Summer 2025 | Issue 78 | Price where sold: £6.25
Colostomy UK's Award-Winning Magazine

Colostomy UK

Tidings

Supporting & empowering ostomates

"My eyes and stoma have made me more determined"

Rebecca Birtwell on life with a stoma while registered blind. Page 34

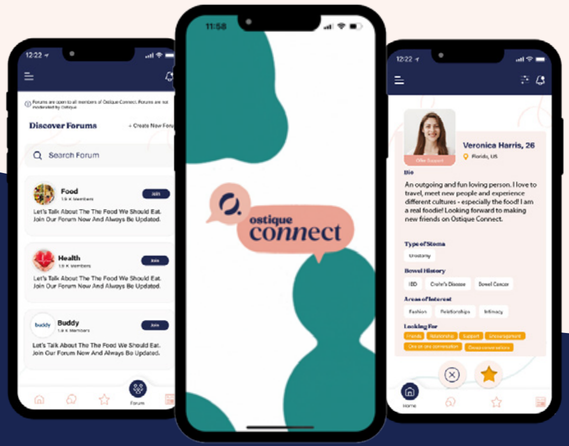
PAGE 23

Air travel tips for summer holidays'

PAGE 9

Embracing an unexpected Stoma After Emergency Surgery

Real stories Real people



Colostomy UK

Editorial Team

Editor, Writer & Researcher
Ross Othen-Reeves

CEO
Libby Herbert

Ostomate Volunteers
Jackie Dudley
Jillian Matthew
Holly Broomfield

Former Ostomate & Volunteer
Leslie Mello

Tidings Digital is identical to the physical copy of Tidings, but can be enjoyed on your laptop, tablet or smart phone.

It is available online for free at: www.colostomyuk.org/support/tidings

If you would like to change your Tidings subscription from a physical copy of the magazine to the online version, please contact us on 0118 939 1537, or use your smart phone to scan this QR Code.

Design & Production
H2 Creative • Digital
www.h2.co.uk

Dear readers

I am writing this column in mid-April, while putting the finishing touches to this summer edition of Tidings. It's one of my favourite times of year.

I've been watching as buds have appeared on the naked branches of trees. Closed tight at first, they have since burst into vibrant green young leaves. This brief window of just a few weeks symbolises renewal, new beginnings and hope - themes which also run throughout this issue of the magazine.

For instance, in our Real Lives articles, you'll hear from 21-year-old Harvey Gladwell, who shares how he is able to live life to the full again after pushing for elective stoma surgery, due to suffering with ulcerative colitis (p.18). After years of physical complications, Harvey is now running in Iron Man competitions. Rebecca Birtwell (p. 34) also lived with ulcerative colitis for years prior to stoma surgery. She explains how she manages life with a stoma while also being registered blind. Lastly, we hear from Matthew Pollitt (p. 9) who had to rebuild his life - and his body - after being hit by a bus which left him needing a permanent stoma.

Tim Cree offers a heartwarming story of how 'the Purps' (Colostomy UK's Rugby League team) has played a pivotal role in helping him regain confidence as he became part of this vibrant stoma community (p.16). Long-term Colostomy UK volunteer, Moira Hammond, extolls the benefits of providing hospital ward visits to fellow ostomates (p. 28). Such visits offer both reassurance and practical advice to patients newly acquainted with their stomas.

We offer plenty of practical guidance ourselves in this issue. Ostomate David Moffat summarises his allergy to certain stoma bag glues and offers tips to others in a similar position (p.7). David Christian, Chair of East Kent Support Groups collective, talks us through the Ostomist Agenda – a manifesto for the five groups which helps guide commercial and clinical priorities in the area (p.42).

Tidings contributor, Leslie Mello, delves into the fascinating world of the microbiome, exploring the ways in which having stoma surgery may affect this delicate ecosystem and increase the likelihood of urinary tract infections (p. 38). Much more research is needed in this critical subject area, however.

Keeping on the topic of research, Ben Saunders of Keele University provides us with his biannual round up of stoma-related studies aimed at improving stoma care (p. 36). Ben covers a wide range of themes, including a review of new "digital ostomy leakage notification system", Heylo.

Scientists and research buffs are not the only ones to have developed such cutting-edge technology, however. A friend of Tidings' reader Bob Shephard created a homemade gadget, 'Stomalert', which notifies Bob when his bag needs changing at night. We salute Bob's can-do attitude in an article which also looks at other incredible technological advances in stoma management (p. 26).

If all of this inspires you to get involved in stoma research yourself, head to page 12, where we talk through Colostomy UK's exciting new partnership with University College London (UCL). This study explores the benefits of taking a 12-hour walk, at a leisurely pace, unplugged from phones and other devices. The researchers are currently looking to recruit ostomates to take part. With the promise of summer ahead – who wouldn't want to spend this amount of time in the great outdoors?

Ross Othen-Reeves
Editor, Writer
and Researcher

You can help Colostomy UK and benefit too!

Just two easy ways to support us are through our lottery, and by recycling unwanted clothing and household items.

Win up to

£25,000!

unity Colostomy UK

‘A lottery entry costs just £1 and at least 50p comes directly to Colostomy UK. Go to unitylottery.co.uk/causes/colostomy-uk to play or see www.ColostomyUK.org/GetInvolved for more information.

Bring the charity shop to your doorstep!

iCollectClothes operates a charity collection service in major UK cities to pick up your donations of clothes and small domestic items, free of charge, on a date convenient to you. Book it online, leave it outside:

www.icollectclothes.co.uk

iCollectClothes Colostomy UK

For any queries please contact us: getinvolved@colostomyuk.org or call 0118 939 1537

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
24 hours a day and completely free.

Adminline for:

Information packs, ID cards, RADAR keys, travel certificates and literature.
0118 939 1537
If we’re not in, just leave a message.
Hello@ColostomyUK.org

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

Editorial Enquiries

Letters, articles or other submissions
Colostomy UK, 100 Berkshire Place,
Winnersh, Wokingham, Berkshire,
RG41 5RD
Editor@ColostomyUK.org

Advertising enquiries

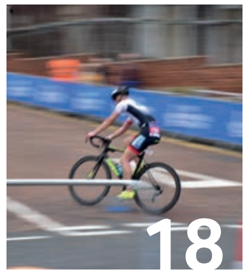
For a media pack and advertising rates:
0118 939 1537
Giovanni Cinque
GetInvolved@ColostomyUK.org

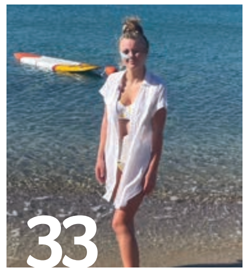
Social media:

Find us on Facebook

Join our private support group today simply put ‘Colostomy UK Support Group’ into your Facebook search bar, click on ‘Group’ and click on ‘Ask to join’ you will be assured of a warm welcome!

Contents





Colostomy UK

Real Lives

Wellbeing

Support

Donating to Colostomy UK

An annual donation of £25 (or what you can afford) allows us to produce Tidings and to continue our vital work, supporting, and empowering ostomates – see page 21 for our donation form.
You can also donate via our website **www.ColostomyUK.org/donate** or by calling us on **0118 939 1537**

Ask Jo!

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

> **A lot of people complain of back ache after surgery. What exercises can you do to strengthen your back to help with this?**

After surgery, moving freely can be difficult, affecting how you breathe, sit, walk, and stand, making it harder to maintain good posture. Spending too much time sitting or lying can add to muscular tension, so gentle movement at regular intervals can help keep you mobile, improve circulation, and support your recovery.

Poor posture also affects how we breathe; slouching contributes to shallow breathing by compressing the lungs and diaphragm, limiting airflow and reducing oxygen intake. This can also create tension in the neck and shoulders, weaken core stability, and make breathing less efficient and feel harder.

Practicing deeper breathing exercises improves oxygen flow, reduces tension, and enhances relaxation and core stability.

Ribcage or lateral breathing focuses on expanding the ribs outward instead of inflating the belly. As you inhale, your ribs gently widen, allowing your lungs to fill with air. When you exhale, the ribs move inward and downward as the diaphragm relaxes, letting the air flow out naturally. Keeping a light core engagement helps support stability and prevents unnecessary abdominal strain or pressure.

You can practice this slow, controlled breathing while sitting upright in a chair to support good posture or lying on your back with your knees bent and feet flat on the floor. In Pilates, this type of breathing is often used with core exercises to improve breath control and stability. Getting familiar with it first can make movement feel smoother and more effective.

How to check your ribcage breathing:

Cross your arms gently and rest your palms on your lower ribs, keeping your shoulders relaxed. As you breathe in through your nose, notice how your ribs expand outward. When you breathe out through your mouth, feel them gently move back toward the center.

Once you are comfortable with this breathing technique, you can practice it with your arms resting by your sides or your hands gently placed on your lap.

Aim to practice 5 to 10 breaths per session, focusing on slow, controlled inhalations and exhalations. Quality matters more than quantity, so prioritise deep, effective breaths over a specific number and build up gradually.

> **I struggle with osteoarthritis in most of my joints, as well as a knee replacement with side effects. I also have an ileostomy which leaks, extensive hernia repair and lots of mesh inside. Any recommendations for gentle exercise, and to lose weight please?**

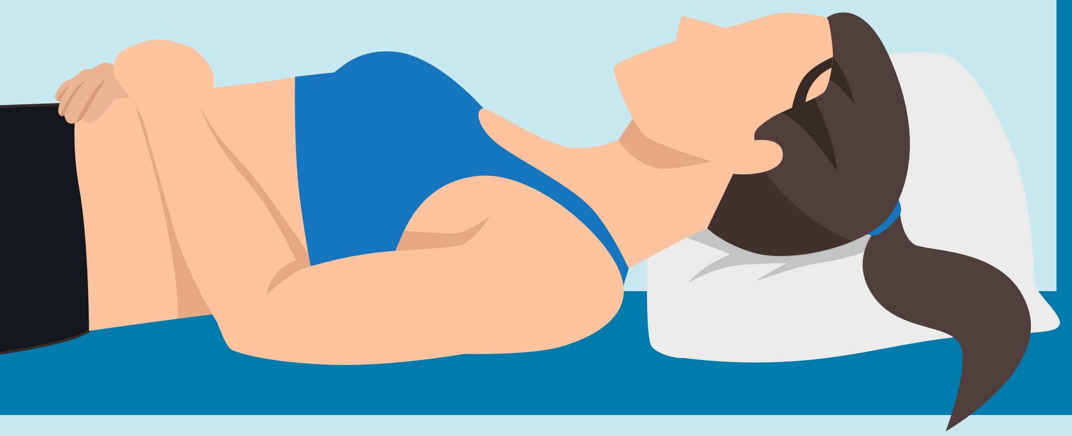
Seated chair workouts and chair yoga provide low-impact exercises that promote mobility, co-ordination and gentle movement. Many of these chair-based classes incorporate resistance training to help build and maintain strength, often using resistance bands or light dumbbells. Dumbbells can be easier to hold than bands for individuals with grip challenges.

Where possible, incorporate some standing exercises to help maintain balance and coordination. Also consider adding in some short walks.

Explore Colostomy UK's online classes, including chair-based yoga

For digital Tidings subscribers, simply click on this link for Active Ostomates

If searching online, type 'Colostomy UK Active Ostomates' into your web browser



David Moffat

Managing Sensitive Peristomal Skin and Allergies to Adhesives

Colostomy UK volunteer, David Moffat is allergic to most stoma bag products. Here he shares his personal experiences and his top-tips for what to do if you are reacting to your stoma care products.

Like most ostomates, David Moffat started off using the stoma bags that he was given at the hospital following his stoma surgery. 'These were fine… initially', he tells me. But after a couple of months, the area around his stoma began to get inflamed and itchy.

David contacted his stoma nurse who identified a lotion to reduce the inflammation, before embarking on a process of trial and error to find a product that wouldn't react with his skin.

> **The issue in question is often the type of glue used in skin baseplates (also known as 'wafers') which adhere to the sensitive peristomal area, as different stoma bag manufacturers use different ingredients and formulas in their adhesives.**

Hence the best way for ostomates to find the best products for sensitive skin is to sample different brands to find what works best for them. This initial process can take some patience, as it may take a few weeks for the skin to decide if it does or does not respond well to the latest adhesive base tested, meaning the process may need to be started over with a new product.

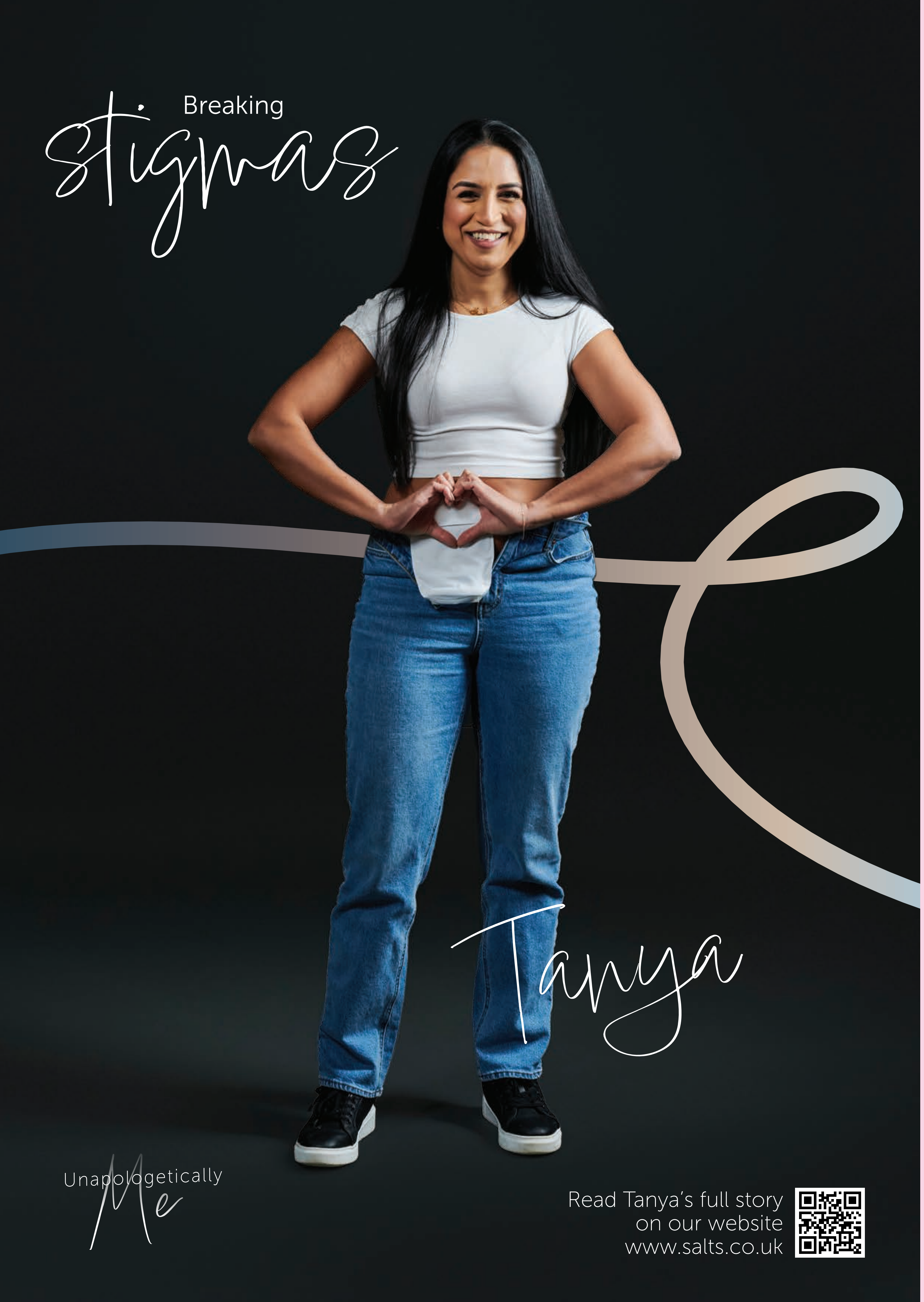
With so many products now available, however, it should only be a matter of time before you find one to suit your skin. As was the case with David, who settled on an older, drainable, one-piece bag. There may be newer designs on the market, but for David the fact that his bag works perfectly with his skin is the most important factor.

