trained volunteers, who also lives with a stoma, answers the phone, which has been diverted from Colostomy UK's offices as it is out of hours. The caller explains that they are down to their last bag. Can we courier them some supplies?

An ostomate posts on Colostomy UK's private Facebook page. They have just arrived on holiday in Spain, and their luggage has not arrived. They have no stoma bags and have sprung a leak. Can we help?

The above examples are increasingly common occurrences for the Colostomy UK team. If someone calls the helpline, they are often surprised that Colostomy UK can't deliver them emergency supplies.

Here, we bring you tips for what to do if you run out of bags, as well as ways to reduce the likelihood of this happening in the first place.

Tip 1
Check for spares in forgotten places

Firstly, try not to panic. Easier said than done, I know! It is likely that you do have some spare supplies hidden away. Have you checked in your car glove box? Your handbag, backpack, sports bag or even that suitcase you took on holiday last year? What about your locker at work? Often, ostomates have spare stoma bags tucked away, which they forget about in a crisis.

Tip 2
Contact your supplier

If rummaging has no success, it's time for plan B. Call your supply company. If they are open, they can arrange for an emergency prescription and speedily post you supplies. Depending on your supplier, this service is sometimes even available overseas, to help with that lost luggage situation! Supply companies often have longer opening hours than 9 to 5, but are not available 24/7. In this case, you need to think outside the box.

Tip 3
Reach out to hospitals and/or the wider stoma community in your current location

- Telephone the local hospital and ask to be put through to the bowel ward. If this fails, ask to speak with a nurse in A&E. Both of these departments keep stocks of stoma supplies and can be very understanding – often providing a small supply to tide you over. If this fails, then telephone a larger hospital (if you can find one that carries out stoma operations, you may be in luck!)

- Visit Colostomy UK's private Facebook page (search 'Colostomy UK Facebook Group') and post a message with your general location, asking for help. We have members living all over the UK, as well as overseas, who are often happy to help a fellow ostomate in distress.
- Go to **ColostomyUK.org/support-groups** to find your nearest stoma support group, which may be able to provide you with some supplies or circulate a call for help to their group members.
- Sometimes, local pharmacies hold stocks of stoma supplies, which you can purchase. Alternatively, supplies can be found online at places like Amazon, with next day delivery.

Tip 4
Get creative!

Whilst on the helpline, callers often say, *"Thanks for the ideas, I'll try those out, but what can I do right now? I have no spare bags and I'm wearing my last one!"* At this point, it's time to get creative.

If you have a drainable bag, you can wash the bag out fairly easily, by using a jug to pour water into the draining spout and then emptying the contents down the toilet. However, in an emergency, a closed bag could be gently removed, washed out and then reapplied. It won't stick as well, but it might help get you out of a tricky spot whilst you obtain more supplies.

An incontinence sheet, or 'puppy pad' (used for training puppies and available at most pet supply stores) can be placed over the stoma bag, helping to contain any leaks. Another alternative is cling film. This can be wrapped around the tummy, also helping to contain leaks until you can obtain supplies.

Tip 5
Preparation is key

Once you've got over the horror of running out of bags, what can you do to reduce the likelihood of it happening again? It is a good idea to set a monthly reminder in your diary or phone calendar to check your stoma supplies and then order more if needed.

Some ostomates even put a paper note in amongst their stoma bags, to remind them that there are only ten left...

If you are going on holiday, or a bank holiday is approaching, make sure to order your stoma supplies well in advance, as these are busier times for suppliers, leading to longer despatch times, and there can often be delays in the postal service too.

If travelling, always pack double the amount of supplies you would usually use. For example, if you normally use three stoma bags a day, and are going on holiday for a week, take 42 stoma bags instead of 21. This should also be the case for all of your stoma accessories, be it remover sprays, cleaning wipes, or stoma paste.

You can ask your GP to dispense your prescription early, if this will help with obtaining enough supplies to cover the holiday. You may find your stoma bags react differently on holiday than they do at home. This can be due to the heat, swimming in the sea or pool, doing more exercise (and so sweating), or applying different lotions such as sun cream. As a side note, applying roll-on deodorant under the baseplate, can help in this situation (but be sure to test for allergies first). Bowel habits can change too whilst on holiday, due to a different diet. Remember – it is always better to have more bags than you need- and bring them home again - than to run out!

When going on a plane or cruise, or even a train or coach, you are likely to be separated from your luggage for some time. Not only do you need to ensure you have adequate supplies in your hand luggage, but it is also sensible to pack your supplies across multiple bags. This reduces the chance of ending up with no supplies if any of your luggage goes missing. If you're travelling with someone else, you could always ask them to put some of your supplies in their luggage too.

For further advice, contact Colostomy UK's freephone Helpline on 0800 328 4257.

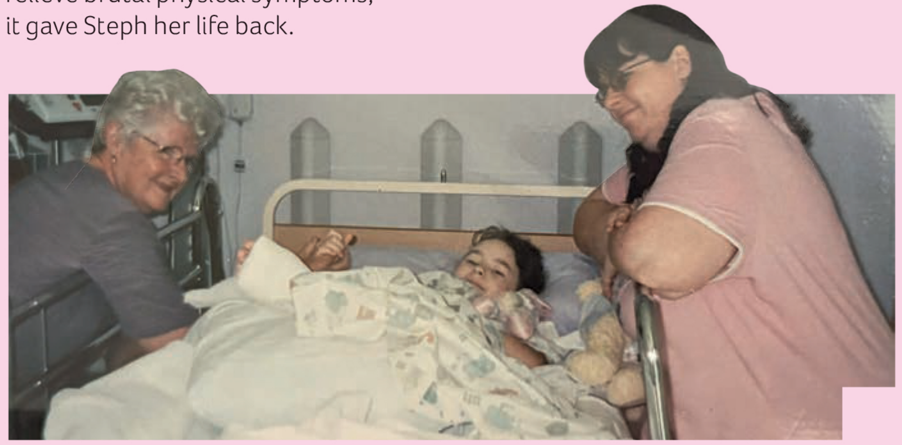
Steph Taylor's Fight for Freedom

BY LESLIE MELLO

When Steph Taylor asked her surgeon for a colostomy, he was surprised. In five decades of practice, she was only the sixth patient to ever request one and just the second he'd said yes to. But, as Steph told Tidings contributor Leslie Mello, stoma surgery was the best decision of her life.

For Steph, stoma surgery wasn't a desperate last resort. It was a chance to reclaim her life."At that point," she says, "I was in the deepest depression I'd ever experienced. I couldn't leave the house or be away from the toilet. I couldn't eat without pain or fear. I couldn't live and I just thought, a colostomy is my only shot at freedom."

That decision became one of the best she ever made. It didn't just relieve brutal physical symptoms; it gave Steph her life back.



With this new freedom she was able to fulfil a lifelong passion: to use her voice, lived experience and creativity to connect with others like her and give them hope.

Steph's story is one about the freedom and purpose that can come from unexpected places. In her case, it came from a stoma named Peaches, and from a passion for volunteering that has reshaped not only her own life but the lives of many others.

A Lifetime of Medical Challenges

Steph was born with a series of complex congenital conditions, including sacral agenesis which means she had no sacrum or coccyx, and parts of her spine and spinal cord were missing. Due to the impact on her nervous system, she also had double incontinence. As a child, she underwent the Mitrofanoff procedure, a rare operation that allowed her to catheterise her bladder through her belly button, and another to enable bowel washouts through a stoma.

Washouts were the only way to empty her bowels and needed to be done a few times a week. They were long and uncomfortable but "My mum did her best to make washout time fun," Steph recalls. "She gave me balloons, Play-Doh or other toys. I also remember feeling like I had some control over my body."

But control over her bowels didn't always mean control over her life.

Ehlers-Danlos Syndrome – Adding Dangerous Complications

Among Steph's diagnoses, the one she feels has impacted her the most is Ehlers-Danlos Syndrome (EDS), a connective tissue disorder that affects her collagen and healing. It's the invisible thread behind many of her most serious complications.

"So many of the things that nearly killed me are rooted in the EDS," she says. The condition means injuries take longer to heal, surgeries are riskier, and fatigue is a constant companion. Post-operative recovery is slower and more painful, and even small accidents can lead to significant setbacks.

Despite these difficulties, Steph hasn't let EDS defeat her. She takes daily supplements to support her immunity and healing, and she dreams of raising more awareness for this widely misunderstood condition. "People see my stoma or my wheelchair, but not the underlying cause. EDS ties it all together and it deserves more visibility."

The Pain That Left the Deepest Scars: Bullying

For all the physical pain Steph has endured, the emotional toll of bullying remains the biggest wound. From nursery school onwards, she was marked as 'different' by a school system that can be widely unskilled at preventing bullying. Due to a lack of support staff, Steph was isolated during breaks and stranded in the medical room instead of being allowed to play with others in the playground. The loneliness and isolation were bad enough, but this created a barrier to forming friendships and soon the other children were bullying her relentlessly.

> "School made it obvious I was different," she says "and once kids see that, they zero in."

On top of her visible disabilities, Steph was coming to terms with her identity as a young LGBTQ+ person in a strict Catholic environment. She later learned she is autistic and has ADHD.

By secondary school, the cruelty escalated to physical violence. Shockingly, teachers dismissed her and her safety was ignored. Eventually, Steph was pulled out of school and homeschooled by her mother, who used museums, documentaries, and real-world experiences to nurture her education.

While she did go on to earn a first-class honours degree in Digital Photography and Radio Production from the University of Chester, Steph still feels the weight of those early years. "Nothing I've been through physically ever hurt like that. The surgeries didn't break me like the bullying did."

When asked how she found the strength to go on, Steph said "My mum was my biggest support. She fought for me when no one else would. Watching her never give up on me made me promise I'd never give up on myself." Steph said that even after her mother's divorce, when they were homeless and having to live in a Travel Lodge, her mum made it all bearable and even made it seem like an adventure at times.

Finding Purpose Through Volunteering

Due to the bullying, Steph found it hard to form friendships in traditional settings. Even one of her few friends felt unsafe being seen with her at school, afraid of becoming a target herself.

But Steph found another way to connect. Volunteering offered her a sense of belonging and meaning. She began at age 16 with Buzz, a youth group for disabled teens, and later immersed herself in university advocacy work, student council, and community projects. Her efforts earned her two of Chester's prestigious community awards.

> "Volunteering gave me purpose," she says. "It made me feel useful and that I had something to give."

That sense of giving grew into mentoring roles, including teaching photography to at-risk girls. Many of her students were struggling with very difficult challenges and for two years, Steph offered them an outlet and a future.

"One of them changed her GCSE options to photography because of that course," she says proudly. "That's all I want. To know I made a difference. That's everything."

Freedom Through a Stoma Named Peaches

By 2020, after decades of managing with bowel washouts, medications, and endless hospital visits, Steph's health hit another crisis point. The usual medical support was no longer enough, and she started to suffer severe pain and constant accidents. She was trapped at home as she couldn't be away from a loo. This isolation gave her a sense of hopelessness so severe she wondered if life was worth living any more.

That's when she asked for a colostomy. Her surgeon admitted it's extremely rare for a patient to request a stoma, but Steph knew it was the key to freedom. The surgery, performed in February 2023, involved a full vertical incision, her fourth through the same scar line. Recovery was complicated by tonsillitis and COVID-19, but Steph still calls it "the best surgery I've ever had."

> "I woke up and I didn't have to plan my day around washouts or worry about accidents. I was free," she says. "Even with complications, I was happier than I'd ever been."

Upon seeing her stoma, it was love at first sight. She named it Peaches because the shape reminded her of one and she immediately bonded with it. "Nothing that's happened since my op has ever been as bad as one day without it."

