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Colostomy UK's Award-Winning Magazine

Colostomy UK
Because every stoma journey matters.

Tidings

Supporting & empowering ostomates

Introducing Colostomy UK's Stoma Aware Day Campaign:

Stomas Unlocked - Unlocking Understanding. Support. Choice.

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Real stories Real people

Colostomy UK

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Dear readers

Welcome to this summer edition of Tidings. A time to indulge in fancy iced coffees and chilled wines — although with the recent heatwaves, this particular summer can feel more like an endurance test than a welcome reprieve from the winter months.

But if most of us are finding the summer intense, we should spare a thought for Tom Plater, who recently took part in what is often regarded as the world's toughest endurance event, the Cocodona 250. A five-day race across Arizona's deserts, forests and mountains, all while managing his ileostomy. Tom kindly fundraised for Colostomy UK as part of his efforts. You can catch his story in an extended Fundraising special (p. 19).

Keeping with the theme of endurance (and heat), our Unique Jobs series focuses on former firefighter Chris Morrison (p. 34), who proves that a stoma need never hold you back from reaching your life goals.

Endurance comes in many forms throughout this issue of the magazine. We tell three very different Real Lives stories, each with determination as the underlying theme. Peta Barratt, an acclaimed ballet teacher, had to reinvent herself following an accident which left her paralysed from the waist down (p.12), and which indirectly led to her having a stoma formed — one she is now very grateful for.

By contrast, Kris Webb struggled to ever accept her temporary stoma and was steadfast in her desire to have reversal surgery (p.36). In a unique Real Lives feature for Tidings, the article is an important reminder that not all ostomates embrace their stomas – and that sometimes, it is ok to not be ok. Kris and Peta have more in common than meets the eye, however, as is revealed on page 43.

Our third Real Lives article follows Javier Munoz Mena, who was granted refugee status in America after fleeing a brutal political regime in Nicaragua (p. 29). His turbulent journey spanned several years and countries, all while managing worsening Crohn's disease, which ultimately led to an unplanned ileostomy.

Staying with an international focus, contributor Jane Fior has written a hard-hitting piece on life with a stoma in conflict zones (p. 38). The article also shines a spotlight on many of the incredible organisations doing their best to assist ostomates in such complex settings as Ukraine, Gaza and Sudan.

Closer to home, Stoma Care Nurse Nelam Kumari explores the reasons why ostomates from within the UK's South Asian communities often struggle to be open about their stomas (p. 16) and offers advice for anyone who finds themselves in this position.

Nelam's colleague Sue Pridham leads this edition's Dear Nurse column (p. 22), discussing common urostomy complications, as does Merv Quick, who shares day-to-day life advice for this with a urostomy (p. 6). Both articles mark Urology Awareness Month in September.

Finally, it may well be high summer, but as our cover suggests, Colostomy UK is already gearing up for Stoma Aware Day in October with the launch of our Stomas Unlocked campaign (p. 24). Almost impossible to believe that autumn is just around the corner, with its shorter and wetter days. But then, us Brits do love nothing more than to bemoan the weather, no matter what it's up to.

Ross Othen-Reeves
Editor, Writer and Researcher

Colostomy UK

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
365 days a year 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
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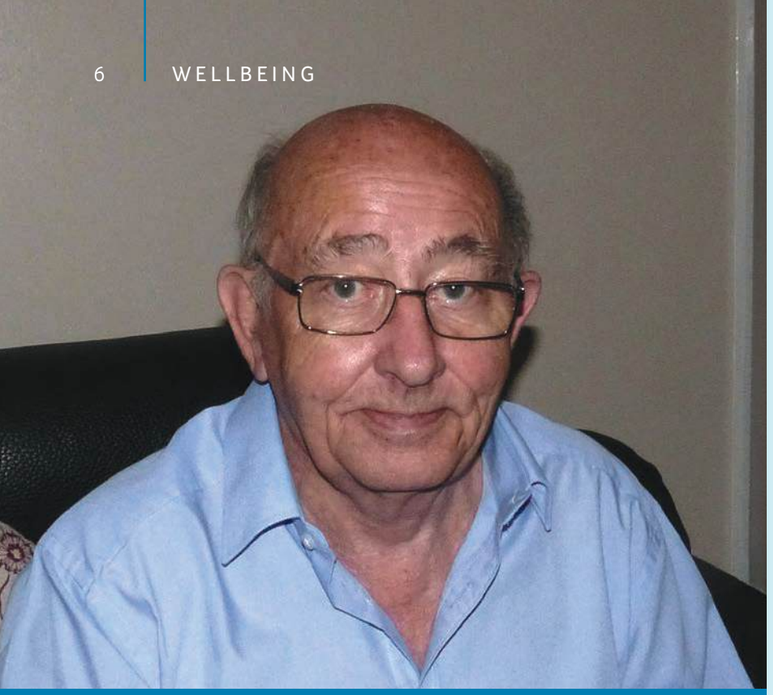
An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 41 for our donation form.
You can also donate via our website **www.ColostomyUK.org/donate** or by calling us on **0118 939 1537**



A Day in the Life of a Urostomate

September is Urology Awareness Month. To mark the occasion, urostomate Merv Quick talks us through his typical day*

Let me walk you through my typical day living with a urostomy, complete with a minor 9am wobble and a mid-afternoon pint. The good news? Nine years on from my surgery, "a typical day" really is just that: ordinary, full, and manageable.

Morning: The Bag Change (...on Alternate Days)

Every other day begins with what most urostomates call their morning ritual: the pouch change. Before I do anything else, I lay out all my supplies in a row: new pouch, adhesive remover spray, and disposal bags. The golden rule: set out your stall before you begin. Running out of adhesive remover halfway through is a special kind of chaos you only need to experience once.

The change itself takes about five minutes. A word of warning, though - your stoma has absolutely no bladder control and will decide to "go for a wee" whenever it pleases.

So changing your bag in a carpeted room is a bold choice! Using a bathroom is the safer option.

Once the fresh pouch is on, I press the palm of my warm hand firmly over the adhesive wafer for a couple of minutes. Body heat activates the bond, and those two minutes of patience save hours of grief later. While I'm at it, I prep several new pouches in one go, putting the safety bung into the drain tap of each pouch. I learnt the hard way what happens when you apply a perfect bag and then realise the tap is still wide open!

Through the Day: Emptying and Getting On With It

On a normal day, I empty my pouch perhaps twice: once mid-morning, once mid-afternoon. That's roughly the same frequency I used the bathroom before my surgery. (This is not the same for everyone. Some people need to empty their pouches much more frequently.)

If the afternoon involves a couple of pints of brown ale, I'll be emptying it rather more enthusiastically. The key point is that you plan around it the same way you always planned around needing the loo.

Out and about, I carry three things: an Emergency 'No Waiting' Card or an ID card, which explains to businesses that I need urgent priority access to their toilet; a Radar Key, which unlocks disabled public toilets across the UK; and a small 'go-bag' with a full change of supplies. The go-bag helps relieve any anxiety of having a potential leak when out of the house.

When the Day Involves Travel

If I know I have a big travel day ahead (a long train journey, or a flight, for example), I put on a fresh pouch that morning regardless of whether it is technically due to be changed, as this is one less variable to worry about. On aeroplanes I also keep a few large-capacity pouches handy, because when you are strapped into seat 23B with the seatbelt sign on, a standard-sized bag runs out of room faster than you might hope. Some airlines also offer increased hand luggage for ostomates through assisted travel services, so it's worth checking ahead. Some airports also issue special lanyards to alert security that you may need additional support.

I have travelled to India and back without a single incident, which ought to reassure anyone worried about whether a urostomy means the end of adventure. The rule I follow is simple: take three times the supplies you think you need, and split between your hand luggage and checked bags. Then, if you lose one bag, you still have everything you need in the other. A travel certificate signed by your GP (available from Colostomy UK in multiple languages) is also worth carrying for airport security, though in nine years I have never actually needed to produce it.

Evening: The Night Bag

Before bed, I connect my pouch to a larger night drainage bag, which sits on the floor beside the bed. Some nurses recommend strapping the drainage tube to your leg, but I find that restricts how freely I can roll over in the night. My solution is a pair of boxer shorts with the tube threaded through the fly opening. It sounds inelegant, and it is, but it gives enough slack to roll left, right, or flat on your back without a second thought. You don't have to use a night bag at all, of course - you can simply wake up to empty as needed. But for sleeping through undisturbed, the night bag is worth its weight in gold.

What to do When Leaks Happen (As They Will, Occasionally)

Even now, I get one or two leaks a year. Invariably it is user error; I rushed the application of the pouch, or I got absorbed in something and forgot to empty the bag until it was considerably past full. In the early months after surgery, leaks are more common simply because your body is still settling into its new shape. A pouch that fitted perfectly in week two may not sit correctly in week six. If that happens, contact your stoma nurse. They will likely recommend a different pouch shape (a convex wafer, for example) that will solve the problem. Don't struggle alone; your stoma nursing team exists precisely for this reason. I would also recommend a waterproof mattress protector as leaks may still happen from time to time.

A Note on Supplies

Your monthly supplies - pouches, night bags, adhesive remover, wipes, disposal bags, etc - are delivered on prescription. One thing worth knowing: **you are not tied to a single supplier.** If the service is poor or a product gets discontinued (as happened to me), you can switch within days. Online communities like the Colostomy UK Facebook group are invaluable for recommendations. Just remember to let your GP know when you change.

The Honest Summary

A urostomy is a significant change. I won't pretend the first few months are entirely carefree—there is a learning curve, and the occasional moment where things do not go to plan. But the rhythm comes quickly. Within a few months, the morning bag change is as unremarkable as making coffee. The travel anxiety fades. The social confidence returns.

Life with a urostomy is not a lesser version of life. It is just life with a slightly more eventful routine.

***Every person living with a urostomy is different, as are their needs, preferences and routines. This article is an account of Merv's personal experiences only.**

Merv is happy to answer your questions. Please email to get in touch.

editor@colostomyuk.co.uk

Colostomy UK

news

Libby Herbert
Colostomy UK CEO

Six Months of Making a Difference

By Colostomy UK CEO, Libby Herbert

Colostomy UK has been incredibly busy over the past several months. Here's a round-up of activities throughout 2026 so far, ordered around our five core values.

As I look back over 2026, I'm struck not just by how much has happened, but by what we've achieved together as a community. One of the greatest privileges of my role is meeting so many of you, hearing your stories, celebrating your successes and listening to the challenges that remain. Those conversations remind me every day why Colostomy UK exists and why our work matters.

Of course, there's still more to do. As demand for our services continues to grow, we're determined to be there for everyone who needs us. If you're able to support our work through a donation, by taking part in one of our fundraising events or by remembering Colostomy UK in your will, you'll be helping us continue to ensure that nobody has to face life with a stoma alone.

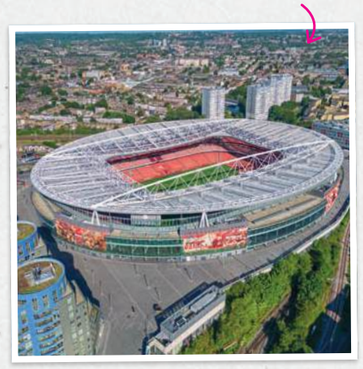
Inclusivity

Our Stoma Friendly Toilets campaign has gone from strength to strength. The year began with the launch of the Stoma Friendly Toilets Finder on our website, and the announcement that B&Q's 300+ branches would all be upgraded to be stoma friendly.

Next up was actress Jenna Robinson's story about the challenges of accessing suitable stoma friendly facilities, which was featured by ITV in February, generating wide coverage across the country.

In March Morrisons became the next major retailer to join the campaign, with nearly 500 of its branches added to our listings. We also visited Arsenal's Emirates Stadium along with ostomate and Gunners fan, Alan Schneider. Alan featured with the clubs Disability Access Manager, Aaron Heskins, to announce that all 100 of the stadium's accessible toilets had been upgraded to be stoma friendly.

Arsenal's Emirates Stadium



On 18th June, Jim Shannon MP led a backbench debate in Parliament on public toilet provision for people with stomas, supported by Colostomy UK. The debate called on the government to look seriously at how public toilet provision can be better supported - for example, whether Stoma Friendly features should be incorporated into future accessibility standards, including building regulations.

Support and Empower

It has been a very productive few months for our support and education work.

Our Stoma Care Workshop reached a significant milestone in January when it received CPD accreditation – an independent mark of quality recognising the high standard of our training content. Since then, we have delivered workshops to unpaid and paid carers, and in April alone ran three workshops reaching 53 professionals, strengthening our community engagement along with it.