One thing David has noted from his time on Colostomy UK's helpline is that there is something of a 'postcode lottery' when it comes to accessing stoma care supplies across the UK. In some areas, people receive excellent support, while in others, ostomates feel their supplies are almost subject to rationing.

David's top tips for managing sensitive peristomal skin

If your skin becomes red, moist and/or itchy, and your bag no longer holds to your skin properly, you may have become allergic to the glue used to stick your bag to your skin. If this is the case, please consider the following:

- Speak to your stoma nurse straight away. They will be able to advise you if you are allergic and give you something to help settle your skin.
- While your skin is settling down, use flange extender strips or tape to make a bigger area for your bag to stick to.
- Contact various stoma product suppliers and ask for some samples of alternative bags.
- Cut off small sections of the baseplate being tested and stick it on a different part of your stomach. Then you can see if it irritates your skin, without risking worsening the skin around the stoma.
- Once your skin has settled down try different bags to see if you can find one that doesn't irritate your skin.
- Keep in touch with your stoma nurse to monitor your skin condition as you may have to try multiple bags before you find one that works.
- If things don't settle down, ask for a referral to see a dermatologist.



The Long Road to Recovery: Embracing Life with a Stoma After Emergency Surgery

BY MATTHEW POLLITT

'You might get hit by a bus tomorrow' - so the saying goes. It's a turn of phrase which reminds us that life is unpredictable, so it's best lived to the full. Of course, the chances of actually being hit by a bus are miniscule. Yet this is exactly what happened to Matthew Pollitt. Here, Matthew talks about his recovery and coming to terms with his unexpected stoma for life.

I have a colostomy as a result of an incident in 2012 when a double decker London bus mounted the pavement, running me over and narrowly missing my wife, Emma, before accelerating into a building with me still underneath.

The driver had lost control of the bus and then pressed the accelerator instead of the brake. The Air Ambulance attended, and I was taken to the Major Trauma Centre at St Mary's Hospital in Paddington. I had a complex pelvic fracture(s) and these resulted in the need for emergency surgery and formation of a colostomy but this was a relatively minor concern for the medical teams in comparison to head and chest injuries and internal bleeding. I had also lost most of one buttock, requiring extensive skin grafts. I was in and out of surgery on a regular basis in those first few weeks and also suffered episodes of kidney, liver and heart failure. I was unconscious for the first eight weeks, and the medical staff prepared Emma for the possibility that I might never regain consciousness, or if I did, that I might never speak or walk again. However, after eight months in hospital, including four months of neurological rehabilitation at the Wellington Hospital, paid for by the bus company's insurer, I was well enough to live at home again.

During my eight months as an impatient, my colostomy bag was changed by the nursing staff. Even at The Wellington, where I had a highly personalised and practical rehabilitation programme, I don't remember being encouraged to participate in managing my stoma. Perhaps this was because it was only supposed to be temporary, and I probably tried to avoid it for as long as possible. When I moved back home, Emma took over from the nurses at first, and I only gradually took responsibility myself. To be fair, it was challenging because my injuries severely affected my left hand, and I also struggled to recognise things happening in my left field of vision (my stoma is on the left). Because of this, I learned to change my bag lying down, and I still find it much easier this way, if it is an option.

Whilst I continued to make steady progress in most areas of my recovery and eventually even returned to work, my first few years with a colostomy were far from plain sailing. Shortly after being discharged from The Wellington, I underwent investigations for the possibility of reversing my stoma at Northwick Park Hospital. A test with a porridge enema (not the most dignified experience) decisively proved that my own sphincter muscles weren't up to the job, and we then had some discussions about artificial sphincters.

> **By this time, I was getting more used to having a stoma, and the alternatives didn't sound any better to me; in the end it felt like a relief to rule these out and accept that I would have a bag for life.**

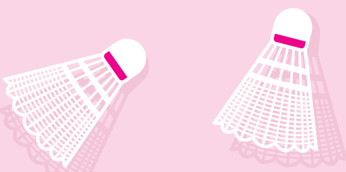
At this point I still had a temporary colostomy with the active gut and the rectal stump both attached to the stoma, and I was getting quite a lot of faecal leakage through the rectal stump. When my stoma was made permanent, removing the connection to the rectum, this stopped immediately. Unfortunately, within a matter of months a similar amount of mucus was coming out instead. Over time, this gradually included more and more blood, which eventually led to a diagnosis of diversion proctitis. A few months later I also noticed blood in my stoma output, which then increased rapidly and was ultimately diagnosed as a separate condition of ulcerative colitis.

> **With the combination of these two I was rather ill again, and whilst the ulcerative colitis responded to oral medication, the eventual treatment for the diversion proctitis was to remove my rectum completely. This was done at University College London Hospital in 2019 and made a huge difference to my quality of life. No more uncomfortable leakage, no more incontinence pants, no need for frequent visits to the loo.**

For reasons I now struggle to understand, I didn't receive any advice about the risk of hernias or the value of support garments during my eight months in hospital and rehabilitation. By the time I left I had a fairly large parastomal hernia. The first repair was carried out at the same time that my colostomy was made permanent. However, the mesh got infected, leading to fistulas around the stoma area, which were challenging for a while, but did eventually heal. Two laparoscopic hernia repairs since then also haven't lasted, but my current hernia is not huge and isn't causing any significant problems at the moment, so I am leaving it alone for now. Because my stoma was initially sited as a temporary measure in an emergency, it is not in the best position and there isn't a lot of muscle around it, so it may always be vulnerable to herniation.

I went through a lot of trial and error to find support garments that fit my body shape, provide the right level of support, and avoid heavy stitching that could damage my skin grafts. I think I've tried every make of stoma and parastomal hernia support garment available in the UK, and whilst I certainly don't conform to any standard size, it seems strange that most manufacturers offer such a limited choice of sizes. Disappointingly, the manufacturer of my favourite support pants changed their materials a few years ago without mentioning it, meaning they no longer work as well, and so I am on the lookout again.

Prior to the accident, I was a keen badminton player, and I was gutted when one of my surgeons suggested that, in order to avoid a re-occurrence of the parastomal hernia, it might be best if I never played again. Fortunately, there was plenty of other advice out there, not least on the Colostomy UK website, that promotes the benefits of exercise for ostomates, and my current surgeon argues that being fit and healthy is the best preparation for any future hernia surgery I might need. After the accident I did take up some more gentle forms of exercise, both Tai Chi and Pilates, but I am also playing badminton again, wearing a good quality support belt designed for ostomates as well as my regular support pants.



Finding the right colostomy bags and accessories has been another area of trial and error for me. I have had problems with leakage, pancaking, and ballooning at various times, and they really affected my confidence. The bags that work best for me have varied over time, perhaps related to changes in my body shape, diet, or digestive system. I didn't find the community stoma nurses associated with individual manufacturers to be particularly helpful with this, so I contacted manufacturers directly for samples. It is remarkable how one design of wafer sticks reliably (for me) day after day, whereas another might regularly fail after a few hours. Or how one manufacturer's filters don't seem to let air out at all, while those of another manufacturer work like a dream, with absolutely no ballooning or smell. I won't name names as I imagine everyone's needs and experiences vary, but I can recommend experimenting with something different if you are having problems with your current bags.

With the right support underwear and bags, I can't think of anything that having a stoma prevents me from doing. However, alongside the medical and practical challenges, I've also had some psychological hurdles to get over. Ending up with a permanent stoma was far from the worst possible outcome of 2012 following my accident, but in some ways, it has been one of the most challenging things to adjust to. For a start, I was brought up believing that it is not polite to talk about poo, and even now I wince slightly as I write that word. Initially, I had quite strong feelings around loss of control, and shame about having a colostomy.

> **This is another way in which Colostomy UK, and Tidings in particular, have been and still are valuable to me. Beyond being a source of practical tips and advice, the stories from other ostomates remind me that there are many other people living with the same difference as me, and doing so with great dignity or humour, or both.**

Reflecting on the last twelve years, I did find it hard to adjust initially, but when things are going well, having a colostomy has very little negative impact on my life at all. And indeed, in common with many other people who may be reading this, I like to remember that my stoma actually helped to save my life.

The 12 Hour Journey:

Discovering the benefits of relaxed, unplugged solo walking

Colostomy UK has teamed up with PhD candidates at University College London (UCL) to explore the mental health benefits of completing the 12 hour 'unplugged' walk, and we'd love for you to be part of this exciting study. Read on for all the details.

What is the 12-hour walk?

The 12-hour walk was originally created by US explorer Colin O'Brady. Having climbed the world's highest mountains and walked solo across Antarctica, O'Brady found himself struggling mentally during the Covid-19 pandemic and the social restrictions which came with it.

One day, O'Brady took himself for a 12-hour walk and came back feeling emotionally rejuvenated. Likening the mental clarity as being similar to what he'd experienced when walking across Antartica alone.

He has since cultivated an online community of other people who have now also walked for 12-hours. Numerous participant testimonials highlight the positive mental health benefits from the embarking on the walk.

The walk involves spending 12 hours outdoors, alone, and unplugged from devices such as phones, creating space for personal reflection and growth.

The purpose of the exercise is not focused on a physical challenge, and fundraising is not necessary.

Participants are welcome to take breaks as often as needed. The goal is not to walk as far as possible; walking is simply a means to spend reflective time alone.

So what does all this have to do with Colostomy UK and UCL?

UCL PhD candidates, Matthew Maclure and Louisa Robinson, are researching the psychological benefits of the 12-hour walk on people living with a stoma. They reached out to Colostomy UK, asking us to provide advice where needed, and to help promote the study to ostomates who might wish to take part.

Why is the research focused on people living a stoma?

For many ostomates, having a stoma formed is a hugely positive experience. For some, it might relieve chronic pain. Others value the renewed independence they experience after gaining back control over their bodies. See Harvey's story on page 18 as a prime example!

Yet some people experience significant challenges as they adjust to life with a stoma, such as increased anxiety, depression, and low self-esteem. Living with a stoma can also lead to self-stigma, leading to lower confidence and making it harder to join in social or physical activities.

What is the basis of the research?

There is a strong evidence-base that shows the positive impact that quiet reflective time as well as light exercise, such as walking, can have on people's mental health and wellbeing. Given this, Matt and Louisa want to find out whether the 12-hour walk will help alleviate some of the negative thoughts and emotions experienced by some ostomates.

That's not to say you have to experience negative thoughts to take part – all ostomates are welcome! No matter where you'd put yourself on a happiness scale, the findings will be useful from a research perspective.

How it works

The research team will ask participants to complete a survey before and after embarking on the study. This will enable them to measure whether people saw improvements in their mental wellbeing due to the walk.

But not only this; Participants will also be randomly assigned into one of two groups:

1. The walking group

- Participants will receive a detailed walking guide. Participants can walk as much or as little as they want during the 12-hour period. The key is to spend time 'unplugged' from devices such as smartphones while taking quality time for yourself

2. The non-walking group (AKA the 'control group')

- This group will continue with their day as normal, without taking part in the walk.
- The group therefore helps the researchers to be certain of whether participants who are taking part in the walk saw psychological benefits from the activity itself, or whether it might be due to another factor (such as a warm sunny day, which is likely to improve everyone's outlook – including those in the control group!)

What will the researchers be measuring?

Participants will complete six different surveys before the study begins, as well as the day after the walk, and again one month later. These surveys assess things like:

- Self-stigma
- Confidence in managing life with a stoma
- General well-being and mental health
- Awareness and mindfulness
- Psychological flexibility (i.e. a person's ability to adapt to challenges)

The walking group will also be encouraged to reflect and record their thoughts during the walk with a pen and notebook

For more information, including details of how to register your interest in the 12-hour walk, please scan the QR code below

Alternatively, you can email the research team, via:

- Louisa at: louisa.robinson.20@ucl.ac.uk
- Matt at: matthew.maclure.23@ucl.ac.uk

You can also learn more about the 12-hour walk by Colin O'Brady via the following links:

- YouTube video: 12-Hour Walk
- Website: 12hourwalk.com

As if by **magic**....

Make your donations worth

25% more

at no extra cost to you!

If you're a UK tax payer, tick the Gift Aid box on the donation form on page 21 and we'll be able to claim an extra 25% from HMRC at no cost to you!

Gift aiding your donation helps us do even more for anyone impacted by stoma surgery.
From producing this magazine, to making sure our stoma helpline and befriending services continue, campaigning for stoma friendly toilets, and getting you more active.

☑ giftaid

For more information visit https://www.colostomyuk.org/get-involved/fundraising/gift-aid
or email getinvolved@ColostomyUk.org

TRE™ barriers absorb moisture up to **4x faster** than other barriers, helping prevent leakage.[1]

Jillian, Dansac TRE™ Champion

Feel Comfortable. Feel Confident. Stay Protected.