With Peaches, Steph can travel, perform, eat without fear, and enjoy daily life in ways she hadn't for years. "I can finally eat veg again, try new foods, and just enjoy eating without fear."

A Thriving Creative Life

With her health more stable and her confidence restored, Steph's creativity soared. She joined Proud Marys, an LGBTQ+ choir in Chester, where she met her girlfriend and soon-to-be fiancée.

Her photography career flourished too. She was commissioned for headshots, rehearsals at Storyhouse Theatre, and local community events. A pivotal moment came when she met actress Cherylee Houston, leading her to DANC (Disabled Artists Networking Community), where she connected with creatives who understood her journey.

> "Seeing people like me succeed in media made me believe I could too."

She's now a credited photographer on Spotlight, continues to shoot for DANC, and even models alongside her best friend Sarah, a fellow EDS and disability influencer. Together, they co-run a vibrant, fun ADHD-fueled Instagram presence @sarahandstephi to document their journey as 'disabled neurospicy besties'.

To celebrate Peaches' second birthday, Steph did a professional lingerie photoshoot proudly displaying both her colostomy and Mitrofanoff. "It's the most beautiful photo I've ever seen of myself. I felt empowered."

Advocacy, Access, and Future Dreams

Steph's advocacy work hasn't slowed. She wrote to her MP and helped initiate plans for stoma-friendly toilets in Chester's new public buildings. "People don't realise the simple things we need like shelves or a sink in the right place. I wanted to change that."

Looking ahead, Steph dreams of telling her story through a documentary, using decades of family-shot footage. But she's also aware her story isn't universal. "It's not a great outcome for everyone," she says of stoma surgery. "But I wish I'd read a story like mine when I was deciding. So I share mine now for anyone who may need to hear it."

A Message of Hope

Steph is now thriving because of her stoma not despite it. But her greatest source of freedom didn't come from the surgery itself. It came from her unwavering spirit.

If only there was a medical procedure to remove bullying – the kind that leaves no scars or lasting damage. But until that exists, we can be inspired by Steph's fighting spirit, her close-knit family, and supportive organisations that helped her survive the wounds others can't see.

Steph's determination, compassion, and radiant positivity have taken her further than any operation ever could. She's fought for every step of the joyful, creative, love-filled life she now leads. And her message to others?

> "It can get better. Don't give up!"

Colostomy UK

news

Changing of the Guard: In conversation with Colostomy UK's outgoing and incoming Chair of Trustees

The Chair of Colostomy UK, Mandi Laing, is stepping down later this year. She is passing the baton to trustee Matthew Pollitt. Here, Mandi reflects on her time in post, while Matthew considers what lies ahead for the charity.

I have lived with a stoma since 2010, following a misdiagnosis of anal cancer that led to an abdominoperineal resection (APR). Thanks to my surgeon, I avoided chemotherapy or radiotherapy. Initially challenging, I adjusted to life with a stoma – whom I named 'Henry' – with the help of the Stoma Care Nurses at Frimley Park Hospital. I have embraced my new normal, becoming the chair of Colostomy UK, a magistrate in Portsmouth's adult and family courts, and an advocate for others with stomas.

I heard about Colostomy UK through a friend and joined the closed Facebook group. This led to volunteering at a Birmingham brainstorming session on funding opportunities, which in turn led to volunteering on the helpline and then joining the board in 2015.

> **I was motivated by witnessing the challenges faced by individuals adapting to life with a stoma, disparities in care and access to supplies across the UK, and the dedication of the team.**

With my lived experience and business background, I was able to contribute to governing the charity. As the charity's reach and influence grew, it became evident that the board, in line with Charity Commission recommendations, needed a diverse skill set. Following the passing of the previous chair, Monty Taylor, I was voted in as the new Chair and began collaborating with Libby Herbert (CEO) to recruit a streamlined board.

Colostomy UK has changed enormously since I joined, yet its core values and aims remain the same. What has evolved is our ambition – we now truly believe the sky is the limit. This mindset has taken us to places we never imagined a decade ago. While we still face challenges, particularly the stigma around 'poo – the final taboo' and increasing pressure to raise funds, we've become the go-to charity for stoma-related issues.

What I'm most proud of is our current strategy document. Developed collaboratively by our team and trustees, it sets out our direction for the coming years and provides a strong foundation for future progress. It's a testament to how far we've come and to the commitment that drives everything we do.

> **Colostomy UK has been a big part of my life for over 10 years, so stepping away is bittersweet.**

I've loved working with Libby, the team, and so many amazing volunteers, including past and present trustees. The team's creativity and dedication never cease to impress me – so many great ideas brought to life by a small but mighty group. I plan to stay connected and have already offered my spreadsheet skills! I'm happy to support the charity and my successor, Matthew, in any way I can. I hope Colostomy UK delivers on its strategy and continues to grow. Meanwhile, I've joined the committee of a local junior drama group – so while Libs and Matthew lobby parliament, I'll be sewing sequins and chaperoning kids backstage!

Continued overleaf.

Lastly, thank you Matthew for taking on this role. It is vitally important, and I know he will do a fabulous job. He will bring a fresh set of eyes and a different perspective and that can only be good for Colostomy UK. Matthew – over to you!

In-coming Chair, Matthew Pollitt

I have had a colostomy since being run over by a bus in 2012, and I came to Colostomy UK for practical advice and to hear about other people's experiences of living with a stoma*. I joined the board of Colostomy UK in 2020, hoping to be of some use to an organisation from which I had benefitted so much. As Mandi outlines in her piece, the board had been through some recent changes, but Colostomy UK was generally in good health with a strong group of committed volunteers and a small but skilled team of staff led by Libby.

Tidings T78, Pages 9-11

One of the most encouraging things about the last three years has been how positive everyone I have met has been about our cause. There is no better illustration of this than the 3,700 responses received for last year's beneficiary survey. We will be sharing the full results in due course, but two things already stand out to me. Firstly, that the support and advice provided by everyone involved with Colostomy UK is incredibly valuable to those who need it. Secondly, that despite the hard work and dedication of so many, most people with a stoma have still at times faced significant problems in accessing the medical care or supplies they need, or in accessing the public facilities that would enable them to live their lives to the full.

One of many legacies of Mandi's time as chair will be in strategic planning. By the time I take over from Mandi at the end of this year, we will have a new strategic action plan in place, developed collaboratively by the board and staff team, which builds on the many good things that are already happening.

> **Providing support and advice will always be at the heart of our work, and we have an ambition to make Colostomy UK even more relevant and accessible to ever more people, whatever their personal circumstances and wherever they live.**

Alongside this, we have an important role to play as a voice for the stoma community, continuing to raise awareness amongst the public of the realities of living with a stoma. We will ramp up our demands of decision-makers to improve the availability and accessibility of public toilets, and to ensure that everyone with a stoma has trouble-free access to the personalised stoma products and expert support they need, regardless of their postcode or any other factors.

These campaigns will already be familiar to regular readers of Tidings, and to have the necessary impact we will need to continue to punch above our weight, building on recent publicity successes at national and local level. We will build alliances with other organisations and individuals with similar goals, and we will forge even stronger links with medical and other experts to continue to inform our advice and campaign positions. We also need to recognise the financial challenges currently faced by charities in general, and that any future success will be reliant on continuing to develop our fundraising skills and developing new streams of income.

> **Alongside the rest of the board of trustees, it will be my privilege to support Libby, her team, and everyone else involved with Colostomy UK to get all this done!**

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*See the Summer 2025 issue of Tidings for Matthew's stoma story

A Quiet Revolution: How the Framework of 'Loss' can Prove to be a Catalyst for Positive Change

*This article is sponsored by Carrie Helman at Parasol Counselling

For many ostomates, particularly those who have lived with chronic and painful underlying conditions, having a stoma formed through elective surgery offers a new lease of life and signifies freedom and wellness.

Others, however, such as those who have undergone emergency surgery, may unexpectedly wake to find they have a stoma and had little or no time to adjust to what this life-changing event means for the future. For this group of ostomates, learning to live with a stoma can be more fraught with emotional challenges.

The psychotherapist, Carrie Helman, specialises in this group of ostomates within her practice. As an ostomate who has experienced these emotions herself, she is uniquely placed to support others in a similar position.

Here, Carrie frames these feelings in terms of 'loss'. For her, acknowledging loss is the first step towards acceptance of change, and ultimately, a more positive sense of self.

Living with a stoma is a journey marked by significant physical and emotional adjustments. While the visible changes are undeniable, the invisible burden of loss can be equally profound. For ostomates, 'loss' extends far beyond the physical, encompassing a spectrum of emotional and social experiences that can deeply impact quality of life.

Physical Loss

At its most basic level, stoma surgery signifies a loss of bodily function. The natural processes of elimination are altered, replaced by a stoma and appliance. This physical shift can trigger a sense of mourning for the body's previous capabilities, leading to feelings of:

- Loss of Control: The unpredictability of bowel movements or urine output can create a sense of helplessness and a loss of autonomy over one's own body.
- Loss of Physical Ideal: Many individuals struggle with the perceived loss of their 'perfect' body, grappling with the changes in appearance and the presence of scars.
- Loss of Sensation: The altered physical sensations associated with a stoma can lead to feelings of disconnection from one's own body.

Emotional Loss

Beyond the physical, ostomates often experience a range of emotional losses that can be just as challenging to navigate:

- Loss of 'Normalcy': The changes in lifestyle and routines can lead to a sense of loss for the life they knew before, a feeling of being different from others.
- Loss of Confidence: Fear of leaks, odours, or social stigma can erode self-confidence, leading to anxiety and avoidance behaviours.
- Loss of Intimacy: Body image concerns and fears about sexual function can impact intimate relationships, leading to feelings of isolation and disconnection.
- Loss of Security: The ongoing management of a stoma and the potential for complications can create a sense of insecurity about the future.
- Loss of Emotional Stability: The constant stress and anxiety associated with living with a stoma can lead to emotional exhaustion and instability.

Social Loss

Stomas can also impact an individual's social life, leading to feelings of:

- **Loss of Social Freedom:** Fear of accidents or social stigma can lead to social withdrawal and avoidance of social situations.
- **Loss of Belonging:** Ostomates may feel different or abnormal, leading to feelings of alienation and a sense of being set apart from others.
- **Loss of Support:** The challenges of living with a stoma can strain relationships, leading to feelings of isolation and a lack of support.
- **Loss of Employment Opportunities:** Fear of judgement, or the physical demands of certain jobs can cause a person to feel that they are unable to work.

The Importance of Acknowledging Loss

It's crucial to acknowledge and validate these losses. Ignoring or minimising them can hinder the healing process and contribute to emotional distress. Therapy, peer support groups, and open communication with loved ones can provide a safe space for ostomates to process their feelings and develop coping mechanisms.

By understanding the complex nature of loss in the ostomate experience, counsellors can provide more compassionate and effective support, helping individuals to navigate their journey with resilience and find a renewed sense of wholeness.

Practical and Emotional Guidance for how to Manage Negative Thoughts

Clients often ask me what tools they can use on a day-to-day basis to enable them to cope with this 'new normal' beyond the therapy room.

At home:

- You can engage in self-awareness exercises, paying attention to your physical sensations and the emotions that arise in different environments/situations related to your stoma.

- Journalling can become a space to explore your internal dialogue and identify any recurring negative themes.
- Experimenting with different ways of relating to your stoma, perhaps through gentle touch or mindful observation, can foster a greater sense of integration.

Within the community:

- Connecting with other ostomates through support groups (online or in person) offers opportunities for shared experiences and mutual support, helping to normalise feelings and reduce isolation.
- Engaging in activities that bring you a sense of joy and accomplishment can also help shift your focus and build a more positive sense of self.

