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Colostomy
UK 

Supporting & empowering ostomates

Tidings



**“I’m a glass-half-full
kind of a person”**

Danny Lloyd-Jones on the
art of positive thinking

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Tidings Digital:
Having Your Say via
our reader's survey



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Dear readers

This may be the winter edition of Tidings, but at the time of writing it is mid-October. Autumn is only just settling in and yet mince pies have been spotted in the shops. This led to some heated debate amongst the Colostomy UK team. Some argued it's never too early to welcome in the festive season. Others (including myself) were, frankly, aghast. Let the pumpkins and fireworks at least have their moments of glory before yuletide begins, surely! But then, life wouldn't be as interesting if we were all the same.

Another area where we've seen a variety of views has been towards our transition to Tidings digital, which we began rolling out in the summer. Some welcomed the change, while others have struggled with the move away from the paper copy of the magazine. We promised we would continue to engage with readers to better understand their concerns, and respond to these issues wherever possible. This being so, you will find an article and accompanying survey starting on page 41, which offers all readers the chance to have their say - so don't miss your chance to help shape this next exciting chapter on the future of the magazine!

Variety continues in the three-and-a-half Real Life stories we have for you in this issue. Melvyn Wilkins, who has written for Tidings twice before, brings us up to speed on how he is finding life with his stoma. Even after many years as an ostomate, he still finds little surprises, such as stepping outside of his comfort zone while on holiday. Lisa Foster tells our contributor, Leslie Mello, about the complex challenges of living with two extremely rare, incurable diseases, and which also led to her having a stoma formed. For Lisa, her husband and son are a constant source of strength and happiness through the difficult times. Positivity also radiates off the page of our cover feature, Danny Lloyd-Jones, who has been on a rollercoaster ride with bowel cancer for five years and counting. His stoma surgery being just one of almost a hundred individual treatments he has had throughout this time, and yet he continues to have a glass-half-full outlook on life.

So that's three Real Life stories. The half refers to a new column by ostomate Jo Prance, (AKA Tidings' resident fitness guru). Jo is taking a break from her regular 'Ask Jo' column to instead bring you 'Jo's Diary'. Part Real Life story, part wellness article, Jo will take us on her journey over the next several issues of Tidings, as she prepares for, and then undergoes, so-called 'barbie-butt' surgery.

As well as this, we have an exceptional range of other wellness articles for you in this issue. This includes practical tips on the use of convex bags, advice on how to irrigate while holidaying, and the academic, Ben Saunders, offers his biannual Research Roundup. Convatec's Clinical Educator, Nelum Khumari, talks us through the Rethink Recovery programme in our regular Dear Nurse column as well. You'll also find an article summarising everything that the sex therapist Sue Lennon and I learned from participants of a Sex Therapy Focus Group which we held in Birmingham in September. We are hoping these fascinating insights will lead to a series of new resources on this important topic.

All of this plus all our regular columns covering our campaigns, fundraising initiatives, support group updates, and sports teams' highlights. Plenty for readers to enjoy with a nice cup of tea and perhaps even a mince pie...

Ross Othen-Reeves
Editor, Writer and Researcher



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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.
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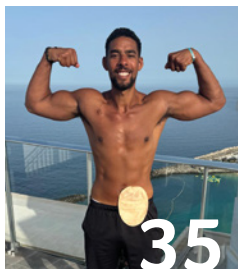
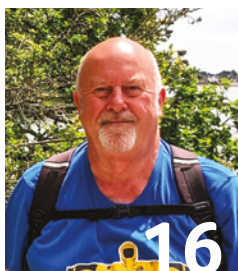
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Nelam Kumari,
Clinical Educator,
Convatec

dear nurse

RETHINKING RECOVERY: Rebuilding Your Core Strength After Stoma Surgery

When recovering from stoma surgery, many people are surprised to learn that one of the most important parts of recovery is rebuilding their core strength. When I talk about your core, I don't just mean your abdominal muscles. Your core includes deeper muscles such as your diaphragm, pelvic floor, side muscles, and those that support your spine. These muscles work together to keep you steady, protect your stoma, and reduce the risk of problems such as a parastomal hernia.



Why your core matters

After surgery, your abdominal muscles are weaker because the surgeon has cut through the abdominal muscle to bring the bowel out to form the stoma. Everyday activity like standing, bending, or lifting can put extra strain on them. If your core isn't strong enough, this strain can increase the risk of a hernia. A hernia happens when part of the bowel pushes through a weakened part of the muscle wall near your stoma.

Your muscles may be weaker due to the incision though the muscle to bring out the bowel to form the stoma. Everyday activities like standing bending of lifting can increase intra-abdominal pressure increasing the risk of a parastomal hernia.

The positive news is that strengthening your core can lower this risk. Doing the right exercises, safely and gradually, will also make daily life easier. A stronger core helps you move with confidence, lift correctly without worrying, and get back to the things you enjoy doing.



How Rethinking Recovery developed

The Rethinking Recovery programme was developed by Sarah Russell, a clinical exercise specialist who also has a stoma.

After her own surgery, Sarah realised there was little clear advice on how to recover safely and the advice that was out there was conflicting. Many patients were told "don't lift," but this was based more on habit than on research.

Determined to change this, Sarah worked with Convatec to design a programme based on physiotherapy principles, patient experiences, and her own knowledge. The result was the Rethink Recovery a programme that is now widely used by stoma care teams across the UK to support patients both preoperatively and post-surgery.

My role as a Clinical Educator

In my role, I train stoma nurses, physiotherapists, and other healthcare professionals to use Rethink and Recovery with their patients. This “train the trainer” approach means more people can benefit from safe, practical advice wherever they are in their recovery.

Healthcare professionals learn simple breathing techniques and gentle core exercises. These simple steps can then be taught either in the pre-op phase or to people living with a stoma. From there, patients can gradually move on to safe, functional activities like bending, lifting, and reaching. The exercises are not about doing high-intensity workouts. They are safe, targeted movements designed to strengthen your core and reduce the risk of a parastomal hernia.

Opposite are some tips for gentle core exercises you can try at home.

If you'd like to know more, ask your stoma care nurse at your next appointment or alternatively you can register with Me+ which is our lifestyle programme for people living with a stoma, here you will find support on movement, parastomal hernia, diet and hydration and many other topics to support you.

1

Breathing exercise to reconnect with your deep core muscles.

- » Start by practising gentle rib or “diaphragm” breathing while lying down. Place your hands on your lower ribs, feel them expand as you breathe in, then let them soften as you breathe out.
- » As you exhale, gently draw in your lower tummy without holding your breath or tensing your shoulders. This helps you reconnect with the deep core muscles that support your stoma.
- » Once you're comfortable lying down, repeat the same technique while sitting or lying on your side. These breathing skills can also be used to support your core when you cough, sneeze, or stand up.



2

Gentle movements you can do lying down or sitting.

- » Simple stretches such as knee rolls (knees bent, gently lowering them side to side) or small arm and leg lifts help to keep joints flexible and muscles active without strain.
- » Pelvic floor exercises can be added at this stage, working in time with your breathing — relax on the in-breath, then gently contract on the out-breath.
- » Sitting upright, practise good posture with a neutral spine. From here, you can add small arm reaches or gentle twists, always keeping your breathing relaxed and core engaged.

3

Exercises matched to your stage of recovery and everyday needs.

- » In the early days, focus mainly on breathing, pelvic floor awareness, and short walks if you feel able. Learn safe techniques for moving in and out of bed or standing from a chair.
- » As you progress, build in functional movements, such as lifting light items with core support, reaching overhead, or practising balance exercises to feel more secure on your feet.
- » Longer term, increase strength and stamina at your own pace. This might mean longer walks, gentle resistance exercises, or more challenging versions of earlier movements. Always protect your core by coordinating breath and movement.



Jo's Diary: Overcoming Mountains



Readers will no doubt recognise Jo as Tidings' resident fitness guru. However, with further medical issues to address over the coming months, Jo is hitting pause on her regular column. In its place, Jo will be sharing personal insights from this latest chapter of her stoma journey.

Climbing Mount Kilimanjaro in October 2025 was set to be my ultimate challenge since becoming an ostomate five and a half years ago. This trek was more than a personal milestone. It was in aid of Chameleon Buddies; a stoma charity whose mission is to support women in Kenya living with birth injuries and stomas, with the goal of building a dedicated stoma care clinic. A cause that resonates deeply with me and reflects my commitment to advocating and supporting women living with the long-term impact of birth injuries. I also hoped to inspire and empower ostomates too.

This adventure was a once-in-a-lifetime opportunity to be part of an all-female team including several fellow ostomates sharing the journey, strength, and solidarity every step of the way. After the climb, I was due to travel to Eldoret, Kenya, to meet some of the incredible women and dedicated team supported by the stoma charity.

Sadly, I've had to step back from this challenge to put my health first. It wasn't an easy decision, but as many of you will understand, sometimes our bodies demand that we pause and redirect our energy. I'm now facing my biggest surgery yet, and with it, another steep climb on the road to recovery.

I'll be undergoing proctectomy surgery, removal of my rectum, often referred to as 'Barbie Butt' surgery, in September just weeks before I was due to depart.

Like so many of you, I know the frustration of having plans disrupted by health, but I also know the courage it takes to keep moving forward. This surgery feels like another mountain in my journey, but mountains are climbed one step at a time. My hope in sharing this is to remind anyone facing their own challenges that it's

okay to prioritise yourself, to slow down when you need to and to take each day as it comes.

It has been an emotional rollercoaster, especially knowing how many people have supported me so far and the amazing women in Kenya we set out to help. I've always taken pride in finishing what I start, so stepping back hasn't been easy but I've come to realise that listening to my body isn't a failure, it's a strength.

Rectal mucus is problematic for many ostomates, and I cannot control the relentless amounts that my body produces daily. It is messy, uncomfortable, and it's made me incontinent again. The irony of my situation isn't lost on me. My end colostomy freed me from the debilitating faecal incontinence I had lived with since a birth injury decades earlier, and having a stoma truly transformed my quality of life. Yet, as one clinician aptly put it, I've now traded one form of incontinence for another – one which has become increasingly intolerable.

When I elected to have a colostomy, it wasn't a short-term decision. I approached the surgery knowing my stoma would be permanent. Technically, it could be reversed if needed, though I have no intention of doing so, as that would simply take me back to the problems I had before.

A proctectomy, on the other hand is final and removes the possibility of reversal entirely. One of my concerns was wondering what might happen if I experienced complications with the stoma in the future.

Making this decision has been tough.

Whilst removing my rectum will eliminate the mucus, the outcomes surrounding rectal pain, rectal spasms, and the constant urge to open my bowels remain uncertain, complicated further by pelvic floor dysfunction.

I have been advised to have robotic surgery 'laparoscopically'; a minimally invasive approach to optimise the result. As with all surgeries there are risks, but I feel confident after much discussion with my surgeon that this is my best way forward and hopefully will increase my quality of life. Naturally, I'm anxious and worried about the surgery and the recovery but I'm also looking forward to being free from constant mucus and the stress of it leaking.



I've been fortunate to receive excellent counselling from my stoma nurse, who happens to be the same nurse that counselled me for my colostomy surgery. We discussed physical movement post-op, wound management, how long to expect recovery to take, (roughly eight weeks) and practical tips such as seating support. On her advice, I've ordered an orthopaedic cushion to help with comfort during my recovery.*

I've also connected with other ostomates who've been through this surgery. Having that peer support has been invaluable. I'm going to try a knee pillow to help keep my knees rested together when sleeping on my side, a suggestion from another ostomate. Hearing about their recovery journeys and learning from their experiences has reassured me that their quality of life is better following the surgery.