Our Community Engagement Lead, Shauna, has been at the forefront of this work, delivering stoma awareness training to airport security staff at Leeds Bradford Airport and attending open days alongside volunteers across the country. As well as Shauna, a number of our volunteers have also supported and spoken at numerous stoma support groups throughout the past six months. I also attended Birmingham Airport's Accessibility Forum to continue guiding management on stoma-friendly procedures.

Shauna

Volunteer growth has been one of the real success stories of the last six months. At the start of the year, we had 41 potential volunteers moving through our onboarding process; that number has now risen to 46, and interviews have continued steadily each month since thanks to the tireless work of our Volunteers Manager, Max. In March alone we welcomed seven new volunteers, supported by existing members of the team who generously shared their personal experiences. As one new inductee commented: "It's really nice to see people who are clearly committed to the goals of the charity."

To mark National Volunteers Week (June 1st - 7th) I shared a public message with our amazing cohort of volunteers in appreciation of their incredible work with us. Our staff team also called each of our volunteers to thank them individually for their commitment to the charity. Throughout the week, volunteers also shared videos about why they support Colostomy UK which were shared across our social media channels.

In March, sex therapist Sue Lennon delivered two Sex and Relationships training sessions attended by 16 volunteers – part of a wider project to better equip our community to have sensitive but important conversations relating to these topics. The sessions were very well received, as one attendee noted: "This was an excellent and thoughtfully delivered session on a topic that deserves far greater visibility."

We continued to distribute our stoma literature titles across the country too, with thousands of booklets sent to nurses and clinicians each month. In total, 10,482 leaflets were posted out. Rectal Discharge, Parastomal Hernias, Travel Advice, Healthy Eating, and Stoma Reversal were among the most popular titles requested.

Compassion

Our Helpline has seen a sustained increase in demand over the past few months. Having averaged 375 calls per month in 2025, January 2026 recorded 424 calls – our busiest month since June 2023 – and March went even further, with approximately 500 calls, making it our busiest month since records began.

Our Helpline survey, launched late last year, is already providing encouraging insights. Results so far show that over 70% of callers felt unclear or unsure before calling, while nearly 90% reported feeling mostly or very confident in how they manage their concern afterwards. Around 90% were satisfied with the help they received, and 96% would recommend the service. As one caller put it: "The way your colleague spoke to me was very helpful. She spoke to me very clearly and this made a big difference."

Our Live Chat service (available via our website) has also grown, from five chats in January to 22 in April, offering beneficiaries a flexible alternative to the phone line.

Knowledge

Our external communications have had an outstanding few months. Thanks largely to the amazing work of our Marketing and Digital executive, Lauren, we have consistently reached large audiences with trusted information focused on life with a stoma.

Social media has been a particular strength. In January, our channels received over 527,000 views, with Facebook alone reaching nearly 390,000 people. March brought a record-breaking moment for national media reach (excluding television) Morrisons, the supermarket, signed up to our Stoma Friendly Toilets campaign, and the announcement featured in over 220 national and local newspapers, reaching an estimated six million people. By April, our Facebook reach over the previous 28 days stood at over 350,000 views, with Instagram contributing a further 83,000+.

Our website has also maintained high traffic throughout the first half of 2026, typically recording around 30,000 views per month.

Web pages on stoma blockages, rectal discharge and the Stoma Friendly Toilets Finder among the most visited.

Spearheaded by our Marketing and Campaigns Manager, Giovanni, our campaigning and policy-influencing activities have seen a particularly productive period. In February, our team met with Andrew Snowden MP at Westminster to discuss standardised stoma care pathways. He has since asked formal written questions to the Department of Health and Social Care on our behalf, in support of our call for a mandated care pathway and mandated annual reviews for people living with a stoma.

We also attended the inaugural meeting of the All Party Parliamentary Group on Access to Medicines and Medical Devices. Membership of the group could be a really important additional tool in helping us campaign for more equitable access to stoma care products. Giovanni followed this up with a meeting with Danny Beales MP, who chairs the group. He raised the prospect of Danny also potentially supporting our campaign to improve stoma care pathways for patients.

In Scotland, MSP Ed Mountain used his final speech in Holyrood to highlight our Stoma Friendly Toilets campaign and call for further action. Ahead of Parliamentary elections in Scotland and Wales in May, we released a statement urging political parties to commit to improving stoma care in both nations.

We have also been proud to support the National Institute of Excellence (NICE) in developing HealthTech guidance, ensuring the lived experience of people with a stoma is reflected in decision-making. Caroline Knight, one of our volunteers, was the focus of this new NICE campaign, highlighting how she and her NHS team were able to review the evidence and identify a one-piece bag she could trust.

Togetherness

February saw the launch of Step Up for Stomas: Active April, our annual fundraising challenge. Led by our Fundraising Executive, Megan, this year's event was inspired by the 55 stoma surgeries carried out every day in the UK. We were thrilled with the results: 117 supporters signed up and collectively they raised an incredible £21,086.70. From walking and running to creative activities, participants embraced a wide range of challenges, and the energy generated across the community was wonderful to see.

Team Colostomy UK has also had an exciting few months on the rugby field. After positive pre-season meetings with the Rugby Football League and Wakefield Trinity, the team kicked off their 2026 season in March with our Physical Disability Rugby League team taking part in a triple-header with Great Britain Police and Stanley Rangers. April brought an even bigger milestone when our wheelchair team competed in its first ever tournament, the Wheelchair Challenge Trophy in Nottingham, facing Salford, Hull KR and Anglian Vipers and coming away with a victory – a powerful statement of what is possible for anyone living with a stoma.

Support groups have continued to grow across the country too, with new groups set up in Manchester and Welwyn Garden City. Our Active Ostomates project, which helps get people active after stoma surgery, kicked off the year in February, with 122 people attending the first week. This is an impressive increase compared to previous batches that usually begin with up to 100 people on average. Our regular classes such as yoga and Pilates were joined by our new 'Creative Minds' programme, which delivers art sessions to support groups across the country.

FREEPHONE STOMA HELPLINE: 0800 328 4257

Turning Over a New Leaf

THE MANY CHAPTERS OF PETA BARRATT'S LIFE

Peta Barratt is Support Co-Ordinator at Colostomy UK. Having been with the charity for about a year, we felt it was high time we shared her astonishing story with our Tidings readership.

'Ever since I was little, all I wanted was to be a ballet teacher', Peta tells me without hesitation early on in our conversation. It might sound like a typical childhood fantasy, but Peta's hard work and dedication ensured her dream became reality. At 18, she enrolled in a degree at a specialist dance college. Three years later, with her teaching qualifications now in the bag, she entered the professional world of dancing in style. Her first job took her to Hong Kong, where she lived and worked for a year. She then relocated to Europe where she taught in southern Italy and which, she assured me, was every bit as fabulous as it sounds.

On returning to the UK in the late '80s, Peta began working at a renowned dance academy in the village of Stoke Poges, Buckinghamshire. In 1991, she bought the school from its retiring founder. Peta rebranded the academy, giving it its current title, Ondine, in homage to a beloved ballet of the same name, written for the celebrated ballerina, Margot Fonteyn. Peta owned and managed the school for thirty years. Under her stewardship, Ondine expanded its intake to some 400 pupils, taught at numerous sites all across Buckinghamshire. During this meteoric rise through her career, Peta also found time to marry her now husband, Kavon, and raise their twins, Ben and Tara.

Then, on an otherwise unremarkable weekend in 2016, everything changed. Peta was in her loft making space for a large new water tank that she and Kavon were having fitted. Engrossed in the task, she had sailed through the morning and lunchtime without any food or water. Perhaps light-headed, or a touch dehydrated, Peta looked at her watch and realised she was due a break. This was the last thing she remembers of the moment.

Seconds later, she fell out of the loft hatch, colliding with the banister as she continued to fall down the stairs to the ground floor of the family home. She landed on the hallway floor, almost at Kavon's feet (he having raced to the hallway on realising something awful had happened).

Despite having no recollection of the accident itself, Peta has memories of lying at the foot of the stairs, as she recalled:

'I couldn't move my legs. I didn't really understand why. It was quite a bizarre moment. I was thinking: "Why can't you move your legs?"'

Peta was rushed to hospital in an ambulance where she underwent emergency surgery. She had severed her spinal cord at the tenth vertebrae upon impact with the banister and was told she would never walk again. It was life shattering news, as Peta explained:

'I've cried enough tears to fill up an entire river. I've been through every emotion possible. I've always been quite a strong, independent, and active person. Everything that I stood for was taken away. The only thing that wasn't taken away - thank the Lord - was my husband. I've been so lucky to have him in my life. He's been amazing.'

Despite the extraordinarily tough journey Peta has been on, her gratitude also extends to her physical health:

'To be honest with you, I was lucky. Really lucky that I only severed my spinal cord. I could have broken my neck, or I could be dead.'

By sheer coincidence, the UK's National Spinal Injuries Centre (NSIC) is based in Stoke Mandeville hospital, within driving distance of Peta and Kavon's home. As the UK's leading provider of specialist spinal cord injury treatment, the NSIC is also the birthplace of the international Paralympic Games, originally known as the Stoke Mandeville Games.

Peta spent 11 weeks rehabilitating at the centre. Yet even in the immediate aftermath of the accident, Peta's mind was on her beloved school, Ondine. The accident had occurred on the Saturday and yet by the following Monday, she had called her secretary to her hospital bedside to make new arrangements for the school in her absence. Peta sounds incredulous as she's telling me this anecdote, as if scarcely able to believe it herself.

'But I was so dedicated to that school' she explained, 'Ondine was my baby and I needed to look after her.'

The accident occurred during the school holidays, meaning that in total, Peta only missed half a term before getting back to work at the academy. But from her very first lesson back, she realised teaching would never be the same again.

'It was a senior class that I went to teach, and so they'd all known me since they were small children. I came in, in my wheelchair, and they just didn't know how to be with me. And I didn't know how to be with them, because I wasn't comfortable in my own skin, I was so self-conscious. Afterwards I just cried. It was awful.'

Peta stepped back from teaching and focused instead on administrative tasks - a role she continued for several years, but which left her feeling out of touch with the wider school community. She no longer had contact with the children or their parents, and so the joy and drive she once felt for Ondine began to fade. Then, one day, Peta had what she can only describe as an epiphany;

'I just woke up one day, and life just completely changed. I needed to get rid of all the old things to be able to move on and create a new life'.

This included Ondine. In fact, selling the school was critical to Peta's plan of starting afresh:

> 'Ondine was the biggest thing in my life, so when I finally sold it, I was euphoric, because it was clinging onto an old life. It was such a weight off my shoulders. I told myself "This is who you are now, and we're going to open a new book"'

With Ondine now sold, she began to focus on volunteering opportunities. This included Macmillan Cancer Support, which she had already volunteered with for years and who were incredibly supportive following Peta's accident. She also took on another voluntary role for the Spinal Injuries Association. For a time, it seemed Peta was finally able to settle into her new life.

This was until one evening, around six years on from the initial accident. Peta found herself suffering from neuropathic pain in her hips – a unique type of pain which rarely responds to standard painkillers. The excruciating aching sensations were even more surreal for Peta, who, being paralysed from the waist down, was unaccustomed to feeling anything in the lower half of her body at all.

A sleepless night and awful day followed in which Peta's overall condition worsened. By 4pm, with Peta's temperature reaching over 40 degrees, Kavon called for an ambulance. Peta was rushed into emergency surgery once more. While on the operating table, her heart stopped and her lungs collapsed. She was put into an induced coma for five days and subsequently spent eight weeks recovering in hospital – almost the same amount of time she had spent in rehabilitation for her initial accident. She had also woken to discover she was now living with a permanent stoma.

It transpired that Peta had been dangerously ill with sepsis due to having ruptured her bowel. On the face of things, two near-fatal incidents in just six years may seem a terrible coincidence. But the perforation was in fact indirectly caused by Peta's earlier spinal cord injury.