Befriending your stoma:

- This may not be for all ostomates, but naming your stoma can be really empowering. Instead of seeing it as just a 'medical thing' that happened to you, giving it a name can make it feel a bit more like a part of you. It's you making the decision to take charge by saying:

> *"This is part of my life now, and I'm going to acknowledge it, and accept it."*

Remember, coming to terms with having a stoma is a process that can take time, and seeking support is a vital step towards living a full and meaningful life as an ostomate.

You can contact Carrie Helman to find out more about her counselling practice at: carrie@parasolcounselling.co.uk

The UK Council for Psychotherapy (UKCP) also lists practising psychotherapists across the country: www.psychotherapy.org.uk

To find your nearest support group, head to page 47.

JET, SET AND DONATE

Colostomy UK

Summer should be a time of excitement and relaxation – but we know that it comes with extra challenges.

From navigating airport security, overcoming body confidence setbacks, and additional stoma management issues in the heat – these hidden hurdles can turn holiday excitement into anxiety.

> *"I worried about how I would cope on holiday, but due to all the information and help I received from Colostomy UK I needn't have worried"*
> **Jan**

Will you support us this summer? So everyone living with a stoma can Jet, Set and **Thrive** just like Jan, Mike, and Justine.

- Call us on **0118 939 1537** to make a donation over the phone
- Complete our **donation form** opposite
- Visit: **cafdonate.cafonline.org/28476** or scan this QR CODE

Please support Colostomy UK

Every 39 minutes someone in the UK has stoma surgery

Your donation today, or pledge of a regular gift, will help ensure we can be there for every one of them. You can make a real difference in real lives.

SCAN HERE TO DONATE

Please complete and return this form to: **Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire RG41 5RD.** Call: **0118 939 1537** to donate by phone or if you have any queries.

Bank details for donations: Colostomy UK, account number 88781909, sort code 60-17-21. Please add reference T78. Thank you

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(Please complete in **BLOCK CAPITALS**)

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I would like to make a one-off donation

Please ensure you also complete the 'My Details' section above

☐ £30 ☐ £50 ☐ £75 ☐ Other (please specify) £

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☐ 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

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Charity name: Colostomy UK

Name and full postal address of your Bank or Building Society

To: *The Manager*
Bank/Building society:
Address:
Postcode:
Name(s):

Bank/Building Society account number Branch Sort Code

Service User Number 6 9 1 2 1 3 *CAF, Kings Hill, West Malling, Kent, ME19 4TA*

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

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T79

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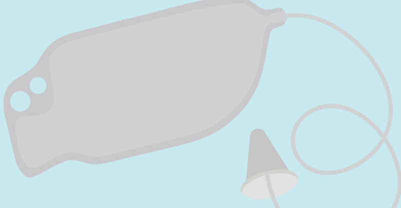
Colostomy UK

Jackie McPhail, Clinical Services Manager Hollister Limited, and Honorary Clinical Nurse Specialist Stoma Care

dear nurse



Colostomy Irrigation

Stoma Care Nurse, Jackie McPhail, talks us through exactly what irrigation is, how it's done, and which ostomates may benefit from for this unique alternative to wearing traditional stoma bags.

What does irrigation entail?

You are taught how to irrigate your colostomy by your Stoma Care Nurse. They will either reach out to your consultant directly or else ask if you have a communication from your consultant, stating it is possible for you to perform irrigation

You will introduce water via a container through a tube which is attached to a stoma cone. The stoma cone is soft and angled into the stoma to introduce the water. Your nurse will let you know the right amount of irrigation fluid for your weight.

Irrigation fluid is water, which is not too hot or too cool, which helps to prevent cramping. It enters your colostomy, and the rate is calculated so that it does not go in too fast, again to help prevent cramping.

> *Stoma Care Nurses often perform the first irrigation with you in the hospital. Thereafter you can do it yourself at home.*

After introducing the irrigation fluid, you will need to use an irrigation drain to collect all the stool and irrigation fluid. An irrigation drain is a plastic sleeve which attaches to the baseplate. Once full, the drain is used to funnel waste and water into the toilet.

While waiting for this, I would suggest that this is a good time to have breakfast and tea or coffee. This will help stimulate peristalsis, which is the muscle action in the bowel to move contents along the bowel. This is called the gastro colic reflex.

After about half an hour all the contents should have drained out of the stoma.

How often does irrigation need to be performed?

> *Typically, irrigation is performed every 24 – 48 hours.*

Initially you will need to perform this daily, but you may be able to extend this to every two days if you do not have any bowel motion in that time.

Irrigation: An Overview

Some of you may have heard of irrigation or been offered this as a way of managing your colostomy.

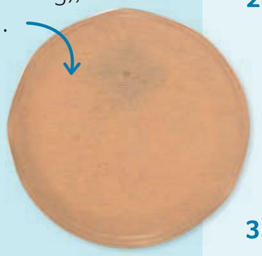
Simply put, irrigation is a way of flushing out the bowel with warm water, via a tube inserted into the stoma via a stoma cone. For those for whom it is suitable, it offers an alternative to wearing stoma bags, as it clears output from the colon.

Irrigation is only suitable for people with a colostomy. It is sadly not suitable for those with an ileostomy (small bowel stoma) or urostomy (urinary stoma). If you have a colostomy and are interested in performing irrigation, ensure you have the permission of your Consultant Surgeon first.

It is not suitable in the first three months following surgery leading to a colostomy. This is to ensure that the anastomosis (i.e. the join in your bowel) has healed.

Do people who irrigate still need to wear a stoma bag?

No. Instead of using a bag, which would normally be changed 1 to 3 times a day (if a one-piece bag), a stoma cap can be used. There are several on the market, these have a filter and small capacity to absorb any mucus. Ask your Stoma Care Nurse for details.



Then, that is it until you need to irrigate again.

What are the benefits of irrigation?

There are several benefits:

- There's no need to wear a stoma bag
- So no need to worry about pancaking or flatus
- You don't need to think about changing a bag at times when work or other commitments may make this difficult
- Many people who irrigate say it improves their quality of life
- It offers discretion under clothing
- No need to worry about pouch disposal
- Irrigating can help reduce odour
- Irrigation can help reduce the risk of peristomal skin complications as there is no need for a baseplate.

I have had patients who, because of their profession, found irrigation fitted well with their lifestyle. For example, a barrister who wanted to return to work after stoma surgery, and a long-haul flight attendant who did not want to worry about bag changes.

> *One of my patients described colostomy irrigation as a 'life changer'.*

What equipment is needed for irrigation?

1. A water reservoir to hold the irrigation water
2. Tubing to connect to the stoma cone. You should also have a valve to regulate the speed of the irrigation fluid flowing through to the stoma
3. A stoma cone
4. Lubricating gel to go on the stoma cone
5. An irrigation drain (or sleeve)
6. A brush to clean the tubing
7. Stoma caps.

All of this equipment should be available to you on prescription.

What are the caveats?

As mentioned above, irrigation is only suitable for those with colostomies, and even then, it's not for everyone.

You must be prepared to do it regularly, so that you get into a regular bowel habit and do not have bowel actions in between irrigations.

Contraindications to performing colostomy irrigation (Jones 2021);

- Issues with your heart or kidneys
- Ongoing cancer treatment
- Crohn's disease or diverticular disease
- Possible radiation damage to the colon.

Your consultant surgeon can advise if irrigation is an option for you.

What else may someone need to consider before irrigating?

You will need to have access to the bathroom whilst performing irrigation (approximately 10 – 20 minutes to insert irrigation fluid) and additional time again after the irrigation fluid and faeces have drained out of the stoma into the irrigation drain.

It can also take between 6 to 8 weeks for your bowel to settle into a routine with the irrigation.

For more information on irrigation, you can view Colostomy UK's videos online. If you're reading digital Tidings, simply click directly on the links below;

- **Colostomy Irrigation for the patients**
- **Colostomy Irrigation for the health care professionals**

If you are reading the paper copy, simply type the title of the videos into a web browser.

You can also learn more on the topic from Colostomy UK volunteer, Sally Laight, in a previous edition of Tidings.

For digital readers, simply click on:

- **Tidings, Autumn 2024. This back issue is also available via the website.**

You can always call Colostomy UK's free helpline on 08003284257 for further advice.

References: Association of Stoma Care Nurses (2016) Colostomy Irrigation national guideline for nurses. Jones H (2021) Colostomy Irrigation (part 1): Impact on quality of life. Gastrointestinal Nursing 19 (3); 24-29. Jones H (2021) Colostomy Irrigation (part 2): Contraindications, barriers to uptake, adherence and nurse education. Gastrointestinal Nursing 19 (5); 22-27.

BACK TO BUMS

Your Stoma Reversal Questions Answered

Part 1 - Chris

Chris* recently underwent stoma reversal surgery. Here, he shares his thoughts on his post-surgical recovery and offers tips to others who are considering a reversal of their own.

Why did you initially need stoma surgery?

I had my stoma formed in October 2022, before my bowel cancer diagnosis and six months of chemotherapy. I had an extended right hemicolectomy, which saw up to three quarters of my large intestine removed. This resulted in a temporary loop ileostomy.

When did you have your reversal and how did you find the surgery itself?

Thankfully I'm now in remission from cancer, so in February of this year I had my reversal.

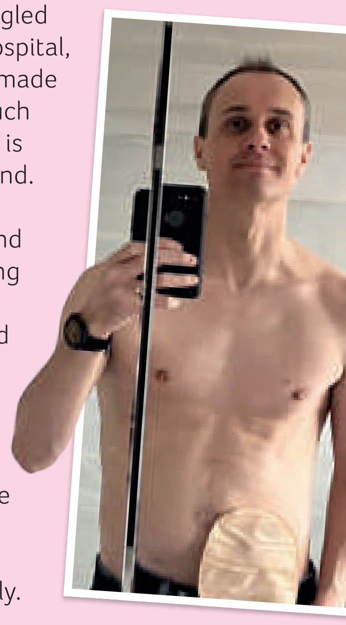
> *It's all going pretty well now, but it wasn't all plain sailing during the first four weeks or so.*

I was told surgery would be laparoscopic [an operation performed in the abdomen using small incisions with the aid of a camera] but on the morning I was due to go to theatre, I found out I had to have open surgery, as I had adhesions and scarring causing additional complications. Still, the operation went well thankfully, although I was in lots of pain straight afterwards.

How was your immediate post-surgery recovery?

I had a 15 day stay in hospital as my bowels woke up immediately, even though my stomach was still asleep. I was pooing a lot of liquid fluid and going to the loo between 20 – 30 times a day at first. I was also vomiting in these early days too. This all led to me losing weight quickly. I lost a lot of energy and was pretty immobile for a time.

I also really struggled to sleep in the hospital, which of course made things feel so much worse. Tiredness is not anyone's friend. I had a partially collapsed lung and pneumonia during my stay. I had a PICC line inserted in my arm and was fed Total Parenteral Nutrition and antibiotics. These made a massive difference very quickly, thankfully.



After this, I started to improve quickly, stopped feeling sick, and my stomach woke up, meaning I could start eating and drinking. Soon I was also walking again. My output, which felt like my bum was on fire at first, stung less and less and took on a more regular consistency and colour.

*Chris chose not to use his surname for this article.

How was your recovery following discharge from hospital?

As soon as I got home with my wife and young children, I was happier, and I could sleep better. It was still tough, but you heal quicker at home where you are meant to be.

I still had a lot of liquid poo during the first month or so. I also often had an uncomfortable feeling that I needed to go to the loo. I never had any accidents, but if I felt anything, I just took myself to the toilet. I was wisely told you should never trust a fart in these early days, so just sit on the toilet in case!

By the end of the first month, things felt more normal and more comfortable.

Sounds like good advice! What other surprises did you encounter?