At the time of writing, my operation is less than four weeks away. As I prepare for surgery, I've been maintaining my fitness with strength training, walking, and swimming.

While I'm staying active, I'm also listening to my body and not pushing myself as I would if I were training for a competition, especially as fatigue has been a real challenge.

Alongside this, I practice 15 minutes of guided meditation each day, concentrating on breathing and relaxation. It's been especially helpful in easing my mind, allowing me to switch off and find calm, particularly at night when I tend to overthink everything. I plan to continue using these meditations in hospital to help me relax.

When it comes to a hospital stay, it's often the little comforts that make the biggest difference. Aside from the basics like toiletries and nightwear, I've found that a few personal essentials can really help. Headphones to tune out the noise, an eye mask for better rest, lip salve to keep dry air at bay, and my favourite full-sugar fruit cordial for a touch of familiarity and comfort during an otherwise challenging time.

As I look ahead to turning 50 next year, I'm setting my sights on new goals and fresh challenges.

If all goes well and depending on my recovery, I would love to be swimming competitively at the end of January. Whether that timeline is possible or not, my focus remains on the bigger picture: returning to competition. When I do return to the start blocks at a swim, my mind will be able to focus fully on the race and not the worry of leaking mucus.

*Various types of orthopaedic cushions are available. Speak to your stoma nurse to explore which is best for your specific needs.



"I will have a stoma for the rest of my life. There are good days and bad days of course, but anything I can do to feel more confident and really take part in life is so important to me. Having a bag I completely trust makes me feel more confident in myself. It truly means the world and makes all the difference."

Natalie

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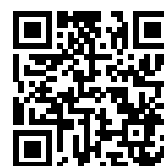
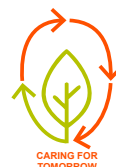
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Research Round Up



Dr Benjamin Saunders
Senior Lecturer in Health
Research, Keele University

Ben has been carrying out research that aims to improve the lives of ostomates for a number of years.



The role of Artificial Intelligence (AI) in stoma care



In this edition, I continue my round up of recent research that's been published on stoma care and experiences.

I'll be discussing three studies, all of which focus on the role of Artificial Intelligence (AI) in stoma care. Some of you may not be too familiar with the use of AI, whilst others may use AI technologies on a daily basis. It seems inevitable that AI will play an increasing role in our lives over the coming years, and this includes its use in health spheres.

TURKISH STUDY

AI Generated Patient Educational Materials for Ostomates

The first study I'll share was carried out in Turkey and looked at whether AI 'chatbots' can be used to produce good quality patient education materials for ostomates. A chatbot is a software application that uses generative AI systems (that is, they can use what they've learned to produce fresh content) and are capable of maintaining a conversation that mirrors human interaction. The researchers in this study wanted to find out if the patient education materials produced were relevant to ostomates' needs and easy to read and understand.

'ChatGPT' was used, a popular, freely available chatbot produced by a US company called OpenAI. The researchers first instructed ChatGPT to carry out a literature

review to identify the information needs of ostomates, through which the following topics were identified: stoma care, nutrition, daily life, psychological support and stoma-related problems. ChatGPT was then asked to create educational content covering these five topics. Finally, it converted this content into a flipbook, including pictures and diagrams, that could be read on a screen or printed.

Study 1 continued overleaf...



The patient education flipbook was then assessed by an expert group of 10 specialist stoma and wound care nurses, using a patient education assessment tool to help them.



ChatGPT was found to provide generally accurate and comprehensive information without any significant medical errors. The information was scored highly on how easy it was to understand (82% on the patient education assessment tool) and on its ‘actionability’ (85%), that is, whether it gives clear, concrete steps the patient can follow in their stoma management. Ease of reading was judged based on guidance from the American Medical Association, which states that patient materials should be targeted at a 12-year-old reading age. The Chat GPT-generated material was found to be pitched at a higher reading age level than this recommendation.

The authors concluded that AI-assisted patient education material for ostomates includes accurate information that’s easy to understand and put into action, though some people may find it difficult to read. However, a key aspect missing from this study— which the authors do acknowledge — is that ostomates themselves were not asked what they thought of this information, nor were they asked how they feel about information coming from a chatbot, which seems like an important oversight. Nevertheless, given that the future role of AI in providing health information seems somewhat inevitable, it’s at least reassuring that the information provided to ostomates is of a good standard.

AUSTRALIAN STUDY

Chatbot Responses to Common Questions on Stoma Management

The second study is on a similar topic. Researchers in Australia were also interested in whether AI chatbots can provide patient education for ostomates, but rather than producing education materials, they looked at the responses chatbots provide to common questions about stoma management. They also wanted to compare the responses from different chatbots. They included two different versions of ChatGPT (an older version, and a newer, expanded version); ‘Gemini’, a chatbot produced by Google; and ‘CoPilot’, which is made by Microsoft, but is powered by OpenAI (who you’ll remember from above also produce ChatGPT).

The questions that the researchers asked each chatbot were based on the 10 most frequently asked questions in stoma nurse appointments at an Australian hospital. This included:

“What should I avoid eating or drinking?”

“Why is my stoma bag not sticking properly?”

“When can I get my stoma reversal?”

Two researchers independently assessed the responses and compared their assessments, with a third researcher available to resolve any disagreements. They used different assessment tools to decide the quality of responses, how reliable the responses were, and ease of reading.

For all four AI chatbots, their responses to the questions were judged as mostly easy to read, clear and relevant to the questions posed. However, the researchers noted that the reliability of responses was difficult to appraise, because the chatbots usually don’t mention where on the internet they got their

information from. In comparing the four chatbots, it was found that CoPilot and the newer version of ChatGPT (version 4.0) produced responses that had better readability, reliability, and overall quality than the other two. ChatGPT and Gemini were found to use a more professional tone in their responses, which the researchers speculate could lead to them being seen as more formal sources of information, but also felt that they could lack empathy. It was found that all four chatbots consistently advised patients to seek guidance from healthcare professionals, therefore framing their responses as a supplement to, not a substitute for, medical advice.

The researchers concluded that AI chatbots are a promising source for responding to ostomates’ questions but are not a substitute for professional advice. They also propose that advancements are needed to allow chatbots to provide more personalised responses.

Once again, a key absence in this study is the view of ostomates themselves on the usefulness of these responses. Also, the questions posed seem to relate primarily to experiences of recent stoma surgery. It would be interesting for future research to explore how AI chatbots respond to questions from people who have lived with their stoma for a longer period.



DUTCH STUDY

Predictive Machine Learning to Support Surgeons' Decision-Making

The final study I'd like to share is a little different, focusing on how AI can help surgeons' decision-making (and this one does involve seeking the views of ostomates). Researchers in the Netherlands looked at Predictive Machine Learning. In simple terms, this is where a computer learns patterns from past data to make future predictions. The study investigated whether Predictive Machine Learning could be used to help prevent colorectal anastomotic leakage (CAL) in colorectal cancer patients. CAL happens when, after surgery to join two parts of the colon or rectum, the new connection (anastomosis) doesn't fully heal. This can mean intestinal content leaks into the abdomen. Predictive Machine Learning can be used during surgery to help the surgeon predict whether this problem will occur. If it is shown that CAL is likely, the surgeon can carefully choose where to place the stoma to reduce the likelihood of this leakage from happening after surgery.



if groups were held with people from each country separately, or a mix of people from different countries).

Everyone who took part expressed optimism that Predictive Machine Learning could be better at assessing the risk of CAL than surgeons by themselves, and could therefore improve surgical decision making. However, some of the participants stressed that the AI model needs to learn from, or be 'trained on', high quality, up-to-date datasets, to make sure it's as accurate as possible.

Participants also expressed some concerns that Predictive Machine Learning could reduce the human element of patient care. They wanted surgeons to integrate the AI insights with their knowledge and understanding,

but for the surgeon to be the one that makes the final decision. Whilst some participants felt it would be important for patients to be given clear information about how Predictive Machine Learning is used, others did not feel that there is a need for the patient to be told. They made comparisons with other fields such as radiology, where AI may be used in medical

scans without the patient being aware. It may be interesting for a future study to explore surgeons' views on this topic also, particularly in light of the patient findings.

Whilst the inclusion of AI technology was largely seen by participants as being a positive addition to colorectal surgery, this study shares similarity with the others discussed, in that AI isn't seen as being able to take the place of healthcare professionals' advice or expertise (or not yet at least). Whilst AI may represent the future of healthcare, it seems that in relation to colorectal surgery and stoma management, the human element is still important in the present.

References:

- Hmido SB, Rahim HA, Ploem C, Haitjema S, Damman O, Kazemier G, Daams F. Patient perspectives on AI-based decision support in surgery. *BMJ Surgery, Interventions, & Health Technologies*. 2025 Apr 2;7(1):e000365.
- Lim B, Lirios G, Sakalkale A, Satheakeerthy S, Hayes D, Yeung JM. Assessing the efficacy of artificial intelligence to provide peri-operative information for patients with a stoma. *ANZ Journal of Surgery*. 2025 Mar;95(3):464-96.
- Yücel Kaçmaz H, Kahraman H, Akutay S, Dağdelen D. Development and Validation of an Artificial Intelligence-Assisted Patient Education Material for Ostomy Patients: A Methodological Study. *Journal of Advanced Nursing*. 2025 Jul;81(7):3859-67.



The researchers wanted to find out what people with colorectal cancer thought about Predictive Machine Learning being used to help surgeons. They carried out online interviews and focus groups via 'Zoom' with 19 people from five different countries – the UK, Netherlands, Germany, France and Sweden (although it's unclear



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Name: _____

Tel: _____

Email: _____

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:

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Why you might need a convex stoma bag

Tidings contributor, Jillian Matthew, explains what convex bags are and how they can help certain ostomates.



Finding the perfect bag

There are lots of different reasons why finding the perfect stoma bag can be challenging. When you first have a stoma, it can be quite surprising to discover the range of options and different types of stoma bags that are out there, and that it definitely isn't a case of one size fits all. There can be a lot of trial and error when trying different bags to find the one that suits you. Getting the right fit can depend on your body shape and your stoma shape, position and size – all of which can change over time.

The impact of not having a stoma bag that fits properly can include pancaking, leaking, and skin irritation. This in turn can limit your activities and make you wary of going out if you are worried about being able to find suitable toilets to change your bag.

Finding a bag that's comfortable and fits your body shape is so important and can make a huge difference to how you are able to live your life.

Convex stoma bags

Baseplates (also called wafers or skin barriers) are the part of the stoma bag that sticks to your skin around the stoma and connects to the bag. When you are in hospital for your stoma surgery, you usually wake up with a standard flat stoma bag attached. This is what I was given and used when I went home. However, my stoma is completely flush to my skin. I was getting a lot of pancaking and leaks under the baseplate because my stoma wasn't protruding into the bag. It was only when I started to investigate this further that I found out about convex stoma bags and how these could help me.

Rather than being flat and flush against the skin, like a standard baseplate, convex baseplates are shaped into a dome that faces into the body.



They are often flexible and mould to the shape of your body. Convexity provides pressure around the stoma, which allows the stoma to protrude further inside the bag. A variety of convex bags are available, including both soft and firm baseplates at different depths and which apply different amounts of pressure.

Reasons for needing convex stoma bags can include having a:

- » flush stoma
- » retracted stoma
- » stoma in a flexible skin fold
- » peristomal ulceration.

If you recognise any of these issues and you think you might need a convex stoma bag, speak to your stoma nurse to get advice about it.



Convex baseplates for urostomies

For a urostomy, you need the stoma to stick out for urine to pour out into the bag and not seep under the baseplate and you may need stronger convexity, however firmer convexity can put more pressure on the abdominal area. There may be other options for you rather than a convex bag, depending on your own situation. As we all know, everyone's stoma is unique!