TRE™ Skin barriers are designed to stop leakage before it happens:

- Only barrier to contain patented super absorbers with Dry lock technology, that is designed to absorb stoma output and lock it away from the skin[1,2]
- The barrier is designed to swell and expand around the stoma, forming a unique seal that helps prevent leakage
- Designed to move with the body, providing a flexible and secure fit, even on uneven skin surfaces

Curious to experience the difference?
Request your sample today and see the benefits for yourself.
visit www.dansac.co.uk

1. Dansac data on file, LN-06901, 11/24. ref-04051, 2024, Laboratory In Vitro Study using water *In comparison to Coloplast Sensura Mio™ barrier, Salts Confidence Be™ barrier, Convatec Esteem™ barrier and Dansac Nova™ barrier. 2. Dansac data on file, LN-06224, 07/22.

Prior to use, be sure to read the Instructions for Use for information regarding Intended Use, Contraindications, Warnings, Precautions, and Instructions. Not all products are CE marked.

Dansac, the Dansac logo, Nova and TRE are trademarks of Dansac A/S.
All other trademarks are the property of their respective owners. © 2025 Dansac A/S

dansac

Rugby League Special

Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

Tim Cree has been a key member of our Rugby League team since he joined in 2022. This is his story.

My journey started in 2020, showing my daughter how to use a skateboard. Ten seconds later, I'd broken my leg and required 3.5 hours of surgery. I still believe this saved my life.

Six months on, my recovery was going well, so I went for a walk, still needing a crutch for support. Back home, I passed some blood clots in my urine. This had happened before but had always been attributed to something else, for example bladder irritation from running. But since I broke my leg, I hadn't been running. So, there had to be another reason.

I contacted the doctor and a month later I had nine tumours removed from my bladder, and as strange as it sounds; I was lucky!

15:52

Team Colostomy UK
@TeamColostomyUK

PDRL and Wheelchair Rugby League from @ColostomyUK. 🏉 #TacklingTheStomaStigma to help create a more #StomaAware UK. #UpThePurps 💜

Sports, Fitness & Recreation · Wokingham, England
colostomyuk.org/active-ostomat... · Joined March 2018

760 Following 2.1K Followers

Pinned
Team Colostomy UK @Tea... · 25/03/2025
PAINT THE TOWN PURPLE! 💥

Introducing our new @KappaTeamwearUK training range.
Available to buy online now
🛒 colostomyuk.bigcartel.com/category/rugby...
Big thanks to our partners for your support 🙌
@medicareplusuk @CUIWearUK @DrEKirkeOstm

#UpThePurps 💜

@TeamColostomyUK

The biopsies showed it was aggressive. So, then I had to choose between having my bladder removed and needing an urostomy, or other treatments. There was little information on the long-term effectiveness of these treatments due to the average age of being diagnosed with bladder cancer being seventy-five (about thirty years older than I was).

It was an easy decision for me. I decided to have a stoma. Even though at times it has been difficult, I would make the same choice again. I have two daughters, who were 12 and 16 at the time, I wanted to have as much time as possible with them. See them grow up, get married, all the usual stuff. They named my stoma. He's called Homer.

Lying in a hospital bed during Covid, with no visitors allowed, in a side room, feeling lonely and very unsure about the future. It felt like all the information appeared to be directed for somebody much older than me. I was 42. Even the stoma nurses, who were amazing, couldn't really give me the answers I was looking for.

I stumbled across a post on Twitter/X, with five people showing their stoma bags and wearing sports kit. This was Team Colostomy UK. Rugby League!? With a stoma? Surely not! Sport had always been a big part of my life. I didn't think what they were doing was possible. So, I replied to the post.

Somebody called Ian Daniels replied and that started my journey with Team Colostomy UK. I now know Ian Daniel's is the president of Colostomy UK, and now even sponsors me and my youngest daughter as players for the team.

Whilst I was happy with the choice I made and pleased with my recovery, I was not prepared for the psychological impact and how I felt about my body. As my wife is a nurse, I knew logically that my having a stoma wouldn't scare her away. But I worried about silly things, like would it burst if we hugged? Can other people smell it? My wife was always reassuring me, but to get my confidence back I felt I needed people who had been through the same thing.

I still remember that first game, and how scared I was (although I wouldn't admit it). I had periods of hiding my bag and not wanting people to see it, but this was different. It was a changing room of men, most of whom had stomas, or who'd previously had one, and nobody cared.

It was just 'normal'. It changed my life. On the pitch, I remember seeing other players with stomas being tackled to the ground and getting up and carrying on. I was still very nervous waiting for my first tackle, then it happened, and nothing bad happened. I just got up and carried on playing. All the nervousness gone. The fear that I had to be very careful doing anything, gone.

While some people struggle to come to terms with their stoma, for others it significantly improves their quality of life. People may not have been playing sport due to underlying conditions that led to having a stoma. So the team has given them the opportunity, support and confidence to play again, or even play for the first time.

The team has grown. My involvement has grown, and it is an integral part of who I am. It's the foundation of my recovery. We play rugby league to raise awareness of what's possible, literally tackling stoma stigma. There still isn't much information available for my age or younger on what you can do, especially for urostomies.

Through the team I've helped a number of people, mostly younger than me, who were scared about having a urostomy. I always signpost them to Colostomy UK because despite the name, they support all types of stomas.

The players are now some of my best friends. Some are much more experienced with their stomas then me and no question within the group is off limits.

We've played all over the UK. We've even played two national teams who were amazed that we had stomas. This was competitive rugby! The recognition of what was possible with a stoma from those games was huge. These matches provided opportunities for discussion and support. Raising awareness of what's possible is important to us.

Being part of Team Colostomy UK is such a positive part of my life. Never in a million years would I have thought I would stand on stage at an NEC event giving a talk; Go to the Houses of Parliament to talk about Team Colostomy UK; Be interviewed on BBC breakfast; Or work with a major high street brand on the development of stoma friendly clothing. None of this would have happened to me without Homer!

The Team continues to expand. We started playing Wheelchair Rugby League last year, which has enabled us to play more teams, and reach a wider group of people. We now have our own chairs thanks to Sport England.

We recently travelled to Scotland for our first matches north of the border. Wheelchair Rugby League is inclusive, you don't have to be a wheelchair user. You can be any age or gender. I am now the coach of the team, and I've watched us go from strength to strength and being welcomed into the sport by every team we have played.

To most people, I am totally at ease with my stoma and for most part I am, thanks to Team Colostomy UK. I'm proud to have a stoma and I know I made the right choice for me.

You can find out more about Team Colostomy UK and get involved by visiting https://www.colostomyuk.org/active-ostomates/team-colostomy-rugby-league/ Or search for 'Team Colostomy UK Rugby' in your webbrowser

Sports Therapy: How Endurance Competitions Helped One Man Bounce Back to Health

Chronic pain is of course debilitating for anyone who has the misfortune to experience it. Yet for fitness-loving Harvey Gladwell, ulcerative colitis not only prevented him from playing sports, but also led to body dysmorphia, due to both the condition and the medication reshaping his physique. That was until his stoma surgery - and exercise - helped turn his life around.

When sports-mad Harvey Gladwell pushed to have an ileostomy formed at the tender age of 17, surgeons were reluctant to agree to the surgery. They were concerned about what the long-term impact on his life might be. How would this young man navigate socialising, dating, and the world of work all while living with a stoma? Fast forward to today, and 21-year-old Harvey still regards his stoma surgery as the best decision of his young life.

He beams with amusement at the idea that life without his stoma could ever be considered preferable.

> **'I have freedom now. I have a glorified Portaloo with me 24/7. I can't really ask for anything better. The stoma has given me the ability to travel, which is the most amazing thing. I'm not tied to a toilet 24 hours a day anymore'**

This statement is hardly an exaggeration. Between the ages of 14-17, Harvey would have to race to the toilet up to twenty times a day, including throughout the night. He was frequently passing blood and lived in almost constant pain and discomfort.

> **'I'm just so thankful that I don't have to live like that anymore' Harvey chuckled while reliving these memories. 'It's such a bonus.'**

It wasn't just holidays that Harvey was missing out on. Due to constant flare-ups, he had to pull out of playing team sports such as rugby, as he felt he was letting his squad down too often. Instead, he turned his attention to solo sports, most notably triathlons, which is an endurance race involving swimming, cycling and running. But again, his training and races were frequently interrupted by his condition, which required hospitalisation up to four or five times a year.

Harvey's way of coping was often to try and pretend the flare-ups weren't happening.

> **'I'd always have this sense of denial, because I wouldn't want to be in a flare-up. Trying to lie to myself that things will be better if I just didn't believe that it was happening'**

But time and again, it did happen, leaving Harvey with 'unexplainable anger' as he put it (though most reading this will likely consider this response completely natural).

> **'It was ruining my life' Harvey explained. 'I'd have yet another flare-up and just ask myself "Why me? Why is this happening to me again?"'**

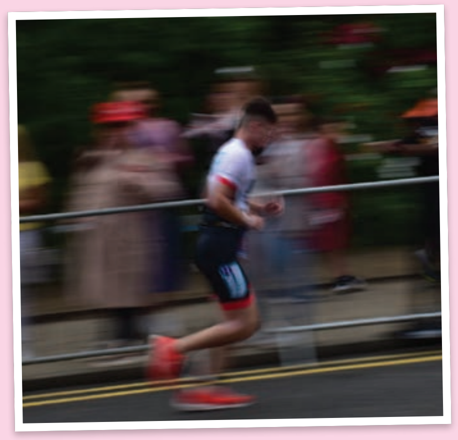
Harvey's rage may have been compounded by the steroids he was on to control his ulcerative colitis, as these are known to cause mood swings (at the age of 15, he took steroids for 49 of the 52 weeks of the year). But anger was only one side-effect of the medication.

Harvey also experienced a puffy face, random 'fatty' lumps of water retention all over his body, oily skin, and thinning hair. He also lived with an insatiable hunger despite the fact that he was underweight due to constantly emptying his bowels and his inability to absorb nutrients.

Adolescence is a difficult time for all young people. A time when completely natural, normal changes within the body can lead to feelings of inadequacy. It's hard to imagine quite the level of mental strain Harvey must have experienced at this time. Even though his weight has now returned to a healthy level, his perception of himself remains at odds with this version of himself, as he explained:

> **'I'd look in the mirror and feel horrible. And from that age I felt I'd got some kind of body dysmorphia. Weight has now become a bit of a sore point. Even though my weight has completely stabilised, I always feel like I'm underweight'.**

Eventually, Harvey and his family convinced medical professionals that an ileostomy was the only plausible option left to him. Unfortunately, Harvey experienced complications including sepsis following his initial surgery. A second operation was therefore needed, but due to his intestines being so inflamed, he lost a lot of blood which required recovery in Intensive Care. Shortly after, Harvey's bowel perforated in his rectum leading to sepsis for a second time. Just when it seemed things couldn't get any worse, Harvey had to also endure pneumonia, kidney stones, acute liver failure, and even MRSA.



And yet in spite of it all, Harvey still firmly regarded his stoma surgery as a new dawn, telling his mum from his hospital bed: 'I'm going to do an Iron Man this year'. As Harvey explained to me, an Iron Man competition is a 2.4 mile swim, 112 mile bike ride, followed by a full marathon at the end 'so just a little bit of exercise' he wryly noted.

Just a few months later, around his 18th birthday, Harvey completed a half Iron Man, and a year later, he had indeed completed a full Iron Man in 15 hours. An exceptional achievement for someone who was chained to the toilet just 18 months before.

Iron Man competitions may not be for everyone (I include myself in that), but for Harvey, sport has become a form of therapy in itself.

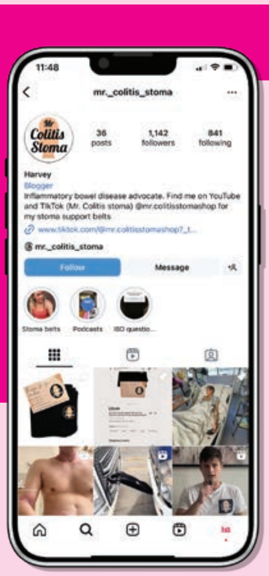
> **'Sport has always given me the mental stability to decompress in some way. The release of endorphins and the like. And swimming is really good exercise. Being in your own world, and completely blocking the whole world out, just helps me'.**

Given his love of health and fitness, it's perhaps no surprise that Harvey has developed a new stoma support belt to reduce the risk of hernias when exercising. His main goals have been to create a belt that is affordable, adjustable, and comfortable throughout periods of intense activity. He is now hoping to work with stoma nurses to refine his product. Quite the accomplishment for a 21-year-old who has spent so much of his youth in chronic pain.

Harvey's passion for helping people extends beyond the creation of his stoma belt, however. Now at university, he is studying to become a paramedic. His aim is 'to give back as much as possible', he tells me.

It's a career choice which makes complete sense, given all he's been through of course. And with such an innate appreciation for physical wellbeing, it's no doubt another mountain Harvey will soon conquer.

To find out more about the development of Harvey's belt, you can find him on social media as: Mr. Colitis Stoma



11:48

mr._colitis_stoma

36 posts | 1,142 followers | 841 following

Harvey

Blogger

Inflammatory bowel disease advocate. Find me on YouTube and TikTok (Mr. Colitis stoma) @mr.colitisstomashop for my stoma support belts

www.tiktok.com/@mr.colitisstomashop?_t...

mr._colitis_stoma

Give a little, change a lot

Colostomy UK

Every year more than 40,000 people living with stomas turn to us for help.

Access to support from people who know the challenges first-hand can have a **transformational impact** on someone's ability to participate fully in life.

Give a little and change a lot for them: A regular gift of **£2 a month** will help us ensure we are there for everyone who needs us, when they need us – for any problem, any time.

> **"The helpline is staffed by volunteers, all with lived experience. This was the third time I've called each time I have ended up feeling uplifted by the kindness and practical support I've given."**

To donate now –
Visit: **colostomyuk.org/gal**
or scan this QR CODE

Complete our **donation form** opposite

Call us on **0118 939 1537** to make a donation over the phone

Thank you!