Urinating was also difficult at first. I had cramps and weeing itself was painful. I wore pads for reassurance at first. I can wee fine now, thankfully, and it is no longer painful. That said, I've still some way to go before things are fully back to normal in the bladder department. I sometimes wake up two or three times a night with a cramp feeling and needing a wee (I had tests done because of this, and all appears normal, so it seems to be my extended settling period).

Another (pleasant) surprise was noticing incremental progress and how I was able to get back to my role as a Dad and helping domestically around the house! Eight weeks in, it was still taking me time to build up my stamina. I hadn't yet returned to work as I was still getting lots of twinges and funny feelings, and I have a physical job.

Being at home 100% of the time and slowly building back up my strength, I found I was able to be much more hands on with getting the kids ready for school, and doing household chores along with my wife, pretty quickly. I was averaging at least 5000 steps a day – with a few 7 – 11km walks thrown in for good measure. Progress is ongoing. That's the key. Any progress is good progress.

Where are you currently at on your reversal journey?

I put on about 10lbs in the past five weeks. I kept the diet mainly beige and boring for the first four to five weeks, then started trying different and more interesting foods. Nothing too brave or adventurous, but it's gone ok.

I also found that the drug Loperamide started to really slow things down, so now I usually only take one 30 minutes before breakfast most days. I follow this by one 30 minutes before lunch if I feel it's needed. Though this is still trial and error.

What tips would you give other people considering having a reversal?

- Everyone's reversal journey is different. I had some bumps in the road during my recovery, but it needn't be like that for others.
- The initial post-operation time in hospital was the most challenging part for me. It can be frustrating and at times overwhelming, especially if you're tired. But when your body starts to settle and you get back home, things soon feel better psychologically.
- Sudocrem is amazing. We had some left in the house after using it on our youngest child and it really soothed my bum.
- If you're not sure of anything call the telephone numbers you've been given at the hospital and ask for advice. I called the hospital a couple of times, and it was great just to have a bit of reassurance.
- Respect your body and listen to it. I got overly confident and tried to move/stretch a couple of times and almost hurt myself in the process.
- Wear comfy clothes, especially jogging bottoms at first. I found jeans rubbed on my scars and were really uncomfortable.
- One of the biggest things that made a positive difference to going to the toilet was to not drink too much before or during meals. I was advised this. Instead, I have a couple of small sips before and during. Then 20 – 30 minutes after a meal I start sipping properly (although definitely not gulping drinks). This helps stools to be better formed and makes it more comfortable to go to the toilet.

Do you have any final comments to those considering a reversal?

Very best of luck on your journey, wherever you are on it and whatever health conditions you're managing. May fortune smile on us and may we live positive, meaningful, fulfilled lives.

Part 2 - Leslie

Leslie Mello is further along in her stoma reversal journey than Chris (see part 1) and had a different set of experiences along the way. Here she shares her own reflections and tips.

Why did you initially need stoma surgery?

I had emergency surgery in February 2023 for a perforated bowel. Due to growths and adhesions on my sigmoid colon, surgeons had to remove it and fit a stoma, with the hope it could be reversed later.

When did you have your reversal and how did you find the surgery itself?

My reversal was in December 2023. In one way, it was harder than my first surgery as I was much more anxious going in, knowing how uncomfortable surgery and recovery in hospital can be. Oddly, the stoma wound hurt more than the larger midline scar, which surprised me since it was a smaller incision.

My recovery, however, was smoother because I was healthier going in. I had a fantastic wound care nurse, prepared myself with the right nutrition, rested properly and was able to bounce back much more quickly.

How did you find post-surgery recovery?

It was more challenging than expected! No one prepared me for the fear and discomfort of using my 'old equipment' after nine months of disuse. Despite avoiding constipating foods, I became severely constipated.

My bowels took a long time to 'wake up' again, but the hospital staff encouraged me to keep eating normally. After eight days without a bowel movement, I begged for an enema. They're not keen to give them so soon after surgery, but I was desperate.

I was so afraid it would become an issue that would cause complications. I also starting to leak around the impaction, which was so uncomfortable and humiliating. Thankfully, the enema worked. It felt like giving birth again, but it was a huge relief!

My stoma wound wasn't stitched as it needed to heal from the inside out, and I was upset when they explained this to me. It looked like a large hole in my side, I hated packing the wound and also worried I'd be left with a huge, weird scar. But the body is miraculous.

The wound closed beautifully, and now it's just a straight line. I was amazed and relieved.

What have been the main milestones in your reversal journey up to today?

In the early weeks, I had mild incontinence and couldn't hold in any farts, which made walks with my daughter undignified but also hilarious. At one point, we laughed so hard I also managed to wet myself. I didn't realise bladder incontinence right after surgery would also be an issue.

I assume it was all just a bit inflamed and sensitive in the entire area. Luckily, I found it pretty funny, and it all resolved within a few weeks as my body regained its functions, and I regained my dignity!

The biggest milestone (and miracle!) is that my digestion is now better than it has ever been. I can eat almost anything and no longer suffer from the chronic constipation I had before any of my surgeries. My digestion is better than it's been in living memory. With this outcome, it's obvious my reversal was 100% worth it. I know not everyone is as fortunate, and my heart truly goes out to them.

Reversal surgery is clearly a major operation and recovery is seemingly not without its challenges. Now that you are almost two years on from surgery, what are your reflections on that period of time?

Everyone's experience is different, but I've been lucky. My initial surgery was dangerous and not straightforward, but they only had to remove a small section of bowel (my sigmoid colon) with the understanding I could have a reversal. Although I was anxious, I knew it was worth attempting, because life without a colostomy bag is of course much easier than with one.

That said, if I had to decide based on how my bowel worked before my stoma surgery, when I was in constant pain (likely due to adhesions probably caused by endometriosis), it would be a tough call. But my surgeon did an incredible job clearing those adhesions and restoring proper function.

While I had my colostomy, I appreciated how miraculous it was. It saved my life and gave me a pain-free existence. It wasn't always convenient, but it worked.

So, for anyone facing this decision, it's essential to have an honest discussion with your surgeon about your condition and potential outcomes.

How has your reversal shaped your life?

I'm deeply grateful that my reversal not only brought me back to normal but actually made me feel better than before. Despite the fear and the ordeal of surgery and hospital recovery, I'm glad I was brave enough to go through with it.

Not having a stoma anymore means I don't have to deal with the usual challenges e.g. skin irritation, pouch leaks, etc. But I would've continued with the stoma gladly if it had been my only path to a pain-free life. Fortunately, I didn't have to make that trade-off in the end.

What tips and advice would you give to people either considering a reversal or who have recently undergone surgery?

For those considering a reversal:

» Get as much information as you can. Discuss with your doctor how your bowel is likely to function post-reversal e.g. whether you're more prone to constipation, diarrhoea, or incontinence.

» Understand that your body needs time to remember and re-educate itself – but it should get there in the end. It can feel scary and uncomfortable, and I wasn't prepared for how difficult that phase would be. I wish I had more patience and faith in the beginning.

» If you've had a stoma and found relief from painful bowel symptoms, weigh the pros and cons carefully. Reversal can be life-changing, but it's not a guaranteed fix for everyone.

» That said, if a reversal could reduce pain and improve quality of life, I'd absolutely recommend giving it a go.

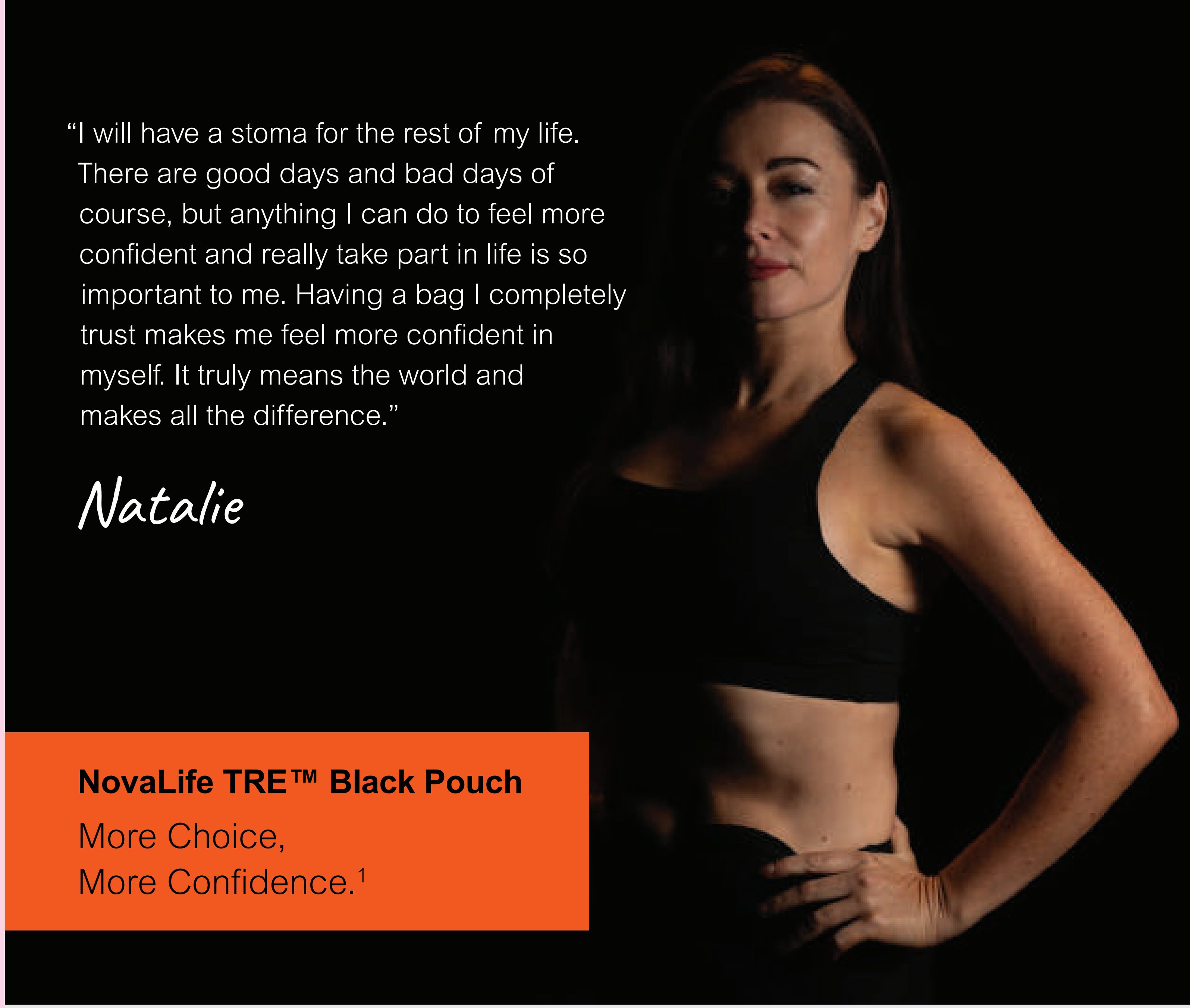
For those recovering from reversal:

» Support your body in every way you can. I focused on nutrition, hydration, and gentle movement. I also did everything I could to strengthen my immune system beforehand.

» A good wound care nurse is invaluable. Mine was amazed at how quickly I healed. At my two-week check-up, she said my wound looked like it was six weeks post-op.

» Mentally prepare for setbacks. I was terrified I might need a second stoma. But knowing I had lived with one before helped me stay calm. I told myself, "If it comes to that, I know I can do it again."

The emotional rollercoaster can be intense but trust your body and give it the support and time it needs. For me, the results were better than I ever imagined.



Team Colostomy UK Rugby League Updates

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

Our Wheelchair and open-age Rugby League teams are now halfway through their 2025 seasons. They have been on a journey which has taken them through Kent, Edinburgh, Widnes, and West Yorkshire.