Living, Travelling, Thriving: Melvyn's Stoma at Five Years

Melvyn Wilkins first wrote about his stoma experiences in the Summer 2020 edition of Tidings. He then followed this with a second feature in Winter 2023. In this third instalment, Melvyn shares how, five years on from his initial surgery, living with a stoma is still full of surprises, not least while on holidays.



To go back to the beginning of my stoma journey – which is owing to having bowel cancer – surgery was planned for January 2018 which required an APER operation (Abdomino-Perineal Excision of the Rectum). Thankfully this went according to plan. I felt relatively OK on returning to the ward. So, what happened? After going home, the wound sites took ages to heal, and I had two abscess breakdowns. One site was being dressed daily, so after nearly two years I went back to Gloucestershire Royal Hospital in

August 2019 for some reconstructive surgery on my APER site. But then the keyhole site got infected. It wasn't painful or uncomfortable, just a daily task to change a basic dressing. I saw the consultant again in February 2020 to determine the depth of the abscess track, and she said a further bit of reconstructive surgery may be needed. However, my GP nurse suggested we try a PICO negative pressure dressing instead. (A 'PICO' being a small, battery-operated pump and special dressing which applies continuous pressure to a

wound, helping it heal by removing excess fluid and bacteria).

The PICO dressing was on for about six weeks, but fraught with leaks and pump failures. An abnormal cavity, known as a 'sinus' had now also formed and refused to heal, so we went back to Plan A – daily dressings. To be honest, these weren't a problem, just a large wound dressing applied each day, undertaken by my wife, Mandy, with occasional visits to my local GP nurse to check the skin and the site itself, which if anyone wonders, was on the very top of my bum, so not a dressing I could do myself!

I decided I could keep this up almost indefinitely and so chose not to have yet further surgery. But then something made me think differently.

Mandy went down badly with Covid in November 2021 and was bedridden for over a week. I needed to drag her out of bed to do my dressings every day. Then I contracted Covid too. Here I had a mindset change – what if she was no longer able to do my dressings?

In January 2022 I went back to the consultant and said I would be prepared for her to attempt a second reconstructive surgery. The second wound site had healed, and I was ready for another try.

After eight months of waiting, I finally went for a pre-anaesthetic assessment – but then heard nothing. This was October of 2022, and as the assessment is only valid for six months, another had to be set up for the following May. Surgery was then at last set for June 2023. Typically, however, I was due to celebrate my 70th birthday that very same month, and I had plans to

holiday in Switzerland with friends and family. So I requested the surgery date be pushed back.

In the meantime, I had an appointment with a new consultant, mine now having retired, and the news wasn't good.

Following his assessment, he concluded that the surgery would be unsuccessful once again, and in effect, I would have to live with constant daily dressings – forever.

It was now time to take that trip to Switzerland and we were going to fly, whereas in the past I drove, or we went by train, as I don't really enjoy the whole air travel fiasco. This created further concern for me; what to do with all my dressing materials, as well as all my stoma products – which were enough to fill a suitcase before even packing anything else. What if they lost my baggage and I arrived in Zurich with nothing to use for the next seven days?!

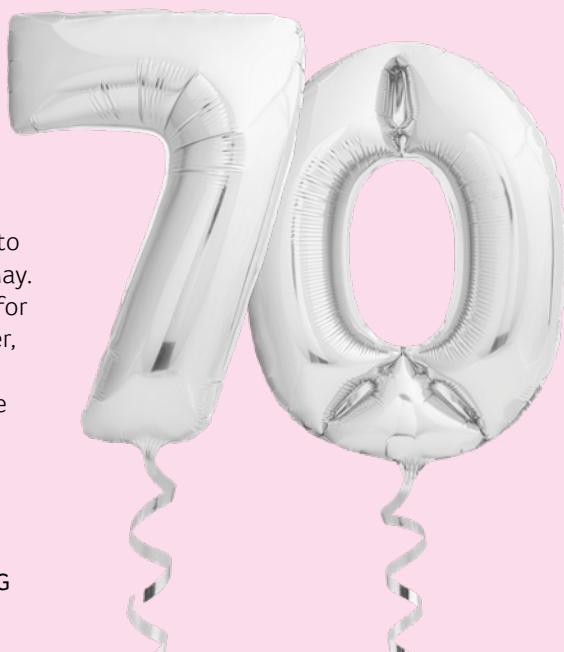
I had a plan though; I had a friend in Switzerland who happened to live about five miles from our accommodation. Labelling all the items, sealing them in plastic sacks, filling out all the different customs declarations and packing them in a box, I posted them all to her in plenty of time to ensure they would arrive. The plan worked and she delivered the box to me on arrival

in our Airbnb, a huge apartment above a Mexican Restaurant – the smells were amazing!

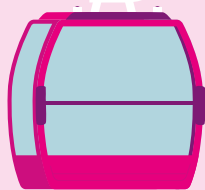
Putting all my worries behind me, I made sure the holiday and celebration would go like clockwork, which it did. My daughter and her partner flew in from Canada and my son and his partner from Gloucestershire. We were also joined by my friend Steve. It was planned that both he and his wife would join us, but she died from motor neurone disease the Christmas before, so it was sadly just him.



On the day of my 70th, I met up with my Swiss friends and we enjoyed a light lunch and a few drinks at a lakeside restaurant, then they started to strip off to go swimming. Ever since the initial surgery I was no longer confident to be immersed in water; no baths, no swimming pools, and no seaside swimming. They all enjoyed it, but I felt that I could never get in water again, as concerns over waterlogged dressings and a leaking stoma pouch filled me with dread.



Every morning, Mandy would do my dressings and we would leave the apartment for the day, me accompanied by my ever present 'man bag' which always contained all my stoma products should they be needed. We travelled around by train, and even paddle steamer. One evening I had pre-booked a table for us all in a restaurant. It was a revolving restaurant at 1898m (6227ft) on the Stanserhorn – a mountain overlooking Lucerne. To get there, we first took a local train from Lucerne to Stans, followed by a 120-year-old funicular for the first quarter of the ascent. From there we transferred to the new CabriO aerial cableway with its open roof. It is a truly amazing feeling to stand on the open roof of a cablecar and experience up close the passage between the supporting masts, just enjoying the headwind and the magnificent view – without any cables overhead. We dined with a panoramic view for about 10 minutes before the clouds rolled in, the wind increased, and we sat through a massive thunderstorm which cleared as quickly as it arrived.



Back home, and several months later, things started to look different, in more ways than one. A small lump appeared on the hole that was where my sphincter used to be. Mandy decided it looked like a wound granulation which we hoped would slowly cover the hole. But over the next few days it got bigger and bigger, until it was finally the size of a broad bean. We decided I should go and see the practice nurse, but then it suddenly came off when Mandy was doing a dressing. Several days later, Mandy declared that the hole was drastically reducing in size and just two days later it had closed completely. Two years on and I've still had no further issues.

Was there a 'foreign body' or dislodged piece of surgical mesh that had been forcing the hole to remain open and discharging, which had finally worked its way out? I will never know.

In June 2025 we holidayed in Brittany, France, with an apartment right on a secluded beach. The year before I had threatened to get in the sea in this same spot, but chickened out as I was still self-conscious about my stoma pouch being visible and the possibility of it leaking. This time I was going to do it. I had purchased some swimming trunks that would cover my stoma pouch, but I felt they looked ridiculous on me – almost coming up under my armpits. I considered going in with a T-shirt on and that was my plan, until I saw something which changed my mindset 100%.

Lying just in front of us on the beach was a woman in a bikini sunbathing. Then she got up and went down to the water's edge – and threw down her crutches, she only had one leg! Then she hopped into the water far enough that she could swim and repeated the exercise to get out.

No-one turned an eye to stare at her. If she could do it, so could I.

Remembering to put a sticker over the stoma pouch filter, I stripped off my T-shirt and walked bravely down the beach.

The sensation of entering water after seven long years was amazing, I did it three more times that afternoon and again the following day – and no-one took any notice. I was cured of my doubts thanks to that woman.

As well as enjoying such holidays, I also run a 1980 Triumph Dolomite Sprint in classic car shows and scenic tours in the summer months.



Throughout the winter, I now write as a hobby, and I have just had my fifth book published. Why worry when there is more to life? Enjoy it and make it the best you can.

You can read Melvyn's previous articles by clicking on the link below for access to the Tidings back catalogue or simply typing the same title into your online search engine.

Colostomy UK Tidings Magazine

Melvyn Features in:

- Summer 2020, page 31
- Winter 2023, page 37



Team Colostomy UK Rugby League Updates



Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org

Turn on your TV again!

In the last issue I ended on the note that the BBC Look North cameras attended our game in Batley in June to film us play against the West Yorkshire Police.

Well, that went a little bit crazy didn't it!

From July onwards, Team Colostomy UK found itself on the BBC website with a story about our team and fullback Mikey Adam's battle to play rugby league again after surgery. Then came TV

spots on BBC News, BBC Look North, SportsLine, and finally the famous BBC Breakfast sofa. The conversations, publicity and goodwill generated were all huge, and gave us a real boost as we headed into our busiest period of the year.



From Sheffield to Neath, via Kent and Chorley.

August started with a visit to Sheffield Eagles and the Eagles Foundation, for our 'Big Day Out 2' event which saw us take on the Eagles at Wheelchair, Touch, Walking, and Physical Disability Rugby League (PDRL) as curtain raisers to the championship game between the Eagles and Widnes Vikings.

It was another brilliant day in sunny Sheffield which highlighted not only the exclusivity of rugby league but also the different opportunities people have to play the sport with us regardless of their age, gender or experience.

A trip to Gravesend followed for our last Wheelchair Rugby League game of 2025, where we faced Gravesend Dynamite. It was a season for 'Purps on Wheels' that started in Edinburgh, with a huge learning curve against Super League side Edinburgh Giants, and which ended in Kent with a 32-22 win. The perfect finish to a season full of promise and growth.



Our PDRL team then played two games in two weeks. First against our old friends Chorley Panthers and secondly, to Neath to face the Wales PDRL team at Gnoll stadium. It's always exciting when we have the opportunity to play at iconic sports stadiums, so it was an honour to play Wales at the Gnoll, one of the most famous Rugby venues in the UK.

Get involved

If you'd like to join Team Colostomy UK either as a player or volunteer, please do get in touch with Giovanni at GetInvolved@ColostomyUK.org. We're especially on the lookout for physios to support on match days, and a team manager.

Going International

July also saw another first for us, as Matt Turner and Tyma Hughes were selected to represent Wales in July against England in a PDRL international fixture. Further evidence that as well as 'raising awareness' of stomas, our players can excel too. Congratulations to both.



Thank you!

As 2025 draws to an end, I'd like to say a huge thank you to our team of partners. Opus Stoma Care, SecuriCare, CUI, MedicarePlus International, Welland Medical, West Yorkshire Wellness Centre, Sto Care, and Kappa - THANK YOU! We couldn't do what we do without you.

Finally, to our players. Each year we continue to push back the barriers of what people living with stomas can achieve in Rugby League. In a year that has seen us zigzag across the country from Scotland to South Wales via Yorkshire, Lancashire, Cheshire, and Kent, your commitment, humour and spirit have been inspiring and unbreakable. It's been a pleasure to spend this season with you. Thank you for all your efforts in 2025. See you next year.



A Way of Life: Gillian Hendry on Irrigation

Irrigation offers freedom to many ostomates - but it requires diligence and routine to be successful, as Gillian Hendry explains.



Tell us a little about yourself

My name is Gill. I live in Cheadle-Hulme and am fast approaching my 70th birthday. I initially trained as a general nurse and then spent the next 40 plus years nursing sick children on paediatric wards and in the community. I retired in 2018, and now enjoy socialising with family and friends, and taking holidays with my husband.