Please support Colostomy UK

Every 39 minutes someone in the UK has stoma surgery

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

SCAN HERE TO DONATE

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

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

Registered with FUNDRAISING REGULATOR

My Details (Please complete in **BLOCK CAPITALS**)

Title*: First name*: Last name*:
Address*:
Postcode*: Phone Number:
Email*:

I would like to make a one-off donation

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

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

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

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

Card number *(Maestro only)*

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

Signed Date D D M M Y Y

I would like to make a regular gift

I would like to make a regular donation of £

☐ *Monthly* ☐ *Quarterly* ☐ *Half Yearly*

☐ *Annually Commencing*

01 / / *OR* 15 / /

If you are a UK tax payer, please add gift aid to your donation at no cost to you.

giftaid it Thank you for your gift T78

Thanks to the Gift Aid scheme – we can reclaim 25p for every £1 you donate to us from HMRC if you are a UK tax payer. All you need to do is tick, sign and date this declaration if you are eligible.

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

Signed: Date: / / 2025

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

Charity name: Colostomy UK

Name and full postal address of your Bank or Building Society

DIRECT Debit

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

Bank/Building Society account number Branch Sort Code

Service User Number

6	9	1	2	1	3

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

Instruction to your Bank or Building Society

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

Signature(s) Date D D M M Y Y

Registered Charity No: 1113471

The Direct Debit Guarantee

DIRECT Debit

- This guarantee is offered by all Banks and Building Societies that accept instructions to pay Direct Debits
- If there are any changes to the amount, date or frequency of your Direct Debit, Charities Aid Foundation will notify you ten working days in advance of your account being debited or
- If an error is made in the payment of your Direct Debit, by Charities Aid Foundation or your Bank or Building Society, you are entitled to a full and immediate refund of the amount paid from your bank or building society - If you receive a refund you are not entitled to, you must pay it back when Charities Aid Foundation asks you to
- You can cancel a Direct Debit at any time b y writing to your Bank or Building Society. Written confirmation may be required. Please also send a copy of your letter to us.

This guarantee should be detached and retained by the Payer

Literature range

Have you seen our extensive range of support literature? Suitable for ostomates, family members, friends, carers, and healthcare professionals. To order your complimentary copies, please download them from our website or contact us by:

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


Active Ostomates sport and fitness after stoma surgery


Campaigns and Projects Flyer


Caring for a person with a stoma


Caring for a person with a stoma and dementia


Colonoscopy through a stoma


Fundraising Pack


Healthy Eating

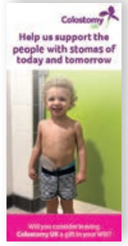

Helpline Cards


How will a stoma affect me?


Irrigation Booklet


Irrigation DVD (nurses)


Irrigation DVD (patients)

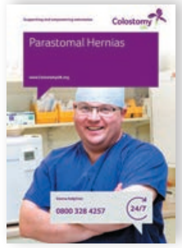

Legacy Flyer


Living with a stoma

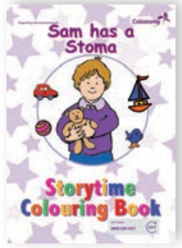

One to one


Ovarian Cancer and stomas


Pain and discomfort

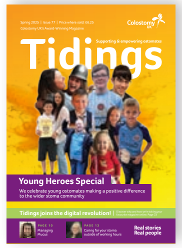

Parastomal hernias


Rectal discharge


'Sam has a stoma' colouring book


Stoma Friendly toilets campaign pack


Stoma reversal


Tidings magazine


Travel advice


Travel certificate


Grandma's new bottom


Welcome pack

You Can Fly!

Navigating Air Travel with a Stoma and any other disability

IFRAH MOHAMED AND LIBBY HERBERT

Summer lies ahead, and with it the promise of foreign holidays. Yet for some, air travel with a stoma can feel daunting. But we have you covered. Here, Colostomy UK's CEO, Libby Herbert worked with ostomate Ifrah Mohamed to develop top tips for taking to the skies with a stoma

> **Flying is important to me because it's a chance to escape reality… be who you want to be, where you want to be.**
>
> Ifrah

Ifrah has been living with a stoma and a medical implant since the age of 20. At first, even simple outings felt overwhelming — let alone flying. But by connecting with others in the stoma community and leaning on resources from Colostomy UK, she rediscovered the freedom of travel.

Now, Ifrah shares her experiences to help others do the same—with confidence, dignity, and preparation. She has joined me at many an event with aviation organisations and starred in an awareness video (you can find this on our website under Information)

Planning is Key

Ifrah's golden rule - plan early. That starts with contacting your airline when booking your flight. Let them know about your condition and any adjustments you might need — such as proximity to a toilet, and additional baggage or assistance.

Most airlines are accommodating when you inform them in advance. As Ifrah recalls:

"The response was so reassuring. There weren't any extra questions. They just said: 'Of course, that's fine!"

Planning Support for Air Travel: What You Need to Know

Airports and airlines are committed to helping you travel with dignity, ease, and confidence. If you live with a visible or non-visible disability, or have a medical condition that affects your mobility, stamina, or confidence, you're entitled to ask for support at every stage of your journey.

You may wish to consider booking assistance if you:

» Are travelling with mobility aids, medical equipment, or an assistance dog

» Would find boarding easier with support

» Experience fatigue, pain, or difficulty standing or walking for long periods

» May feel anxious or overwhelmed navigating through a busy airport

» Need extra help checking in, moving through security, or collecting luggage

If your condition varies day to day, or you're unsure how you'll feel when travelling, we encourage you to book support based on your worst day, not your best. That way, you'll be better prepared—especially if there are delays, long queues, or unexpected health changes.

At many UK airports, you're free to travel independently if you choose, and still access assistance if and when you need it. The goal of these airports is to help you travel on your own terms, with as little or as much help as suits you.

To make sure the right arrangements are in place, we recommend booking assistance at least **48 hours before your flight**. While last-minute requests are possible, they may involve longer wait times or limited availability.

Please note that if you're travelling with certain medical items (like electric wheelchairs, equipment, or assistance dogs), your airline will need advance notice to safely prepare for your journey. Without this, boarding may be delayed or—in some cases—denied.

If in doubt, ask. Assistance exists to make flying possible for everyone.

Know Your Airport

Visit the airport's website ahead of time:

- If you need to find the location of accessible toilets (some airports also have stoma-friendly toilets)
- If you have booked assistance - Locate the assistance desk and accessible security lanes (not all airports are able to have these)
- Check their policy on disabilities and what support is available for you

Many UK airports and airlines now recognise the **Sunflower Lanyard** as a symbol of a non-visible disability. You can request one before you travel or pick it up at the assistance desk.

Medical Documentation

We recommend you travel with:

- A **Colostomy UK travel certificate** or a **Civil Aviation Authority (CAA) Medical Device Awareness Card**
- A **copy of your prescriptions,** or have access to your **medication list via the NHS app** when travelling through airport security—especially if you're carrying:
  - **Prescription medication** (particularly controlled substances)
  - **Medical supplies** (such as stoma bags, catheters, or syringes)
  - **Assistive devices** or liquids exceeding the standard 100ml rule (this might change, but hasn't yet)

Why This is Helpful:

- **Reduces delays at security:** A clear prescription helps explain the presence of medication or devices in your hand luggage.
- **Supports your rights:** If questioned, you can show proof that items are medically necessary.
- **Backs up your Travel Certificate or Medical Device Awareness Card:** These are helpful, but a prescription adds official detail.

These documents should help smooth the security process and reduce anxiety.

"I told security I had a stoma bag and a catheter. I had my doctor's letter, and they were absolutely fine," says Ifrah.

What to Expect with New Airport Security Scanners

Airports across the UK have now introduced next-generation security scanners designed to speed up the process and improve safety for all passengers. These advanced scanners create a detailed image using safe, millimetre-wave technology — not X-rays — and help staff detect prohibited items without the need for physical contact.

For many passengers with medical devices, stoma bags, or disabilities, it's natural to feel anxious about this part of the journey.

If you're nervous about public searches or scans, you have the right to request a private search in a private room, and you can ask for a chaperone.

Here's what you need to know about new-generation scanners:

How They Work

- The scanner produces a generic, anonymous outline of a human body. It doesn't display intimate images or details and protects your privacy.
- The system highlights areas where additional checks might be needed—for example, where a medical device or stoma bag sits.

If You Have a Medical Device or Stoma

- You do not need to remove your bag or medical equipment.
- You may carry a doctor's letter or a Colostomy UK Travel Certificate, which you can discreetly hand to security staff if you'd prefer not to explain in public.
- If the scanner indicates something, you might be asked for a quick check. You can always request that this is done in private with a same-gender officer.

Your Right to Ask

- As above, you can politely request a private search at any point.
- Security teams are trained to treat passengers with dignity, but don't hesitate to speak up if you need privacy or additional time.

Helpful Tips

- Let security staff know about your stoma, implant, or device before entering the scanner, if this will give you peace of mind.
- If they want to search your hand luggage, you can request that they put on clean gloves to do this.
- Keep all medical items in your hand luggage with documentation handy.
- Arrive early to give yourself extra time to move through security without feeling rushed.

In your hand luggage, be sure to carry:

- Enough stoma management supplies and medications for the journey and emergencies (hopefully there won't be any delays, but best to be prepared)
- Prescription medication (in original packaging, with a doctor's note)
- Extra clothes and wipes, just in case
- Any documentation mentioned above

You're entitled to:

- Additional hand luggage for medical equipment
- Extra checked baggage allowance, if required for medical reasons — just notify the airline in advance

On Board Confidence

Ifrah had concerns about how her stoma bag would respond to cabin pressure:

"But actually, all bags have a filter. My fears were in my head. Nobody knew anything — I realised it wasn't an issue at all."

Ask to board early if that would make you more comfortable. Let cabin crew know if you need discreet support — they're there to help.

Final Advice

"Honestly, I would say do it. Take the plunge."

Speak with your GP or stoma care nurse well in advance to ensure you're medically ready. Reach out to Colostomy UK or other support groups for guidance.

Final thoughts from Ifrah and Libby Herbert

Flying is freedom. And with the right tools and support, **you can fly** with comfort and confidence. You're not alone — and you hopefully never have to leave your dignity at the departure gate.

And when it comes to air travel with any disability or stoma: **you absolutely can fly.**

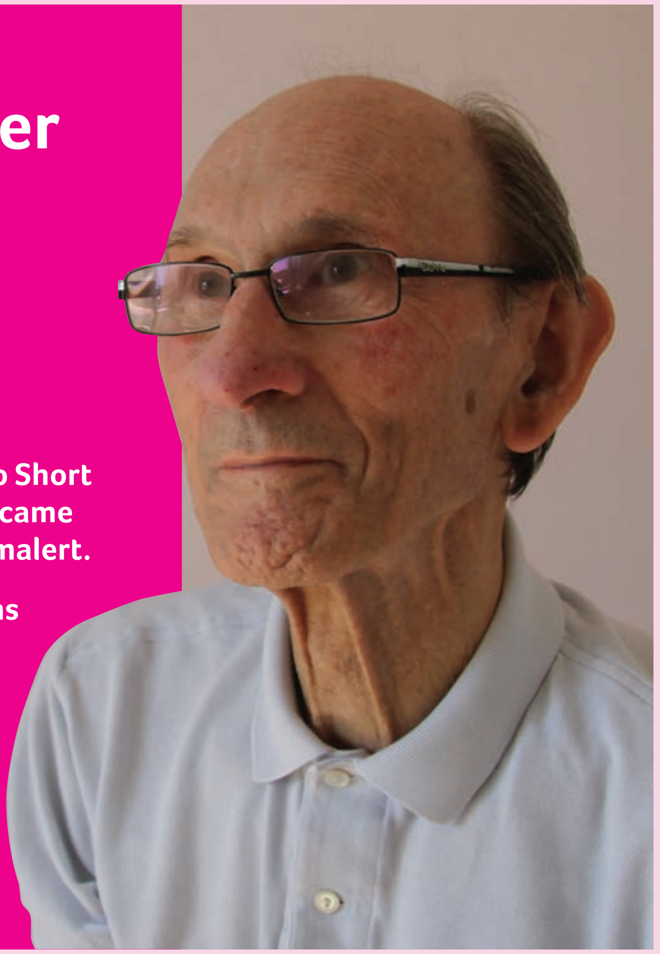
If you would like any further information or talk to one of our volunteers who has a stoma and is a regular flyer please e-mail us hello@colsotomyuk.org or call 0800 328 4257

For a copy of our travel certificate and travel advice booklet please go to our website www.colostomyuk.org/information/travel-advice Or e-mail us at hello@ colostomyuk.org and we can e-mail or send you copies.

Necessity is the Mother of Invention: Smart Technologies in the Stoma World

Having lived with constant broken sleep due to Short Bowel Syndrome (SBS), Bob Shephard's friend came to the rescue with an ingenious solution – Stomalert.

Bob's invention joins a raft of other innovations being developed within the stoma care industry itself. Here we tell Bob's story and explore what other Research and Development (R&D) is underway in the stoma world.



After years of suffering with ulcerative colitis, Bob Shephard, now 83, had his stoma formed in 2001 following the removal of his colon. Several months later, Bob's remaining small intestine twisted, requiring emergency surgery which left him with just 1.8 metres of small bowel. The operation saved Bob's life but left him with Short Bowel Syndrome.

Bob needs to eat and drink frequently to absorb what nutrients he can with the small amount of bowel he has left. Dehydration is a constant concern, and frequent bowel movements are also a part of Bob's life, including all through the night. Broken sleep due to accidents in the night were adding to Bob's challenges – until one day, a resourceful friend of his came up with an incredible innovation, which the pair named 'Stomalert'.

Stomalert is a custom-designed device which lets Bob know when his stoma bag needs emptying. The ingenious contraption involves a fine ribbon looped around the stoma bag. When the bag expands to a certain fullness, the stretched ribbon triggers a vibrating device which rests on Bob's stomach, alerting him to the fact that his bag needs changing. Bob and his friend have refined Stomalert over the past few months and believe they have near enough perfected it with the latest version (V.5), as Bob has not had a single accident while using it. That said, the pair are constantly finessing the wearability of the device and are currently testing different materials to encase the vibrating mechanism in, for additional comfort.

Bob and his friend don't have the capacity or resources to mass produce Stomalert for other ostomates unfortunately, but they are keen to share their design with any stoma care companies who might be interested in manufacturing the device for the wider stoma community (so anyone working in Research and Development do get in touch!)

Smart Technologies for Stomas

Newcastle Hospitals and Newcastle University: Reviewing Digital Leakage Notification Systems.

Bob is in good company when it comes to creative solutions for leaks. In January, a team led by Consultant Colorectal Surgeon at Newcastle Hospitals and Newcastle University, Richard Brady, published an academic paper investigating the impact of another 'digital leakage notification system'.

92 ostomates took part in the study, and 39% initially said they were worried about leakage. After using the device, the number of patients worrying about leaks dropped to 14%. Overall, 82% of participants said the device had improved their stoma care routine.