It's really important as a national charity that we have as wide a geographical spread as we can, so we were really excited that in March, Team Colostomy UK headed to Scotland for the first time. Both our sides travelled 'North of the Border' for our Edinburgh Big Weekender.

The weekend saw us take on Glasgow Rugby League on the Saturday, followed by Edinburgh Giants' Wheelchair team on the Sunday. Both games were hosted by the University of Edinburgh and supported by Scotland Rugby League. We played some great rugby, made lots of noise in the local media, and built some great friendships. We're looking forward to hosting both teams in 2026.

In May, we headed to Cheshire for another double header which saw our Wheelchair team take on Widnes Vikings followed by our PDRL team playing a Wales development team.

Arguably the highlight of the year so far came at the end of June, when we headed to West Yorkshire for our 'Back to Batley' weekend.

Batley Bulldogs have previously hosted us in 2022 and 2023 where we had two really high-profile games against the British Asian Rugby Association. This attracted lots of local and National media, including the BBC and ITV cameras descending on Mount Pleasant, and the local MP and CEO of the Rugby Football League also in attendance.

This year we had two games across the weekend. On the Saturday, our wheelchair side came out on top 22-18 in a tight game against Batlkey Bulldogs A. A crowd of over 1,500 were in attendance on the Sunday when we played the West Yorkshire Police as a curtain raiser to Batley Bulldogs V Sheffield Eagles, going down 42-8.

Because we're here to both raise awareness, and challenge and change perceptions, partnerships with professional clubs like Batley and Sheffield are really important.

Firstly, they allow us to reach out to a new audience through spectators at games and followers of their social media accounts. Secondly, they provide us with a platform to tell our players' stories to the media. This was evidenced again this year when we welcomed both the BBC Look North cameras, and sports presenter Ross Fiddes who both filmed stories on our team.

Save the dates!

We finish off our season with events at Sheffield Eagles (**August 3rd**), Gravesend Dynamite (**September 6th**), Chorley Panthers (**September 13th**), and Wales Rugby League in Pontypridd or Neath (**September 28th**).

If you'd like to become involved as a player or supporter, you can find out more about us on X and Instagram **@TeamColostomyUK** or email **GetInvolved@ColostomyUK.org**.

We're also looking to fill two match day volunteer roles, photographer and Physiotherapist. Again, if you're interested in finding out more about either role please email **GetInvolved@ColostomyUK.org**.

Ask a Helpliner: Managing Dips and Creases

Managing your stoma can sometimes feel like a real challenge. This is especially the case if you have creases or dips in the peristomal skin (the area of skin around the stoma). Here, two of our helpliners, Holly and Debs, share ideas for how to manage these issues.

Creases and dips can make it difficult to get a stoma bag baseplate to properly stick to the skin, increasing the chance of leaks and negatively impacting confidence. There are many reasons why an ostomate may have creases or dips, and this can change throughout your stoma journey. Sometimes, especially if you have emergency surgery, a stoma can be situated in a dip on your abdomen. Others have difficulties due to hernias causing an uneven tummy shape. Weight gain or loss, as well as pregnancy, can change the shape of your tummy too, resulting in lumps and bumps, bony prominences, or loose skin. Abdominal scaring, particularly if you have had multiple surgeries, can also cause difficulties. Despite the reason for the dip or crease, many of the management tips can be tried by all.

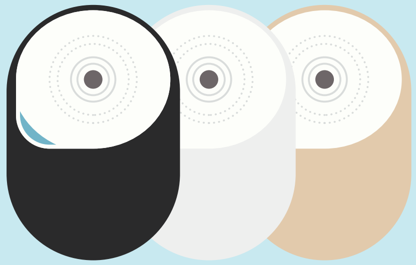
Applying the stoma bag whilst lying down can help to even out any lumps or bumps. Alternatively, standing up whilst pulling the skin taught with one hand, and applying the stoma bag with the other, can smooth out creases.

Of course, there are some dips and creases which cannot be so easily managed, however there are different types of accessories that can help.

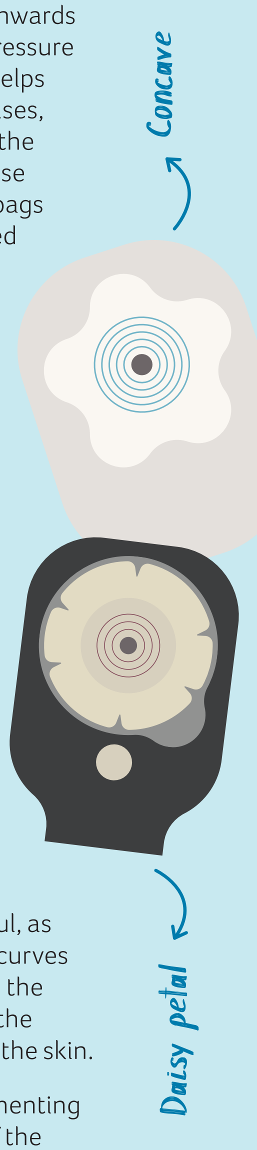
Washers (which look like a flattened doughnut) can be placed around the stoma before applying a bag. These fill in the dip, making a flat surface for the stoma bag to stick to, helping create a better seal. If the dip(s) are only in certain places around the stoma, then the washer can be cut or broken into sections and applied to the dips to fill them in where needed.

Stoma paste comes in a tube and looks a bit like toothpaste. It can be used to fill in the dips and creases around the stoma, evening out the skin. The paste can be moulded but is very sticky to handle – having damp fingers helps to prevent it from sticking in the wrong places!

As well as accessories, different types of stoma bags can help.

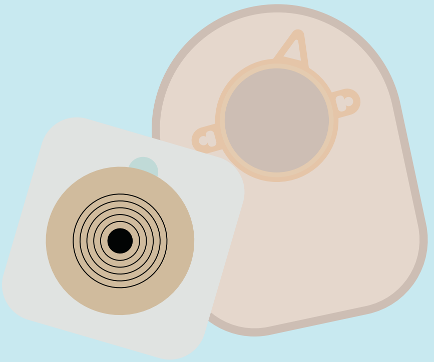


Convex stoma bags have a baseplate which curves inwards at the centre, applying pressure around the stoma. This helps to even out dips and creases, ensuring a better seal of the baseplate. However, please note that convex stoma bags must always be prescribed by your stoma nurse, who will ensure the pressure does not cause any damage to your peristomal skin.



Concave stoma bags curve outwards, creating a shape that looks rather like a bowl. These can be helpful if you have a hernia, or other bulges or curves around the stoma, as the baseplate hugs the contours of the tummy. Baseplates with a '' design (instead of being a circle/oval/square shaped baseplate, these are shaped like petals), may also be useful, as the fit wraps around the curves of the tummy, increasing the chance of all sections of the baseplate being stuck to the skin.

If you have scars, experimenting with cutting the edge off the baseplate, or making your own 'daisy petal' shape, by snipping ever so slightly into the baseplate around the edges, can ensure the baseplate avoids the scar. However be careful not to cut off too much of the baseplate, as it still needs to cover enough peristomal skin to adhere well.



Finally, there is a two-piece appliance. This is where the baseplate and bag are separate. The baseplate attaches to your skin as with a one-piece system, but then the bag attaches to the baseplate separately. This means that the stoma bag can be detached and changed regularly, without having to remove the baseplate itself. A two-piece can be particularly useful if you use lots of accessories to manage your dips and creases, as these can increase the amount of time it takes to change your baseplate, especially when out of the house. With a two-piece, you simply detach the bag and reattach a new one.

Deborah Meredith's Experience

I have suffered with dips and creases due to the complex surgeries I have had over the years for rectal cancer.

I previously had an ileostomy that was reversed and a urostomy sited over this scar. This caused me lots of problems and I was having leaks on a daily basis. The importance of working with your stoma nurse and finding the products and bags that work for you is essential.

Convex bags were a game changer for me and improved the leaks, but they were not perfect. I then added a barrier ring around the stoma, switched to a deeper convex bag and added Coloplast Brava tape. This seemed to be the winning combination, and I have used this set up for the past 4 years with great success. The barrier ring around the stoma helps to fill the dips and creases and provides a stronger seal to the urostomy bag. The tape around the outside of the bag gives extra security against leaks and is great if I am going swimming or using my hot tub. I rarely have a leak now and if I do it is usually from a faulty bag or an airlock at night connecting to the drainage bag. Having the correct fitting bags and accessories is the key to your confidence and living a good life with a stoma.

Deborah's products

You can read Debs' Real Lives feature on page 37

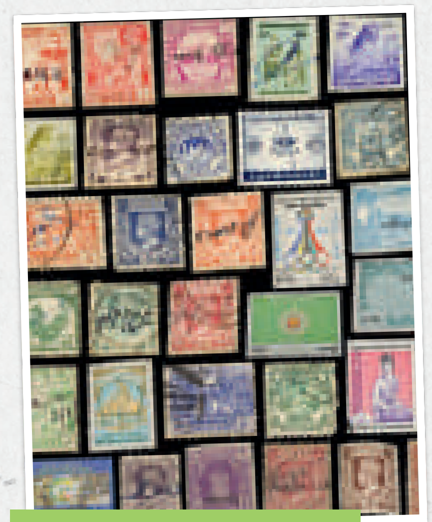
As you can see, there are many different stoma bags and accessories available, which can help you to manage your dips and creases with confidence. Your stoma nurse can assess your individual circumstances and help you to find the most suitable products for your stoma. Volunteers on Colostomy UK's stoma helpline can also recommend tips and tricks that worked for them and troubleshoot any problems with you.

You can call Colostomy UK's 24 hour, free helpline for practical and emotional stoma support on:
0800 328 4257

Colostomy UK

fundraising

Megan Lowden
Fundrasing Executive



Used Stamps = Unlimited Support

A number of Colostomy UK supporters have been in touch in recent months, asking if we still accept used stamps as a form of donation. Helpfully, we do! All kinds of stamps are welcome, on or off paper.

If you would like to donate your used stamps to raise much needed funds for Colostomy UK, simply cut the postage stamp from the used envelope, being careful that you don't damage the stamp. Once you have a small collection, you can pop them in an envelope and post to us at:

Colostomy UK
PO Box 16992
Sutton Coldfield
B73 9YA

Please note: postage needs to be applied.

Fundraiser Highlight!

Many of you may have already heard of superstar ostomate, Jack Dale (10) from our previous Fundraising updates.

In June he decided to ramp up his fundraising efforts once again by running 2 miles every single day in June, raising £712 for Colostomy UK in the process!

£712 Raised

We'd Love to Hear from You

If you just want to chat over any fundraising ideas with us please email us at: GetInvolved@ColostomyUK.org or give us a call on **0118 939 1537**.

Fundraising is invaluable for Colostomy UK, helping us to cover the running costs of all our support services, including Tidings, which we would not be able to continue without the generosity of our fundraisers.

Online fundraising

Our Fundraising Executive, Megan Lowden, and our Marketing and Digital Executive, Lauren Ross, combine forces to explain the novel concept behind online fundraising platforms and how they are helping to make donating to charity easier than ever.

What are online fundraising platforms?

Online fundraising platforms offer people the opportunity to raise free donations for charities, schools, sports clubs, and other good causes - simply by shopping online.

The purpose of these platforms is to make fundraising simple and accessible for all. It removes the need for traditional methods like bake sales or raffles, turning everyday online shopping into a source of regular income for good causes.

They have been around for about twenty years already, and operate as both a website and as apps on smartphones. Two of the most well-known platforms are **Easy Fundraising** and **Give as you Live**.

Both platforms partner with over 7,000 retailers, including major brands like Amazon, eBay, Argos, and Marks & Spencer. When users shop through the **Easy Fundraising** or **Give as you Live** website or app, a percentage of the purchase is donated to the buyer's chosen cause – at no extra cost to them! The retailer covers the donation as part of their marketing and affiliate budget.