When and why did you have a stoma formed?

I was diagnosed with endometrial cancer in 2016. This resulted in a hysterectomy. Unfortunately, this didn't resolve the problem and in 2018, the cancer was still evident.

Despite radiotherapy, I was informed that this hadn't worked and that I would need a total pelvic clearance resulting in a colostomy and urostomy.

I was understandably devastated, but there was sadly no alternative. Surgery took place in August 2019.



Why do you prefer to irrigate rather than solely use stoma bags?

As I have both a colostomy and a urostomy, I looked into the possibility of irrigation as at least I might then have control over the situation with my colostomy and help with my confidence when dealing with both bags.

What is involved in irrigation?

As described in previous Tidings articles*, irrigation involves warm water being directed via a tube into the stoma and then draining the stool out through the attached drainage sleeve.



This is initially done with support from a stoma nurse, and the amount of water administered is calculated. The procedure doesn't hurt but can become a bit uncomfortable towards the end of the water being administered.

I prefer to sit facing the toilet and have a folding chair to facilitate this. I like to be prepared and as I usually do my irrigation in the morning on alternate days, I get all the equipment ready the night before to save time.

When starting my irrigation, I usually place an incontinence sheet on the chair and floor, just in case there is an unforeseen leak during the irrigation process. I usually watch programmes on my tablet or catch up with the newspaper online as the process can take approximately an hour.

Following irrigation I put on a stoma bag and then shower. I prefer to use a stoma bag as there is sometimes some residual fluid still present especially when I start to be mobile. I will then change the bag for a new one which should last, content free, for 48 hours.

What are some of the things that ostomates should be aware of if they wanted to try irrigation?

Irrigation is great for me as it has given me control of my output. However, to irrigate successfully there needs to be a high level of commitment, especially when people initially start, as it usually needs to be done daily until the bowel adjusts. You therefore have to ensure it fits in with your lifestyle.

I normally irrigate in the morning, but it can be done at any time of the day. Though it's best to do it around the same each day. Sometimes, however, if I have a very early start -

a flight for instance - then I may get up much earlier or complete my irrigation the night before. Then continue on my normal pattern.

Whilst I can normally go 48 hours between irrigations, it's important to be aware that occasionally, due to things like a change in diet, you may find your bowels work in between your regular irrigation times. I always continue to irrigate alternate days to keep on track. I still sometimes produce gas which I have to relieve from the bag, but fortunately not too often.

What are your top tips for anyone considering irrigation?

I continue to irrigate on holiday.

If travelling by car within the UK, I take my fold up chair so I can still sit facing the toilet when irrigating.

If abroad, the first thing I check out in the accommodation are the bathroom facilities, to decide how I am going to set up my irrigation process, and what chair is suitable for me to use. I always find a way to facilitate my irrigation.

When abroad, I use bottled water to irrigate.

If finding enough bottled water is a challenge, or it is particularly expensive, I may use boiled bottled water and then top it up with cold bottled water to get the right temperature. To enable this, I take a small plastic measuring jug and pour the cooled water into the irrigation water container.

I take a plastic hook with me on trips too, to enable me to hang the irrigation water container up - usually from the shower screen (or anywhere else which allows gravity to do its thing, enabling the water to flow into the stoma). After each irrigation I dispose of the sleeve into a disposable

bag. I also usually double-bag before putting it in the bin.



I find if staying at family or friends' houses, they are always accommodating to my need to irrigate, as I am very open about my colostomy and urostomy.

It is important to be aware that, if travelling to unfamiliar parts of the world, you may get a stomach upset. It is therefore a good idea to take extra colostomy bags with you on any such trips. I still try to continue irrigating, even if I have a stomach upset - or if I am unable to do so, I will get back on track as soon as possible.

If travelling by plane, I always pack my supplies in hand luggage to ensure I don't lose anything in transit, and ensure my sleeves are pre-cut so I have as little extra to do as possible while away.

Any final thoughts?

I find irrigation suits my lifestyle and would personally recommend at least giving it a go if you are able to. It means I have control of my colostomy rather than it having control over me. It also makes it easier for me to deal with my urostomy.

I hope this gives some positive insights into colostomy irrigation which isn't as complicated as it might initially appear.

For more Tidings articles on irrigation, see:

- » Dear Nurse column from the Autumn 2025 issue
- » Extolling the Virtues of Irrigation from Autumn 2024 issue



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Living with the Unknown

Lisa Foster's Journey with Rare Digestive Disorders



Lisa Foster lives with two rare, incurable, and under-researched conditions. This has meant that her journey to date – as well as what the future holds – have been impossible to predict. Yet one thing that is certain is the new lease of life that Lisa's stoma has given her.

When Lisa Foster welcomed her son George in 2018, she never imagined that just a few years later she would be facing the most debilitating time of her life – and that George would become a beacon of strength and courage in the way he handled his mother's illness.

Lisa is living with a permanent ileostomy and navigating the uncertainty of chronic intestinal pseudo-obstruction (CIPO) and mesenteric plexitis. To have one condition on its own is considered very rare – but to have both is

extremely rare. It is estimated that she may be one of only six or seven people in the entire UK who have both. Frustratingly, her consultants admit there is little research to guide them because the conditions are so uncommon.

A Lifetime of Gut Struggles

Lisa's health struggles began from birth. At times, she would go for long stretches without a bowel movement, sometimes weeks at a time, even as a newborn.

For years, doctors dismissed it as "IBS with constipation", but the true cause was far more complex.

By her late twenties, Lisa developed achalasia, a disorder of the oesophagus that made swallowing difficult and required major surgery. But it was after the birth of George in 2018 that her gut began to fail in far more serious ways.



"I once went 24 days without a bowel movement while pregnant," she recalls. "By the time I had my son, I looked like I was carrying triplets."

In 2021, her bowels stopped functioning almost entirely. After 49 days without a bowel movement, surgeons performed a subtotal colectomy, reconnecting her small intestine to her rectum. Unfortunately, adhesions later closed that connection, so intestinal contents had no way to exit and she became very sick.



Two weeks later she underwent emergency surgery to create a permanent ileostomy. "I thought my life was over," Lisa admits. "But the stoma saved me. Without it, I wouldn't be here."

Eight Months in Hospital

Her recovery was anything but straightforward. After surgery, Lisa's small intestine went into ileus multiple times – a form of paralysis in which the bowel refuses to function.

Eating or drinking while in ileus can cause serious risks, so the first line of treatment is to be 'nil by mouth', meaning Lisa had to stop all food and drink while her small intestine had a chance to rest.

Most patients endure this for two to four days depending on their circumstances and are supported with IV fluids in the meantime.

For Lisa, however, things were very different. An unfortunately blunt registrar told her she would be dependent on TPN (total parenteral nutrition) through a central line for the rest of her life, and that she would not live to see 40. "It was devastating," she says. "But later, I was told by a different intestinal failure specialist that patients can live on TPN for decades. It was a lesson that a prognosis isn't always fact, and I felt a bit of hope."

She then had to come to terms with the idea that she would never enjoy food or drink again. Even small sips of water were forbidden. It was hard to imagine, and she struggled with the daily meal service in hospital when others were eating and she had to sit

with nothing. Lisa remembers fondly how the nurses helped her through this. "Mealtimes were very hard. I couldn't eat or drink anything – even a sip of water. But the nurses would sit with me, chat, and keep me company. Their kindness got me through some very dark moments."

From Hospital to 'Big Brother House'

One of the hardest parts of Lisa's long hospital stay was feeling incredibly homesick. She was missing out on everyday family life with her young son George, their two beloved dogs, Milly and Ted, and her wonderful husband, Craig. Visiting was difficult for her family because Lisa was in a specialist hospital, over two hours away from home.

Craig, determined to help her reconnect with home life, came up with a simple but ingenious solution. He installed cameras in their home and garden, then set up a private live stream Lisa could log into from her hospital bed. Suddenly, she could watch George racing around the garden, kicking a football, playing with the dogs, or snuggling down at bedtime with his storybooks. She could hear them and talk to them over a speaker. She could even read George his bedtime stories as Craig sent her screenshots of the book they were reading that night. Lisa jokingly referred to the situation as their own personal "Big Brother House".

"Of course, it wasn't the same as being there," Lisa says, "but it gave me such comfort. I'd log on at night and see George fast asleep, looking so peaceful. It reassured me that at least he was happy and safe."



That digital connection helped Lisa feel part of family life at a time when she felt incredibly isolated and alone in hospital. It became a reminder of what she was fighting for, and of Craig's unwavering creativity and love in keeping their family close despite the distance.

The Joy of Eating Again

After more than a year on TPN, Lisa treated herself to "one sip of water" at her husband's birthday dinner. When she realised her body coped, she checked with her Intestinal Failure Care Team, who advised her to cautiously begin sipping water, then clear fluids like tea and Bovril, and finally soft foods. To everyone's surprise and delight, her digestion started to work again and by Christmas 2024, she managed to enjoy a festive dinner with her family.

"I sometimes cried during those first meals."

"I never thought I'd taste mashed potato or sit at the table with my son enjoying a meal together again. The feeling of relief and joy was overwhelming."

Today, Lisa eats a modified diet, avoiding foods that can block her stoma, but enjoys a relatively normal life. She requires regular B12 injections and iron infusions but has regained her strength and her weight mainly through food and drink – something most of us take completely for granted.

George's Bravery

Lisa and her husband chose never to hide the truth of her condition from their son. Instead, they used humour and creativity to help him understand and cope. Together, they gave her medical devices playful names: her stoma is affectionately called Petunia.



She recalls, "Past central lines were Perry the PICC line, Terry for TPN, and Peter for the Hickman line – named after the famous motorcycle racer, since my husband is mad about motorsports. And let's not forget Nigel the NG tube, who helped me during my long admission." George, meanwhile, calls her stoma his mom's "belly bum" – surely the most adorable name for a stoma yet.

George, now seven, has grown up with these realities and has always shown extraordinary empathy and understanding. "I was bursting with pride," Lisa recalls. "When another child once called me disgusting because of my stoma, George looked them straight in the eye and said: 'My mummy isn't disgusting. She's beautiful inside and out!' Hearing that from him melted my heart. He's only little, but he's already wiser and kinder than most adults."

Because of how well he has coped, Lisa nominated George for a BBC Make a Difference bravery award last year, recognising the resilience he has shown throughout her illness.

He was named a runner-up, and celebrated with a special day out on bumper cars at Weston-Super-Mare pier. "He's coped with more than most adults," Lisa says proudly. "He deserved that recognition."

Craig, too, has been Lisa's anchor, stepping away from his career to care for her and George full-time, often holding the family together through housing crises, financial strain, medical emergencies, and, sadly, the untimely deaths of their beloved dogs, Milly and Ted. "If I could nominate him too, I would," Lisa says.

"We've been through so much as a family."

Facing the Future

Lisa first reached out to Colostomy UK through Instagram, hoping to raise awareness about rare, incurable diseases such as hers and the many different types of stomas. "Some people think stomas are just about colostomy bags," she explains. "But each type comes with its own challenges and benefits. I want people to understand it's not the end of life – it's the reason I'm still alive".

She is honest about the difficulties like skin soreness, leaks, fatigue, but also about her gratitude. "I don't love my stoma, but I accept it. It gave me a second chance.

And I've learned that life isn't about waiting for the storm to pass – it's about learning to dance in the rain."

Doctors have warned Lisa that her rare conditions may cause further intestinal failure in time, potentially requiring TPN again or even a multi-organ transplant. It is a frightening prospect, but she chooses to focus on the present. "No one knows when their time is up," she says. "I just happen to live with a bit more uncertainty."