For all the latest on stoma medical studies, head over to our Research Round Up with Dr. Benjamin Saunders, on page 36

OstoForm: FLOWASSIST Seal

FLOWASSIST seal was developed by a team of engineers and designers working in association with Stanford University's BioInnovate programme. The FLOWASSIST is a non-absorbent little spout which integrates into the baseplate of a two-piece stoma bag.

The spout ensures that output falls is caught and drops into the bag a few millimetres away from the skin, reducing the risk of leaks, and therefore the sore skin that often accompanies it.

To find out more, visit: www.ostoform.com/flowassist-seal

Or simply search online for 'Ostoform Flowassist Seal'

11 Health: The Alfred SmartBag System

The late Michael Seres, who lived with Crohn's Disease, underwent a small bowel transplant in 2011. Facing similar issues as Bob, such as high risk of dehydration, Michael developed a digitally enhanced stoma bag to detect when leaks were likely to occur. The device led to the creation of his company, 11 Health - the world's first ostomy digital platform company.

Through 11 Health, Michael and his team went on to create the Alfred SmartBag, suitable for ileostomates, which has sensors which detect risk of dehydration. Additional skin sensors also monitor for inflammation, leakage, and skin barrier (aka 'wafer') detachment.

Ileostomates can find out more by clinking on the hyperlink: www.11health.com/survey/

Or search online for 'Alfred Smartbag'.

OstomyCure: Transcutaneous Implant Evacuation System (TIES®)

One of the most exciting and innovative developments for ileostomates in recent years has got to be a creation of the Transcutaneous Implant Evacuation System, better known as TIES®, by the company OstomyCure.

Created by a joint Norwegian and Swedish team, this ingenious concept does away with the need for a permanent stoma bag. Instead, the ostomate where's a permanent titanium implant (called the TIES 'Port') which is integrated into the soft tissue of the abdomen. The Port is made using 3D technology to create a unique structure that helps promote healthy tissue growth around it.

A Lid then attaches onto the outside of the Port and has a sliding hatch which can be opened and closed for emptying the stoma whenever the wearer so chooses. The system also comes with its own uniquely designed emptying pouch which can be attached to the Port whenever needed. The whole Lid can also be removed and rinsed when necessary also.

Aside from doing away with the need for a permanent bag, TIES® also prevents unwanted odours, noises and leaks, and reduces the risk of hernias and skin irritation.

It might sound futuristic (and looks it too), but TIES® has been in research for almost 18 years, with some ostomates using the technology for almost 15 years already.

To find out more, visit OstomyCure's website at: www.ostomysecure.com/ties-information

Or simply search for 'OstomyCure TIES'

The Rewarding World of Hospital Volunteering

BY MOIRA HAMMOND

Veteran Colostomy UK volunteer, Moira Hammond, shares how she found herself in the unusual position of volunteering on hospital stoma wards, providing support to new ostomates.

Retirement!! How it is looked forward to – a chance to relax, travel, enjoy time with the family, try new hobbies.

Well, that is what I thought too – until a visit to the Doctors and referral to the colorectal surgeon revealed a cancerous rectal polyp (a haemorrhoid, I thought). Okay, they will get rid of that and on we go. But No! Abdominoperineal resection (APR) surgery was required (removing the rectum and creating the so-called Barbie Butt), and a permanent colostomy formed.

What will that do to my life? Of course, I was scared, but in January 2005 I underwent successful surgery (an excellent surgeon at the Royal Stoke University Hospital), and began a slow but steady recovery and the subsequent good news that everything was clear.

So, a bit of background is necessary – I have now been happily married to Chris for more years than seems possible! We have three children, 3 grandchildren and one great grandchild. My life up to 2005 had involved part time secretarial work, acting in a drama society, swimming and travel, occasionally to New Zealand to see our eldest son. Could I do these things again? My surgeon said - Yes, of course. Mind you, acting on stage was a bit nerve-wracking, but thankfully, I never had a (stoma) accident.

> **I first met Ernie Hulme – my wonderful support always - whilst recovering on the ward. Ernie was a Trustee of the Colostomy Association (now Colostomy UK) for 24 years. He had started off as a stoma ward volunteer shortly following his own surgery. He was encouraged to speak to other stoma patients at Royal Stoke Hospital by their lead stoma nurse of the time, Val Moss.**

The encounters and reassurance which Ernie gave to other patients was so successful that it ultimately led to the formation of a support group, called the Outlook Group. Ernie visited me when I myself was on the ward and invited me to the group. This I did and quickly became involved.

After about three years, Ernie asked if I would like to help new patients re-adjust to life after stoma surgery and I felt this was something I would really like to do. I joined the Colostomy Association, undertook training, had a 'DBS check', read articles, and finally began visiting patients on the ward along with another volunteer.

So here we are. Many years on and not a moment to spare. I chair the Outlook Group, and along with two other volunteers, visit patients on hospital stoma wards on a weekly basis. We follow this up with five meetings a year with speakers and a trade representative, plus a large Open Day. Meetings in Stafford also take place, and a very successful 'Coffee in the Corner' at a local hotel on a monthly basis. Keeping up with emails and reports means my tech abilities are kept fresh. I am also a volunteer on the Colostomy UK's helpline (who are always on the lookout for more volunteers!)

I want to take this opportunity to encourage many more stoma nurses and hospitals to bring experienced ostomates onto the ward. Usually there is one visit a week. The routine is to meet the nurses, who give me names of patients (and their stoma types) who have just had surgery, then I go to the ward where I confirm with nurses that the patients are well enough to receive visitors. This liaison is vital, as trust is so necessary. I introduce myself to the patient with my ID card. Sometimes the person is anticipating my visit and has questions. It is very useful to meet relatives as well.

> **The hospital consultants and stoma nurses agree that visits from us fellow ostomates does far more than their words of re-assurance can do.**

It is an enormous privilege to do this work – the friends I have made are numerous. Who would have thought my 'unwanted gift' of stoma surgery would result in this rewarding life.

If you would like to find out more about hospital volunteering, please email the editor, who will be happy to assist you in contacting Moira to discuss this unique activity in more detail: editor@colostomyuk.org

My name Sime Ndlovu and I'm the Lead Stoma Care Nurse Specialist at the University Hospitals of North Midlands. Moira volunteers at the hospital and visits patients who have just had their stoma formed to introduce the support group, provide support, personal experience, feelings, coping strategies and firsthand information about living with a stoma. The support given by Moira and the support group is invaluable to our service and patients often mention that talking to someone who has a similar condition helps them cope better and reduces anxiety. Moira is an asset to the stoma services as a whole and we appreciate the support she gives our patients.

Volunteers Week

BY RIA ROBINSON

Our Volunteers Manager, Ria Robinson marks this year's National Volunteers Week by paying tribute to our very own volunteers

With volunteers week this year being celebrated 2-8th June 2025, we wanted to take a moment to thank all our wonderful volunteers who support Colostomy UK's work.

Volunteers are at the heart of our charity and always have been. We couldn't do what we do without the help that they give, from answering our Lived Experience Stoma Helpline, supporting with our Facebook page, to representing us in the community and at events, where they act as ambassadors of the charity.

The skills, experience, time and energy they bring to our charity make a difference to the lives of people in need. Most of our volunteers have lived experience and want to support others living with a stoma, their families, friends and carers. Colostomy UK boasts around 100 volunteers UK wide, including our Rugby League team.

Once again, a huge thank you from Colostomy UK, and Happy Volunteers Week 2025!

We are always on the lookout for new volunteers. Our roles are flexible, and some can be done remotely. You don't need to commit to huge amounts of time. You will be given training and have the support of the team and fellow volunteers. If you are interested, please contact us:

volunteer@colostomyuk.org
Tel: 0118 9391537.

Colostomy UK

fundraising

Megan Lowden
Fundraising Executive

Our Fundraising Executive, Megan Lowden, gives us the lowdown on many ways our supporters have helped raise vital funds for Colostomy UK over the past three months.

Soaking Up Success

Judy took on the challenge of swimming every single day during February and March to mark her 10th year since her stoma surgery, all while raising over £1,000 to support the work we do here at Colostomy UK.

£1000+ Raised

Winning in More Ways Than One

As part of Team Colostomy UK's Edinburgh Big Weekender in March, our Wheelchair Rugby League team, 'Purps on Wheels', faced off against the Edinburgh Giants in a charity day aiming to raise funds for both organisations. As well as some great action on the pitch and friendships built off it, the day raised an amazing £3,500.

£3500 Raised

£500+ Raised

A New Lease of Life

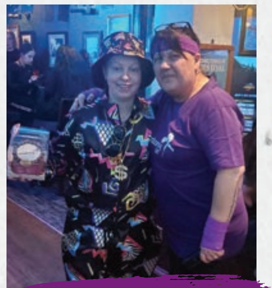
Heather, Lindsay and Olivia took part in the Glasgow Kiltwalk challenge in April, raising over £500 for us in the process. Heather shared with me why they chose to support Colostomy UK in this way. "As a team, we decided to help support Colostomy UK - a cause that is very close to our hearts. Earlier this year, a beloved family member underwent life-saving surgery and received a colostomy after a long battle with diverticular disease. Since her surgery she has been able to gain back not only her quality of life but also her bright smile and positive attitude".

Feel the Fear (and Do It Anyway)

Tracy is taking to the skies for a tandem skydive to raise funds for us, after we supported her through her stoma surgery journey ten years ago. At the time of print, Tracy was well on her way to smashing her £500 target "This year, with my fear of heights, I've decided to do a tandem skydive at 15,000ft to raise funds for Colostomy UK in May and to raise awareness about colostomies and hidden disabilities."

80s Pub Classics

Lynn Ford organised an 80's themed event filled with fundraising activities at The Red Bear pub in Thirsk, following a request from punter Libby, who underwent stoma surgery in March. They had an incredible day and were able to raise £526 in vital funds for Colostomy UK.



£526 Raised

Company Fundraising Highlights

Over the last three months we have seen an influx of companies undertaking different fundraising activities, all to raise funds for Colostomy UK.

Country Style Foods in Stockton have once again committed to raising money for Colostomy UK in 2025. Last year they raised £5,000 and have already started planning for this year, with activities happening EVERY MONTH. HR Manager for Stockton, Claire, has kickstarted their fundraising by growing her very own Purple Iris plants that she hopes to award us with at the end of the year. We really can't wait to see these flowers and their fundraising flourish!

Many companies are also taking part in Step Up for Stomas – Active April.

18 members from the Illness Team at Irwin Mitchell have all joined forces to Step Up for Stomas and raise over £1,000 at the time of print!

14 members of the Cegeka Team along with ostomate employee, Kelly, took a 16km hike around the Surrey Hills on the 11th of April to raise vital funds as part of Active April.

Stoma suppliers StoCare and Convatec are both getting involved with Active April this year, to raise funds for the people Colostomy UK and both companies directly support!

Convatec Team

Step Up for Stomas ACTIVE APRIL

Step Up for Stomas – Active April highlights so far

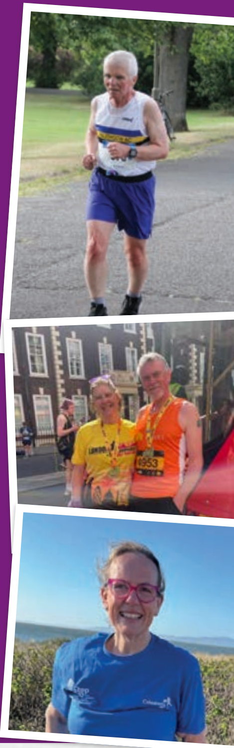
At the time of print, we are half way through our very first Step Up for Stomas – Active April Challenge. Over £10,000 has been raised already by incredible participants.

We want to highlight some of the wonderful efforts of those who have got involved:

Alex decided to mark running his 250th park run 13 years post stoma surgery, by taking part in Active April. He has raised an amazing £1,000.

Anne-Louise ran the London Landmarks Half Marathon on the 6th of April as part of Step Up for Stomas – Active April and raised £1,140 in the process!

Charlotte set up her Active April fundraising page with the goal in mind of raising £200 for Colostomy UK. At the time of print she is smashing it, with over £695 and counting!



An awesome 15 people on Facebook chose to set up fundraisers to celebrate their birthdays and other personal events and raised £1,000 collectively over the past three months.

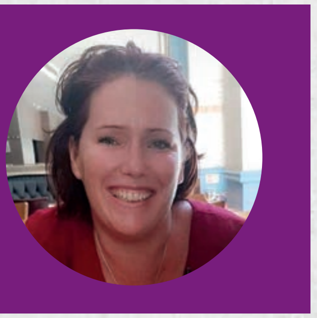
Facebook gives its users the option to ask for donations for a special cause for the duration of the online celebrations (usually a period of about two weeks). So please do keep us in mind if you have a birthday or special occasion coming up!

We'd Love to Hear from You

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

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

A Word from Our CEO



Our CEO, Libby Herbert, reflects on Colostomy UK's recent decision to move many Tidings subscribers online.

The Spring 2025 edition of Tidings marked an important and emotional milestone —we've begun making the transition from print to digital.

We know that for many, Tidings has been more than just a magazine— it's been a familiar companion, a source of comfort, and a way to stay connected with a community that understands. That's why this change, while necessary, hasn't been easy for everyone.

We've heard from readers across the spectrum—some who have welcomed the new format with open arms, and others who are still adjusting, or worried about how the shift might affect those with limited access to technology. We truly appreciate every message, every concern, and every kind word you've sent our way.

> **So I just wanted to take a moment to say a heartfelt thank you to all of you who've reached out and shared your thoughts about our move to a digital Tidings**

It's been really encouraging to hear how many of you are enjoying the new format —whether it's for the ease of access, the added digital features, or the fact that it's better for the environment. Your support and positivity have meant a lot to us.

At the same time, we know this shift hasn't been smooth for everyone.

Quite a few of you have expressed concern for those in our community who might not be as comfortable online, or who face challenges with internet access. Please know — we're listening. And we've already put steps in place to hopefully make sure no one misses out on Tidings, no matter their situation.

We'll also be sending out a short survey soon to get even more of your thoughts. That way, we can keep improving and make sure the magazine continues to feel like a place where everyone belongs.

The truth is, moving to digital wasn't an easy decision—it came from a place of needing to make sure Tidings (and all the other services Colostomy UK provides) can carry on strong into the future. So thank you again — for your feedback, your patience, and your continued support. It really does make all the difference.