Overall, using platforms such as Easy fundraising and Give as you Live is a win-win: supporters feel good about helping without spending extra money, and charities benefit from ongoing, hassle-free donations. It's a smart, modern approach to fundraising in the digital age.

Sounds innovative. Is it complicated to use?

No, not at all – using these platforms is super simple. All you need is a phone, tablet, or laptop with internet. Just sign up for free on one of the platform websites, or via their smartphone apps, pick a cause that you want to raise money for, and then simply shop online as usual.

The retailers then do the technical stuff, ensuring donate a small percentage of the purchase is donated to your chosen cause.

You don't even need to give your bank details, and it doesn't cost you anything.

The ease of online fundraising platforms is one of its greatest strengths. Supporters can raise funds effortlessly just by doing what they already do – shopping online. Quick, easy, and feel-good!

Will I be able to see how my money has supported Colostomy UK?

Yes! With both **Easyfundraising** and **Give as you Live**, you can see exactly how much you've raised for Colostomy UK. Your account shows a running total of your personal donations, plus how much has been raised by all supporters to the charity overall. It's a great way to see the difference your shopping is making – in real time!

Sounds great – How can I be sure it's secure?

Using online fundraising platforms such as Easy fundraising and Give as you Live are totally safe. You don't pay through them – you shop directly with trusted retailers like Amazon or eBay, using your usual method. The platforms do not handle your money – the donation comes from the retailer, not the buyer. Over 2 million people in the UK use these platforms to raise money for good causes, so you're in safe hands!

Ok, you've won me over! Where do I sign up?

Brilliant! You can sign up in seconds using either of the following two links:

www.easyfundraising.org.uk

www.giveasyoulive.com

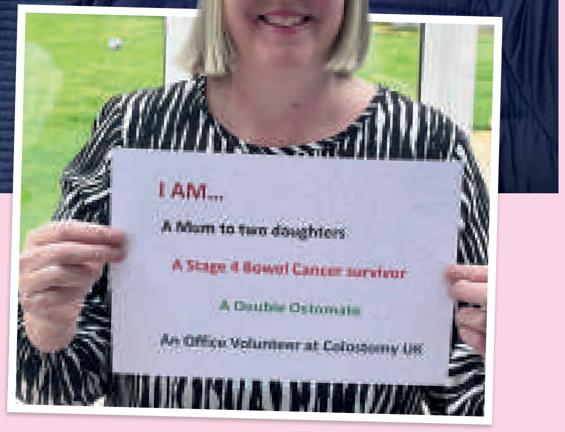
Or download the app for either **Easyfundraising** or **Give as you Live** from the **App Store** or **Google Play**, to get started on your phone.

Then simply shop as normal and start raising free donations today!

We understand that online donations aren't for everyone, so if you would like to donate via post you can do so using our donation form on page 24.

Everything, Everywhere, All at Once

BY ROSS OTHEN-REEVES



For many ostomates, stoma surgery is a once in a lifetime experience. It is rare indeed to meet someone who can claim the stoma hattrick of living with an ileostomy, colostomy and urostomy - and undergone a reversal, just for good measure. Deborah Meredith is one such rare creature. But her stomas only tell half the story.

Deborah Meredith has been volunteering for Colostomy UK since 2023, before officially joining the staff team earlier this year. I won't pretend that drafting the life events of a valued colleague doesn't come without added responsibility (it does, dear reader, I assure you!)

Even while bearing this in mind however, Deborah (or Debs, as she's better known within the team) has a remarkable story to tell. All ostomates do, of course. No-one has a stoma formed without having first endured a life-altering experience.

Yet the fact that Debs has undergone surgery for all three of the main types of stoma hints at the scale of what she has been through physically - and emotionally - to save her from an aggressive form of rectal cancer.

This tumultuous time began in 2018. Debs was 46 years old when she spotted blood in her stool. Tests didn't show anything to be particularly alarmed by. Results suggested she was slightly anemic, so Debs began taking iron supplements and continued with life as normal.

With nothing having improved by early 2019, however, Debs went for a colonoscopy, followed by a biopsy, which revealed she had stage-three rectal cancer.

"It was a massive shock. I was expecting them to say I had severe piles or something -because I wasn't really feeling unwell, apart from the bleeding and feeling a little bit tired, but I put that down to the anemia".

Debs was immediately put onto chemotherapy and radiotherapy tablets to try and reduce the size of the tumor, but with limited success. This left her with a difficult decision to make.

> "I had to choose between having a low anterior resection with a temporary ileostomy, or major surgery resulting in a permanent stoma, possibly two. It was a difficult choice to make".

Ultimately, Debs opted for a temporary ileostomy. Her recovery from the cancer, which included four months of chemo-infusion, went well. She felt great again. Yet her relationship with her newly formed stoma was difficult to accept.

As is often the case when emergency stoma surgery is involved, the lifesaving gift that the stoma gave Debs was overshadowed by the unexpected, and unwelcome, aspects of living with it. This included sore peristomal skin and humiliating accidents in public.

Given these issues, Debs was relieved when she was booked in for reversal surgery in July 2020. The operation was scheduled just two weeks after the death of her husband Howard's father, however, adding emotional strain and family upheaval to the moment.

Reversals are also complex procedures, often needing a long period of recovery, as our current article on the topic highlights (page 27). In Debs' case, this meant living with incontinence for some time after the operation. Unsurprisingly, this had a huge impact on her confidence. But with both Howard's mother and her own father both unwell with cancer themselves at this time, and her mum suffering with Alzheimer's disease, Debs had no choice but to continue engaging with the world.

Howard's mother sadly died in the April of 2021. Then, while still recovering from her reversal and grieving for Howard's parents, came the news that Debs and her family had all been fearing – the cancer had returned. It was also extremely aggressive. In just three months since her previous check-up (which had come back clear), the cancer had managed to pierce through the bowel wall, into the vaginal vault and pelvic side wall. A cancerous nodule had also been found on Debs' lung, and would of course need attention too, but the pelvic area had to be seen first as a matter of urgency. As Debs explained: "After seeing the surgeon, my only option was to have a Total Pelvic Exenteration operation. The news was heartbreaking".

> Heartbreak is completely understandable. Debs required full open surgery, lasting twenty hours, to remove her bladder, rectum, anus, appendix, gallbladder, and coccyx.

She would have had her cervix and womb removed as well, had she not undergone a hysterectomy several years earlier. She now had to have 90% of her vagina removed too, as surgeons needed to strip the entire pelvic area of anything the cancer could potentially spread to. Debs then had her whole pelvic floor rebuilt using animal-derived mesh, and a so-called 'Barbie butt' formed with the permanent closure of her rectum and anus.

> As Debs put it, quite simply: "It was a massive, massive, massive operation".

Given the complexity and risks involved with the surgery, Debs struggled to cope emotionally.

"The whole run up to surgery was so overwhelming. I have never cried so much in all my life. I knew I had to go through with the operation to have more time with my family. The thought of leaving my two daughters and husband behind was awful. I had even planned my own funeral in advance".

Like anyone of any age when facing such a dangerous procedure, Debs longed to simply have a hug with her mum. But due to her mother's advanced Alzheimer's, she was unable to comprehend what Debs was going through.

Alzheimer's wasn't the only disease keeping Debs from connecting with her family, however. Being 2021, the COVID-19 pandemic was at its peak, as were lockdown regulations along with it.

This wasn't the first time Debs had to face hospital alone. Restrictions had been in place for both her ileostomy and reversal surgeries, and these were of course extremely difficult experiences to cope with. But nothing compared to being dropped at the doors of the hospital by Howard ahead of her total pelvic surgery.

"I was so scared and went into surgery sobbing" Debs explained. "It was all the unknowns of what might happen - Will I survive? And if so, what state will I be in?"

> Following the operation, Howard was allowed to visit Debs in ICU – albeit only briefly.

"They brought him in, in full PPE gear, just so he could see that I was alright. I very rarely see him cry, but he did cry that day in hospital. I think it was a sense of relief seeing that I was still alive".

While contact with family was limited, Debs was placed on a ward with two other women recovering from similar operations, and the three of them kept each other's spirits lifted as best as possible.

Because the tumour had grown close to her sciatic nerve, Debs knew her mobility would be affected from the operation. She was told she may have reduced mobility, potentially requiring a wheelchair, or else be left with severe drop foot, or even never walk again. Thankfully, aided by a lot of physiotherapy, she was able to manage a few steps with a Zimmer frame by the time she was ready to leave hospital four weeks later.

Once home, Debs could finally surround herself with friends and family once again. She continued to make a remarkable recovery, given all her body had been through, and the fact that she had to re-learn how to walk.

A key motivator for Debs was to regain her independence. In these early months, she was dependent on Howard and others to care for her and to drive her to medical appointments. The lack of freedom coupled with guilt over being a burden weighed on her mind as someone who prides themselves on being self-reliant. Debs was also determined to get back to health as soon as possible as her two ageing and incapacitated parents needed her support.

Another reason to regain her strength was the fact that Debs would soon also be back in the operating theatre for two further operations to remove cancerous nodules from each of her lungs. The first of which took place in February 2022, which coincided with the death of her mother. Debs found herself planning her mother's funeral from her hospital bed in the days following surgery.

No sooner had the funeral taken place, when Debs was back in hospital again to have nodules removed from her second lung. Then, at the end of the year, Debs' father also died; the last of her and Howard's four parents to pass away within two years.

> "It was just one thing after another. Year on year, something was happening. I was in such a low place. I remember thinking 'Just give us a break.'"
>
> Thankfully, that break was finally on its way.

By mid-2023, with the waves of bad news and family crises now finally behind her, Debs could, for the first time, stop and take stock of the past few years. Only now, with the space to reflect, could the psychological work begin to make sense of everything she had been through.

"I think I was trying to process everything, because [in the moment] I just had to keep going. Then I had this sort of realisation: 'What the hell have I been through the last few years?"

Body image - and adapting to life with two permanent stomas - have had their challenges. Interestingly, Debs has coped better living with her

colostomy than her urostomy. This is partly because she continues to have more issues with her urostomy, particularly with leakage.

But it is also due to the fact that, ahead of her major surgery, Debs was told she would definitely need a permanent colostomy. This gave her time to mentally prepare for this stoma. This was not the case with her urostomy, as surgeons had initially hoped to save the bladder. Waking to discover she would be living permanently with both stomas was a huge blow at the time; it was yet another part of her body that Debs had hoped to save but lost.

Losing almost all of her vagina has of course had implications for her relationship with Howard as well.

“I had to come to terms with the fact that I wouldn’t be able to have sex anymore, and that surgery had taken all feeling away from my ‘women’s parts’. I felt a sense of loss and guilt that I couldn’t be intimate with my husband anymore”.

‘Loss’ is a word that Debs often returns to in our conversation. The psychotherapist, Carrie Helman, says that this sense of loss is familiar to many ostomates – so much so that Carrie dedicates a whole article to the topic on page 21.

Despite so many mixed emotions and bodily changes to contend with, Debs has ultimately gone from strength to strength in her recovery, both physically and mentally.

Already, by the summer of 2022, Debs had been well enough to fly to Antigua for a well-deserved holiday with Howard and good friends.

> Debs went into the swimming pool without even thinking about her stomas.

She was only reminded of them when her friend supportively noted how positive it was that she wasn’t worrying about them.

As Debs recalled: “From that point on, there was no stopping me. The more things I did, the more my confidence grew. There would still be a love/hate relationship with the stoma bags on bad days, but generally life was good again”.

Another major step forwards came when Debs began working with Colostomy UK in early 2023. Her neighbour had seen an advert for an office volunteer and encouraged her to apply, which – thankfully for us – she did.