For Lisa, living with a stoma is not the end of her story, but the beginning of a new chapter. "It hasn't always been easy," she reflects, "but it's given me a strength I never knew I had. My stoma doesn't define me – it reminds me that I'm a survivor."

She knows the journey is never all sunshine and rainbows. But she wants others to know they are never alone. "You are not broken," she says. "You are stronger than your scars, braver than you realise, and you never have to face this journey alone."

You can follow Lisa's journey on Instagram: @LisaStomaLife



Give a little, change a lot



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.

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



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 been given."

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.



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.

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The Direct Debit Guarantee



- 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
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Health Ability Passports



Shauna Ann,
Community Liaison Lead

Colostomy UK has partnered with the Royal College of Nursing (RCN) to develop a 'Health Ability Passport'. Our Community Liaison Lead, Shauna Ann, tells us about the scheme and where the novel idea came from.



In a nutshell, what are 'Health Ability Passports'?

The Health Ability Passport has been created for nurses who live with a stoma. The idea came from the RCN's UK Professional Lead for Long-Term Conditions, Callum Metcalfe-O'Shea and Disability Officer and Operational Lead, Holly Chadd. It is a form designed to help the RCN's members have meaningful discussions with their employers about their condition, to ease them back into their nursing roles while avoiding unnecessary challenges in the workplace.

Where did the idea come from?

I met Callum at the Best Practice conference in 2024. Callum. We spoke about how limited stoma awareness is within certain

healthcare environments. From this conversation, he invited us to speak at the RCN's Long Term Conditions Conference, with a speciality focus on gastrointestinal care, taking place in 2026.

We have continued to work together since then. For instance, we invited Colostomy UK volunteer, Linda Griffiths, to attend the RCN's 'Long-Term Health Condition Updates' webinar. Linda is both an ostomate and a nurse, so instantly proved herself the perfect person to provide feedback into the draft version of RCN's Health Ability Passport.

Callum and Holly had the vision and led the creation of the 'passport', while our team at Colostomy UK provided feedback along the way.

Why is the scheme needed within the nursing sector?

Our research suggests that non-specialist GPs and ward nurses (i.e. doctors and nurses who don't work in the field of stoma care) are more likely to deliver care deemed 'Poor' or 'Very Poor' to those with stomas.

At Colostomy UK, we of course want to ensure that all clinical staff receive greater stoma-related training so that their patients have a better experience.

By extension, Callum realised that nurses who also happen to be ostomates, may be working under clinical managers who don't therefore have a thorough understanding of stomas or the needs of ostomates.

Both Callum and our team at Colostomy UK wanted to address this.

Could it be used in other sectors beyond nursing?

This is definitely a possibility. We will be watching the success of RCN's initiative with keen interest, as there is certainly a need; our research shows that just 14.5% of people disclosed living with a stoma to their employer.

We hope that RCN's Health Ability Passport will give more people the confidence to inform their employers that they are living with a stoma, so they can get the additional support they might need in the workplace.

For any nurses living with a stoma, who might be reading this, where can the Health Ability Passport be found?

The Health Ability Passport is now live and available at: [Stoma | Long Term Conditions | Peer Support Service | Royal College of Nursing](#). Alternatively, you can search 'Stoma Long Term Conditions. Peer Support Service. Royal College of Nursing'.

If you would like further advice on returning to work, you can:

Contact our staff and volunteers with lived experience via our stoma helpline on **0800 328 4257**, or email Hello@ColostomyUK.org.

You can also click on our website hyperlink: [Returning To Work](#).

Or search 'Colostomy UK Returning to Work' in your web browser.





The Last Taboo(s)!

Insights from an Ostomate Sex Therapy Focus Group



Sue Lennon

There are many contenders for society's 'last taboo' – topics that we often find terribly embarrassing to discuss openly. Sex is of course one such subject. Bodily functions are another. No wonder then that there is comparatively little guidance on the topic of sex and bodily functions combined. At Colostomy UK, we decided to tackle this issue head on.

We partnered with Sue Lennon, a sex therapist with years of experience in supporting ostomates to regain sexual and body confidence, enabling people to live their sex lives to the full.

Together, we invited a diverse range of people living with stomas to attend a focus group session* to talk about sex and all that goes with it – the highs, the lows, and crucially, how these experiences and knowledge might inform new resources and services at Colostomy UK and within the wider stoma community.

Participants

The focus group drew a mix of participants, reflecting the variety of the stoma community. The ages amongst attendees ranged from 22 years up to 70+.

We also had representation from the LGBTQ+ and disability community, a mix of men and women, as well as a range of underlying conditions.

Between the participants, all three of the main types of stoma were represented (colostomies, ileostomies, and urostomies). Two of our attendees were also living with two stomas, including one person who lives with a

lesser-known type of stoma, called a mitrofanoff.

Some were relatively new to life with a stoma, and were able to share recent experience regarding issues of self-esteem and managing relationships. Others had been living with their stomas for many years, bringing years of wisdom to the conversation.

The Purpose of the Focus Group

The aim of the session was to hear ostomates' experiences of sex in relation to living with a stoma. We of course wanted to understand participants' challenges and concerns, but also the positive aspects to sex as well. The physical freedom that a stoma brings to many, for instance, or the reassurance that comes from the loving support of a partner.

By hearing directly from participants, we hope to inform future initiatives, from educational materials to interactive resources, ensuring that they are relevant, accessible, and genuinely helpful within the wider stoma community. The focus group was just stage one of this piece of work (read on to find out how you could also get involved).

Topics Covered

Led by Sue, participants opened up about a wide range of topics, reflecting the many facets of sex while living with a stoma. Some of the main areas covered included:

Practical Living

Participants shared tips and experiences around day-to-day stoma management in relation to sex. This included discussions about bags, accessories, and stoma care companies which offer relevant products, as well as managing hygiene and comfort.

Intimacy and Confidence

One of the most valuable parts of the session was exploring issues around sex, intimacy, and body-confidence. Attendees highlighted how a stoma can impact relationships, and shared ideas for navigating these challenges. Participants also noted how experiences differed depending on gender, sexual orientation, age, and other characteristics.

As many ostomates would affirm, living with a stoma is not the only aspect which may affect someone's sex life or confidence in the bedroom. The group talked for some time about underlying conditions and medical procedures which had also impacted on their ability to have sex, including chemo and radiotherapy, and surgeries. From erectile dysfunction or risk of impotence for men, through to a loss of sensation or partial removal of the vagina for some women in the group.



Emotional Wellbeing

The psychological side of engaging in sex while living with a stoma was another key theme. The group talked about the sense of loss or anxiety that can come with bodily changes, and the importance of rebuilding body-confidence and self-esteem. It seemed clear to us that any future resources on the topic of sex should have a focus on psychosocial support if they are to be truly effective.



Community and Support

Another key theme was the importance of connection and peer support. Many participants reflected on how sharing personal stories and practical tips helps to normalise the topic of sex amongst the stoma community, as well as providing reassurance to others facing similar challenges.

The focus group was itself an example of this peer support in action, as participants listened attentively to one another, offered words of encouragement and shared advice to each other based on their own experiences.

Ideas for Future Resources and Services

We are still in the very early days of working through all the rich learnings from the focus group session – but we can hint at some of the great suggestions which participants came up with while together. Ideas included guidance on conversations with partners, tips for managing intimate moments, and how best to broach sex with your stoma nurse.

Other top tips included:

- » Practical, easy-to-access advice that addresses both general sexual health queries as well as intimacy concerns should be high priority.
- » The importance of emotional support, helping people feel more confident and comfortable in their bodies when it comes to sex.
- » Thinking outside the box, with creative and inclusive approaches to engagement (rather than just relying on resources like printed booklets) is likely to increase people's interest and help them to feel relaxed around the topic of sex.
- » The need for resources that reflect diverse experiences, acknowledging that everyone's journey is different.

It is our hope that these ideas will become the guiding principles for any initiatives and resources which we develop on the topic of sex while living with a stoma.

Get involved

If one thing became clear from our focus group session, it was that everyone's experience of sex and perceptions of themselves are different. Which is why we would love to hear from as many ostomates as possible to help inform any future resources we create from this project. Any contributions will remain anonymous and focus on exploring sex while living with a stoma through a therapeutic lens.

If you would like to get involved, please contact us via the editor inbox:
Editor@ColostomyUK.org

*Colostomy UK would like to thank Irwin Mitchell Solicitors in Birmingham, who kindly hosted the sex therapy focus group session at their offices. We would also like to give a big heartfelt thanks to everyone who took part in the focus group.





fundraising



Megan Lowden
Fundraising Executive

Our Fundraising Executive, Megan Lowden, shares the latest news on fundraising, highlighting all the fantastic ways our supporters have raised funds for Colostomy UK.

In Memory of a Much-Loved Nan

Natalie James ran the Manchester Half Marathon in October and very kindly raised much needed funds for Colostomy UK while doing so, in memory of her dear Ninny Jean who passed away earlier this year.

Jean lived with a stoma for over 50 years of her life along with other health conditions, including breast cancer, Alzheimer's and dementia. Colostomy UK were able to support Natalie and her family, and as a result Natalie has raised a staggering £845 to contribute towards our cause.



£845 Raised



£600+ Raised

Back with a Vengeance

Team Colostomy UK Rugby League player, chair of WAMS stoma support group and ostomate, Isabel Pena Barrientos, was finally able to run the Windsor Half Marathon for us in September, raising funds and awareness while also taking on a personal challenge.

After being injured right before the 2024 Windsor Half, Isabel didn't let this stop her and she came back more determined and stronger than ever this year! Isabel has raised over £600 at the time of print and her fundraising total is still on the rise.

Keeping It in the Family

Ian, his wife Shelley and his wonderful children laced up their walking boots and took to Snowdon this October, raising funds for our charity after Ian's stoma surgery in 2023, following a 24-year battle with IBS and Diverticulitis.

So far, they have raised £1,385 and the total is still rising!



£1,385+ Raised



£2,042 Raised

Hard Work Breeds Reward

In September Rob Harris ran the Richmond Marathon to raise money for both Colostomy UK and St Marks Hospital after the charities supported his brother James who underwent stoma surgery in 2024.

In Rob's words "Colostomy UK were able to offer support, coach James through his decision-making process and helped him to see a brighter future on the other side of any potential surgery." When asked how his training was doing Rob told me that "The training has been hard. Running 4 days a week and strength training has taken up a significant amount of time but is nothing compared to the inconvenience that can be experienced by people with bowel disorders and stomas."

Rob has raised an incredible £2,042 for Colostomy UK and we could not be more thankful!

Fighting Fit

Back in July, George Hitchon took on the challenge of competing in a charity boxing match to raise vital funds for our charity as a way of giving back.

Ten years ago, George's mum had lifesaving surgery resulting in her needing a stoma. In his words his mum's surgery was "lifesaving but also life altering, impacting her physical, emotional and social well-being". Over £350 has been raised from this brilliant event, what an achievement!



£350+ Raised

A Fundraising Knockout

Four years post emergency stoma surgery and following an 11-year battle with Chron's disease, Carina took to the ring to raise funds for Colostomy UK in an amateur boxing event - the Ultra White Collar Boxing Match.

Carina explained to us that she wanted to raise funds for "a charity that provides vital support to people like me". Carina's incredible efforts have raised over £480 at the time of print, and her total is likely to continue to grow.



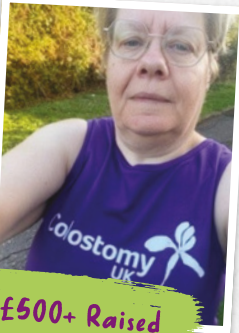
£600+ Raised

Onwards and Upwards in Support of Owen

In November, Erin Hicks and a group of friends ran the Helston 10K in aid of Colostomy UK, after Erins fiancé, Owen was rushed to hospital in April during a bad flare up of his ulcerative colitis and underwent emergency ileostomy surgery to save his life.