Being paralysed from the waist down, Peta no longer had control over her bowel and bladder functions. This led to her having a suprapubic catheter fitted to manage urine output. When it came to bowel management, however, Peta effectively had to perform a colonic irrigation on herself every other day. This required her to insert a catheter into the rectum to flush the bowel with water, which then aided the passing of stool. Yet this procedure was not without risk for someone in Peta's situation, as she explained:

> 'The professional opinion is that, because I couldn't feel where the catheter went, I pushed it up too far and ruptured my bowel. But I didn't know that I'd done anything wrong at the time'

Once explained, it's easy to see the inherent danger for paraplegic people irrigating their bowels without support. Yet the concerns are not well known according to Peta:

> 'A doctor at Stoke Mandeville hospital said he wanted to write a report on it because it had not been recognised before, that this form of bowel management could potentially end with this disaster'

Peta believes all spinal injured people should be offered stoma surgery as an option over irrigation. Both because this would prevent the risk of damaging the bowel, but also because, in her opinion, life witha stoma has proved infinitely preferable to irrigation. As she told me bluntly:

> 'Irrigation was an absolute pain in the arse – if you can excuse the pun'

Without the ability to push, Peta simply had to sit on the toilet after flushing her bowel, waiting for gravity to do its thing. A long, slow, frustrating process which she does not miss at all.

> 'My colostomy is great. I love it. It's not time consuming, it just does its thing and then you take care of it. So from a management point of view, it's fantastic.'

Living with a stoma may have made Peta's daily routines more manageable, but it wasn't something that she gave much attention to in her everyday life. That was until her volunteering role for the Spinal Injuries Association led her to meet Colostomy UK's CEO, Libby Herbert, through an aviation disability forum. The two hit it off immediately and met regularly through the forum over the coming months.

During this time, and owing to conversations with Libby, Peta became increasingly aware of her identity as someone living with a stoma. So, when a job opportunity opened up at Colostomy UK a few months later, she didn't hesitate to apply. The role was for Support Co-Ordinator, which, amongst other duties, would see Peta regularly taking calls on Colostomy UK's helpline, offering advice and an empathetic ear to people living with stomas across the UK. It's no spoiler to say she got the job of course; her first paid role since parting with Ondine years before. Being back on a salary has given Peta a renewed sense of freedom and autonomy, she says:

> 'I love volunteering. Absolutely love it. But as part of my strong will to be as independent as possible, I hated not having my own money, and I was desperate to get a job. I felt that at 60, I still have so much to offer.'

What Peta was less prepared for, however, was just what a positive impact she would have on other ostomates through her role, and conversely, what a positive impact this would then have on her as a result.

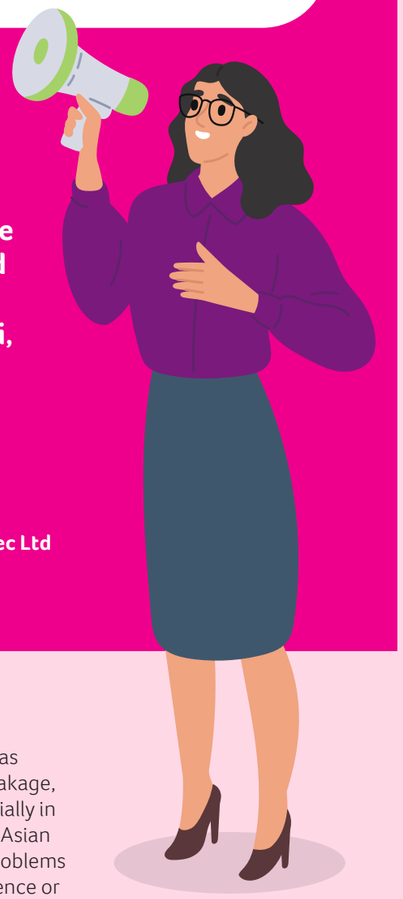
> 'When I started talking to people [on the helpline] I realised just how grateful people were to talk to me, because I have a stoma, and so I understand what they're saying. You can almost hear them breathe a sigh of relief that they'll be talking to somebody who's actually got one. It feels so privileged. It's amazing. I never thought about that side of things before I started, but I love it. I think that's probably my favourite bit of the job.'

So how does working at Colostomy UK measure up to her once glamorous career in professional dance? I wondered. Peta responds with the same conviction she once held for her childhood dream of becoming a ballet teacher.

'I enjoyed my job when I had my career, but this is something completely different. I have never enjoyed working as much as I enjoy working now. This was the missing piece in my jigsaw to a completely new life.'

Support and Strength for South Asian Patients with a Stoma

BREAKING THE SILENCE:



For some people in South Asian communities, living with a stoma can feel especially hard. Alongside the surgery itself, there may be silence, shame, worry and fear of being seen differently. Stoma Care Nurse, Nelam Kumari, brings both her professional experience and personal knowledge to raise awareness of these communities.

By Nelam Kumari, Clinical Educator, Convatec Ltd

> While this article is written mainly for patients, families and the general public, it may also help nurses and other healthcare professionals better understand the cultural, emotional and practical needs of South Asian patients living with a stoma.

Having a stoma can affect body image, confidence, relationships and daily life, as well as physical recovery. Many people worry about leakage, smell, clothing, socialising and intimacy, especially in the first months after surgery. For some South Asian patients, this can feel harder because bowel problems and stoma surgery may be linked to shame, silence or fear of judgement.

South Asian communities are diverse, with different languages, religions, family roles and beliefs. Not everyone will feel the same. Even so, studies suggest that stigma, language needs, family expectations and faith can affect how some South Asian patients ask for help and adjust after treatment.

Silence, stigma and bowel health

In some families and communities, bowel symptoms, cancer and stoma surgery may be seen as private, taboo or shameful topics. Some patients worry that a stoma will make them seem unclean, weak or different, and may fear pity, gossip or judgement. For younger patients, there may also be worries about marriage and relationships. When these fears stay unspoken, people may delay asking for help and carry distress on their own.

> "In my culture, we don't talk about these things. I felt I had to deal with it on my own."

If this feels familiar, please know that you are not alone. Stoma problems are medical problems, not something to hide. Asking for help early can prevent skin problems, improve confidence and reduce isolation. It can also ease the emotional burden of feeling that you have to manage everything in silence. Writing questions down before an appointment, asking for a longer review, or requesting time alone with your stoma nurse can make it easier to talk honestly if family or community expectations feel hard to navigate.

Faith, cleanliness and worship

For many South Asian patients, faith is part of daily life. A stoma may raise questions about cleanliness, prayer, fasting, worship and pilgrimage. Some Muslim patients worry about ritual purity and leakage, even though faith guidance often supports prayer and attendance with a stoma. Similar concerns can also affect Hindu and Sikh patients, although experiences differ from person to person.

> "I didn't know whether fasting during Ramadan was allowed or safe for me anymore."

> "I worried constantly about smell or leakage at the temple, so I stopped going for long periods."

These worries matter and deserve to be discussed. If you want to fast, travel on pilgrimage or return to worship, ask your stoma nurse or doctor for advice. You can also request written information in your preferred language or speak with a trusted faith leader who understands health issues.

Modesty, gender and asking for help

A stoma involves intimate care, and for some South Asian patients this can feel especially sensitive. Modesty may be closely tied to dignity and family expectations. Some women may feel uncomfortable talking about their stoma or intimacy with male professionals. Some men may feel pressure to stay strong and not show vulnerability. Research shows that embarrassment and fear of judgement can stop people asking for help, even when problems can be treated.

You can ask for a clinician of the same gender where possible, request an interpreter, or ask to speak without family present. Good care should protect your dignity and give you choices, not make assumptions about what matters to you.

Family, marriage and relationships

Family can be a great source of love and support after surgery. But some patients worry about being a burden, affecting marriage prospects or bringing shame to the family. Some may also fear that relatives or in-laws will see them differently. Studies suggest that family beliefs, misunderstanding and stigma can affect how people cope and whether they ask for help.

If your family is very involved, that can be helpful. But your wishes still matter most. Healthcare professionals should ask who you want in the room, what you want shared with relatives, and whether there is anything you would rather discuss in private.

Body image, intimacy and confidence

Many people worry about how they look after stoma surgery, whether they will still feel attractive, and what might happen during intimacy. Studies show that body-image concerns, sexual worries and fear of leakage can affect confidence and quality of life. For some patients, the hardest part is feeling too embarrassed to ask what is still possible.

> "I didn't know what I could or couldn't do, and I was too embarrassed to ask."

> "I thought having my rectum removed meant I could never have sex again, but I was too embarrassed to ask, and nobody ever made me feel it was okay to talk about."

These are important questions. They are not embarrassing, and you deserve clear answers. If intimacy feels difficult, ask your stoma nurse, consultant or GP for support. Practical advice, reassurance, counselling, and specialist help can all make a difference.

LGBT+ South Asian patients: being seen and supported

Some South Asian patients also identify as lesbian, gay, bisexual, trans or queer. They may face extra pressures around identity, family expectations and being open about relationships, and a stoma can make these conversations even harder. Research shows that patients want healthcare professionals to avoid assumptions and make it clear that different identities and relationships can be discussed safely.

> "I was worried about the stoma, but I was also worried about whether I could be honest about who I am."

If this applies to you, you deserve care that is respectful, private and inclusive. You should not have to choose between cultural identity, faith, family belonging and being honest about your relationships or gender identity. Healthcare professionals should use open language and avoid making assumptions about who you are.

References for this article are available upon request. Please contact the editor at editor@colostomyuk.org.uk if needed.

This is a non-sponsored article written in collaboration between Convatec Ltd and Colostomy UK.

SC-81118-GBR-ENG-v1

What can help?

Evidence suggests that education, person-centred follow-up and peer support can improve confidence, self-management and quality of life for people living with a stoma. The following steps may help:

For patients

- Write down questions before appointments, especially about prayer, fasting, diet, travel, clothing, intimacy, or skin problems.
- Ask for private time with your nurse if you do not want to speak in front of family.
- Ask for the same-gender clinician or interpreter if that would make discussion easier.
- Use trusted support groups, helplines or online support if talking face to face feels difficult at first. (See the support section below for more on this).

For families

- Try to listen without shame or blame.
- Remember that a stoma is a medical treatment, not a sign that a person is unclean or less able to live a full life.
- Offer practical support while still respecting privacy and independence.

For healthcare professionals

- Do not assume that all South Asian patients believe the same things; ask what matters to the individual.
- Use permission-based language to open sensitive conversations about faith, body image, and intimacy.
- Offer privacy, language support and follow-up over time, as needs often change after discharge.
- Signpost patients to reputable charities, peer support and specialist psychological or sexual wellbeing support when needed.

Where to get support

You do not have to deal with this on your own. Support is available. Some people prefer a helpline. Others prefer a patient group, a nurse or a trusted online service.

- **Colostomy UK** offers various services to anyone living with any kind of stoma and which includes their stoma helpline
- **Ileostomy Association** supports people living with an ileostomy or internal pouch.
- **Urostomy Association** offers information and support for people with a urostomy.
- **Macmillan Cancer Support** can help if your stoma is linked to cancer.
- **Convatec me+** offers free stoma support, advice and lifestyle information.

Your stoma nurse, GP or hospital team can also tell you about local support, including groups, interpreters and specialist services in your area. You are not alone, and support is available.

Colostomy UK

fundraising

Megan Lowden
Fundraising Executive

The Impossible Race

TOM PLATER AND THE COCODONA 250

In a shake-up to our usual Fundraising format, we're focusing on just one particular individual, Tom Plater, who has kindly raised funds for Colostomy UK. Not content with a regular challenge, Tom flew out to America to take in the Cocodona 250 – a brutal 253-mile ultramarathon in Arizona. Here he talks Megan through this incredible experience.

Please share a little about yourself

My name is Thomas (Tom) Plater. I'm 40 years old and live in Windsor with my wife and our two children. I previously served for nine years in the British Army before moving into construction project management.

I've always enjoyed pushing myself physically. But since my cancer diagnosis, endurance running has become much more than a hobby – it has become a way of rebuilding myself after some significant health challenges.

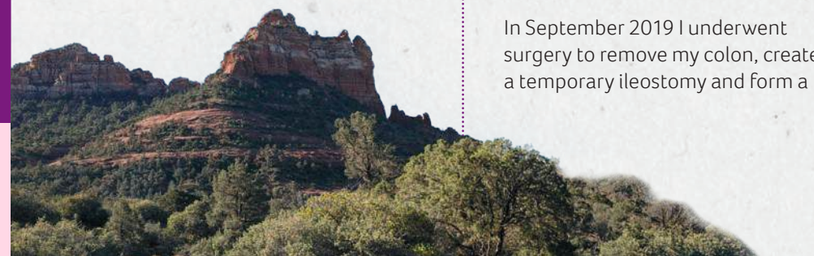
Talk us through your stoma journey

I currently have a permanent ileostomy, which was formed following emergency surgery in 2024, although this isn't my first experience of living with a stoma.

In 2019, shortly after losing a close friend to bowel cancer, my wife persuaded me to speak to my GP about symptoms I'd been ignoring for over a year. That decision almost certainly saved my life. I was diagnosed with bowel cancer caused by an inherited genetic condition.