Warmly, Libby

You can find a selection of readers' views on the switch to Tidings digital in the 'Your Letters and Emails' column, on page 44.

Colostomy UK

campaigns

Much of the recent success of our Stoma Friendly Toilets campaign has been down to the bravery and tenacity of our campaigners. People like Emma Sellars, who featured on BBC Television, Radio, and online back in February, sharing her frustration about a lack of suitable facilities in her local community. This is her story.

My name is Emma and I'm 24 years old. I was diagnosed with Ulcerative Colitis in 2017, at the age of 16. I went through a whole list of medications, infusions, injections to try and get it under control, but unfortunately, nothing was successful, and my body also became reliant on the steroids.

I was just in a constant state of flare-ups. Bleeding, severe abdominal pain, fatigue, frequent toilet trips (I could go up to 30-40 times in a day), weight loss, nausea/ vomiting - the list goes on.

I was becoming sicker and sicker by the day, and the doctors told me I had no other option than stoma surgery.

I had my stoma formed in February 2019 at the age of 19, and since then have had a very turbulent journey with multiple bowel perforations, bowel obstructions, and a further nine surgeries.

I have unfortunately now been diagnosed with small bowel dysmotility and intestinal failure.

In September 2022, I ended up needing artificial nutrition to keep me alive (feeding into the veins) but one year on I'm tolerating enteral feeding into my bowel and having fluids at home to keep my hydration up.

Life with a stoma for me has been life changing, it's saved my life and given back so much of my life. One thing I'm really passionate about is raising awareness of just how inaccessible the majority of accessible toilets are. I chose to support Colostomy UK's stoma friendly toilet campaign because in the six years I've lived with a stoma, I've come across just one toilet that's been completely accessible for me.

> **Having a stoma friendly toilet is so important. It gives us more comfort as we often need to use a toilet more frequently than others so having one that meets all the requirements makes this process a lot easier for us. It provides us with privacy to help us manage our condition more discreetly and reduces the stress of trying to quickly change or empty our ostomy.**

It provides us with more convenience, making it easier to store and access products when changing our ostomy bag which in turn makes the process less stressful. Lastly, it supports our emotional wellbeing. Having a toilet that is designed with the needs of ostomates in mind can help reduce our anxiety, making us feel more at ease with our condition. It fosters a sense of independence and normalcy which contributes positively towards our mental health.

> **I recently worked with my local news outlets and radio stations to help spread the word about stoma friendly toilets and why it's important to me. All this coverage made me feel proud to be a voice and advocate to help get the message out there."**

If you'd like to join our Stoma Friendly toilets campaign, please email getinvolved@ colostomyuk.org with your name and address, and we'll send you one of our packs in the post.

Rebecca Birtwell: A Healthy Dose of Perspective

43-year-old Rebecca Birtwell has been registered blind since birth and lived with a stoma since the age of nine. Far from limiting Rebecca's ambitions in life, living with both conditions has shaped her positive view of the world.

When Rebecca Birtwell's older brother was born blind, their parents were a little surprised but soon adjusted to his needs and got on with life as usual. It was only 18 months later, when Rebecca was also born blind, that their mum and dad realised that they both carried a rare gene which caused congenital cataracts.

The condition stops the eyes from developing while still in the womb, preventing muscles and lenses from forming properly, and in Rebecca's case also resulted in detached retina. Despite these complications, multiple surgeries as a baby ensured that Rebecca does now have some sight, as she told me, throwing in a little anecdote for her own amusement:

'I had over 20 operations from the age of three weeks old. I don't remember any of them. They used to pop my eyes out and lay them on my cheeks'.

Rebecca continues to live with tunnel vision and nystagmus (meaning her eyes make uncontrolled movements), but with the aid of contact lenses she is able to make out shapes and read text when increased to a large font.

We talk a little more about Rebecca's eyesight, as I'm curious to understand exactly how much she is able to see compared with people with regular vision, but it's an almost impossible question, as she explained:

> **'I get asked this every day and it is the most difficult question to answer, because I don't know what you can see'.**

This makes complete sense to me once it's pointed out, though Rebecca continues to humour me by describing how she can make out my orange t-shirt but cannot see my specific facial features. Likewise, most text is a blur, but with the aid of a smart phone she is able to zoom in on things like bus timetables and restaurant menus.

Rebecca also had Guide dogs for many years from the age of 16 onwards. Though now married with two children of her own, she no longer relies on a dog for support, as much as she misses them. As she quipped:

'It's hard enough getting on public transport with a guide dog, let alone a guide dog, a pushchair, and a bunch of shopping!' Instead, Rebecca buoyantly told me - 'I've just got on with it'.

This attitude has also shaped how she feels about her stoma, which she had formed at the age of nine after years of suffering with ulcerative colitis.

'From the age of three, I was in almost daily pain' she told me. 'I used to sleep on the toilet because I'd always have to get up so much in the middle of the night, and when I did go it was just pure water and blood. I didn't really eat as a result - I was literally just skin and bone.'

And yet despite this, the doctors at the time still weren't convinced that there was anything wrong with Rebecca. Eventually, her parents took matters into their own hands and pushed her to be referred to Great Ormond Street hospital. Realising the extent of her health problems, Rebecca was quickly booked in for emergency ileostomy surgery.

Rebecca still vividly recalls the day before her operation, seeing another young person on the ward and asking what they had on their tummy. When it was explained to her that it was a stoma, and she would soon have one too, she was 'completely oblivious' as to what it really meant. That was until she came round from surgery and promptly fainted at the first sight of her own.

After a few days of recovery, her stoma kicked into action. Rebecca still clearly remembers this first time that her stoma had output. Laughing, she recalled how this time it was her dad's turn to faint, leading the nursing team to run to his aid, leaving her to manage this momentous occasion on her own for a minute or two.

> **'From then on, it's been my bag for life' Rebecca told me, having quickly realised that her stoma was the thing that made the difference between a life with and without pain.**

In fact, two years on from having her ileostomy formed, Rebecca's medical team put it to her parents that she may be able to undergo reversal surgery. Yet being such an important decision about their daughter's future, it was not something they felt they could decide on her behalf. As Rebecca remembered:

> **'My parents sat me down and said "We know you're only young, but this is your body. You're the one who's felt the pain. We're gonna let you make this decision". I said, "No, I don't want to have it reversed", because it wasn't 100% certain it would work. Then I'd go back to being poorly. And the thought of that... I wasn't having it. I'd much rather keep my stoma'**

But how has it been managing life with a stoma while also being severely sight impaired, I ask. Not too bad, as it turns out, Rebecca told me in her standard upbeat tone. By far the biggest challenges occurred while pregnant with both her children.

'When I was pregnant, my bump was growing, and my stoma was also growing under my bump, and changing shape all the time, so my flanges weren't fitting. Then the bag was leaking all the time. Most pregnant women will look in a mirror to deal with their stomas but because of my eyes I didn't have that option obviously. My husband was having to change it for me every time instead'

Perhaps Rebecca is simply lucky to have lived her life juggling two significant health conditions without much of a concern. Or perhaps it's the conditions themselves which have shaped her outlook towards life. As she put it:

'I've had to really fight for what I want, because it has been harder for me. My eyes have made me focus more on what I want to do in life. I'm well now. I have a normal life. I've run marathons, I exercise, I lift weights, I do everything everyone else can do. Nothing will stop me from doing the things I want to do. If anything, my eyes and stoma have made me more determined'.

Research Round Up

Dr Benjamin Saunders is a Senior Lecturer in Health Research at Keele University in Staffordshire. Ben has been carrying out research that aims to improve the lives of ostomates for a number of years. He is providing a regular round up of recent research on stomas that's been published in healthcare journals.

In this edition, I continue my round up of research that's been published on stoma care and experiences over recent months. I'll be discussing three studies, two of which focus on challenges related to living with a stoma, the other on the choice not to have stoma surgery.

The first study I'd like to share with you focuses on pregnancy with a stoma. Researchers in the Netherlands investigated how common stoma-related complications were during pregnancy and in the postpartum period. They searched patient medical records in five university medical centres to identify patients with IBD who were pregnant with a stoma, between 2016 and 2023. Patients were then invited by email to participate in the study, with a link to an online questionnaire asking them about any stoma-related pregnancy complications they had experienced.

Fifty patients were included (62 pregnancies in total). Stoma-related complications were reported in 44 pregnancies (71%), half of which occurred in the second trimester. In 33 pregnancies (53%), a major complication occurred. This included obstruction in 22 pregnancies (35%), and parastomal hernia in 12 pregnancies (19%). No significant associations were found between these complications and either having been pregnant in the past, having had stoma surgery less than a year before, or smoking. In 31 (50%) of pregnancies a Caesarean section was performed.

The researchers conclude that pregnancy for women with a stoma is of course possible; though, most women will experience stoma-related complications, often in the second trimester. However, most complications were successfully managed through conservative treatment.

Whilst this study included only a relatively small group of 50 women, and only those with a stoma resulting from IBD, these results nonetheless allow ostomates to be more informed about possible complications, which can help their conversations with healthcare professionals.

The second study follows up on research that I first shared back in the Autumn 2023 edition. A UK-led team of researchers tested a new innovation – a "digital ostomy leakage notification system" called "Heylo". This is a medical senor device that attaches to an ostomy baseplate and sends messages to a smartphone App via Bluetooth (all very technical!). These messages tell the ostomate when they are at risk of getting a stoma bag leak. The researchers tested whether using this device could reduce the number of leaks that people experience. They also looked at whether using Heylo led people to worry less about getting bag leaks and whether it improved their stoma management routines. It's these last two aspects that I'll be discussing here.

The researchers recruited 100 people with a stoma from UK hospitals to use Heylo for three months. They also had access to a telephone support service. Participants all had a stoma for nine months or less, with liquid or mushy output. Participants completed a questionnaire before they started using Heylo, and completed the same questionnaire after four, six, eight, 10 and 12 weeks, to assess any changes whilst using it.

The results showed that at the beginning of the study 15% of patients worried to a very high degree about leaks and 24% worried to a high degree. However, by the end of the study only 3% of patients worried to a very high degree and 11% to a high degree. This change in worry led to fewer bag changes. At the start, patients estimated that they had changed their stoma bag on average 2.47 times in the previous two weeks due to worry about leaks rather than due to actual leaks. After using the device for three months, this number halved to 1.24 bag changes in the prior to weeks. 64% of participants said that using the device made it easier to know when to change their stoma bag, and 88% said that the device gave them greater peace of mind.

This study has a few limitations. Firstly, participants all had a stoma for nine months or less. As the researchers themselves acknowledge, we do not know how beneficial the device would be for people living with their stoma for longer. Additionally, the availability of telephone support may have helped people feel less worried, so it's unclear how much this accounted for the findings. Nevertheless, these are exciting results. The Heylo device certainly has a lot of future potential to support ostomates who worry about stoma bag leaks.

For more on research into stoma leaks, see our article on smart stoma technologies on page 24.

The final study I'll share investigated the decision-making process of IBD patients who, having been offered the option of stoma forming surgery, decided against this. Researchers in Poland interviewed three men and four women with IBD, recruited from a gastroenterology department and from online forums.

The participants shared a number of reasons for choosing not to have surgery. This included fears about the future; for instance, how their lifestyle might change and that they may experience stigma from others as a result of having a stoma. They also expressed fears about the surgery itself, as well as mixed feeling about how they might cope with life with a stoma.

The researchers also identified that participants had received inadequate information about stoma surgery from health professionals. The participants held onto hope that new treatment options would become available so they could achieve remission of their IBD and would no longer need surgery.

The researchers shared a recurring observation that participants tried to avoid discussing the surgery so that they could deny its existence. But despite deciding against surgery, the participants expressed ongoing struggles with their decision.

This study is limited by the small number of participants. It's also unclear what information patients receive in the Polish healthcare system and whether this differs from the information provided by health professionals in the NHS. Nevertheless, these are fears that I imagine many readers can relate to having felt before their own surgery. The researchers recommend the need for better support for individuals to help them to make informed decisions about stoma surgery.

UTIs and Thrush After a Stoma: The Hidden Microbiome Link

BY LESLIE MELLO, FORMER OSTOMATE

Leslie Mello explains the link between the microbiome and urinary tract health, how living with a stoma can disrupt this relationship, and what can be done about it.

When I got my colostomy, I expected some changes – but I didn't expect repeated urinary tract infections (UTIs) and symptoms like thrush and irritation in the vaginal area. As a trained nutritional therapist, I knew how to support my gut microbiome, but the usual approaches of supplementing with pre- and probiotics didn't seem to help after my stoma surgery.

Remembering my studies in nutrition, I suddenly realised why: many of the good bacteria that protect the urinary and vaginal areas come from the gut. These bacteria naturally travel across the perineum (the area between the anus and the vaginal opening). With a stoma, this channel is essentially closed therefore eliminating a major pathway for good bacteria to reach the urinary and vaginal microbiome.

After realising this, I decided to target the area directly and tried a probiotic pessary once a week. To my relief it worked! My symptoms cleared up, and I stayed infection-free. I treated myself at home because my symptoms were mild, and I wanted to avoid the potentially harmful and miserable cycle of constant antibiotics and antifungals I had read about on forums. As it worked so easily for me, I wanted to share this here in the hope that it may help others to avoid unnecessary discomfort and medications.

Important: please speak to your doctor if you notice any symptoms of a UTI (like urgency, burning when peeing or cloudy, smelly urine) or vaginal irritation. These can become serious if left untreated. This article is not meant to replace medical treatment.

How the Gut Supports the Vaginal and Urinary Microbiomes

In people with intact digestive systems, gut bacteria – especially Lactobacillus – help keep harmful bacteria and yeast in check by supporting a healthy vaginal and urinary microbiome. One way they do this is by causing a slightly acidic environment, which protects against infections. They also compete for space and essentially crowd out pathogenic bacteria that can cause symptoms.

With a colostomy, this natural reseeding no longer happens. As a result, some people may experience thrush, bacterial vaginosis, or repeated UTIs – not due to hygiene, but because of a microbial imbalance.

What Helped Me

Once I realised supporting my microbiome needed a more 'direct approach', I used Optibac's Intimate Flora probiotic supplement and simply inserted it as a pessary instead of taking it orally. It worked quickly and kept me well, as long as I continued using it weekly. I had my colostomy reversed in 2023, so I no longer need to take these precautions.

At the time I double-checked with a nutritional therapist colleague, microbiome expert Marina Townsley, who reassured me that using the probiotic as a pessary was safe.