Erin explained to me that she is "not a runner, but I wanted to set myself the challenge to do this for myself, Owen and the amazing Colostomy UK who do amazing things for people with Stomas". Thanks to their dedication and passion they have raised over £2,200 to enable us to continue to support people like Owen. An incredible sum, which Erin and her friends should be rightly proud of!

£2,200+ Raised



£500+ Raised

From Surgery to Start Line

Denise Taylor-Silk very bravely took on the challenge of the Great South Run in October after only having her loop Colostomy surgery in June!

Denise told me that she "would like to give back a little for the help & support I have been offered". Denise has raised an incredible £500 already and her total is still growing at the time of print.

Colostomy UK Christmas Cards are Back!

Keep your eye on our social media accounts, or head over to our shop to ensure you don't miss the drop of our new Colostomy UK Christmas Cards, coming soon!

If you're reading Tidings digital, simply click on the following link:
colostomyuk.bigcartel.com

Or else type 'Colostomy UK Merchandise' in your web browser and follow the link titled '**Big Cartel - Colostomy UK**'.



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.



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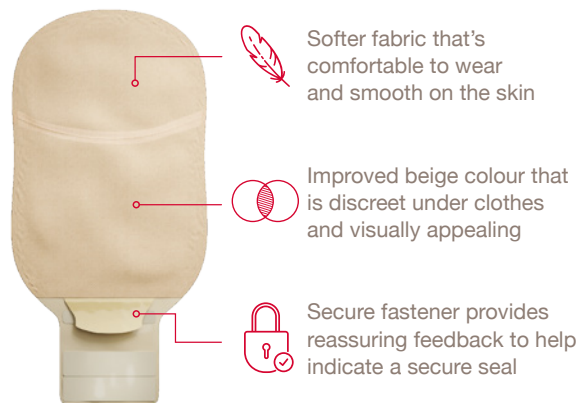
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*CeraPlus™ Skin Barriers contain the Remois Technology of Alcare Co., Ltd.

**compared to our previous pouches. 1 Data on File, 2023; n=43. 2 Data on File, 2024. 3 Data on File, 2023; n=110. 4 Data on File, 2023; n=68 OSO Registry.

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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!



Danny Lloyd-Jones: A Glass-Half-Full



Danny Lloyd-Jones has the ability to harness the power of positive thinking, even in the most challenging of times.

37-year-old Danny Lloyd-Jones is a keen sportsman. He talks like one too — avoiding hyperbole in favour of understatement. The way a tennis player might tell reporters they were just “a bit unlucky today” after losing Wimbledon.

He uses similar restraint when describing the long list of physical and psychological setbacks he’s endured since discovering he had cancer in 2020. He uses phrases like “not ideal” and “a bit unpleasant,” where others might opt for stonger language.

Danny’s cancer journey continues to this day and required him to have stoma surgery in 2021, but as he told me: “I’m a glass-half-full kind of a person.” It’s an outlook that has kept him positive through the most difficult times, but which also meant he was blindsided when, after “some recurring pain and a bit of bleeding,” he was finally diagnosed with bowel cancer. It was news neither Danny nor

his doctor had anticipated, given his age and general health — blood tests had been taken, but a stool sample had not, as it was initially presumed to be piles or similar.

“In all honesty, I thought maybe I had an ulcer or something. I wouldn’t have ever thought that it was cancer, because I was young and fit and active, and you just don’t think that’s going to be your story. So for me and my wife, Cherida, it was a big shock.”

The catalyst for further tests was Danny’s “excruciating pain.” (‘Excruciating’ not being a word he uses lightly.)

“I couldn’t sit down, I couldn’t really lie down, I couldn’t really walk, so I knew something was wrong.”

Danny had a large tumour that couldn’t immediately be removed by surgery.



He first needed radiotherapy to shrink it due to its awkward positioning. His optimistic streak made him thankful he would at least avoid intravenous chemotherapy, though he still needed chemo tablets.

He was also told the surgery would leave him with a permanent stoma — something he'd never contemplated:

"It was the first time I'd ever even heard of the word 'stoma'. I've never spoken to anybody that's had one. My awareness was nonexistent. I didn't know what they looked like, who had them, or anything."

But in light of everything else Danny was processing, living with a stoma seemed a price worth paying for being cancer-free.

"You get told that you've got cancer, and then you get told you're having a stoma. It's kind of two things at once, but you focus more on the cancer because that feels scarier. I just thought, 'well if a stoma is what I need to have then I'm sure I'll adjust.'"

Supported by a loving wife and strong network of friends and

family, Danny took the news in his stride. As he put it: "It was the side dish to the main course."

Up to this point, the cancer had been classified as Grade 3, until tests noted it had metastasised on his liver. It was now stage four, and with this Danny had to undergo the intravenous chemotherapy he'd hoped to avoid. The side effects were every bit as bad as he feared.

The treatment made everything sensitive to the touch, especially cold things, and left him with permanent neuropathy in his toes — nerve damage which means he now lives with pins and needles '24/7'. Everything he ate was tinged with the taste of iron. Perhaps strangest of all was how chemotherapy affected Danny's sense of self.

"It changed the pigmentation of my skin. I'm quite dark for someone mixed race, and I could see my skin getting lighter. I normally have an afro and a curly beard too, but this treatment made all my hair straight. Which is quite strange, because it kind of changes your identity too."

The side effects from radiotherapy were equally challenging. The skin around the target area was burnt, becoming extremely sensitive before peeling away.

Doctors also warned the radiotherapy could impact his fertility and advised him to freeze his sperm if he and Cherida hoped to have children — which they certainly did. In fact, their lives up to this point had been gearing up for parenthood. As Danny explained:

"We've been together 16 years now and always wanted a family, but we've been doing things the traditional way. We got together, moved in, got engaged, bought a house, got married. We wanted to get financially stable



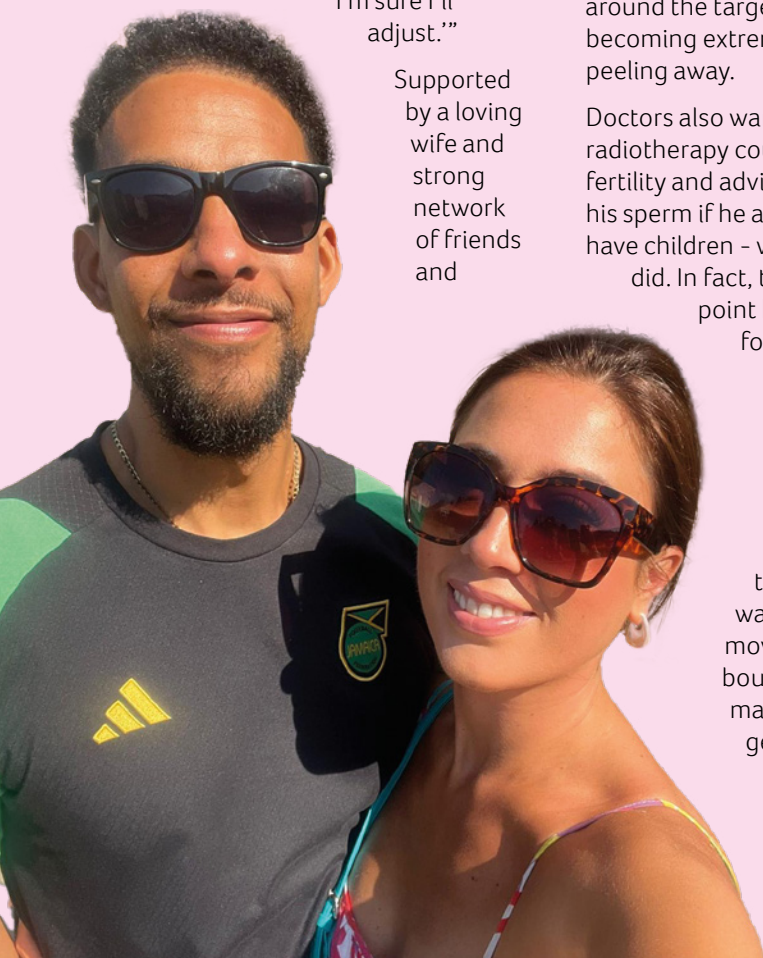
before trying for a family. So it was really devastating. It meant looking into IVF in the future, so there was suddenly a lot of fear and uncertainty."

Thankfully, the treatments worked, enabling Danny to have surgery to remove the tumour in January 2021. The operation itself was successful, but recovery was slow. His bowel struggled to kick back into action, and he experienced painful blockages.

He spent 19 days in hospital during peak lockdown, having to become acquainted with his new stoma without visits from loved ones. It was — as he told me with his trademark temperance — "a tough time."

"Of course, one of the first things you do is look down at your newly modified body and see the stoma. I remember feeling quite tearful, because I thought, 'Wow, this is my new norm.'"

Eventually, Danny's stoma began working. But owing to the stool-softening medication, his output was initially very loose, leaving him fearing whether this would always be the case.



By the time Cherida collected him from hospital, he had lost a substantial amount of weight and was still adjusting to life with a stoma. Cherida later recalled how he was broken – unrecognisable from the strong character she had always known.

Yet, true to form, Danny soon bounced back. Cherida encouraged him to complete his daily recovery exercises, and he returned to work within just ten days of surgery, welcoming the routine his job as a development engineer provided.

In fact, Danny was so keen to take charge of his life again that he soon applied for – and won – a new role in a different company.

“My wife thought I was mad,” Danny told me. Not least because there was still a chance at this stage that the cancer could return. As indeed, it did.

Between his surgery in 2021 and today, Danny has been on an almost constant rollercoaster. He would receive the all clear, “crack on with life” for a bit – getting a puppy, doing up the kitchen, etc. – only for the cancer to reappear months later, including on his lungs and liver.



Further treatments would follow, including more chemotherapy, new and exciting drug trials, as well as ablations which he'd initially been



told he wasn't suitable for. Danny's body would respond fantastically almost every time. Normal life would resume – before the whole cycle would start all over again. At this point, Danny is close to having received 100 individual treatment interventions.

He finds this wild ride toughest when it prevents him from exercising and playing his beloved basketball. All of which has taken its toll psychologically. Yet his optimism always finds a way to shine through:

“It is difficult to balance the mental aspects of it, but I'm always trying to be positive. I'm just grateful I've responded well to treatment up to this point.”

Amid all this, Danny and his wife also tried starting a family via IVF. Sadly, three and a half rounds over the past four years have proved unsuccessful, adding emotional strain to an already difficult time. So why add to the challenges? Danny's answer is simple:

“We just really wanted a family. We needed some kind of light within the tunnel.”

As if cancer treatments, fertility treatments, work commitments, exercise, and rearing a puppy weren't enough, Danny has also found time to represent two cancer organisations in his local area, Shropshire. The first being the Cancer Care Coordinators linked to his GP practice, where he helped increase the number of radar-accessible toilets in the area after highlighting the poor state of public facilities.

This initiative led to Danny working with the charity, Lingen Davies on their

“Bins for Boys” campaign. Suddenly, he found himself being interviewed on the BBC, attending charity balls, and popping up on friends' social media feeds. The partnership was so successful that he was invited to join their board of trustees, after an application process, in March this year. It's a role he's thriving in:

“I could sit around and be sad about living with bloody bowel cancer at my age, and all of these treatments. But instead, if I can use my experience to help others, then why wouldn't I?”

As ever with Danny, there is no grandiosity in the way he says this. To his mind, giving back is just the right thing to do. It's just how he sees the world and very much in keeping with his optimistic outlook on life, no matter what it throws at him.