In September 2019 I underwent surgery to remove my colon, create a temporary ileostomy and form a j-pouch. Unfortunately, my j-pouch never functioned as hoped. Over the next four years my health gradually deteriorated until it failed catastrophically in July 2024. I was rushed into emergency surgery and woke up with what I knew was likely to be a permanent ileostomy.

Looking back, that operation didn't just save my life for a second time – it became the starting point for a completely different outlook on recovery, and on life itself.



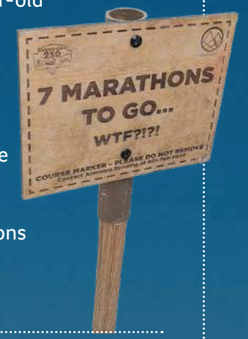
How has having a stoma shaped your life?

The biggest change has been my attitude.

When I had my first temporary stoma in 2019, I saw it as something to endure as quickly as possible. I didn't really engage with the support available because I was focused entirely on getting rid of it and returning to my old life. I now realise that approach was a mistake.

When I woke up from emergency surgery in 2024, I decided I was going to approach recovery differently. I accepted that this wasn't something to hide, but something I needed to learn to live well with. Becoming more open about my experience has helped me far more than trying to deal with it privately.

Living with a stoma has also introduced me to the incredible work of charities such as Colostomy UK. Seeing my two-year-old nephew also begin life with an ileostomy reinforced just how important that support is and made me want to help challenge some of the misconceptions people have about living with a stoma.



What drew you to running an ultra marathon?

I've always enjoyed endurance sport. During my military career I learned to enjoy operating in physically and mentally demanding environments, and after leaving the Army, I found endurance events filled that gap.

Following my emergency surgery in 2024, a close friend and fellow Army veteran attempted the Cocodona 250 in Arizona. I'd followed the race for several years, fascinated by what many regard as one of the world's toughest ultramarathons, but had never imagined I would one day stand on the start line myself.

Cocodona isn't simply a 250-mile race. It crosses the Arizona desert before climbing into mountains and forests, covering more than 35,000 feet of elevation over five days. Runners experience extreme heat during the day, freezing temperatures at night, very little sleep and long periods of complete self-reliance. The race has a reputation for breaking even the most experienced ultrarunners, with around 30% unable to finish.

That complexity and hostility became part of the attraction. I needed something that seemed almost impossible, because if I could rebuild myself to complete Cocodona after surgery and while living with a permanent stoma, it would completely redefine what I believed was possible.

The race became much more than a sporting challenge. It gave me a reason to rebuild, to structure my recovery, and to prove to myself that life with a permanent stoma didn't have to limit what I was capable of achieving.

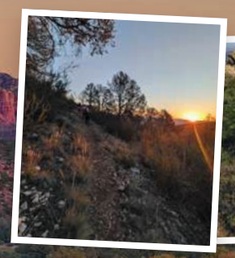
What preparations did you have to make?

Training for Cocodona had two equally important parts.

The first was preparing physically. Over the course of a year, I built my endurance through structured training, strength work, hill running, long hours on an inclined treadmill and stepper while carrying weight and even using saunas to help prepare for the heat I would experience in Arizona.

The second part was preparing to manage my ileostomy over five days of continuous running. I tested different bags, adhesives, skin preparation products, clothing systems, and running packs. I deliberately tested equipment during long training runs and in hot conditions to understand its limits. I also had to carefully plan hydration, nutrition, spare equipment, and the support my crew would provide.

By the time I stood on the start line, I wasn't worried about whether I could cover the distance physically. My biggest concern had always been managing everything that came with running such a race while living with a stoma.



How did the race itself go?

Cocodona 250 is unlike most endurance events. It isn't split into stages with overnight stops. Once the race begins, the clock never stops. Whether you sleep, eat or keep moving is entirely your own decision. Aid stations are positioned roughly every 12 miles, stocked with food, drinks and medical support, although the opening 30-mile section provides only limited water because of the inaccessible terrain. Many runners sleep at aid stations or on the trail, but having a dedicated crew and support vehicle makes an enormous difference.

I was fortunate to be part of a close-knit team made up of three runners, two pacers and an additional crew member, led by Steve, the Crew Chief. Two I knew from my military career, three had attempted Cocodona in 2024 and only one, Scott, had completed it. Their experience, encouragement and organisation were invaluable throughout the event.

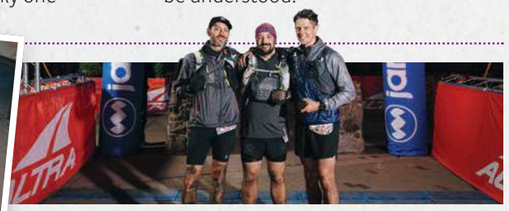
Months of preparation meant my stoma caused far fewer problems than I had feared, although not everything went to plan. Halfway through the race, because of time pressure and exhaustion, I skipped what should have been a routine bag change before setting out on day three. About ten miles later, while climbing the iconic Hangover Trail, I realised the bag was beginning to peel away from my skin.

Initially, I wasn't too concerned. I thought I could make a quick change, catch my teammates and reach the next aid station. Instead, I discovered that the spare bags I'd been carrying had been stored for too long and had lost much of their adhesion. Suddenly the situation became far more serious. I faced a choice: turn back almost ten miles to the previous aid station and almost certainly abandon the race, or patch the problem together as best I could and hope it held until the next checkpoint. There was only one option. I improvised, caught my teammates, apologised for disappearing and eventually reached the next aid station, where I could make a proper change. Physically I was still moving forward, but mentally it was the closest I came to believing my race was over.

Looking back, that experience reinforced the importance of preparation but also of remaining calm when things inevitably don't go according to plan.

The most memorable moment, however, wasn't an individual section of trail or a spectacular view. It was crossing the finish line alongside the two teammates I'd started with five days earlier. That moment as a team felt incredibly special.

People often ask what the highlights were. But nothing truly captures what Cocodona feels like. It's one of those experiences that has to be lived to be understood.



Why did you choose to run the race in support of Colostomy UK?

Originally I hadn't intended to fundraise. Cocodona was a personal challenge and a way of rebuilding after emergency surgery.

However, as more people learned what I was attempting, they wanted to support the journey. But it soon became obvious that I had an opportunity to raise awareness and funds for two charities that had become personally important to me.

Colostomy UK provides support for people living with a stoma and their families. Seeing both my own experience and that of my young nephew reinforced just how valuable organisations like this are. If sharing my story helps make life even slightly easier for people like my nephew, then being open about my own experiences is worthwhile.

I also chose to support REORG, a charity that had previously funded my gym membership during my recovery from surgery. As an Armed Forces veteran, their support played an important role in helping me rebuild both physically and mentally.

Together, the fundraising has raised more than £5,000 before Gift Aid

Is there anything else you like to share?

If I could offer one piece of advice, it would be not to place limits on yourself too early.

Recovery after stoma surgery takes time, and everyone's journey is different. There will inevitably be setbacks, but having a stoma doesn't mean your ambitions have to become smaller.

> I spent years trying to hide my experiences because I wanted life to return to how it had been before cancer. It wasn't until I accepted that life had changed, and started embracing that new reality, that I truly began to recover.

Whether your goal is simply getting back to everyday life or taking on an endurance event, don't assume it isn't possible. Give yourself the opportunity to recover, ask for help when you need it and take things one step at a time. You may be surprised by what you're capable of.

Colostomy UK

dear nurse

Sue Pridham
Head of Clinical and Nursing Services, Convatec

Living Well with a Urostomy

UNDERSTANDING INFECTIONS, SKIN CARE AND FINDING THE RIGHT FIT

Living with a urostomy can take time to adjust to, and it's completely normal to encounter challenges along the way. While many people go on to live full and active lives, there are some common concerns that can affect day-to-day comfort and confidence. Two of the most frequent issues are urinary tract infections (UTIs) and problems with peristomal skin (the skin around the stoma).

Understanding what to look out for, knowing when to seek help, and finding the right products for you can make a real difference in how you feel and manage your stoma

Spotting a Urinary Tract Infection (UTI)

Urinary tract infections can be more common for people living with a urostomy, but they are not always easy to recognise. This is because the usual symptoms people might expect - such as needing to pass urine frequently or a burning sensation - often don't occur in the same way.

With a urostomy, urine drains continuously into your pouch, so there's no sensation of needing to pass urine. Because of this, some of the typical warning signs are no longer present. In addition, mucus is mixed in with the urine, which can sometimes make it harder to spot changes that might indicate infection. This means that UTIs can occasionally develop without being noticed straight away

Therefore it is important to become familiar with what is normal for you and watch for changes such as:

- Urine that appears cloudy or darker than usual
- A strong or unusual smell from your urine
- An increase in mucus in your pouch
- Feeling generally unwell, tired, or lacking energy
- Loss of appetite or feeling slightly “off”
- Fever, chills, or back pain, which may suggest a more serious infection

Even small changes can be important. Often, people say they just “don't feel quite right”- and this instinct should never be ignored.

If you notice any of these changes:

- Contact your GP or stoma care nurse straight away
- Try to increase your fluid intake, unless you have been advised otherwise
- A urine sample may be needed - your stoma nurse specialist will be able to advise on the best way to do this
- Seek urgent medical advice if you develop a temperature, pain, or feel significantly unwell

Early treatment can prevent the infection from becoming more serious, so it's always better to seek advice sooner rather than later.

Peristomal skin Health

Healthy skin around your stoma is key to feeling comfortable and confident. Ideally, the skin should look similar to the rest of your abdomen - smooth, intact, and not red, broken and irritated. However, when you have a urostomy, the skin can be exposed to urine, which can cause moisture, associated with skin damage and irritation. This can result in erythema (redness) and pain and will require an intervention to resolve. Stoma powder can help with this and it is key to ensure your pouch fits correctly.

Repeated exposure to leakage can lead to hyperkeratosis. While the name sounds complicated, it simply refers to a build-up of thickened skin.

Hyperkeratosis can appear as:

- Thickened or slightly raised patches of skin
- A rough or uneven texture
- White, grey, or yellowish areas
- Dry or scaly skin

It usually develops gradually and may not be painful at first, which is why it can sometimes go unnoticed.

> **The most common cause is repeated exposure to urine that is more alkaline, often due to small leaks that may not always be obvious.**

Although it may not seem serious at first, having sore skin around your stoma can make it more difficult for your pouch to stick properly. This can lead to further leaks, creating a cycle where: Leakage > Skin damage > Poor seal > More leakage

Breaking this cycle early is important to protect your skin and improve your overall comfort.

There are some simple but effective steps you can take:

- Check your skin regularly when changing your pouch
- Make sure the opening of your pouch fits closely around your stoma
- Avoid leaving damaged skin untreated
- Follow a gentle skin care routine recommended by your stoma nurse
- Seek advice if you notice any changes that don't improve

Remember, healthy skin helps your pouch stay secure, which in turn helps prevent leaks.

One of the most important parts of urostomy care is using a pouch system that fits well and feels comfortable. Not all stomas are the same, and your needs may change over time.

> **If you're experiencing leaks or skin problems, it may be a sign that your current product isn't the best option for you.**

You may hear about convex products during your care. Convex pouches have a gentle outward curve that helps the area around the stoma push slightly inwards. This can help the stoma protrude more and allows the pouch to form a better seal. The urine can then drain more easily into the pouch preventing leakage onto the skin

Convex products can be particularly helpful if:

- Your stoma sits flat against the skin
- Your stoma is slightly retracted (dips inwards)
- You experience frequent or ongoing leaks
- Your body shape makes it difficult to get a secure seal

For many people, switching to the right convex product can significantly reduce leakage and improve confidence.

There isn't a “one size fits all” approach. The best product for you will depend on:

- The shape and position of your stoma
- The condition of your skin
- Your body shape and movement
- Your lifestyle and activity level

> **Working closely with your stoma specialist nurse is the best way to ensure your products are the most appropriate for your needs.**

Small changes - like recognising early signs of a UTI, improving your pouch fit, or adjusting your skincare routine - can make a big difference to your comfort and confidence.

If you're having problems there is help and support available. Your stoma specialist nurse is an expert and often the best place to start. There are also patient support charities which have a wealth of knowledge and expertise.

Talking about concerns, even small ones, can help prevent bigger problems later. Urostomy care can feel overwhelming at times, understanding your body and knowing what to look out for can help you feel more in control.