Marina is also a master herbalist and has a lot of tools to help people with chronic UTIs. She shared her three-pronged approach with me:

Marina's 3-Step UTI Strategy

1 Support your immune system

A healthy immune response helps prevent infections in the first place. This means reducing sugar, alcohol & stress, and increasing whole foods, hydrating fluids, and rest. There are also many supplements like Vitamin C, A, D and Zinc and herbs that can help support your immune system (check with a registered health professional for correct dosages and advice).

2 Use probiotics locally

Apply probiotics directly to the vaginal area and around the urethral opening (this also works on the penis). This helps restore a healthy microbiome where it's needed most. You can open a capsule and mix it with plain Greek yoghurt or a soothing gel like aloe-based lubricant. You can also coat a tampon and insert if you want. Marina's favourite probiotic for this is called UT+ probiotic by Garden of Life – but please check for any allergies before using.

3 Act fast at first signs of a UTI

If you feel early symptoms like urgency, burning, or foul-smelling urine:

- Use a high-strength cranberry product (Marina's favourite is Natures Plus Sustained Release Ultra Cranberry supplement). Take it every 4 hours for 1–2 days. Do not use cranberry juice drinks as these have very little of the active ingredient and the added sugar will cancel out the benefits.
- Use probiotics both orally and locally (see above for topical application suggestions).
- Keep very hydrated to flush out the bladder. Drink at least 2 litres of water throughout the day (not all at once!) and add in some coconut water for extra electrolytes and herbal teas with ingredients like nettle, buchu, marshmallow, or bearberry for extra benefits.

This early intervention often stops a UTI before it takes hold. If infections continue, testing the urinary and vaginal microbiome can help identify the cause and guide more personalised treatment. Please always work with a professional health practitioner before starting any supplements or home treatments.

What About the Male Anatomy?

With male anatomy, the pathways are different and poorly understood. Bacteria from the gut may still reach the bladder via the skin on the penis, urethra, or even the bloodstream. This can explain why some ostomates experience UTIs or prostatitis despite good hygiene. More research is needed in this area. However, if you follow the tips above, it should help.

Urostomies: Another Layer

If you have a urostomy, your urinary microbiome is directly affected. Since urine no longer flows through the bladder, the usual defence systems are disrupted. Long-term antibiotics are common, but they can make things worse by damaging good bacteria. It's worth speaking to a specialist in microbiome health for natural options that can help support your overall health.

It's Not Just Hygiene

A frustrating part of this journey was being told that poor hygiene may be causing my infections. That wasn't true. Without the right bacteria being delivered to the right place, no amount of washing can stop infections from returning.

Even though good hygiene is important, restoring the microbiome is just as important as staying clean!

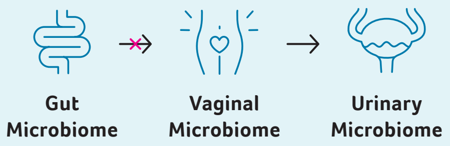
Final Thoughts

Living with a stoma brings many challenges, but constant infections don't have to be one of them. Probiotic pessaries changed my life, and they may help others too. Everybody is different, but supporting your microbiome – with guidance from a trusted health professional – can make a big difference.

If you're struggling with UTIs or thrush, you're not alone. The answer might lie not in more medication, but in restoring the natural balance to your body with a few simple hacks.

You can contact Marina directly at MarinaTownsley.com if you have any questions or want to book an appointment.

Stomas interrupt an important pathway



When the microbiome pathway from rectum to vagina is diverted because of a stoma, the microbiome can be disrupted causing vaginal and urinary symptoms.

Make the gift of a lifetime

A legacy to support future generations living with stomas

Colostomy UK

It won't cost you a penny during your lifetime (and it's free from inheritance tax!)

Safeguard our support services for the future, ensuring they're accessible to everyone who needs us, how and when they choose.

Expand our range of Active Ostomates classes to help more people build confidence, fitness and strength after stoma surgery.

Grow our information library to include all the topics we know people most need help with, helping to prevent some common issues.

A legacy of any size really can make a difference.

FREE WILLS

Through our partnership with FreeWills.co.uk, you can create or update a legally-binding Will completely free of charge in just 15 minutes, with live support from their Will specialists, and checked, vetted and approved by a solicitor.

For more information see our website: www.colostomyuk.org/get-involved/fundraising
or contact Megan on 0118 228 1358 / Megan.Lowden@ColostomyUK.org

---

Get your Stoma Aware pack and help us make a difference

Can you help us to make your community become more #StomaAware?

Our Stoma aware pack includes some great resources to help you engage with local businesses and organisations including:

- Stoma Friendly Toilets letter
- Stoma Aware Info poster
- Stoma Friendly Toilets guidelines

To get your pack, email GetInvolved@ColostomyUK.org and help us make a difference!

#StomaAware

Colostomy UK

To whom it may concern

I am writing to request that the accessible toilets in your organisation are made 'stoma-friendly'. This is quick and inexpensive to do and will make a positive difference to lives of many people like myself, who have undergone life-changing surgery.

In case you didn't know, a stoma is a surgical opening in a person's abdomen through which bodily waste is collected in a bag. Stoma surgery is used in the treatment of many things, including bowel cancer, Crohn's disease, diverticulitis, and child-birth trauma. People of all ages have stoma surgery, even babies and children. There are approximately c200,000 people with stomas in the UK, that's 1 in 335 of us.

After you have had stoma surgery, your needs change. In particular it is very important that you have easy access to appropriately equipped toilet facilities. Without these, many people with stomas are fearful about the everyday things in life that most people take for granted, like going shopping, or visiting the cinema, or going to work. In some cases, it can lead to them becoming lonely and isolated.

All a toilet needs to be 'stoma-friendly' is a hook to hang personal possessions, a clean shelf on which to lay out stoma/medical supplies, inclusive signage and a mirror to help with changing a stoma bag. To find out more details I suggest visiting Colostomy UK's website: https://www.colostomyuk.org/campaigns/toilets/ .

You will see that Colostomy UK produce toilet stickers to show that a toilet is stoma friendly. You can obtain these by emailing getinvolved@colostomyuk.org, As well as despatching the stickers to you, the team would be delighted to work on a joint communications piece to promote that your toilets are Stoma Friendly.

This charity also provide other services that might be of interest, such as providing 'Stoma Aware' training to employers and employees (including those in customer-facing roles) and HR departments. So that your employees and customers feel supported and understood.

Yours sincerely

Colostomy UK

#StomaAware

More information
ColostomyUK.org/StomaAware

What is a Stoma?

A stoma is a surgically-created opening in the abdomen. It diverts the flow of bodily waste from a damaged or non-functioning bowel and/or bladder, allowing it to be collected in a bag.

*A stoma can be temporary or permanent

There are three main types of stoma:

Colostomy: Diverts faeces from the colon
Ileostomy: Diverts faeces from the small intestine
Urostomy: Diverts urine away from the bladder

A person wears a bag on their abdomen to collect bodily waste

200,000 People in the UK have a stoma

Who has a Stoma?

Anyone can have a stoma.

Why do I need to be Stoma Aware?

Empower people to access the information and Support they need.

To stop Prejudice and discrimination.

Not all disabilities are visible

#stomafriendly

Why do people need a stoma?

- Diverticulitis
- Cancer
- Crohn's & Colitis
- Childbirth
- Endometriosis
- Trauma
- Medical Negligence

It is … that one in 550 people in the UK have a stoma. Often referred to as ostomates, these people (who can be adults and children) have a 'hidden' condition. They have additional needs when using the toilet.

… safe and easy.

…ccessible Toilet signage is frequently misleading. It can inadvertently suggest that the facilities are only for use by people with physical disabilities.

Why make your toilets stoma friendly?

Inadequate accessible toilet facilities act as a form of social exclusion. When an ostomate goes out, they need to be sure that if necessary, they can find a suitably equipped toilet in which to change their stoma bag.

Our research has also revealed that ostomates are often verbally challenged and sometimes even physically assaulted when they use accessible toilets. Poor signage contributes to this problem. Remember, ostomates have a hidden condition.

The stoma friendly toilet

Hooks
- To hang clothing and personal belongings while changing stoma bags.
- British Standards suggest two clothes hooks, one at 1050mm and the other at 1400mm above the floor.

Shelves
- To provide a sanitary surface on which to lay out medical supplies.
- Placement is important. The shelf needs to be positioned so that an ostomate can stand in front of it and access their supplies. We suggest a flip up/down shelf if your toilet is small.
- British Standards suggest a flat topped close-coupled cistern providing a changing surface. For high or low-level cisterns, a separate changing shelf 125mm to 150mm deep and preferably 400mm wide, with its surface 950mm above floor level, should be provided.

Bin
- To enable the disposal of used stoma bags. To avoid embarrassment, this should ideally be located in the toilet cubicle.

Mirror
- Allows ostomates to see their stoma while changing their bag.

Accessible Toilet Signage
- Signage that draws attention to the hidden nature of some conditions and disabilities helps to reduce hostility towards users without an obvious physical impairment.

Not all disabilities are visible

For More Information and Free Stickers
T: 0118 939 1537 W: www.ColostomyUK.org
E: info@ColostomyUK.org Charity No: 1113471

Colostomy UK

The East Kent Stoma Groups' Ostomist Agenda

David Christian is Chair of East Kent Support Groups collective. In 2014, the group drafted the Ostomist Agenda, which has proved a powerful manifesto for ostomate care in the region. David tells us how it came about, followed by the Ostomist Agenda itself.

Who are the East Kent Stoma Groups?

The East Kent Stoma Groups Committee is made up of representatives of each of the five Stoma support groups in East Kent. Four in-person groups based in Ashford, Canterbury, Dover, Thanet, and our regional Facebook group.

It also includes clinical staff, such as the Deputy Head of Nursing, and representatives from our Stoma Services sponsors Hollister/Dansac, and Fittleworth.

What led the group to create the 'Ostomist Agenda'

In 2014, the Hospitals Care Management Team acknowledged the need to review Stoma care provision. This provided the opportunity for service-users to get involved.

Consultations took place with ostomates through the local support groups to hear what improvements could be made to the existing stoma care. This then led to our "wish list" regarding what the Agenda should include.

How has the Ostomist Agenda shaped stoma care in East Kent?

The Agenda has become an integral part of the stoma care pathway in our region. It specifies what levels of service companies will need to provide and is an important aspect of the tendering process which takes place every five years.

Representatives of our regional stoma support committee are involved along with the clinical and financial teams in the tendering and selection process.

We routinely review how stoma teams are performing in relation to the points within the Agenda. These reviews are reported to the clinical team and any suggested changes to how the service is delivered are then discussed.

We believe we have the best stoma service in the country as a result!

What has changed since the Ostomist's Agenda was created?

The Agenda is a "live" framework. Recent amendments include;

- Carers/partners needs being accounted for
- The inclusion of social media and a focus on service-users who cannot attend face-to-face meetings.
- Stoma friendly toilet provision within Trust hospitals.
- Engaging with the Integrated Care Board Medicines Optimisation team to reduce delays in the system, from placing prescription orders to delivery.
- We recently joined a partnership called The Coalition for Personalised Care (C4PC); an organisation which shapes how personal care is delivered.

What advice would you have for other Support Groups looking to create a similar model in their own regions?

- Collaboration is the key! Liaise with neighboring Ostomate groups within your Trusts region (if you have any).
- Establish what you would want to include in your objectives.
- Engage with clinical nursing teams and any commercial partners to agree aims.
- Contact your Trust's Patients Voice/Engagement team to see if they can assist.
- We are happy to offer additional advice if anyone would like to learn more.

Email: editor@colostomyuk.org, to be put in touch with David

The Ostomist Agenda

2025

A - As someone who is going to have a stoma, I expect:

1. For me, and my carer if I have one, to be introduced to a specialist nurse who will be looking after me after I have got my stoma and who will talk to my GP about me and my needs with a stoma.
2. My carer to be kept up to date with any developments while I am having surgery.
3. To have all the implications of having a stoma explained to me, and to my carer, including how I get my stoma supplies and the kinds of problems that can arise with a stoma, including the risk of hernia and the use of support garments.
4. To have access to services to support my psychological well-being and the well-being of my carer, especially in the period when I am adjusting to the idea of life with a stoma.
5. To have a chance for me, and my carer, to talk to someone like me who has a stoma.
6. To be introduced to my nearest Stoma Friends Group and helpful social media groups.

B - As someone who has recently had a stoma created, I expect:

1. To be shown how to change my stoma bag, and for my carer to be able to assist me.
2. Advice to me and to my carer about how and what I should eat and what I should be careful of eating.
3. To have access to services to support my psychological well-being, and the well-being of my carer, especially in the period when I am adjusting to life with a stoma.
4. My GP and my practice nurse to know that I now have a stoma and that I may need help and advice.
5. To be referred to an appropriate exercise programme to support my recovery from surgery.
6. To have daily checks following my discharge from hospital until I feel confident.
7. If I have a temporary stoma to know when I will be readmitted for a reversal.
8. To have someone who is a specialist with stomas come to see me at home until I am happy and confident with my stoma, my appliances and my accessories.
9. My stoma prescription to be set up with my GP and to be able to order my stoma supplies from my GP surgery in the way that is easiest for me and to receive them within four working days of ordering.

C - As someone with a stoma, I expect:

1. To be able to contact someone who can advise and help me, even at weekends and in the evening, either personally or through my carer.
2. Not to have to travel to the hospital every time I have a problem with my stoma.
3. My GP and my practice nurse to be able to offer me some basic advice and help when I have a problem with my stoma.
4. To be seen by a specialist nurse at least once a year to review my stoma and the appliances and accessories that I am using and to be accompanied by my carer if I want to.
5. To have access to services to support my psychological well-being and the well-being of my carer with any problems relating to my life with a stoma.
6. To be offered the most up-to-date and effective appliances and accessories which best suit me and my stoma.
7. To be able to get into hospital quickly when I really need to.
8. To be told when and where my nearest Stoma Friends Group meets and about any helpful social media groups that I can join.
9. To have my Stoma Friends Group supported.
10. Help for my Stoma Friends Group in promoting Stoma Health and wellbeing Days which benefit the whole stoma community in East Kent.
11. Accessible toilets should be stoma friendly.

Your Letters and Emails

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

Dear Editor,

Thank you for including the wonderful story of Teigan Griffiths in the latest issue of Tidings.

What a story and what an inspiration! Sadly, I was not surprised to read that Teigan had paid several visits to her GP describing the pain, weight loss and other symptoms of her constipation. In return, only receiving an increase in laxatives. Why is there such ignorance about the reasons the bowel stops working?