“Right now, I know that there's still about three lines of new treatment that have come out since I've been having my treatment that I haven't even tried yet. So you do have to look for the positives, because if you don't, I think you could get into a mental spiral of how difficult everything is and not get out of it again”.

It's hard not to be inspired by Danny's glass-half-full attitude, given all he's been through – his daily saying is that he's blessed to see another day.

“Life is a Game” goes the old adage. If this is true, then Danny is most definitely in it to win it.





Giovanni Cinque
Marketing & Campaigns Manager
GetInvolved@ColostomyUK.org



campaign news

In this issue we report on two projects that may have an impact on how stoma care looks in the future in the England and Wales.

NICE Guidance on One-piece Closed Bags for Colostomies

NICE National Institute for Health and Care Excellence

As we have previously reported on, Colostomy UK has been working with The National Institute for Health and Care Excellence (NICE) to look at the use of one-piece closed colostomy bags in the NHS.

NICE is the organisation that provides national guidance for the NHS in the UK. Their role is to make sure care is based on the best available evidence, is consistent across the country, and represents good value for taxpayers' money.

This review focused on bags that are already widely used in the NHS. The aim was to check whether differences in price between products are justified by differences in quality, effectiveness, or benefits for people living with a stoma.

The final guidance has now been published. Here's what it means for you.

What NICE recommends

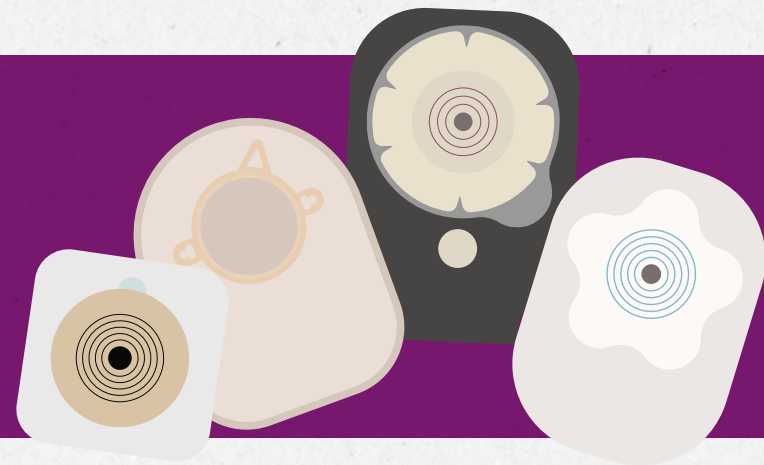
- » There isn't enough evidence to show why some one-piece closed bags cost more than others.
- » You should have access to a wide range of one-piece closed bags on NHS prescription, so you can find the one that works best for you.
- » Choosing a bag should be a shared decision between you and your stoma care nurse or healthcare professional.
- » Decisions should consider things like:
 - » preventing leaks or seepage
 - » protecting the skin around your stoma
 - » your individual needs and preferences, which may change over time
- » If more than one bag is suitable for you, and you are happy with all the options available, the NHS will usually provide the least expensive option, but this should only be if you feel it meets your needs and are happy with it.



What this means for people who use one piece, closed colostomy bag.

- » You have the right to discuss different bag options with your healthcare professional.
- » The bag you use should be chosen based on what's right for you, not just cost.
- » If you ever experience problems like leakage, discomfort, or skin irritation, ask your stoma care nurse for a review. Your needs may change, and switching bags or using extra products could help.
- » Remember: your voice matters. Decisions about your care should always be made with you, not for you.





What this means for healthcare professionals

- » Bag choice should never be influenced by sponsorship or brand promotion.
- » Decisions should follow NICE's principles of shared decision making.
- » Clinical appropriateness and the person's needs come first – but if more than one bag is suitable, the least expensive option should be used.
- » These recommendations apply when someone is starting on a new bag. If the bag you already use works for you, there's no need to change.

Why NICE made these recommendations

- » There is currently limited and low-quality evidence comparing one-piece closed bags.
- » There isn't enough proof that one bag is more effective than another, or that higher prices mean better outcomes.
- » What matters most to people with a colostomy is reducing leaks, preventing skin problems, and feeling confident in daily life.
- » More research is needed that focuses on outcomes that truly matter to people living with a stoma.

Colostomy UK's response to the NICE recommendations

While the NICE guidelines refer specifically to people who use one-piece closed colostomy bags, we believe that the considerations for health care professionals and patients provide a sound basis for joint decision making and improved patient choice for everyone living with a stoma, and should be considered best practise by health care professionals regardless of which type of stoma they have, and bag they use.

Product choice should always be based on clinical appropriateness and the needs and preferences of the person with a colostomy. However, we recognise the financial burden of stoma care to the NHS, so support the recommendation that if more than one bag is suitable, the least expensive option should be used. We all have a responsibility to ensure value for money.

NHS England review of stoma and continence products

In July NHS England announced that they are carrying out a major review of how stoma and continence products are prescribed and supplied through the NHS. This includes all products listed on Part IX of the Drug Tariff (the official NHS list of appliances and items that can be prescribed).

The review aims to:

- » Ensure patients receive products and support that meet their clinical needs.
- » Improve outcomes and patient experience.
- » Deliver services that are sustainable and offer value for money.

As part of the process, NHS England has issued a Request for Information (RFI) to stoma care manufacturers and delivery companies to gather insights into current products and services. Topics covered include the role of industry-funded specialist nurses, support partnerships and prescription management services.

Colostomy UK is actively engaging with NHS England on this review to ensure that the voices and experiences of people living with a stoma are heard, and that future services reflect patient needs and priorities.



Tidings Digital: Having Your Say

Here's your chance to have your say on the future of Tidings

A Recap of What's Happened So Far

Earlier this year, we made the decision to transition a large number of our readership from the paper magazine over to Tidings digital.

With print costs soaring and advertising spend down across our sector, the financial squeeze made this move essential – and urgent.

We did what we could to prepare readers for this via emails, as well as an article featured in the Spring 2025 edition of Tidings.*

Some wholeheartedly welcomed the move to digital. Yet others got in touch to express concerns about the change. We aired some of these views in the 'Letters and Emails' column of the Summer 2025 issue, alongside an article from our CEO, Libby, in which she promised a future survey to get a better picture of readers' opinions to help us make better informed decisions on where we go from here.**

What's Happening Now

As promised, that survey is now here. We want to hear from as many of you as possible to help us to continue improving your favourite magazine.

There are two ways to fill out the survey:

1

Complete and cut out the survey on the following pages, and send it back to us, addressed to the following:

**Colostomy UK
100 Berkshire Place,
Winnersh,
Wokingham
RG41 5RD**

2

Fill out the form online. You can do this by either:

- » Scanning the QR code
- » Clicking on [this link](#) to the online survey



Or call our admin team between 10am – 4pm on 0118 939 1537.

*See [Tidings Spring 2025](#) or search 'Tidings Colostomy UK Spring 2025' in your browser. **See [Tidings Summer 2025](#) or search 'Tidings Colostomy UK Summer 2025' in your browser.



Tackling the Question of a Tidings Subscription

Lots of readers that have already been in touch have said they would happily pay a subscription fee to keep receiving the paper version of the magazine.

Others have explained that they thought their monthly or annual donation to Colostomy UK covered Tidings' running costs (in fact, these generous donations help keep all of our services running).

So why don't we just start charging a subscription fee for Tidings?

One of the challenges is that we don't currently know just how many people would be willing – or could afford – to pay for a subscription fee.

It might be the case that the majority of readers (who haven't been in touch) would prefer not to pay for the magazine, and so it wouldn't be fair to spring this on them.

The fact is, we just don't know right now, which is why the survey includes questions about subscription fees, and why it's so important we get your views on this.

Other Things We Are Doing

Our teams are looking at ways we can make reading Tidings online more enjoyable. You'll find lots of questions on this topic within the survey.

Your feedback is vital in helping to ensure Tidings continues to be the cherished magazine it is.

Thank you for helping make this happen!

Final Note

This survey is a purely fact-finding mission. We are committed to ensuring that anyone that struggles to access Tidings online or is unable to pay, still has access to the magazine.

TIDINGS READER SURVEY



Exploring how readers access and value Tidings

We're exploring how readers access *Tidings* and whether there's interest in a possible printed subscription option.

This survey should take about 5 minutes to complete.

Please return or submit your answers by **20 December**, sending it back to the following address:

Colostomy UK
100 Berkshire Place, Winnersh, Wokingham, RG41 5RD

A) ABOUT HOW YOU CURRENTLY READ TIDINGS

1. How do you usually read Tidings?

- ☐ Online (digital version)
- ☐ Printed copy (paper magazine)
- ☐ Both
- ☐ I don't usually read Tidings

B) YOUR EXPERIENCE READING TIDINGS DIGITALLY

(If you only read the printed version, you can skip to Section C.)

2. How easy do you find it to read the digital version of Tidings on your device(s)?

Device	Very easy	Somewhat easy	Neutral	Somewhat difficult	Very difficult	I don't use this
Mobile phone						
Tablet						
Laptop / Desktop						

3. If you've been receiving Tidings digitally instead of in print, how has that affected how often you read it?

- ☐ Much more inclined
- ☐ Somewhat more inclined
- ☐ No difference
- ☐ Somewhat less inclined
- ☐ Much less inclined

(Optional) Please tell us why you feel this way:

4. If a printed copy was no longer available, and online was the only option, how likely would you be to continue reading Tidings online?

- ☐ Very likely
- ☐ Somewhat likely
- ☐ Unlikely
- ☐ Very unlikely

C) FEEDBACK ON THE PRINTED VERSION

(If you only read Tidings online, you can skip to Section D.)

5. How important is receiving Tidings in print to you personally?

- ☐ Essential – I really struggle to read online
- ☐ Really important – I can use the internet, but I value the printed version
- ☐ Nice to have – I enjoy the printed version, but could manage online
- ☐ Not very important – I prefer reading online

6. What do you value most about having a printed copy? (Select all that apply)

- ☐ Easier to read than on a screen
 - ☐ I like to keep physical copies
 - ☐ Reading a printed copy is part of my routine when it's in the house
 - ☐ I don't use digital devices much
 - ☐ I find print more relaxing/enjoyable
 - ☐ I share it with others (family, friends, healthcare team, etc.)
 - ☐ Useful for waiting rooms or support groups (for nurses and support group leads)
- Other (please specify):

**7. Have you ever read the online version of Tidings?
(whether on your phone on computer)**

- ☐ Yes, regularly
- ☐ Occasionally
- ☐ I've looked once or twice
- ☐ No, I haven't
- ☐ I didn't know there was one

8. If you haven't read Tidings online, what's the main reason?

- ☐ I don't have internet access or a suitable device
- ☐ I find digital versions hard to read or navigate
- ☐ I prefer reading on paper
- ☐ I wasn't aware of the online version

Other (please specify):

9. If the digital version were improved (e.g. easier to read, better layout, simple navigation), would you still prefer print?

- ☐ I'd still want the printed version
- ☐ I might switch to digital if it improved
- ☐ I'd be happy with digital as it is now
- ☐ Not sure

D) SUBSCRIPTION AND ACCESS OPTIONS

10. Would you be willing to pay a small subscription fee to continue receiving a printed copy?

- ☐ Very willing
- ☐ Somewhat willing
- ☐ Not very willing
- ☐ Not willing at all

11. If you said "very" or "somewhat" willing, how much could you afford per issue?

- ☐ £2-£4
- ☐ £5-£7
- ☐ £8-£10
- ☐ I can't afford to pay
- ☐ I wouldn't pay – I think it should remain free

Please note: We are a small charity with no statutory funding.

Each issue costs us a significant amount to produce –

including postage, design, and printing – so every contribution helps us continue sharing the magazine with our community.