Key takeaways

- Changes in your urine or how you feel are important - trust your instincts
- Healthy skin is key to preventing leaks and maintaining comfort
- The right product choice, including convexity if needed, can make a real difference
- You don't have to manage this alone support is always there

STOMAS UNLOCKED
— from Colostomy UK —
Because every stoma journey matters
UNDERSTANDING. SUPPORT. CHOICE.

Unlocking Understanding

At the heart of the campaign is a simple idea: The more people understand what it means to live with a stoma, the easier it becomes to break down barriers.

To help with this, we will be rolling out our Unlock Your Story initiative. We will be sharing stories from people living with a stoma across our website, and social media channels.

UNLOCKING UNDERSTANDING.
UNLOCKING SUPPORT.
UNLOCKING CHOICE.

STOMA AWARE DAY
3 October 2026

Every day, people living with a stoma overcome challenges that most people never see.

For some, it is rebuilding confidence after surgery. For others, it is planning journeys around toilet access, returning to work, travelling, socialising or simply dealing with a lack of understanding from others.

But many of the issues people face are not caused by their stoma itself.

They are caused by misconceptions, poor awareness and environments that do not always meet people's needs. Over the years, Colostomy UK has used Stoma Aware Day as an opportunity to challenge these issues, starting important conversations that have led to a greater understanding of stomas and what it means to live with one.

Which is why, for Stoma Aware Day 2025, we launched our Stoma MythBusters campaign, aimed at directly addressing these misconceptions. That work remains as important as ever.

But increasing stoma awareness on its own does not improve the quality of lives for those living with a stoma.

Which is why, for Stoma Aware Day 2026, we want to progress things a step further, by asking ourselves:

- **How do we turn understanding into meaningful change?**
- **How do we help more people access support?**
- **How do we ensure people feel confident in the choices they make?**

We believe that unlocking the answers to these three questions will lead to a world where people living with a stoma are seen, heard, and empowered.

Unlock Your Story

These stories will reflect the challenges and achievements of everyday life events such as:

- Returning to work
- Taking a holiday
- Enjoying a meal out
- Spending time with family and friends
- Playing sports

Our aim is to show the wider world that a stoma should not be a barrier to living a full and active life. Unlocking people's stories can be incredibly powerful. It can:

- **Help someone newly recovering from surgery feel hopeful about the future.**
- **Help family and friends better understand what their loved one is experiencing.**
- **Help challenge the many assumptions that still exist today.**

Turning Understanding into Action

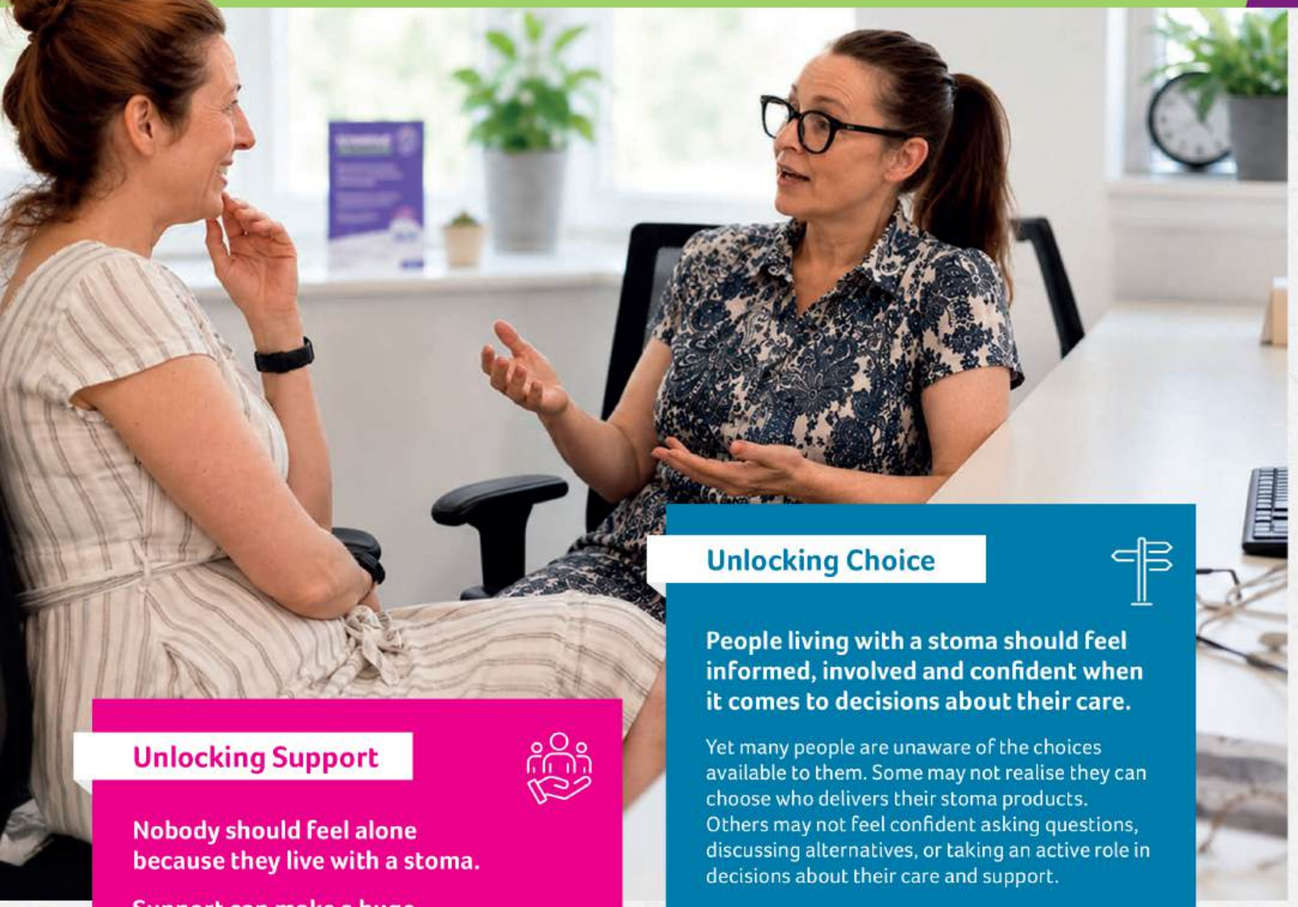
Through our Unlock Your Venue challenge, we want to encourage practical action that improves everyday experiences for people living with a stoma by supporting establishments to become stoma friendly.

Whether through better toilet access, cleaner facilities, or improved awareness among staff, such small changes can make a significant difference.

Not all disabilities are visible
#stomafriendly

Stomas Unlocked

UNLOCKING UNDERSTANDING. SUPPORT. CHOICE.



Unlocking Support

Nobody should feel alone because they live with a stoma.

Support can make a huge difference to someone's confidence and wellbeing.

Yet we know there are still people living with a stoma who do not know where to turn for information, advice or reassurance.

As part of Stomas Unlocked, we will be shining a spotlight on the importance of support and exploring new ways to help people connect with the information, services and community available through Colostomy UK.

Unlocking Choice

People living with a stoma should feel informed, involved and confident when it comes to decisions about their care.

Yet many people are unaware of the choices available to them. Some may not realise they can choose who delivers their stoma products. Others may not feel confident asking questions, discussing alternatives, or taking an active role in decisions about their care and support.

We want to increase knowledge around stoma care and rights.

To do this, will make it easier for people living with a stoma to access and digest information relating to patient choice, as well as actively encourage greater personal involvement in health care decisions that affect everyday life.

That includes understanding supplier choice, promoting shared decision-making and giving people the confidence to advocate for themselves in health care settings

How you can get involved

AUGUST 2026

Stoma Aware Day will be held on the **October 3rd 2026.** We will be launching Stomas Unlocked in the run up to the big day.

From the August 20th you'll be able to visit the Colostomy UK website to follow the campaign.

We'll be sharing:

Campaign updates, stories from across the stoma community, and opportunities to support our work as we build towards Stoma Aware Day.

You'll also be able to find information about our Stomas Unlocked pop-up stands, which will be at locations across the UK on Stoma Aware Day itself, as well as details on how to take part.

01 Share

Share your experiences as part of our Unlock Your Story Initiative

02 Encourage

Encourage local business and venues to become stoma friendly as part of our Unlock Your Venue challenge

03 Awareness

Help raise awareness of the Stoma Unlocked campaign on social media or by supporting our pop-up stands across the country.

Every story matters.
Every conversation matters.
Every voice matters.

Together, our actions can help create meaningful change.

We hope you will join us as we build towards Stoma Aware Day 2026.

Together, we can unlock understanding. Unlock support. Unlock choice.

Follow the campaign from 20th August | ColostomyUK.org

Colostomy UK

Because every stoma journey matters

Do you provide stoma care or emotional support to someone in the home or for work?

We're inviting them to join our CPD accredited online workshop
Caring for a Person with a Stoma

This 90-minute interactive session is designed for anyone providing support. That might be a professional, partner, family member, friend, neighbour or unpaid carer who helps you manage your stoma, whether through practical help or emotional support.

Workshop overview:

- Understanding how stomas are formed
- Types of stoma bags and how to change them
- Stoma management challenges
- Patient worries and lifestyle adjustments
- Physical and psychological issues associated with having a stoma
- Q&A with a stoma care nurse
- CPD Certificate

Held via Zoom

Facilitated by a qualified stoma nurse

Free for anyone providing unpaid care

CPD Accredited

Register using the QR codes below, or get in touch at **getinvolved@ColostomyUK.org** or **0118 939 1537**

13th October 2026
2pm - 3.30pm
(free for unpaid carers)

19th November 2026
2pm - 3.30pm
(for health care professionals)

CPD The CPD Certification Service

BEATING THE ODDS:

Refugee, Ostomate, Champion: Javier Munoz Mena's Incredible Story

By Javier Munoz Mena | Edited by Jillian Matthew

37-year-old Javier Munoz Mena escaped a brutal political regime in his native Nicaragua, fleeing first to Costa Rica and then onto the United States, where he was granted refugee status. Such life events would be challenging enough for anyone. Yet Javier lived through these turbulent times while his health was dealt a series of devastating blows, ultimately leaving him with an unplanned ileostomy.

I was born and raised in Nicaragua. I studied nursing and then specialised in surgical assistance (what is known as a 'scrub nurse'). However, in 2018, the country fell into a sociopolitical crisis which led to the establishment of a dictatorship which remains in power to this day. I fled to neighbouring Costa Rica that same year to escape the situation at home. I worked in different hospitals and clinics in Costa Rica for six years.

It was while I was there in 2021 that I was initially diagnosed with ulcerative colitis, having always suffered with bowel issues. Much later I would be re-diagnosed with Crohn's disease - a chronic illness that has no cure, although there are treatments available to manage it, thankfully.

Living with Crohn's disease teaches you to listen to your body, especially when it affects your mood. But this is not an easy thing to do - it can be difficult for adults to break old habits and learn new ways of doing things which are better for our bodies. Of course, it can also affect self-confidence because it makes you doubt your abilities. But that improves once you build new, beneficial routines into daily life - not only when you feel motivated, but also when you don't.

I was treated with prescription anti-inflammatory medication for two years, which really helped relieve my symptoms. But then everything changed. A lack of attention to my diet led me to eat contaminated meat which triggered a flare-up of my symptoms that nearly cost me my life. I ended up in hospital, where poor medical management during surgery led to my colon being perforated and which resulted in intra-abdominal sepsis. I ended up in a coma for seven days. When I woke up, I had an

ileostomy as the surgeons had removed almost my entire colon following the perforation. I have now lived with my ileostomy for almost three years.

Living with a stoma has been a radical life change. Learning how to care for, clean and adjust the pouch in daily life wasn't easy. Even for me, as a nurse with clinical knowledge and experience, this was a completely new world. I had to teach myself how to manage everything that comes with a stoma.

> **It's not just about physical changes either. I would say that the most important and significant aspect of having a stoma is how it affected me mentally, especially while also living with an auto-immune disease.**

Seeing my body change so much has been hard. I lost a lot of weight for one thing. From a young age, I've enjoyed physical activity. I grew up in a country where children play soccer, jog and stay active. Because of this, I've always loved going to the gym, running, and cycling. So when I came out of the coma and realised that my body weighed just 49 kg, it was devastating. I thought I'd never be able to do the same things again. Recovery did not happen in a few days or months. It has been a huge challenge to gain weight, work out which foods and supplements nourish me best, and build the discipline to reach my goals.

It was also hard for me to see my intestine on my abdomen, and to live with the uncomfortable and sometimes embarrassing sounds caused by gas. It's also worth mentioning that with an ileostomy, bowel movements are more frequent, which can be frustrating because the bag needs emptying many times a day.