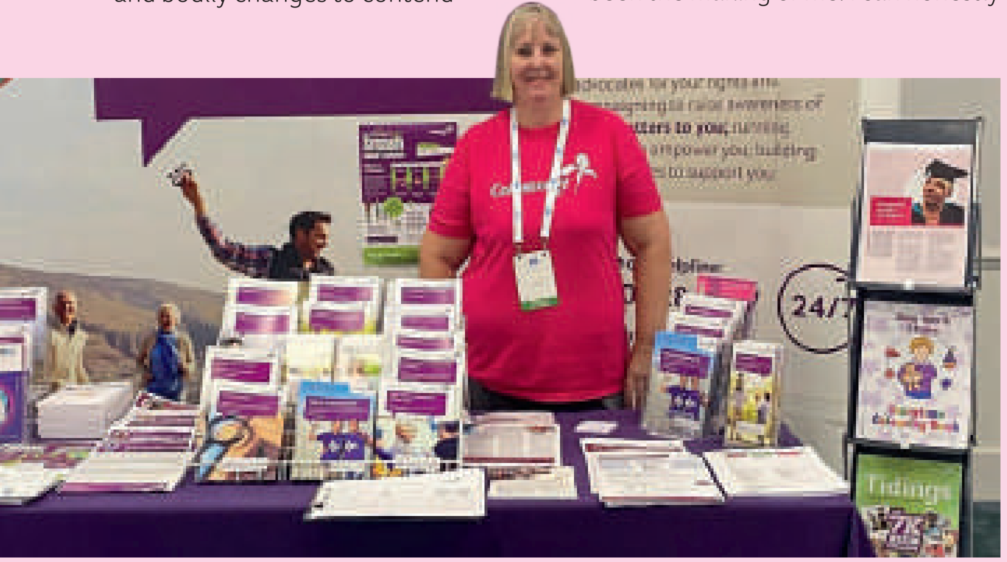
“Volunteering with Colostomy UK really helped me to get back into the workplace and to build my confidence again after a difficult few years. It has been the making of me. I can honestly say that I have never enjoyed working anywhere as much as I do here”.

The rest of the staff team will all say that the feeling is mutual. Debs has become such an integral part of the team it’s hard to imagine where we would be without her.

Debs represents the charity on several forums as a person with lived experience. She has featured in stoma-care training videos. It was also Debs who took the initiative (unprompted) to contact Marks and Spencer (M&S), suggesting to them that they should consider creating a stoma knicker range. She then took part in a wearer trial, and alongside our CEO, Libby, helped with the launch and bringing the product onto the market. This is all aside from offering vital peer-based support to other ostomates calling through on Colostomy UK’s helpline. To top it all, last year Howard even took on Africa’s highest mountain, Mt. Kilimanjaro, to raise much-needed funds for the charity.

Fast forward to today, and Debs is no longer a volunteer but a highly valued member of the staff team. Now 52, she has been cancer free since March 2022, and her oncologist has been amazed at the speed of her recovery and progress. As Debs put it:

> “I am now living life to the full in-between working and travelling the world. Every holiday, every special moment in life, I feel blessed to have been given another chance in life with my two stomas.”



Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

campaign news

A Tribute to Lyn Morgan

In June we were deeply saddened to hear of the passing of a great friend of Colostomy UK's, Lyn Morgan.

Lyn was a fearless advocate for our Stoma Friendly Toilets campaign, appearing on many television and radio shows, and convincing dozens of organisations in her native Yorkshire and beyond to do more for people living with stomas.

I worked with Lyn from 2023 and can honestly say that without her we wouldn't have had nearly the success we've had over the last couple of years. It all started when Lyn visited the White Rose shopping centre in Leeds shortly after her surgery and went to use the toilets. In her own words:

"I stood there in shock. There was nothing: no shelf, no hook, no mirror. I just stood there and cried because I didn't know what to do. I thought, what's the point of going out if I can't find somewhere that is hygienic? So many places aren't stoma friendly."

Lyn (right) with Louise Smith, Manager of North Point Shopping Centre

Lyn got in touch with us, and soon after she had the White Rose on board with upgrading their accessible toilets to meet our stoma friendly guidelines. White Rose is owned by the property management giant LandSec, and before long, their other outlets in Yorkshire and the wider country followed. LandSec's competitors, including British Land PLC and Saville's, followed suit and there are now over 100 retail centres and parks in the UK with stoma friendly facilities.

Our work with TransPenine Express, West Yorkshire Combined Authority, and Leeds Council, were all hugely influenced by Lyn. She didn't stop at toilets, however. Lyn also set up a much-needed support group in Leeds too.

In an interview with the BBC following the news that Leeds Kirkgate market had also joined our campaign, Lyn said:

> "I just want to help other people who have a stoma. Many people are in the same position and it's a mission"

She more than succeeded in that mission, and thanks to her drive and passion, the UK is a much more Stoma Friendly place than it was prior to 2023.

in loving memory

Debating incontinence in Parliament

On June 19th Parliament held its first ever debate on incontinence. Sonia Kumar, MP for Dudley, chaired the Backbench Business Committee debate and before the day, she said the issue "affected millions across the UK", but that it remained "overlooked and under-discussed". She hoped the debate would help to bring incontinence "out of the shadows" and give it the "attention it deserves."

We were really encouraged that several parliamentarians who spoke during the debate, including Jim Shannon, Chris Vince and Marcus Campbell-Savours, highlighted the challenges people living with stomas can face finding suitable toilets.

All three backed our call for Government to legislate, to ensure local authorities provide a level of public toilet provision that ensures people living with stomas and other conditions do not face social exclusion and isolation. Jim Shannon also referenced the great work we did in partnership with Ards and North Down Council which led to them upgrading 43 of their accessible toilets to meet our guidelines.

We have since been in touch with Jim Shannon, Chris Vince, and Marcus Campbell-Savours, to try and gain their guidance and support for our campaigns.

Your Letters and Emails

Here's a round-up of all your letters and emails

Moira Hammond's article on hospital volunteering drew interest from the community.

Readers can contact us at **editor@ColostomyUK.org** to be put in touch with Moira to learn more about this unique form of volunteering.

Tidings Issue 78 (Summer 2025), Pages 28-29

Hello,

I have just finished reading an article in Summer Tidings about Hospital Volunteering. Our support group in Edinburgh are in process of trying to give a similar service to patients on stoma wards in the local hospital. We would love to hear your experiences and guidance of getting volunteers into hospital.

Allen Howie

Dear Sir,

I enclose images recorded recently at Loughborough Station on the Great Central Railway (a heritage railway).

Their disabled toilet has been 'rebranded' as accessible and inside they have established a small unit to aid us ostomates with bag changes.

Yours faithfully,
John Atherley

Hi,

I must say I could not put down this issue of Tidings [Summer 2025] well done everyone who contributed. As a volunteer I do receive a printed copy for which I am very grateful for. I agree with some of the other members it's just not the same or easy to read Tidings on my iPad. This magazine really helps support so many of us. Thankfully things have changed dramatically since I had my first stoma in 1960, but has left me with many issues. There were no stoma nurses until the mid 70s, no disabled toilets, so much has changed.

Kind regards,
Beryl Goddard

Something you'd like to share with the community? Get in touch.

You can email us at:
editor@ColostomyUK.org
or write a letter to us at:
The Editor, Colostomy UK,
100 Berkshire Place,
Winnersh, Wokingham,
Berkshire, RG41 5RD.

Please also say if you're happy for us to use your first or full name. If we don't receive permission to use your name, we will use your initials only. Happy writing!

Support Group News

Jackie and Sue (AKA Thelma and Louise) at the B.O.T.S Open Day

Two of Colostomy UK's veteran volunteers, Jackie Dudley and Sue Hatton, drove to Shropshire to attend an open day of B.O.T.S. (Bums on Tums). Our CEO, Libby Herbert, joined them - doing her best to keep this 'Thelma and Louise' duo out of mischief. Jackie shares her reflections on their adventure.

When Colostomy UK heard that B.O.T.S.- a support group in Shropshire, were organising an open day, a wonderful idea was put forward to suggest that Sue Hatton and I should both visit and support such an important event, as two long-term volunteers for Colostomy UK.

This was the first open day organised by Emily Hackworthy, a young ostomate who took over the running of B.O.T.S. from Irene Constable, the volunteer who initially started the support group. Irene had had a spell of ill health and realised that she could no longer run the group, and so Emily, who had been helping Irene, stepped in to keep this wonderful group going.

> Irene had been awarded the Order of Merit in 2023 from The League of Mercy Foundation in recognition of her voluntary service to ostomates.

The League of Mercy Foundation was set up in 1899 to honour those who give so much to of their free time to charitable causes. Sue had also been awarded the medal around the same time, as someone who had outstandingly served our organisation for over 20 years and had offered support for the welfare of ostomates throughout the UK.

As a colostomate (and also a recipient of the League of Mercy award myself in 2024), I was invited to help with the journey from Berkshire to Oswestry, Shropshire. But then we googled the distance and found that with a comfort break it would take about five hours! Distraught at thinking of us both driving all the way there, Colostomy UK's CEO, Libby Herbert, volunteered to drive us.

> How could Libby be so concerned about us? As CEO of the charity, Libby had visions of us accidentally driving into Birmingham, only to find out how awful the traffic was, abandoning the car and walking home!

Well, that is exactly what would have happened had I been behind the wheel. I have never been so surrounded by so many huge lorries, lanes of fast-moving cars and endless lines of traffic joining us at each junction. The journey itself was amazing with life stories being swapped between Sue and Libby as we made our way up the motorway. It seemed such a long way that I expected us to end at the top end of UK to find Noah and his ark!

After passing Birmingham, the countryside was so beautiful, and we arrived at a small village called St. Martins where we stayed overnight.

After an overnight stop, we arrived the following day in Shrewsbury where B.O.T.S. were hosting the open day. We met with Emily outside the Hope Church Hall alongside another Colostomy UK volunteer, Pete Vernon, who was manning the charity's stand.

> I smiled and laughed on entering the hall when I saw and read the word 'baggies' on the banner – never dreaming I was one of the 'baggies'. The first stand was Sue and mine, and I was to learn that the pair of us were the oldest 'Baggies'!

I met lots of members who had volunteered to bake the most amazing cakes, sell raffle tickets and support all those who were attending. There were many representatives from stoma bag manufacturers and the charity 'A Bear Named Buttony' (which supports children and young people who have a stoma). B.O.T.S. members were able to attend talks on various subjects concerning diet, travel and various problems they might be experiencing.

The event was beautifully organised and was a credit to Emily and her fellow members. It takes time and a great effort to make such an open day run smoothly, ensure it is so well attended, and enjoyable!

Sue and I did sit at our table (under the banner!) and offer advice on our favourite subject – the puppy wrap. This is a technique Sue and I use to cope with leakage (see the Winter 2024 issue of Tidings for an article on this).

The day was full of laughter and meeting new people. I thought it wonderful that everyone was pleased to share their stories and how much they enjoyed the support group. By volunteering her time, expertise in organising and her uplifting attitude to life, Emily has volunteered to change people's lives.

> In fact, the whole day was about volunteering. Time is the most precious gift that anyone can give another.