I wanted you to ask Teigan "How did you remain so positive when it seems that nothing was improving with your health"? Now I have the answer.

Well done Teigan in remaining the fighter – shown and read later in your story. You have a dream – and are following it – attending volunteer police courses to better understand the Police Force that you hope to join.

As a new ostomate with some problems, I am determined to follow your "Anything is possible if you believe in yourself" attitude.

I can see joy ahead.
Thank you.

T.K Braithwaite

Mrs Valerie Skelton (87) lives in Tilehurst, Reading, in a block of retirement flats for residents over the age of 65. She has lived with an ileostomy for over 30 years.

Every few months, she places an advert on the community notice board, where other residents write down all the items that they want to be collected. She then has everyone deliver the bags of items to her flat ready for collection (sometimes she also asks the House Manager to help with storage, as she only has a one-bedroom flat). She has used this fantastic service several times in the past and all the residents support Colostomy UK.

See page 4 for the iCollectClothes service.

Regular Tidings readers will be aware that in recent issues this column has seen plenty of discussion about the electronic irrigation system called the Braun IryPump which is no longer being manufactured. Readers continue to get in touch, offering their thoughts on the issue.

Hi,

We've recently used the excellent service provided by ElecFIX in Cornwall for the Irypump base pumping unit*.

However, the IryPump also has a tank that sits on top of the base unit, holding the water that is then pumped in through the stoma by the IryPump. These tanks have two stages which collapse for transit. It is common to get leaks at the sealing area between the two halves of the tank.

Do you know of anyone who can repair the Irypump tanks? We have one that is now leaking between the two halves and would dearly love to get it fixed.

Thanks & regards

David Hawkes

** Editor's note: ElecFIX were noted in the last edition of Tidings, and who can oversee electronic repairs of the Braun IryPump. Email info@elecfix.biz.*

If you know anyone who can fix the IryPump tank, please contact the Editor at: editor@colostomyuk.org

The Spring 2025 edition of Tidings also saw us make a significant transition away from the physical version of Tidings in favour of the digital format. The move has meant that a large number of Tidings readers now receive the magazine via email rather than in the post. Understandably, the move has prompted mixed views from readers, some of which are shared below.

I totally understand the position of the charity and why this decision has been made. Unfortunately I get absolutely no pleasure from reading magazines online.

I read my Tidings from cover to cover, and I also often cut articles that are of particular interest to me, and bits and pieces that I find motivational and I have a book that I stick all of these things into. I love going through that and re-reading them. Obviously, I can't do that online!!!

I do hope that you are able to offer a subscription going forward, but if you don't thank you for the magazines that I have received and for being with me in my first 8 months post-surgery

S.T

I am perfectly happy to move to digital format. Being a retired printer, it's sad to see printed products on the decline, but I understand the large implication of cost saving.

P.V

Hello,

Just to say as someone with a stoma and a monthly donator I feel very disappointed to read that you're stopping the printed copy of Tidings magazine. I fully appreciate the savings aspect but it appears that little consideration has been given to people like myself who don't want to look at a computer to read Tidings, it's just not the same.

Your decision takes away the feel-good factor of reading a printed copy as well as ultimately jobs lost nationally in the drive to make savings.

B.P

I have just looked at the first Digital Issue of the magazine and am suitably impressed with the quality of the text and pictorial content of the magazine. I can appreciate the reasons for going digital because of printing and postage cost being high. I was in printing for over 40 years and understand the reasoning behind the changes.

Congratulations on the first Issue.

T.N

We genuinely appreciate all the feedback to date, and are reflecting on how we can use readers' views to continue making improvements to Tidings digital. On page 32 you can read more about these plans direct from Colostomy UK's CEO, Libby Herbert

Something you'd like to share with the community? Why not get in touch.

You can email us at: editor@colostomyuk.org or write a letter to us at:

The Editor, Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD.

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

Support Group News

Here we catch up on the progress made by Stoma Support Groups.

Stoma Mates Support, South Cheshire

After years of struggling with endometriosis, my journey took a life-changing turn in 2023 when I underwent a full hysterectomy and bowel surgery. I began HRT patches but suffered a severe reaction, leading to unexpected second surgery. When I woke up, I had a stoma, (affectionately named Mimi). Not quite the designer bag I had in mind for my 40th, but one that ultimately gave me a second chance at life.

A couple of months into my recovery, I realised there were no local support groups in South Cheshire. I reached out to Colostomy UK. Then, after further surgery in 2024, I reevaluated my life, left my career in hospitality, and found a new purpose, caring for the older generation with my new employer, Home Instead. A conversation with the company owner, Nick Lamming, led to the creation of Stoma Mates Support South Cheshire, with the backing of Home Instead and our fabulous Community Engagement Officer, Sara.

We now meet every eight weeks, and provide a safe space to discuss life with a stoma, including topics like clothing, exercise, and diet.

Please contact Jess on:

☎ 01270 611555

✉ Jessica.davies@southcheshire.homeinstead.co.uk

The next meeting is at Nantwich Town Football Club, on 20th June, 2-4pm

If you would like to share highlights about your own Support Group in Tidings, you can contact us via editor@colostomyuk.org

If you would like advice on setting up your own Support Group, you can contact Community Engagement Lead, Shauna Hemphill, on Getinvolved@colostomyuk.org

Stoma Essex Patients Support (STEPS Essex) Turns Twenty

In 2004, Stoma nurses at Basildon Hospital invited Patients to a meeting. No one knew what to expect, but what grew out of it was a very successful support group run by Patients, for Patients.

The group has been led since its inception by Maxine Lockwood who still Chairs the Committee. Apart from the regular meetings, day trips, theatre trips and short breaks are also enjoyed by our members and their friends.

Our 20th anniversary celebration last December was attended by the Mayor of Thurrock, Councillor Kairen Raper, and over 50 members, who were also entertained by a Singer. We were well fed and watered thanks to the members of the Committee. Maxine has since been added to Thurrock's Mayoral Role of Honour.

St Katherines Church, Wickford

Last Tuesday of the month, 7-9pm

St Margarets Church, Stanford-le-Hope

Every second Saturday of the month, 11am-1pm

✉ Email: stepsessex@gmail.com

☎ Or contact Hilton Ellis on: 07752 234516

The Wessex Stoma Support Group (WSSG)

The WSSG is a very active group which meets up on a monthly basis, usually on Saturdays (and some Sundays also). Locations vary depending on the activity in hand, but include regular meetings, coffee and chat afternoons, painting classes, swimming sessions, Stoma Nurse Open Days, and the Christmas Dinner – which is already booked in!

For more information, including specific details on events, contact:

Kenneth Edwards,
Chair of WSSG

✉ Email: chair@wessex-stoma.co.uk

Channel Islands

Guernsey

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

Jersey

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

England

Berkshire

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

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

Bristol

Bristol Ostomy Self Support (BOSS)
Margaret Slucutt T: 07967102141

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

Buckinghamshire

High Wycombe Stoma Support Group
T: 0800 318965

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

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

Cambridgeshire

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

Cheshire

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

Christchurch

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

Cleveland

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

Co. Durham

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

Cornwall

Cornwall Bowel Cancer Support Group
James T: 01872 241 145

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

Cumbria

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

Derbyshire

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

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

Devon

Devon IA
E: devon@iasupport.org

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

Plymouth & District Bowel Cancer Support Group
Rita T: 07855571840
E: admin@plmdistbcsg.com

Essex

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

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

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

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

Optimistic Ostomates
Stoma Care Team T: 01702 385158

STEPS - Stoma Essex Patients Support
T: 01268451937 or 07752234516
E: stepsessex@gmail.com

Hampshire

Replummed Stoma Support Group
W: www.replummed.me

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

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

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

Waterside Stoma Support Group
Ian Gapp T: 07710288785
E: iangapp13@gmail.com

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

Gloucester

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

Herefordshire

Herefordshire Stoma Support Group
E: herefordstoma@gmail.com

Hertfordshire

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

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

Isle of Wight

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

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

Kent

Ashford Stoma Support Group
Malcolm Jones T: 07709 534463

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

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

Dover Stoma Friends Group Support
Carolyn T: 07720723445

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

Maidstone Stoma Support Group
T: 01622 224305

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

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

Thanet Stoma Buddies Support Group
Kathy T: 01843 291 825

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

Lancashire

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

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

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

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

Leicestershire

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

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

London

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

Bowel & Other Cancer Support Newham
T: 020 8553 5366

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

Newham Stoma Support Group
Lauren King T: 020 7055 5576

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

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

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

Merseyside

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

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

Middlesex

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

Norfolk

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

Kings Lynn Ostomy Friendship Support Group
T: 01406 363756 or 01553 775698

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

Northamptonshire

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

Northumberland

Berwick Ostomy Support Group
Bobbie Minshull T: 07714 479 320

Hexham Ostomy Group
Marie Douglas T: 07941 433 600

Nottinghamshire

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

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

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

Shropshire

B.O.T.S. (Bums on Tums)
Emily T: 07972519165
E: emily.hackworthy@live.co.uk

Somerset

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

Staffordshire

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

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

Suffolk

East Suffolk Ostomy Group
Ian Denison T: 01473 684865

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

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

Surrey

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

Guildford Stoma Support Group
01483 57 11 22 ext 2558

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

Sussex

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

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

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

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

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

Tyne and Wear

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

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

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

Warwickshire

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

West Midlands

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

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

Wiltshire

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

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

Wirral

Wirral Stoma Support Group
T: 07956 216218

Worcestershire

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

Yorkshire

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

Airedale Stoma Support
Sue Hall T: 01535 646 373

Barnsley Bottoms Up Stoma Support Group
John T: 07980388966
E: jkhminor2@gmail.com

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

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

Bradford Stoma Support Group
Lisa Hall T: 07552 276 747

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

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

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

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

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

Isle of Man

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

Northern Ireland

County Antrim

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

County Armagh

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

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

County Down

Ulster Hospital
Sarah, Jacqueline and Lisa.
The Colorectal Nurse Specialists
T: 028 9055 0498

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Republic of Ireland

County Mayo

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

Dublin

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

Scotland

Ayrshire

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

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

Angus

Angus Stoma Support Group
Valerie T: 07359766289

Dundee Stoma Support Group
E: Rachel.ferguson2@nhs.scot
T: 07581 797605

Edinburgh

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

Glasgow

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

Greater Glasgow

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

Hamilton

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

Moray

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

Scottish Borders

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

West Lothian

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

Wales

Aberystwyth

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

Conwy

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

Gwent

Cwmbran Ostomy Support Group (COSG)
Philippa Lewis
T: 01633 791 339 or 07504 713 069
E: pip112002@yahoo.co.uk

Mid Glamorgan

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

Mold

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

Pembrokeshire

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

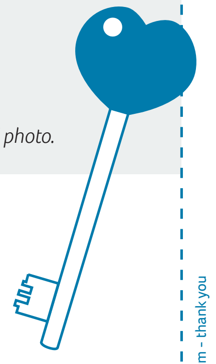
Powys

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

Rhondda Cynon Taf

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

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



Ensure you always have access to a toilet by purchasing a Radar Key and Photo ID card. Through the National Key Scheme, Radar keys open the doors to over 9,000 accessible toilets in the UK in places like shopping centres, pubs, cafés and department stores.

A Colostomy UK Photo ID card, which is endorsed by Disability Rights UK (and displays their logo), can be helpful if you need to use accessible facilities urgently, particularly if they aren't part of the National Key Scheme.

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

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

Title: ____________________
Name: ____________________
Tel: ____________________
Email: ____________________

Address: ____________________
____
____
Postcode: ____________________

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

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

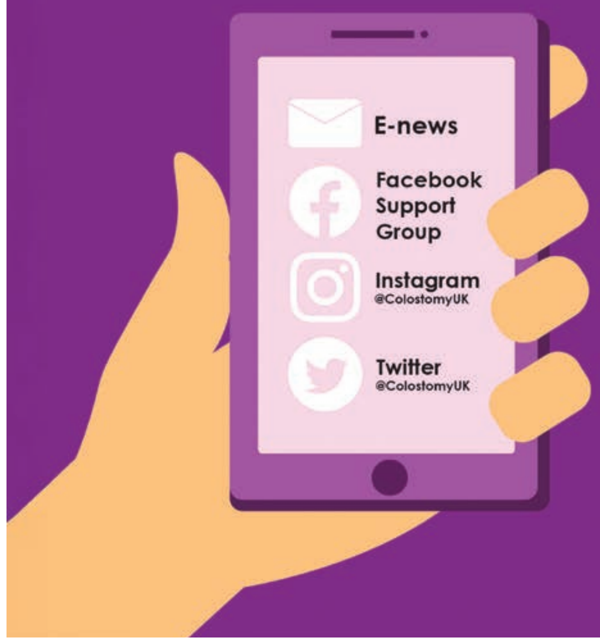
Please **tick** as appropriate:

☐ I would like to receive a Radar Key for £4.50 (inc. postage and packing).
☐ I would like to receive a photo ID card for £6.50 (inc. postage and packing) and enclose a passport photograph.

Return all required items to: Colostomy UK, 100 Berkshire Place, Winnersh, RG41 5RD. Cheques should be made payable to Colostomy UK. For payment by credit card, send your documents in the post with a contact telephone number, we will then call you to take a card payment when received. (If you have any queries or would like to pay by credit card, please contact Colostomy UK office: 0118 939 1537 or Hello@ColostomyUK.org).

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

E-ngage with us!



Go online to access all the support you need from Colostomy UK

Visit our website: www.colostomy.org.uk for downloadable versions of all our advice booklets, information on stoma support groups and events, the latest Active Ostomates classes and practical guidance on living with a stoma.

And while you're there, subscribe to our free, monthly e-newsletter delivered straight to your inbox.

Or connect with fellow ostomates, their family and friends in our private Facebook Group. Search Colostomy UK Support Group Facebook and click to join.

Why not share your news on Instagram and Twitter: @ColostomyUK

...and get involved!

We need your support to Smash Social Exclusion for people living with stomas

Be #StomaAware
Smash Social Exclusion

Nobody should feel excluded from doing the normal things in life, like going to the shops, having a coffee with friends or watching a football match at their local stadium.

To donate, scan this QR code

Visit www.colostomyuk.org/donate or go to page 21 for our donation form

Stay In Touch!

With Colostomy UK

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

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

Colostomy UK Your Way!

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

Colostomy UK

Helpline 0800 328 4257

Looking for information on managing your stoma?

Being Stoma Aware Matters

A TO Z of stoma support

Latest News

London Paddington supports

Scan me to Stay In Touch!

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