> **But what feels impossible at first does change. You learn to cope with all of these things; it's a matter of time and adaptation, even though at first you may doubt that you will ever cope.**

Not too long after I had my stoma formed, I received a phone call inviting me to come to the United States with official refugee status. I of course accepted the offer; my primary motivation for moving was the fact that medical treatments here are of the highest quality. There was also a possibility of reversing my ileostomy one day.

There is definitely a big difference in terms of the resources and care available in North America. In many Hispanic or Latin American countries, there is still not much information on comprehensive treatments, and even specialists have few resources available to educate patients and families. There is also a lack of critical medications, not to mention a shortage of accessible stoma supplies.

But equally, in my view, the American system only works well if you are covered with health insurance. There are life-insurance programmes that use taxes to cover expenses for people with chronic illnesses, operating through the social services departments of each state and county. If you have Medicaid or Medicare, your care and stoma supplies will be covered. The key here is having insurance that covers all of your care, including medications, because without it, it would be nearly impossible to pay for all your treatment – unless you win the lottery or are incredibly rich, as medicine here is extremely expensive!

I came to the USA two and half years ago now, and settled in Raleigh, North Carolina. I continue to learn English every day, both through study as well as communicating with people in everyday life. This helped me get a job at a hospital in North Carolina. Unfortunately, I recently had to leave that job because I needed more surgery. Even so, the experience was wonderful. I still feel I have a long way to go to communicate confidently on more complex topics, but language has not been a problem when it comes to receiving supplies or medical care. Thankfully, hospitals in the USA offer interpretation services in different languages, either by video or in person. Currently I am receiving a biological treatment every 28 days - a monthly injection of Skyrizi, which has kept my intestines free of inflammation and the disease currently in remission, I'm thankful to say.

> **In Spanish-speaking countries we say: "No sabes lo que tienes hasta que lo pierdes" – "You don't know what you've got till it's gone." For me, being bedridden, unable to move, to take care of yourself, or even speak – it changes the way you view life.**

Then having the chance to breathe again, to do such simple things that we take for granted, like taking a shower, you start to see them as gifts, as luxuries, as something you should treasure. That has motivated me to love, care for, and value myself much more. Just opening my eyes and having a coffee is enough to find inspiration to train in the gym.

As I rebuilt my strength, I began following fitness pages in the United States and came across the 'Mr. Health & Fitness' competition. I submitted my photos and was accepted. I led the top five in my group for a while but unfortunately I did not make it past the quarter-finals in the competition. Being recognised as a winner would have meant a lot to me and the cash prize would have also provided additional financial security. Having no family or friends nearby makes the situation all the more difficult. However, on May 19th I underwent my stoma reversal surgery. Everything went very well I'm currently recovering and trying to find a work-from-home job.

Looking ahead, and given everything I have lived through, I would love to study nutrition and specialise in inflammatory bowel diseases. I know first hand how much diet, education, treatment and support can shape a person's chances of recovery and quality of life.

> The one thing I would like to say to anyone who is just starting out with their stoma is: "You are not alone." Every day people begin this journey, and whether the stoma is permanent or temporary, it is possible to live a comfortable and fulfilling life with the resources available.

Team Colostomy UK Rugby League Updates

Giovanni Cinque | Marketing & Campaigns Manager | GetInvolved@ColostomyUK.org

It's Super League!

Marketing and Campaigns Manager Giovanni Cinque reminisces on how far The Purps have come.

July 18th, 2018. A rugby league team representing Colostomy UK took to the field against Medway Dragons in Gillingham, Kent. At the time a huge milestone for an idea that had started to develop in 2015 shortly after I joined Colostomy UK.

> That July day was very much a step into the unknown with so many unanswered questions. Would we have enough players? How would everyone gel together? Would it be a one-off or would it generate enough momentum to look further forward to more games and long-term plans?

The day was a huge success and sent the team off on a journey to challenge and change perceptions about life with a stoma that has taken us all across the UK. The team has been showcased on countless local and national TV shows, radio slots, and newspaper features, as well as playing as curtain raisers to professional games. We also launched a wheelchair team and have had players selected to represent their country as a result!

Although our ten-year anniversary is still some time away, this article provides an apt moment to reflect on the past due to our visit to Wakefield Trinity in June. Our Physical Disability Rugby League (PDRL), and Wheelchair teams were invited to take part in the club's annual inclusion round. This was no small thing. It meant that after nine years of 'the Purps' in action, we had finally reached the big time and appearing in our first Super League curtain raiser!

There was a huge sense of excitement on match day for our PDRL team. For once, everyone arrived earlier than the meet time, and as we were guided to the changing rooms, we were met with murals of many of the greats of rugby league.

Our opponents were Wakefield Trinity PDRL and our game was the opening entertainment to the Wakefield against Hull KR fixture, with a crowd of nearly 10,000 expected. It was also live on BBC and Sky Sports. Our game itself more than lived up to the occasion with end-to-end tries and actions in front of an appreciative crowd.

Winger Ryan Owens summed the day up perfectly:

> "It's the first time we've played in a stadium like this and in front of a crowd like this too. It's a really good opportunity for us to show what people with stomas can do and I think we did the badge and charity proud"

The Sunday saw our Wheelchair team take on a Wakefield Trinity Development side. An opportunity for both teams to embrace the inclusion message from the weekend.

Fixtures update

Earlier in the spring, our PDRL team had a competitive and enjoyable game with Leeds Rhinos, while our Wheelchair team took part in their first tournament, the Wheelchair challenge trophy in Nottingham.

There's still plenty more to look forward to this year too!

If you'd like to find out how you can get involved as a spectator, player or volunteer, please email Giovanni at

GetInvolved@ColostomyUK.org

Unique and Exciting Jobs

Chris Morrison (56) from Derry City, Northern Ireland, was a firefighter – an intense career, but one which his stoma never held him back from.

My stoma was formed in November 2016. In July of that year, I went to my GP after experiencing severe weight loss, extreme fatigue, constipation, rectal bleeding and a large lump that had to be manually pushed back after every bowel movement. Despite how alarming these symptoms were, I was initially misdiagnosed with haemorrhoids.

Things deteriorated to the point where I was admitted to hospital for nine days. Further tests finally uncovered the real cause: a 10 centimetre tumour in my rectum. The medical team explained that the safest and most effective treatment would be to create a permanent colostomy.

I've been fortunate not to experience major complications since then. I deal with the occasional leak or minor blockage, but nothing that has ever stopped me from getting on with life. What challenged me most in the early days wasn't the physical side of things, but the emotional and psychological adjustment. I struggled with body image, confidence and the fear that I might never return to the activities I loved before surgery.

> **Over time, though, I learned that a stoma doesn't end our life - it simply asks you to navigate it differently. And once I accepted that, I realised I could still live fully, confidently and on my own terms.**

A Lifetime of Fighting Fires

I joined the Northern Ireland Fire and Rescue Service in April 1993. This was 23 years before my stoma surgery, and at the time, it genuinely felt like I was stepping into the life I'd always imagined for myself. Firefighting was the only career I ever truly wanted. From as far back as I can remember, I idolised my grandfather Jimmy. He served as a firefighter during the Blitz.

Hearing his stories and seeing the pride he carried with him had a huge impact on me growing up.

> **To me, he was a hero and I knew, even as a child, that I wanted to follow in his footsteps. It wasn't just a job; it was the realisation of a lifelong ambition.**

Firefighting is a role that demands the very best of you - physically, mentally, and emotionally. It is about protecting life, property, and the community. One moment you're responding to a house fire, the next you could be at a road traffic collision, or dealing with flooding. No two days are ever the same, and that unpredictability is part of what makes the job so compelling.

What sets firefighting apart is the combination of teamwork, trust and adrenaline. You train to the highest standards, but when the bells go down, you rely just as much on instinct and the bond you share with the people on your crew. Every call out matters. Every decision counts. You never forget that your actions can genuinely change - or save - someone's life.

Vivid Memories

One moment that has always stayed with me happened during a house fire. When we arrived, the house was smoke-logged, and visibility inside the building was almost non-existent. We were told that a young couple had been trapped upstairs. Conditions were deteriorating quickly, but we made entry and carried out a search.

In that intense, smoke-filled environment, you rely entirely on training and communication with your breathing apparatus partner to carry out a methodical and thorough search. We eventually located the couple in an upstairs bedroom and were able to bring them out to safety and pass them to the waiting paramedics. Thankfully, they were only suffering from slight smoke inhalation. Unfortunately, there is also the side of the job where you need to deal with the aftermath, when people have been seriously injured or even lost their lives in fires or road traffic collisions.

> **Moments like that are both humbling and motivating. They're the reason firefighters put on the uniform day after day. The challenges are real, but so are the rewards, and that's what makes the job unlike any other.**

Fire Fighting with a Stoma

When I was first told I would need a permanent stoma, one of my biggest worries was whether I would still be able to do the job I loved. By that stage, I had been promoted to Crew Commander, and I was determined to keep climbing the career ladder.

One of the first questions I asked my surgeon was simple: "Will I still be able to work as a firefighter?" To my relief, he told me there was no medical reason why I couldn't return to full operational duty. Hearing that gave me hope, but it didn't erase the long list of concerns running through my head.

Naturally, I wondered lots of things. Would my stoma bag cope under full PPE? Could the heat and pressure inside a fire affect the adhesive? Would wearing breathing apparatus straps cause pressure or damage to my stoma? Would I need to adapt how I moved, lifted, or worked? These were real fears - not just about comfort, but about safety.

Returning to work meant learning how to factor my stoma into a high pressure environment. I had to think about things I'd never considered before: making sure I fitted my appliance securely before a shift, keeping spare supplies close by, and being aware of how PPE sat against my abdomen and ensuring I wore my support garments. It wasn't about limiting myself; it was about being prepared and staying in control.

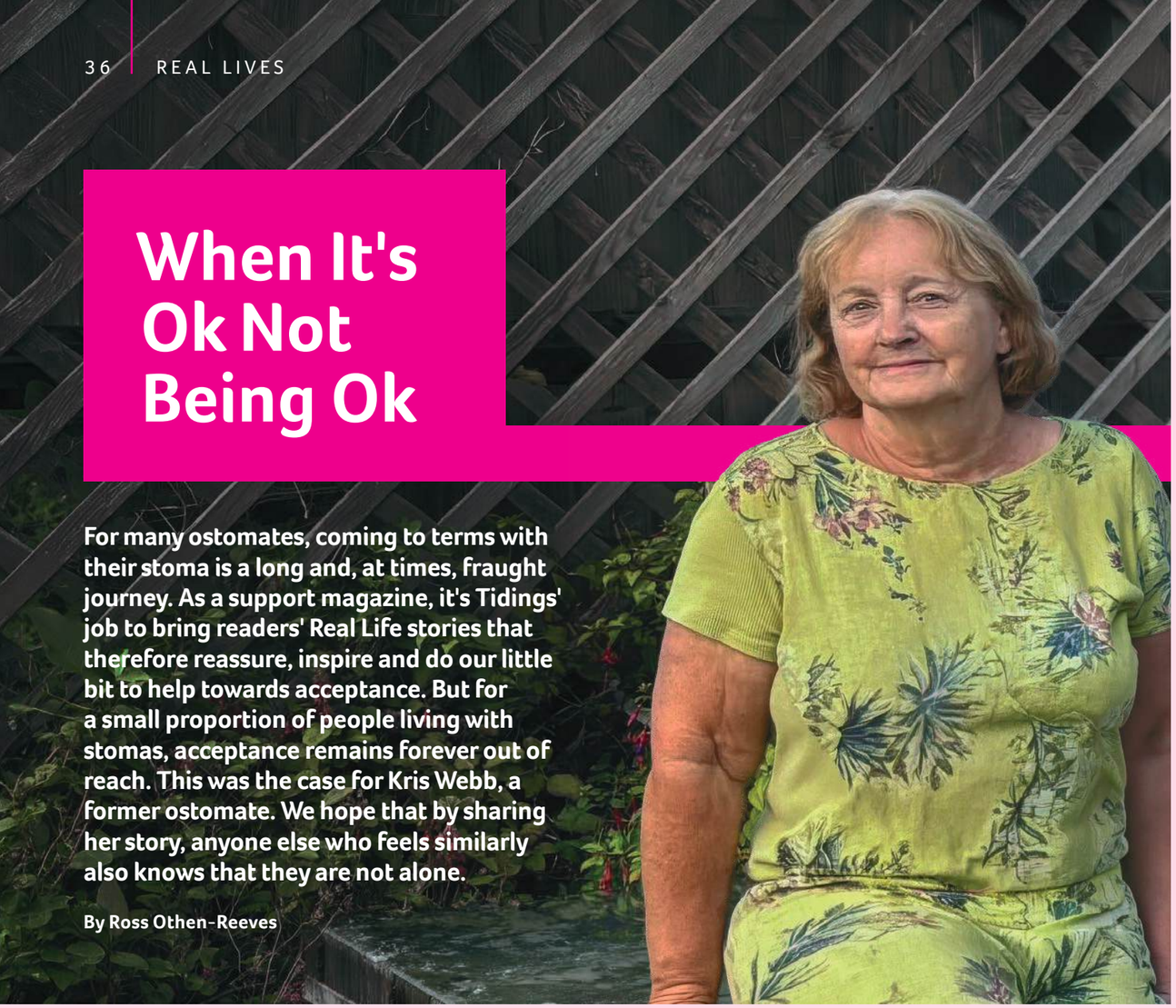
I was lucky that I only ever had one or two close calls with leaks or my bag becoming detached. But in these cases, I found a discreet place to sort the issue out, usually in the cab of a fire engine, and returning to the operations.