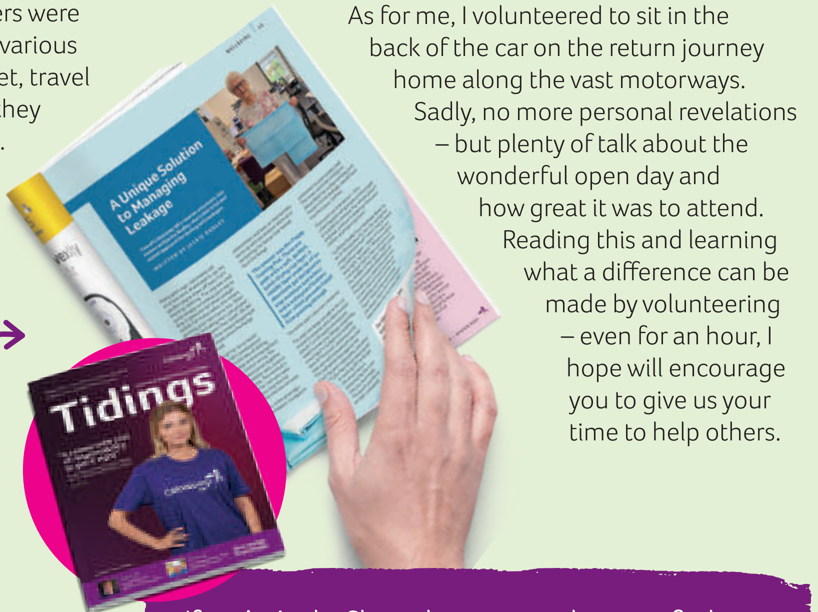
Emily gives her time to support the B.O.T.S. members as well as all of the admin tasks that go along with running a support group. It was so rewarding to realise what a difference that day made to so many.

It is the difference that you make when you volunteer your time – even to answer a telephone call of someone asking for advice can change their perception of living with a stoma.

> There are so many new ostomates that need the reassurance from someone who is a little further along the journey of managing their stoma.

Colostomy UK has a wonderful volunteer training session that supports you until you become confident enough, so that you can make this precise difference should you want to.

As for me, I volunteered to sit in the back of the car on the return journey home along the vast motorways. Sadly, no more personal revelations – but plenty of talk about the wonderful open day and how great it was to attend. Reading this and learning what a difference can be made by volunteering – even for an hour, I hope will encourage you to give us your time to help others.



Tidings
Issue 76,
Page 23

If you're in the Shrewsbury area and want to find out more about B.O.T.S. you can email Emily via: **emily.hackworthy@live.co.uk**

For all other Support Groups in the UK, head to our listings from page 47 onwards.

If you would like to hear more about volunteering or how to set up a support group of your own, you can email us at: **getinvolved@ColostomyUK.org**

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)
Margaret Slucutt T: 07967102141

Nailsea and District Ostomy Group
Peter T: 07355 038255
E: johnandjames4help@googlemail.com

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

Milton Keynes Stoma Support Group (MKSSG)
E: support@mkssg.org.uk
T: 07843 768386

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

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

Christchurch

StoMuchLove Christchurch
Jess E: jess.hurst@hotmail.co.uk

Cleveland

Oops Group
E: stees.stoma@nhs.net
T: 01642 944324

Co. Durham

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

Cornwall

Cornwall Bowel Cancer Support Group
James T: 01872 241 145

Lanhydrock Ostomist Group
Mandy Rowe T: 07980 432072
E: murphy.rowe781@btopenworld.com
Ceri Moore T: 07871926631
E. ceri.moore75@outlook.com

Cumbria

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

Derbyshire

F.I.S.H.Y.S. (Friendship, Information, Support & Help for Young Ostomates (age 18-45)
Yvette T: 07800646006
E: fishysderbyshire@gmail.com

Mercia Inside Out Stoma Support Group
E: merciassgroup@gmail.com
Sally T: 07500 441 442
Jackie T: 07919002 612
Stuart T: 07725909995

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: 07855571840
E: admin@plmdistbcsg.com

Essex

Castlepoint Stoma Support Group
Sally T: 07779139953
Sue T: 07802773458

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

Mid Essex Stoma Support Group
Paul T: 01245 441 894
E: fox.paul@hotmail.com

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

Optimistic Ostomates
Stoma Care Team T: 01702 385158

STEPS - Stoma Essex Patients Support
T: 01268451937 or 07752234516
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
Ian Gapp T: 07710288785
E: iangapp13@gmail.com

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

Gloucester

Gloucester Ostomates
Julie T: 07979129001
E: juliematthew@hotmail.com

Herefordshire

Herefordshire Stoma Support Group
E: herefordstoma@gmail.com

Hertfordshire

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

Stevenage Ostomistics
Judy Colston T: 0795 775 4237
E: neilcolston@btinternet.com

Isle of Wight

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

The Baguette Group
Debbie Lumley T: 01983 741384
E: debbieattwiggs@gmail.com

Kent

Ashford Stoma Support Group
Malcolm Jones T: 07709 534463

Canterbury Stoma Support Group
Beth T: 07999667515
E: canterburyssg@gmail.com

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 T: 07720723445

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

Maidstone Stoma Support Group
T: 01622 224305

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

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

Bowel Buddies Preston
Calum T: 07463 880 652
Vine House T: 01772 793 344

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

Speak Stoma Group
Candy Elliot E: candypoos@icloud.com

London

Bowel Cancer Support Group
Sue Berry T: 01737 553 134
John Amos T: 020 8668 0796
E: john.amos@sechc.org.uk

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
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

Merseyside

Bowel Cancer and Stoma
Support Group (BeCauSe Group)
Helen T: 07729 750622
E: becauseliverpool@gmail.com

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

Middlesex

Middlesex Inside Out Stoma
Support Group
Barry, T: 07811084514
E: Info@iossg.org.uk,
W: www.iossg.org.uk

Norfolk

James Paget Ostomy Support Group
Sheila T: 01493 600 934
E: hshowlett@aol.com

The King's Lynn and District Ostomy
Support Group
T: 01406 363756 or 01553 775698

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

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

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)
Emily T: 07972519165
E: emily.hackworthy@live.co.uk

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

James Paget Ostomy Support Group
Sheila T: 01493 600 934
E: hshowlett@aol.com

West Suffolk & District Stoma Group
Jessica Pitt (Stoma Nurse)
T: 01638 515 525

Surrey

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

Guildford Stoma Support Group
01483 57 11 22 ext 2558

Replumed - Frimley Park Hospital
Support Group Meetings
Stoma Department T: 03006136301
E: fhft.stomacareteam@nhs.net

Sussex

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

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

East Sussex Stoma Support Group
Vicki Blaker T: 0300 131 4603
E: esh-tr.StomaCareDept@nhs.net

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

West Midlands

Birmingham, IA
Michael Jameson
T: 0121 355 2745 / 07842 555 070
W: birmingham.iasupport.org/events

Coventry Stoma Support
Martin T: 07947 385 643
E: coventrystoma@btinternet.com

Wiltshire

Ostomy Mates
W: www.swindon-ia.org.uk
E: secretary@swindon-ia.org.uk

Wessex Stoma Support Group
Sally T: 01980 611978 or 07584 574311
E: info@wessex-stoma.co.uk
W: wessex-stoma.co.uk

Wirral

Wirral Stoma Support Group
T: 07956 216218

Worcestershire

Kidderminster & District
Collossus Support Group
Brendon Drew T: 07850 269758

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
John T: 07980388966
E: jkhminor2@gmail.com

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

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

Isle of Man

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

Northern Ireland

County Antrim

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

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

Ulster Hospital
Sarah, Jacqueline and Lisa.
The Colorectal Nurse Specialists
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

Sligo

Sligo Stoma Support Group
Mary T: (00)353863608798

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Susan T: 07790929268

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

Angus

Angus Stoma Support Group
Valerie T: 07359766289

Dundee Stoma Support Group
Nicola T: 07801702054

Dundee Stoma Support Group
Dolores Johnson T: 01382 740453
E: dolores.johnson@nhs.scot
Nancy Rattray T: 01382 632999 or
E: nancy.rattray@maggies.org

Coatbridge

Providing Ongoing Ostomate Support
Scotland CIC
E: info.poosscotland@gmail.com
W: www.poosscotland.co.uk/peer-support-groups

Edinburgh

Providing Ongoing Ostomate
Support Scotland
E: info@poosscotland.co.uk

Scotland (cont.)

Glasgow

Providing Ongoing Ostomy Support Scotland CIC
E: info.poosscotland@gmail.com
W: www.poosscotland.co.uk/peer-support-groups

Greater Glasgow

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

Hamilton

Providing Ongoing Ostomy Support Scotland CIC
E: info.poosscotland@gmail.com
W: www.poosscotland.co.uk/peer-support-groups

Moray

Moray Ostomates Support Group
Hazel T: 07926 300450
Kathleen T: 07789 684285

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

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
E: pip112002@yahoo.co.uk

Mid Glamorgan

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

Mold

3 Bags Full
Sharon Davis T:07359 267075
Robert Rowley T: 07429 622635
Paul Hunt T: 07802 499049
Lindsay Hicks T: 07545 431723

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

Literature range

Have you seen our extensive range of support literature? Suitable for ostomates, family members, friends, carers, and healthcare professionals. 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


Caring for a person with a stoma


Caring for a person with a stoma and dementia

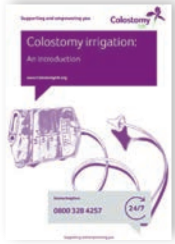

Colonoscopy through a stoma


Grandma's new bottom


Healthy Eating


Helpline Cards


How will a colostomy affect me?

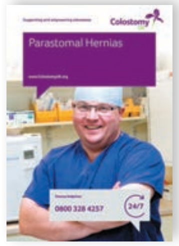

Irrigation Booklet


Living with a stoma

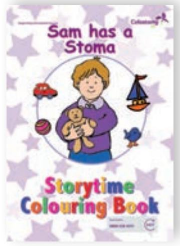

One to one


Ovarian Cancer and stomas


Pain and discomfort


Parastomal hernias


Rectal discharge


'Sam has a stoma' colouring book


Stay in touch


Stoma Friendly toilets campaign pack


Stoma reversal


Tidings magazine


This is Colostomy UK


Travel advice


Travel certificate


Welcome pack


What is a stoma?

Stay In Touch!

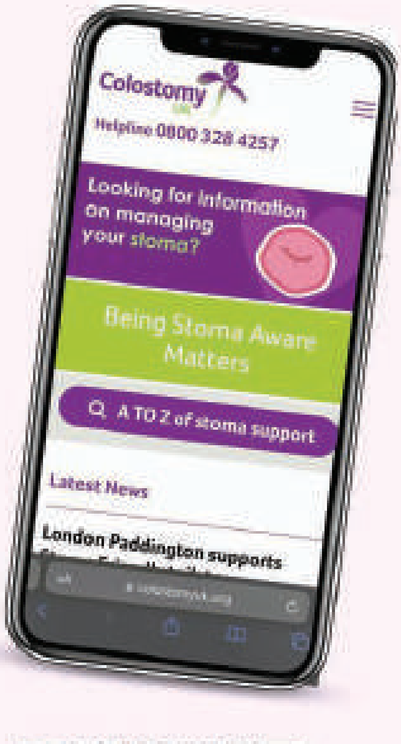
With Colostomy UK

Colostomy UK

We'd love you to be a part of our growing community supporting people with all types of Stomas, so why not register with us today!

Once you're signed up you can choose to access the information you want, when and how you want it.

Colostomy UK Your Way!



Colostomy UK
Helpline 0800 328 4257
Looking for information on managing your stoma?
Being Stoma Aware Matters
A TO Z of stoma support
Latest News
London Paddington supports
colostomyuk.org

- Tidings Magazine direct to your email
- Regular email updates
- Podcasts and Webinars
- Facebook support group
- Practical Stoma support
- Active Ostomates Virtual Classes
- Caring For a Person With a Stoma Workshops
- Open days and Events
- Rugby League Team Colostomy UK
- Volunteering Opportunities

Scan me to Stay In Touch!

www.ColostomyUK.org. Admin line 0118 939 1537. Stoma Helpline: 0800 328 4257.