12. How would you prefer to pay (if a subscription was introduced)?

- ☐ Annually
- ☐ Quarterly
- ☐ I'm not sure
- ☐ Other
- ☐ I believe it should be free
- ☐ I'll just read it online instead for free
- ☐ I can find the support elsewhere

If you wouldn't be willing to pay, could you tell us a bit about why?

13. If a physical copy was only available via subscription, and you chose not to subscribe, would you:

- ☐ Continue reading Tidings online
- ☐ Stop reading Tidings altogether
- ☐ Not sure

E) ACCESSIBILITY AND INCLUSION

14. We're committed to ensuring everyone can still access Tidings, even if they can't pay or struggle with digital formats.

If we ever had to change how the magazine is distributed, what would help you most?

- ☐ Being able to complete surveys or renew subscriptions over the phone (so you wouldn't need to post anything back)
- ☐ An option to request a free printed copy if I can't afford a subscription
- ☐ A more accessible digital format (e.g. large text, audio version)
- ☐ I'd need help accessing it online
- ☐ Other (please specify)

F) ABOUT YOU (FOR ANALYSIS ONLY)

15. Age:

- ☐ Under 30
- ☐ 30–49
- ☐ 50–64
- ☐ 65–75
- ☐ 75+
- ☐ Prefer not to say

16. Which best describes you?

- ☐ Someone living with a stoma (or who has lived with one)
- ☐ Nurse
- ☐ Carer
- ☐ Supporter / family member
- ☐ Other
- ☐ Prefer not to say

Thank you for your time.

Your feedback helps us plan the future of Tidings and ensure everyone can continue to enjoy and access it.

Your Letters and Emails

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

Dear sir,

I see a major newspaper recently carried an article about a female rugby player who has a stoma, with a reasonably insightful discussion of how she manages. But the headline was that she plays "with the hindrance of a stoma", which I view as unfortunate to say the least.

While the article is good in providing inspiration, raising awareness, and helping to stop "demonising" stomas – a stoma is not like leprosy! It also paints a picture which for many people is false. A stoma is a nuisance from time to time but ostomates learn resilience and lead largely "normal" lives. And if, as in my case, it is a stoma or death, I'll take the stoma.

Perhaps mainstream journalists or at least headline writers need a little more research on this subject.

Michael Turner



Dear Editor,

Congratulations are really not enough. This issue is remarkable and the graphics that accompany each story are truly amazing. To say I loved every written word would not be enough to tell you how each story moved me and how I had tears in reading the stories of Tony, Steph and Debs.

The words that leap out onto the pages are STRENGTH, COURAGE, VALOUR, BRAVERY, POWER, PLUCK and GUTS. This isn't only for those who are facing the same problems of the writers, but the LOVE and SUPPORT they received from mothers, fathers, husband, wives, and friends. The last issue has given a pride to having a stoma. Many of us will not have faced the challenges of others but what an inspiration the stories are. You have shown we can all come through, join a rugby team, receive good and helpful advice, enjoy life again and what is more become part of FAMILY COLOSTOMY U.K.

I loved the memorial page. We owe so much to the earlier volunteers who gave their time and inspirational service.

J.D



Tidings Issue 79

Dear team,

I'm writing to share a personal poem titled "Sammy the Stoma", inspired by my own experience of living with a colostomy.

*I once had a bowel — dependable, solid,
Until it exploded and the pain was quite horrid.*

*Ambulance came, sirens, blue lights.
A life saving surgery. One hell of a fight.
Next thing I know, I'm stitched and I'm sore,
And surgeon says, "Taylor, you're pooing no more."*

*Enter young Sammy, my colonic stoma
A collapsed little thing with a pungent aroma.
Not stoma-model worthy, no proud fleshy bump,
Just a cheeky red hole with a strong urge to trump.*

*He performs when he wants, he's noisy, he's loud,
Especially when quiet and I'm stuck in a crowd.
He farts in the office, he can break wind mid-hug,
And if you don't watch for leaks, he might stain the rug.*

*But let's not despair — help is on hand
The doctors are ready, a reversal is planned.
My stoma may retire, and I'll miss all his strife.
Because lovely young
Sammy once saved my life.*

By IJ Taylor



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. Happy writing!**



Community Updates

Our Community Liaison Lead, Shauna Ann, shares all the news from the wider stoma community across the country



It's been another busy quarter, with lots going on in the world.

In September, we did a free stoma care workshop for unpaid carers, such as family members and neighbours. The aim of these workshops is to ensure that money isn't a barrier to all carers getting access to good quality stoma care training. The workshop was delivered by the fantastic stoma care facilitator, Rali Marinova.

Our Active Ostomates classes started up again at the end of September, with 77 participants taking part in the first week! These sessions focus on health and wellbeing, and include Pilates, yoga, and mindfulness. Feel free to get in touch if you might want to join a future session.

We started collaborating with Redcar council to make their organisation more stoma-friendly. All of their council owned buildings already have stomach-friendly accessible toilets, which is a fantastic achievement. They now want to promote this fact to encourage other organisations and venues to increase stoma-friendly facilities in other regions. We are also working with the council on delivering stoma awareness training across the town of Redcar in beautiful North Yorkshire.

You might have spotted an article on page 29 about the Royal College of Nursing's Health Ability Passports. This - as well as best practice advice to employers of nurses, has now gone live! This includes a video from our volunteer, Ian Fletcher, talking through the advice and guidance. Another of our volunteers, Linda Griffiths, contributed to the details within the Health Ability passport. Hopefully this can inspire other employers to follow suit!

We are working with researcher, Gill Hubbard, who is looking into exercise interventions for people living with a stoma. In particular, the impact of Pilates and the benefit this can have for ostomates. We are in the early stages of putting together a focus group, including people with lived experience, with the main outcome being to codesign a website or app for Pilates interventions. **Please contact getinvolved@colostomyuk.org if you are interested in joining this exciting initiative.**

Support Groups

We assisted two new support groups to get set up; one in Shropshire and the other in St Albans.

"The group was amazing and 25 turned up! It is amazing how many turned up and already asking for the next date!" Mel North, Friends with Stomas, St Albans.

Our volunteer, Karen Ashman, and I visited Swindon IA support group, Ostomy Mates, where Karen spoke about her experiences of living with a stoma, travelling, modelling, and running support groups in her area.

Karen has also created an Ostomy Calendar featuring different incredible Ostomates to be displayed for each month of the year. The aim is to raise the confidence of people living with a stoma and Karen kindly donated some proceedings to CUK.



Our volunteer, Tracey Green, attended a meeting for Stevenage Ostomistics where she spoke about what we do and how to access support, as well as share her own experiences.

Last but not least, the Mold Support Group celebrated its one-year anniversary on September 10th, and they marked it with a get-together at Northop Hall Cricket Club in North Wales. Happy belated birthday to Mold from all at Colostomy 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@plmdistbcs.org

West Devon Stomates
Scarlett Moon T: 07736936731

Dorset

CUPID Colostomy Urostomy Pouch Ileostomy Dorset Support Group
Jenny Pipe T: 01202 740440

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

Gloucester

Gloucester Ostomates
Julie T: 07979129001
E: juliemathew@hotmail.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
Mandy Hallisey T: 0751 820 8550
E: dawdie05@gmail.com
Sandy Le Saux T: 07453 888008
E: sandy.63@outlook.com

Waterside Stoma Support Group

Ian Gapp T: 07710288785
E: iangapp13@gmail.com

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

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: debbieattwiggsg@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.phoenixgroupbvvh.com

Leicestershire

Kirby Ostomy Support Group.
Colostomy, Ileostomy and
Urostomy in Leicestershire

Janet Cooper T: 07464 957 982
E: kosg2013@btinternet.com

Speak Stoma Group

Candy Elliot E: candypoos@icloud.com

London**Bowel Cancer Support Group**

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

Bowel & Other Cancer Support Newham

T: 020 8553 5366

**Homerton Hospital Bowel
& Stoma Support Group**

Irene Fernandes and Glyn Fountaine
T: 02085105318 or 07785971120

Newham Stoma Support Group

Lauren King T: 020 7055 5576

**Rectangle - Colorectal Cancer
Support Group**

Regina Raymond T: 020 7472 6299

South Woodford Support Group

Nurse Christina and Lisa
T: 020 8535 6563

Merseyside

Bowel Cancer and Stoma
Support Group (BeCauSe Group)
Helen T: 07729 750622

E: becauseliverpool@gmail.com

St Helens Cancer Support Group

Bob Martin T: 01744 345 365
E: contact@sthelenscancersupportgroup.
org.uk

Middlesex**Middlesex Inside Out Stoma
Support Group**

Barry, T: 07811084514
E: Info@iossg.org.uk,
W: www.iossg.org.uk

Norfolk**James Paget Ostomy Support Group**

Sheila T: 01493 600 934
E: hshowlett@aol.com

**The King's Lynn and District Ostomy
Support Group**

T: 01406 363756 or 01553 775698

**STARS (SToma And Reconstructive
Surgery social support group)**

Sylvia Hughes T: 01263 733 448
E: sylvia.ruth.hughes@gmail.com

Northamptonshire**Northampton Ostomy Support Group**

T: 07801 316 403 (evenings) or
Trish T: 07703 188 386

Northumberland**Berwick Ostomy Support Group**

Bobbie Minshull T: 07714 479 320

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**Bag Buddies**

Susan E: 134powerhouse@gmail.com

B.O.T.S. (Bums on Tums)

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

Somerset**Ostomates Support Group**

Fiona Rogers T: 01225 873657

Stoma Heroes Support Group

Shane Green T: 07802 428 074
E: Shane@stomaheroes.com

Staffordshire**County Stoma Group**

Moirra Hammond T: 07788 402 195
E: cm.hammond@ntlworld.com

Outlook The North Staffs

Ostomy Support Group
Moirra 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
Colossus Support Group
Brendon T: 07850 269758

Yorkshire

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

Airedale Stoma Support
Sue Hall T: 01535 646 373

Barnsley Bottoms Up Stoma
Support Group
John Holmes T: 07980388965
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: dewsssg@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-ostomyyork
shire.org

Isle of Man

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

Northern Ireland

County Antrim

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

County Armagh

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

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

County Down

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

Londonderry

Causeway Support Group
Mary Kane T: 028 7034 6264

Republic of Ireland

County Mayo

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

Dublin

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

Sligo

Sligo Stoma Support Group
Mary T: (00)353863608798

Scotland

Ayrshire

Ayrshire & Arran Stoma Support Group
Susan T: 07790929268

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

Angus

Angus Stoma Support Group
Valerie T: 07359766289

Dundee Stoma Support Group
Nicola T: 07801702054



Scotland (cont.)

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

Coatbridge

Providing Ongoing Ostomate Support Scotland CIC

E: info.poosscotland@gmail.com
W: www.poosscotland.co.uk/peer-support-groups

Edinburgh

Edinburgh Support Group - 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-](http://www.poosscotland.co.uk/peer-support-groups)
[support-groups](http://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-](http://www.poosscotland.co.uk/peer-support-groups)
[support-groups](http://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
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

Recycle and Raise Money for Colostomy UK

We've teamed up with [icollectclothes](#) to offer you a hassle-free way to clear your home of unwanted items and raise money.

collectclothes will pick up your unwanted clothing, shoes, bedding, towels, curtains, accessories (bags, belts, hats, scarves) books, DVDs, CDs, soft toys, electronics and even small domestic appliances and convert them into a donation for Colostomy UK.

Help us to continue supporting and empowering Ostomates.

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



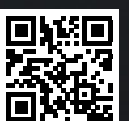
Learning to
love myself



Dec

Unapologetically
Me

Read Dec's full story
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www.salts.co.uk



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



Scan me to Stay In Touch!