Advice for Others

If you're an ostomate considering a unique or challenging role, please be aware of this: I have been where you have been, I've faced the doubts, the fears and the 'what ifs' that my stoma might somehow hold me back. In many ways, you've already faced a tough battle; you've faced the daily challenge of living and working with a stoma head-on. You've endured the leaks, the blockages and the mental challenge of it all, so how much more difficult is a unique or exciting job going to be?

So, my advice is to grab the bull by the horns and go for it! What have you got to lose? There will be moments when things don't go perfectly, don't let those moments define you or hold you back.

When It's Ok Not Being Ok



For many ostomates, coming to terms with their stoma is a long and, at times, fraught journey. As a support magazine, it's Tidings' job to bring readers' Real Life stories that therefore reassure, inspire and do our little bit to help towards acceptance. But for a small proportion of people living with stomas, acceptance remains forever out of reach. This was the case for Kris Webb, a former ostomate. We hope that by sharing her story, anyone else who feels similarly also knows that they are not alone.

By Ross Othen-Reeves

Kris Webb, a retired data and systems analyst from London, had always suffered with bowel issues on and off. But it was only in September 2022 while on holiday in Edinburgh for the festival that her condition significantly deteriorated to an unmanageable degree for the first time.

After a dramatic journey home, which saw Kris suffer from severe diarrhoea and vomiting, she made it to her GP who was immediately alarmed. CT scans revealed a blocked bowel on the verge of rupturing. Emergency surgery was needed, and a stoma essential along with it.

> 'It was a scary thing,' Kris recalls. 'I was asked to sign my life away before surgery. But I knew nothing about stomas, really. So I said, "I can't have this done unless it can be reversed" but the surgeon responded, "You'll die if you don't have this done, so let's get on with it".'

When Kris came round from surgery, she found a temporary colostomy had indeed been formed. Now she was out of immediate danger, however, she would require further procedures to ascertain the reason for the blockage. Her consultant feared that cancer was to blame, but a colonoscopy and further tests confirmed that Kris was in fact living with undiagnosed diverticulitis.

Kris lived with her temporary colostomy while waiting for a slot to become available on the NHS to have major surgery to remove the diseased section of her bowel. This would result in an ileostomy being formed. Once she had healed from this second operation, she would finally be able to be put on the waiting list for a stoma reversal, something she was adamant she wanted. As Kris put it:

> 'It was my whole objective in life to not have it [her stoma].'

Kris lived with her temporary colostomy for a year, supported by her husband, who she describes as 'absolutely incredible'. She was also strengthened by her friend Diane, who lived with a permanent stoma herself. Diane encouraged Kris to not be held back by her colostomy. As she explains:

> 'She made me go swimming with her, and I would never have dreamt of doing that. I wouldn't have thought it was possible. She gave me the confidence to do a lot of things - but to go swimming! I thought that was quite incredible, really. I don't think I would have done that without her encouragement.'

In November 2023, Kris got a call from the NHS to say a cancellation slot had become available for a week's time to have surgery to remove her diseased bowel and form an ileostomy. It was short notice, but Kris was actually relieved not to have too long to mull over the intimidating prospect of major surgery.

At this point, Kris' consultant sat her down to discuss whether she needed the surgery at all. As she recalled:

> 'He said "Look, you're coping very well with a stoma, and you can live a very full and ordinary life. Do you really want to go through major surgery just to get to the stage where it could be reversed?" In my opinion, there was absolutely no question. I knew it was going to be major surgery, but rightly or wrongly, I did not want to live with a stoma.'

The operation was a success, and although the recovery period was long and not without its challenges, the consultant was pleased with how well Kris healed. She was by now focused on her ultimate goal of a stoma reversal. She knew she was lucky to be eligible for a reversal, as the option is not possible for many ostomates due to medical reasons. However, she was shocked to discover that the waiting list on the NHS would likely be up to two years.

It was a prospect Kris could not entertain and elected to go private for the reversal surgery instead, which was booked in for six months later. Knowing she would soon be stoma-free brought Kris great relief, but she was also very aware of how fortunate she was to be able to go private. As she put it:

> 'I feel I've been very lucky, not just because I had surgery when I had it, and I had very sympathetic hospital consultants and staff, but also because I had the money to pay for a private reversal.'

Where her previous two surgeries had caused her understandable anxiety, Kris' mindset completely shifted when it came to her stoma reversal. Seeing what she considered as the finish line of her ongoing health issues, she viewed this third and final operation as a 'slight inconvenience' only - one well worth bearing to be able to return to the version of herself she felt most comfortable with.

But why was the need to be stoma-free so strong, I asked, when so many others accept, embrace, and even celebrate their stomas?

> 'Ultimately, I didn't like the inconvenience'. Kris reflected. 'And I was always worried that it [her stoma bag] would come unstuck. I suppose I never really trusted it from that perspective, and I did have a few leaks. It gave me that extra thing to worry about. I was very grateful to have had my stoma, and it saved my life, but I wanted normality back.'

Kris' feelings are not rare amongst the stoma community. It's likely many Tidings' readers will resonate with her fears and frustrations. What is rare, however, is the opportunity for ostomates and former ostomates like Kris to be able to share their stories. And to acknowledge that for some – it is ok not to feel ok.

It is an interesting thought experiment to wonder how Kris would feel now, several years on, if reversal surgery had not been an option. Would she have come to terms with her stoma? It's impossible to say of course. But I like to think she may have found Colostomy UK and the wider stoma world, where not just one Diane, but thousands of Dianes, were ready and waiting to show her a world of possibilities.

Stoma Communities in Conflict Zones

By Jane Fior

Life with a stoma can be tough no matter where in the world you live. However, for ostomates living in conflict zones the situation can be exceptionally difficult – to say the very least. Here, contributor Jane Fior guides us through the many concerns and challenges experienced people living with stomas in these contexts.

Adapting to life with a stoma is challenging, especially at the beginning when getting used to this change in body image and function. However, we are very lucky in the UK because we have access to skilled surgery, excellent aftercare with experienced stoma nurses, and most importantly, from then on, a reliable and regular source of pouches, adhesives, flanges and other accessories for which we do not have to pay.

> When there is a major emergency somewhere in the world, international humanitarian agencies are quick to respond, addressing the need for shelter, clean water and medical aid. We can donate to the Red Cross, Oxfam, Save the Children, Médecins Sans Frontières (MSF) and many other charities in the hope that this will help alleviate the immediate suffering of civilians caught up in conflict or some natural disaster.

But what about the long-term consequences for populations when the situation is ongoing and individuals somehow have to find ways to cope when normal services no longer exist? As people who understand the realities of having a stoma, it is impossible not to wonder how our fellow ostomates, adults and children, manage in hospitals in conflict zones, such as Ukraine, Gaza, and Sudan, which struggle to support ostomates in such volatile settings. Hospitals (already under enormous strain in such circumstances) find they have increasing numbers of patients with abdominal wounds as a result of conflict. Such incidents require urgent treatment, adding more pressures to already precarious health systems.

And following surgery, how do the necessary supplies reach patients who then have stomas when normal distribution routes are disrupted, health centres and pharmacies are out of action, and experienced medical staff are dispersed or no longer available? Is there anything we can do to help, however limited that help has to be?

> Before conflict, places such as Ukraine, Gaza, and Sudan had functioning (if often imperfect) health systems capable of providing stoma care. War has drastically reduced their capability. Medical staff now face the simultaneous destruction of hospitals and infrastructure alongside an unprecedented rise in patients requiring emergency abdominal surgery: soldiers and civilians near frontlines, victims of indiscriminate violence, and people whose existing conditions, including cancer, have gone untreated as health systems have collapsed.

For those left with stomas after surgery, the situation is often dire. Stoma supplies, including pouches, bases, gauze, adhesive tape and remover, are extremely scarce. A report on a humanitarian mission published in The Lancet describes how the scarcity of wound-care products has led to makeshift solutions: plastic bags, gloves, tissue paper and rags glued and taped to the abdomen being used as stoma bags and dressings. Distribution networks that existed before conflict, such as regional centres, pharmacies, supplier routes, have been disrupted or destroyed. Where supplies are still available, the price has often risen sharply, putting them beyond the reach of most people.

There is also the profound difficulty of managing stoma care with dignity while living on the move, in a refugee camp, or in a society where cultural perceptions of bodily hygiene and purity are deeply felt. Access to clean water, privacy, and consistent supplies – taken for granted by most ostomates in the UK - become impossible to rely on. The psychological toll compounds the physical: studies of health consequences in conflict settings report very high levels of anxiety, depression and poor quality of life amongst those affected.

The need extends beyond war wounds alone. Doctors are faced with patients requiring colostomies as a result of colon cancer - rates of which are steadily increasing and represent one of the most common cancers in some affected regions. Organisations working through cancer projects at hospitals such as Nasser Medical Complex and Al-Shifa are currently supporting more than 100 patients who require colostomy bags, with availability that is deeply inconsistent: supplies may be accessible at a hospital one week, through a Primary Health Care Centre the next, or not available at all. This creates significant challenges for patients trying to manage their condition with any reliability. Small children presenting with abdominal congenital deformities also require life-saving surgery and subsequent stoma care. Where specialist surgical skill is needed, patients may face complex transfers to facilities in other territories, with aftercare back home difficult to achieve.

> Aid agencies, both large and small, are doing their best to bring in medical equipment and essential supplies. A number of organisations are working to reach ostomates specifically - collecting donated pouches and stoma products, sorting them by size and type, and shipping them by container to local networks in affected areas (these organisations are listed at the bottom of this article). The difficulties on arrival are immense, however: boxes are often damaged or quickly looted, and staff networks are dispersed as people flee. Where supplies do get through, they are directed to urban centres, with rural ostomates often unable to access anything at all.

In the face of such enormous and complex need, it is easy to wonder what as individuals we can offer. However, raising awareness of the situation facing our fellow ostomates, and donating spare supplies where we are able to do so, will in its small way make a difference to someone who, just like us, is doing their best to cope with life with a stoma.

For more information on any of the organisations mentioned in this article, please see the following:

For more on support in Ukraine, see:
- Jacob's Well Ukraine Appeal

In Gaza please see:
- Medical Aid for Palestinians (MAP)
- Medecins Sans Frontieres in Gaza

For Sudan see:
- Island Giving
- Sudan Doctors Union-UK
- Medecins Sans Frontieres (MSF) in Sudan

Community and Support Group News

Our Community Engagement Lead, Shauna Ann, shares all the news from stoma support groups across the country, as well as updating on all of Colostomy UK's latest community-based initiatives – read on for how you might be able to get involved yourself!

Friends with Stomas

Last year, Mel North and Sam Lewis set up their own support group, Friends with Stomas, based in St Albans. The new group got off to a flying start, hosting a successful Wellbeing Day earlier in the year, and another one in June, kindly fundraising for Colostomy UK at both events. Here, Mel explains how it came to be.

'Sam and I met at work in 2018. Sam was there for me when I was diagnosed with rectal cancer in 2022. She supported me through my treatment, as well as being by my side when I began my new life with my permanent colostomy. When she had an unexpected ileostomy formed in April 2024, it was fate that I had a stoma and could now support her. It was in her early days that we noticed that we had been given different information about supplies, what to use, and general care - so we then decided to help others with our tips. The idea of forming a stoma group had also been on my mind a while, as I didn't have anyone close enough for me to go to when I was first in need of support. So I decided to go alone and set one up a monthly morning social. We had 25 people turn up to the first one in September 2025. Sam has since had a reversal and recently welcomed a baby boy into the world but still keeps up with what's happening with the group.'

Friends with Stomas meets every second Friday of the month from 10:00am to 12pm in St Albans (currently waiting to confirm a new venue).

Recent activities have included two Wellness Events. Both were great successes and the group even raised finds for Colostomy UK in theprocess – thank you Mel and Sam!

For full details contact Mel at:
friendswithstomas@outlook.com

Community News

On the June 12th, volunteer Leslie Mello attended the British Journal of Nursing Study Day, focused on stoma care. Leslie spoke to around 15 nurses on the day, highlighting the work that Colostomy UK does in supporting all people who have been affected by any kind of stoma. Nurses were especially interested in our free webinars and CPD-accredited events, while our MythBusters campaign was the clear favourite. One nurse even mentioned she has a double-sided copy she photocopies and puts up by patients' beds!

As Leslie noted:

> "Attending the BJN Study Day was such an honour and a joy. It was wonderful to speak with these nurses face to face and hear first-hand how much they value Colostomy UK - for themselves and for their patients. Supporting such hardworking, dedicated health professionals, who in turn support stoma patients every day, felt like a real privilege."

Could you benefit from a Radar Key and Photo ID?

Radar keys open the doors to over 9,000 accessible toilets in the UK in places like shopping centres, pubs, cafés and department stores.

A Colostomy UK Photo ID card, can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

To obtain a key or a photo identity card please complete the form and declaration below, or visit: www.ColostomyUK.org/information/radarkey/

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.

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Parallel Lives

If you've already worked your way through this issue's Real Lives features, you would have been introduced to Peta Barratt (page 12) and Kris Webb (page 36) - two very different stoma stories.

Peta's stoma was formed owing to an injury; for Kris it was because of diverticulitis. Peta lives with a permanent stoma, Kris had a reversal. Peta loves her stoma, while Kris never accepted hers.

But the two women do have one critical thing in common – they are in fact sisters.

Here, the siblings reflect on their stoma experiences together (words by Kris, and agreed with Peta)

Tell us a little about your relationship as siblings.

Peta is the baby of the family and nearly seven years younger than me.

We are a close family although I'm rubbish at staying in touch, we text and see each other when we can and regularly share holidays, theatre trips, family BBQs and meals out.

I live in North London and Peta in Buckinghamshire. Peta is great at arranging fun and exciting get-togethers and Christmas would not be Christmas if we didn't spend it together with our families (Peta the organiser arranges food, activities, and timetable with precision!).

It is such a coincidence that you both have stomas for completely different reasons. How much did you discuss your stomas and support one another on your stoma journeys?

Peta had her stoma first, I don't recall discussing it a great deal, both of us being quite stoical. On saying that, I knew I could have asked any question I wanted and got an honest 'no nonsense' response.

Without doubt, we both appreciated the unconditional emotional and practical support of our husbands, especially during the dark, early days of uncertainty.

I feel we have both been strong and resilient throughout the years of medical setbacks, but life has plenty to offer and we both embrace every opportunity to live the lives we want to live irrespective of what life throws back!

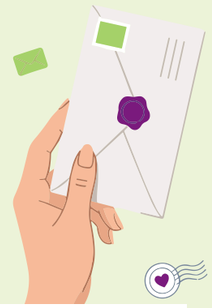
Has the fact that you have both lived with stomas changed your relationship in any way?

I'm not sure the shared stoma experience changed anything about our relationship. We were both there for one another but 'got on with it' and life carried on. We've both been through a lot of surgery and come through the other side thanks to the skill and dedication of medical professionals, which is very humbling.

Any final thoughts on your shared stoma experiences?

Neither of us entertain the idea of stigmatising life with a stoma and both talk openly about stomas in a positive way. We have both supported friends who have gone through the same trauma and hopefully alleviated their fears. I am now stoma-free but it's an experience that will always be part of who I am. Peta is grateful she has the security of her stoma which allows her to carry on with 'business as usual'.

Your Letters and Emails



Here's a summary of your most recent letters and emails.

Dear Editor,

I am writing to share my frustrations with the new B.O.B. [Berkshire, Oxfordshire and Buckinghamshire] prescribing service in my area. Last year we were advised that there would be a central prescribing service who would handle our appliances/catheter supplies prescriptions.

About three months ago, I was informed by my home delivery service that deodorants for use with my ileostomy were no longer allowed to be prescribed. They sent an email to my local stoma nurse to ask them to review my stoma care products. It has been nearly 11 years since my surgery, so I know what brands suit my skin best. My stoma nurse sent a couple of emails to B.O.B supporting my use of the deodorant items. In my particular case, odour is an ongoing issue. The deodorants were not prescribed. Three months later, I have tried again to justify my use of deodorants. Again, my stoma nurse was asked to review my use of stoma care items.

Where can we get any support with this? My stoma nurse informed me that there were several other patients facing the same dilemma.

Yours sincerely,

[Anonymous]

The prescription service that the reader is referring to, 'B.O.B', is now called the Thames Valley Appliance Management Service Bullen Healthcare have been commissioned to run the service by the local Integrated Care Board (ICB). It is a new central ordering service in the area which bypasses (and therefore frees up) GP surgeries. This should be a good thing in the long run, but we are aware of teething issues being reported, such as the one above.

B.O.B is not the only service to be evolving. There is a growing trend amongst ICBs to of introducing Prescription Management Services in their different parts of the country. For more on this, see our Campaigns column on page 44 on the Summer 2026 edition of Tidings.

Our team began looking into the case for the reader, but happily, they able to resolve their issue through their own efforts (see follow up email to us, below):

Dear editor,

I did send a polite statement/complaint of my concerns to B.O.B. They advised me that a member of the management team would be in touch. A few weeks have passed and I haven't heard anything further.

On a very positive note, I feel my statement/complaint has got validated because I have been informed by my home delivery service that I will be prescribed pouch deodorants.

I also did some detective work and went online to see if these pouch deodorants were in fact blacklisted or taken off the NHS formulary; they are still on the nurses formulary and are allowed to be prescribed.

I read with interest the article about changes to our appliances prescriptions in the most recent issue of Tidings magazine [Summer 2026]. It was great that one of the highlights was that we can still ask our GP for help in prescribing our prescriptions for appliances. My stoma nurse backed that up and had to approach a patient's GP surgery for support with prescriptions for deodorants.

I did add that most of us ostomates did not choose this lifestyle and it was through a genuine medical need that we required these items in our daily stoma care routine. I also added that it seemed like rationing was back in 2026!

There is hope on the horizon and we need to keep advocating for ourselves with the help of CUK.

Yours sincerely,

[Anonymous]

Dear Sir,

I am curious about the effect of the gut bacteria with respect to stomas and wonder if one of your expert consultants could offer advice.

I am 76 and have had a colostomy since 2012, after bowel and bladder cancer. I irrigate quite successfully, allowing me usually 24 hours of carefree activity – swimming, cycling, golf, days away etc and social events - without worrying about stoma activity. I lost almost a third of my bowel, resulting in shorter transition and looser bowel movements. I also have a neobladder, and use disposable catheters.

However, about a year ago, things changed after a meal out one evening. My stomach was upset and I started having much quicker passage through my bowel and excessive frequent wind bloating problems. This was not just temporary and just continued the same. This caused me restrictions and problems, with stoma output starting before my next irrigation, embarrassing noises. It meant disturbed nights and sometimes interruptions in the evening, spoiling social engagements. This continued as the 'new normal' for the next few months. I tried changing my diet and times of eating but with no benefit.

However, I then contracted a urinary tract infection. After treatment with antibiotics, my system, miraculously it seemed to me, returned to the previous regime, as described in my second paragraph – lasting 24 hours and much reduced wind between irrigations. I am at present back to my active routine, almost carefree with respect to stoma management.

I think that the antibiotics must have cleared the existing gut bacteria and the new bacteria which re-established in my gut returned me to my old successful regime. Is this a plausible explanation?

I worry about changes to my gut equilibrium occurring and ask if there is some way of controlling this? Perhaps one of your experts could advise on the subject of gut health.

Regards,

Andy

We were curious to find out whether Andy's hunch was indeed true, and so contacted the dietitian Marianne Williams to get her take on things:

Dear Ross

Indeed, antibiotics are often used to try and solve gut symptoms in conditions like small intestinal bacteria overgrowth. So, it is completely possible that the antibiotics had an accidental effect causing a beneficial change in his gut bacteria. However, without further investigation and asking a gastroenterologist it would be impossible to confirm this.

At the moment, as his bowel routine has now returned to normal, there is no need to follow dietary intervention. However should anything change then it may be possible that the FODMAP diet would be helpful but it would be sensible to have a full dietetic assessment by a gastroenterology dietitian before commencing any dietetic interventions.

Hope this helps,
Best, Marianne

Channel Islands

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Guernsey Ostomates
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Jersey

Jersey Ostomy Society
Fiona Le Ber T: 01534 445 076
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England

Berkshire

Reading Bowel Cancer Support Group
Ted Wingrove
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E: ted.wingrove@ntlworld.com

WAMS (Windsor, Ascot, Maidenhead & Slough) Stoma Support Group
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Bristol Ostomy Self Support (BOSS)
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W: www.ostomy.org.uk

Nailsea and District Ostomy Group
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High Wycombe Stoma Support Group
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Milton Keynes Stoma Support Group (MKSSG)
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E: support@mkssg.org.uk
T: 07843 768386

You Are Not Alone Stoma Support Group - Chesham
Carla T: 07846 354 918
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Cambridgeshire

Peterborough Stoma Support Group - Ostomistics
Alan Wright
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E: aww100gun@aol.com
W: www.ostomistics.org

Cheshire

Warrington Stoma Care Support Group
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E: bchft.warringtonstomacareteam@nhs.net

Cleveland

Oops Group
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Cornwall

Cornwall Bowel Cancer Support Group
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Stoma Sistas Support Group (Women Only)
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Lanhydrock Ostomist Group
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Ceri Moore T: 07871926631
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Cumbria

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Facebook West Devon Stomates

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CUPID Colostomy Urostomy Pouch Ileostomy Dorset Support Group
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Gloucester Ostomates
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Audenshaw Stoma Support Group
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Hertfordshire

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Ostofriends Stoma Support Group
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GOGS (Gravesend Ostomy Support Group)
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Helen T: 07710 780 958

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Thanet Stoma Buddies Support Group
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Tunbridge Wells Stoma Support Group
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Bowel & Other Cancer Support Newham
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Eltham's Stoma Support Group
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Newham Stoma Support Group
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South Woodford Stoma Support Group
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St Helens Cancer Support Group
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Middlesex Inside Out Stoma Support Group
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W: www.iossg.org.uk

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Replumed Support Group
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Chichester Stoma Support Group
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East Sussex Stoma Support Group
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The Ostomy Friends Group
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West Sussex Princess Royal Stoma Support
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Leeds Bowel Cancer Support Group
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Scarborough Stoma Support Group
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Second Chance Ostomy Yorkshire
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Scotland

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Kathleen T: 07789 684285

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Chapellhall Community Development Group CCDG & POOS
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W: www.poosscotland.co.uk

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
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Wales

Ceredigion

West Wales Stoma Support Group
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Flintshire

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

Gwent

Cwmbran Ostomy Support Group (COSG)
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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

Information and support for life with a stoma

Colostomy UK

Because every stoma journey matters.

Whether you are preparing for surgery, adjusting to life with a stoma, supporting someone you care about or working in healthcare, **our free literature is here to help.**

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Guides for every stage of life

Getting started

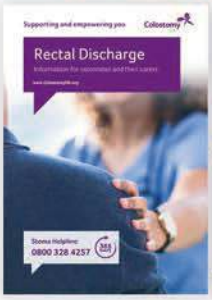
Helpful information before and after surgery.

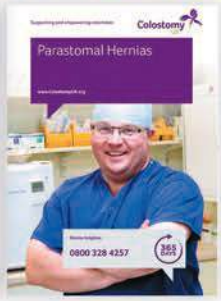
Everyday living

Practical advice for day to day life, diet, travel, relationships and more.

Health and treatment

Information about your health, treatment and managing symptoms.



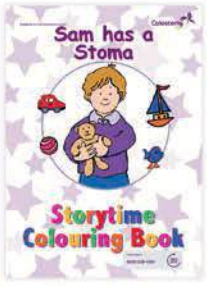


Family and carers

Supporting someone with a stoma and looking after yourself.

Children and young people

Information and support for younger people and their families.



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